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Proceedings of the GReAT Consultation 2019

Volume B – Day 2

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Global perspectives on assistive technology: proceedings of the GReAT Consultation 2019

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Global perspectives on assistive technology

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Volume B – Day 2

Foreword

The World Health Assembly recognizes the need for improving the access to assistive technology across the world and, through its resolution 71.8, has commissioned the World Health Organization to prepare a global report on effective access to assistive technology by 2021. The development of the Global Report on Assistive Technology (GReAT) is led by a Steering Committee with representatives from the WHO Secretariat, the Global Cooperation on Assistive Technology (GATE) and UNICEF, and an Ad-hoc Advisory Group of Experts on Assistive Technology. The work is carried out in collaboration with international experts and stakeholders in assistive technology.

As a first step to inform the development of the Global Report, WHO Headquarters in Geneva hosted the GReAT Consultation on 22-23 August, 2019. Over 260 participants from 60 countries representing academia, civil society, users of assistive technology, global assistive technology stakeholders, States and UN agencies participated in this global consultation.

There was an overwhelming response to the call for contributions addressing the objectives of the Global Report, which are to highlight the current need, demand and supply of assistive technology, as well as to outline good practices for innovation and recommendations to improve access. More than 130 abstracts were submitted, and following a review process considering the relevance, quality and geographic representation, over 80 manuscripts or illustrative contributions were subsequently invited to be developed into full manuscripts for presentation at the GReAT Consultation.

Contributions were sought to illuminate the range and breadth of assistive technology and to recognise the diversity of stakeholders within the complex system of assistive technology. An encompassing view of evidence ensured that evidence-based practice, practice-based evidence, and situated knowledges were recognised and considered. Submitted manuscripts were reviewed from academic, technical and accessibility perspectives. These Proceedings represent the first foundation for the Global Report. Its 76 sections comprise 72 manuscripts and four abstracts, and are presented across eight themes:

1. Needs and supply
2. Access
3. Outcomes
4. Policies and programmes
5. Procurement and service provision
6. Capacity building
7. Innovations
8. Enabling the sector

Many sections are authored by international groups of authors, and a substantial proportion were received from author teams who had not previously published. All authors are to be congratulated on sharing their knowledge and perspectives. The sections present a 'state of the science' for the assistive technology sector in 2019 at a time of great need and great opportunity.

Work will now continue to identify and fill knowledge gaps, collect data and listen to unheard voices to further inform the development of the Global Report. Our sincere wish is that the spirit of the GReAT Consultation – great things happen when great people meet – will inspire us to continuous concerted efforts to improve the access to assistive technology worldwide.

Natasha Layton and Johan Borg
Editors

Acknowledgements

We would like to thank all authors whose rich and diverse contributions have made these proceedings into a valuable resource for years to come. Recognition is also due to the Co-Chairs of the GReAT Consultation, Mac Maclachlan of Maynooth University and Rosangela Berman Bieler of UNICEF, and the GReAT Consultation moderators Arne Eide, Desleigh DeJonge, Lynn Gitlow, James Rwampigi Aniyamuzaala, Claude Tardif, David Constantine, Catherine Holloway and Patanjali Nayar. Across sessions and throughout the two days, their skill and commitment wove a coherent narrative from the diversity of presentations.

Ultimately, tribute must be paid to Chapal Khasnabis for guiding the programme development and for an encompassing approach to contributions. His visionary leadership over many years has led to this pivotal moment for assistive technology access globally.

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Procurement and service provision

Models of assistive technology service delivery in low resource settings: A literature review of different approaches and their quality and impact

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Abstract

Assistive Technology (AT) has a huge potential to support people with disabilities in their daily lives, though for many people with disabilities access to AT is not guaranteed. This is especially the case in many low- and middle-income countries (LMICs). There are many different possible policies, systems and service models for AT provision. Little is known about which ones are the most effective and efficient approaches. This paper presents the results of a pragmatic scoping review of models/schemes for AT provision in LMICs. The aim is to describe and analyse published information about such service delivery models/schemes and to determine what is known about their quality and impact. We found information about 24 models/schemes. The most important conclusions of this review are that not much is published about AT service delivery in LMICs and that there is very limited or no evidence about the quality and impact of existing models/schemes. Most models are impairment- or technology-specific and have a limited reach, which indicates that AT service delivery in LMICs is very fragmented. There is a clear need for solid research into what works and what doesn't. It is also important to develop clear analytical frameworks to evaluate AT service delivery models/schemes in a systematic way, so that results can be compared.

Keywords

AT service delivery; models; low resource settings

Introduction

Assistive Technology (AT) has a huge potential to support people with disabilities to live an independent and fulfilling life and to participate optimally in society. In many countries, however, people with disabilities only have very limited or sometimes no access to AT, for a variety of reasons. One of the major reasons in low resource settings is the absence of targeted policies, easily accessible organisations, professionals and procedures that can

provide AT to those who might benefit from it. Other reasons are lack of awareness, unavailability of AT devices, issues with affordability, and many others.

There are many different possible policies, systems and service models for assistive technology provision. Little is known about which ones are the most effective and efficient approaches. Many low- and middle-income countries (LMICs) do not have established systems and models in place, and very often provision is dependent on the activities of NGO and charitable organisations. Evidence of what good practices exist and what are the most suitable approaches in a given context is important for countries to develop or improve their policies, systems and service models. This is particularly the case for LMICs, where limited resources and poor infrastructures demand highly efficient models based on the best available evidence.

This paper presents the results of a literature review into existing models of AT service delivery in low resource settings. The central question to be answered is: What AT service delivery models currently exist, and what is known about their quality and impact? The results of this review should provide directions for any country, organisation or professional who want to set up or improve AT service delivery systems or processes.

Methods

The method used for this review is that of a pragmatic scoping review. We included grey and published literature and performed an open Internet search about AT provision and service delivery in LMICs. We followed two separate procedures to find relevant resources. The first was a direct request to five international colleagues who had earlier published about AT service delivery models, asking them whether they were aware of relevant publications after presenting to them the research question for this study. The second was an open Internet search using the literature search engine of Maastricht University, which accesses all large literature databases, and the search engine of Google Scholar. Search terms for both searches were: assistive technology; assistive devices; service delivery; AT provision; models; low-and middle-income countries; low resource settings. We wanted to identify papers/studies that described models or schemes for AT service delivery for any category of users in low resource settings. For models mentioned in publications older than 10 years, we checked whether they were still active. Only those that were found to be active were included. Only publications in English were considered for this review.

After selecting the relevant publications/resources using the above procedure and criteria, basic information about the models/schemes they described was extracted. Where necessary we searched for additional information about these models/schemes through websites. On the basis of the information gathered each model was assessed against the in- and exclusion criteria mentioned above. All the models/schemes resulting from this procedure were scored on the following characteristics: a) whether they were based on a medical model (provision on the basis of a medical diagnosis) or applied a more social model; b) whether they were impairment- or technology specific or more

comprehensive/generic; c) whether they had an active outreaching approach (for example working with mobile camps) or a passive approach (were people had to go to a centre to get advice or help); d) whether they were centralised (for example in a hospital of specialised centre) or decentralised (for example in the community); e) whether they were aimed towards producing and/or providing products, providing or training personnel or working at a higher level with governments and other agencies to produce policies (3 Ps). We also tried to find out whether anything was known about the quality and impact of these models.

Findings

The procedure described above yielded a total of 59 resources, partly research papers and partly reports of websites (see reference list for an overview). The request to colleagues resulted in 35 suggested resources, the open search in another 35. There were 4 duplicates, 4 papers were from before 2009, 2 were not in English and 1 book could not be retrieved. In these 59 resources a total of 55 models that might potentially be relevant for our search were presented. After applying the in- and exclusion criteria to these models a selection of 24 models were included in the further analysis.

Table 1 gives details about these 24 models and a characterisation of them. It appeared to be very difficult and sometimes impossible to find the information regarding the characteristics we were interested in. The 'scoring' in the table must therefore be interpreted carefully. Taking this uncertainty into consideration, the table shows that most models are based on a medical model (14 of the 24 with 2 unknown), 15 are impairment specific and 8 have a broader scope (1 unknown). The table also shows that most models are impairment- or technology specific: 16 models focus on mobility (wheelchairs and prosthetics/orthotics), 3 on hearing aids, 1 on solutions for blind people and 4 have a broader scope. Most models had an active outreach approach (14, with 5 unknown), and about half was centralised versus the other half with a decentralised approach. Looking at the three Ps (products, personnel, policy) it appears that all but of one the models (38) focuses on products, 21 also on training of personnel and 10 also on policy.

We found no published evidence of the quality and/or impact of the models. As far as information was found, this is all self-reported and basically limited to numbers of devices provided. We found no external evaluations of these models/schemes, nor anything about their effectiveness in terms of reach and outcome.

Discussion and Conclusion

The aim of this paper was to provide insight into existing AT service delivery models in LMICs and the available evidence on impact and quality. The results show a fragmented field with often impairment- or technology-specific programmes, and very little or no evidence of their impact in terms of reach (how many of the people with needs are actually reached by the service?) and impact on the lives of people. This is clearly an under-researched field.

There are some important weaknesses of this review. The first is that we started the process with a list of resources provided by a limited number of experts in the field. Although it is unlikely that they would not have known about the most important studies in this field, they will certainly have missed relevant papers. This shortcoming is partly compensated by the separate open search. That search, however, was also limited in its approach: we did not analyse all the reference lists of identified publications, and the fact that we used a literature search engine that links to a large number of databases in one and the same search may have yielded less publications than more specific searches in the underlying databases individually would have. Another weakness is that we limited the search to resources in the English language. It is likely that there is more literature available about this topic than we have been able to capture. It is, however, unlikely that such literature would have provided a very different picture of the field. In 2018 Matter et al (39) performed a scoping review about AT in low-resource environments. Their review was not specifically focusing on AT service delivery models/schemes and their quality and impact, but they had very similar results. Finally, an important weakness of this review is that it only captures information that has been published, either in academic literature, grey literature or on websites. That is a weakness of all reviews, but it leads to a 'picture' of the situation that is by definition not up-to-date and will only come from settings that have the possibilities to do research and to publish. To obtain a realistic view of the actual situation this literature review needs to be supplemented with case studies and evaluations on the so-called grass root level.

It appeared to be very difficult to find detailed information about the models identified. That will very likely have resulted in incorrect interpretations and maybe also 'wrong' scores in Table 1. It is, however, not very likely that the overall picture of the field is very much different from what we found.

Even when keeping the weaknesses of this review in mind, the most important conclusion is that not much is published about AT service delivery in LMICs and that there is very limited evidence about the quality and impact of existing models/schemes. Another conclusion is that most models are impairment- or technology-specific and have a limited reach, which indicates that AT service delivery in LMICs is very fragmented. There is a clear need for solid research into what works and what doesn't. As mentioned, such research should focus on the reality at a grass root level. It is also important to develop clear analytical frameworks to evaluate AT service delivery models/schemes in a systematic way, so that results can be compared.

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Appendix

Table 1. An overview of 24 service models or schemes with their main characteristics

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
Christian Medical College (46)	Vellore, India	Faith-based educational and research institute, linked with group of primary, secondary and tertiary health services around Vellore. PO department is able to support amputee patients with footwear modifications and prostheses, with a large on site workshop.	1	1	1	1	2,3	/
Colombo Friend-in- Need Society (59)	Colombo, Sri Lanka	This group runs a PO fitting service in Colombo, where amputees from outside the city are given free lodgings and food to support them whilst their PO are being made, fitted and they are being shown how to use them. There is also a mobile bus outreach service. The Jaipur foot is used.	1	1	2	2	2,3	/
Mobility India (59)	Various locations, India	Provides services in Bangalore and Kolkata for PO and wheelchair provision. Also have an research and development department and workshop for AP, as well as a foot production unit run by women with disabilities. MI also provide assistive technology to prevent drop-out of children with disabilities from school school in Chamarajnar District, Karnataka.	?	1	2	2	1,2,3	2017/2018: 4464 people get 6060 assistive devices, 199 wheelchairs. 1286 people receive activities of daily living and gait training. Created a device specifically for

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
								children with CP to be supported in whilst sitting and standing - the Twin Device. This was in response to parents' feedback about previous devices. It is adjustable as the child grows.
Mukti (59)	Madras, India	Provide low-cost artificial limbs to amputees and calipers to people affected by polio. This requires a doctor's prescription. Also do outreach "Artificial Limb Camps" in different regions for around a week for people who cannot travel to Madras. This can lead to 60-100 artificial limbs being fitted.	1	1	2	2	2,3	/
Rehabilitatio n Centre, SMS Medical College (59)	Jaipur, India	Hospital providing PO free of cost, location of invention of unpatented Jaipur foot.	1	1	?	1	2	/
Spastics Society of Tamilnadu	Chennai, India	Provide PO and other MA to disabled people. Has other non-AT services for disabled people such as livelihood creation, training, children's services etc.	2	1	?	1	2,3	/

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
(SPASTN) (59)								
Tahanan Walang Hagdanang (59)	Cainta, Rizal, Philippines	Centre that focuses on improvement of quality of life, with multiple interventions, including providing mobility aids. Also have wheelchairs, educational aids and occupational therapy / physiotherapy aids on website.	2	2	?	1	2	/
Worth Trust (59)	Various locations, India	Multiple divisions: WORTH Plastics produce parts that are used in assistive products. WORTH Rehabilitation is a Speech and Language centre for children and fits hearing aids. WORTH Brailers and Mobility Aids produce low-cost and subsidised Braille educational assistive products and mobility aids. WORTH Digitisation is embossing a large volume of books in Braille for the visually impaired to enjoy. They are also converting them into audio files.	2	2	2	2	2,3	2017/2018: 44 assistive devices given to people from WORTH Rehabilitation. 87 students at the Speech and Hearing Impairment School, 27 children in the Early Intervention Centre

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
CBM Kenya (59)	Kenya	Supports adults and children with all disabilities. Works with many partner organisations. Promotes surgery/ rehab /assistive devices for orthopaedic services. Also supports special educational needs schools by providing materials, classroom adaptations and training.	?	2	2	2	2,3	/
PROJIMO (59)	Durangito and Coyotitan, Mexico	Two arms - the Rehabilitation Program and the Skills Training and Work Program (wheelchair workshop). David Werner (himself disabled), from the USA, began the program with local disabled people in a grassroots approach to provide a sustainable assistive technology service "look at their strengths, not their weaknesses."	2	2	?	1	2,3	/
Jairos Jiri Association (59)	Masvingo Province, Matabelela nd South, Mashonalan d East and high density suburbs of the Bulawayo Metropolita	CBR approach to generic disability service which includes AT provision, amongst others. Includes physical, mental, visual, hearing and other. Community rehabilitation workers work with CBR and Advocacy Committees. These are volunteers representing the community, and they sense of ownership and future sustainability of the programme once funding is withdrawn. This grassroots effort reports upwards to the national government level.	2	2	2	2	1,2,3	/

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
	n Province, Zimbabwe.							
Centre for the Rehabilitatio n of the Paralysed (45)	Various locations (12 centres), Bangladesh	Interdisciplinary team approach to PO. Aims for best outcomes to reduce isolation and enable people with disabilities to be active members of society. Works with all neuro-muscular-skeletal disorders, paediatric scoliosis, cerebral palsy etc. PO department has attended two mobile health camps.	1	1	2	2	2,3	/
The Solar Ear (48)	Sao Paulo, Brazil	Brazil based social enterprise formed by USA philanthropist/entrepreneur. Design and produce solar-charging hearing aids at low prices in Brazil, China and Botswana. Employ only deaf/ hard of hearing people to manufacture products.	1	1	1	1	2,3	To date, Solar Ear has supported over 50,000 children to receive a low-cost hearing aid, and thus to have the ability to attend school (2019)

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
Artificial Limbs Manufacturi ng Corporation of India (ALIMCO) (38)	India	State-owned AT production company. Non-profit. Produces mobility aids, braille products and hearing aids.	1	2	1	1	1,2	"Responsible for establishment of 170 Limb Fitting Centres all over India. Has around 8% of its employees who are disabled. Has transitioned into a product, service & solutions company from generally a manufacturing company in the past. Has achieved consistent growth in sales & production during last ten years. Distribution of Aids & Appliances is done up to Village / Block level."

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
Persons with Disabilities Foundation (38)	Various locations, Cambodia	State-run service which runs 11 Physical Rehabilitation Centres (PRCs) and the Phnom Penh Orthopaedic Component Factory. All Cambodian nationals are able to access services. PRC's provide accommodation and food allowance if they have to stay away from home. In 2018 15,175 assistive devices were provided. Provide services for: amputees/ stroke recovery/ diabetes/ cerebral palsy/ spinal cord injury/ club foot/ epilepsy	1	2	2	1	1,2,3	In 2018: Assistive devices provided : 15,175, Services provided : 28,045, Clients visited PRCs : 60,400
Humanity and Inclusion (38)	Various locations, Cambodia	Support state-run PRCs, working with government agencies. Focus on orthopaedic fitting training for people affected by mines and explosive remnants. Also provide outreach services.	1	1	2	2	1,3	/
International Committee of the Red Cross (ICRC) in Cambodia (38)	Various locations, Cambodia	Support state-run PRCs, working with government agencies. Orthopaedic fitting and provision of mobility aids.	1	?	1	1	1,2,3	Provided artificial limbs and donated mobility devices to over 100,000 PWDs in 26 years in Battambang and Kampong Speu

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
Veterans International in Stong Trenng and Prey Veng (38)	Various locations, Cambodia	Support PRCs, working with government agencies and also provide CBR in Phnom Penh, Kandal, Prey Veng, Svay Rieng, and Kratie. This is a USA based NGO. Northeastern Cambodia was affected by Agent Orange in Viet Nam War so birth defects such as club foot and cerebral palsy are more common, and VI works with communities affected by this.	1	2	2	2	1,2,3	/
Sound Seekers (35)	Sierra Leone, the Republic of the Gambia, Malawi, Cameroon, Zambia	United Kingdom-based NGO that works with government agencies, hospitals, schools, local communities and donors. Outreach programmes and provide refurbished hearing aids.	1	1	2	2	1,2,3	Two audiology clinics opened in government hospitals.
Motivation United Kingdom (54)	India, Kenya, United Republic of Tanzania, Malawi, Uganda	Provide training and help to improve services as well as providing wheelchairs. Provide wheelchair users and families with peer contacts (other wheelchair users) to deal with isolation, lack of knowledge and low-self esteem.	2	1	2	?	2,3	In 2018: They provided 3,509 wheelchairs and 369 follow up visits - low? Also provided 155 other AT.
United Cerebral Palsy Wheels for	Indonesia	Provides wheelchair fittings and services across the country. Trains personnel. Also works with government and NGOs to develop policies.	2	1	2	2	1,2,3	/

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Humanity: Roda Untuk Kemanusiaa n Indonesia (54)								
Comprehensi ve Mobility Support Project (CMSP) (57)	Zimbabwe	This was implemented by the Jairos Jiri Association and the Christian Blind Mission. From January 2012-February 2015 59 Rehabilitation Service Providers were trained in the WHO basic wheelchair service training packages, and 30 in the WHO intermediate wheelchair service training packages. 20 workshop personnel were trained in assembly and ongoing maintenance. This led to a total of 1316 wheelchairs being produced and distributed to users, with all associated services.	2	1	?	2	2,3	This led to a total of 1316 wheelchairs being produced and distributed to users, with all associated services.
EARs Inc (18)	Los Alcazirro, Dominican Republic	Based at Dr Elias Santana Hospital in Los Alcazirro. Non-governmental hospital offering high-quality, low-cost care to the poor. EARs inc no longer involved.	1	1	1	1	2,3	Project is self-sustaining with seven full time staff and 437 patients/month. Provides audiology servies including hearing aids fitting and repair.

Project/ organisation name	Location	Description	A. Medical (1) / Social (2)	B. Specific (1) / Generic (2)	C. Passive (1) / Active (2)	D. Centralise d (1) / Decentrali sed (2)	E. Policy (1) / Products (2) / Personnel (3)	Evidence of quality or impact
Lucy Montoro Rehabilitatio n Mobile Unit (4)	State of Sao Paulo, Brazil	Mobile unit. Travels to different regions as an outreach service. Works with regional government departments to take referrals of people needing PO or other MA. Multidisciplinary team. Each patient can visit the clinic up to three times for assessment, fitting and receiving the product.	1	1	2	2	1,2,3	The data collected from the MU was used to predict the need in each region. This data was used in setting up permanent rehabilitation services in the regions. In Sao Jose do Rio Preto, 113 AT devices were provided by the MU. Once a permanent facility was set up in 2012, 1314 devices were delivered, then 2223 devices in the following year.

The Global Assistive Technology Information Network: Progress and challenges

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Abstract

Objectives. Information on available assistive technology products and services (AT) plays a key role in improving effective access to assistive solutions to those who need it. To address their information need, public databases have been established in several countries over the years. Unfortunately, most other countries have no such information service. The WHO GATE initiative calls for a global approach whereby the wealth of information available worldwide is put together to serve all countries. **Approach.** EASTIN – the Global Assistive Technology Information Network - was created in 2005 by six Organizations based in the European Union, as the result of a collaborative project initially funded by the European Commission. The initial objective of EASTIN was to provide comprehensive, accurate and unbiased information on assistive technology products available in the European market to all the stakeholders needing it. Recently, the network evolved from a European to a global perspective, with the goal of gradually becoming the worldwide AT information hub. The network is operated by the EASTIN Association, a non-for-profit legal entity supported by its members through their annual membership fees. The current membership includes 7 Partners and 16 Affiliates. The core of the EASTIN network is the online information system www.eastin.eu, which provides – currently in 24 languages – information on AT products available in various countries, supply companies and other useful material such as fact sheets, case studies and manuals. The EASTIN system is not a database in itself; it is a search engine that aggregates the contents of several independent national databases, each running on a different technological platform: HMI-Basen (Denmark), DLF-Data (UK), Rehadat (Germany), SIVA (Italy), Handicat (France), Vlibank (Belgium) and AT-AUST (Australia). **Findings.** The EASTIN system provides a unique picture of the range of AT products available on the market worldwide. Currently it provides documentary evidence of over 60,000 assistive products. In relation to the twelve main classes of the ISO 9999:2016 standard classification, they include (in decreasing numerosity): 13,109 products for

mobility and transportation (ISO 12); 10,471 for self-care activities (ISO 09); 10,109 related to furnishing and fixtures (ISO 18); 8,652 for communication and information management (ISO 22); 5,530 for measuring, supporting or training body functions (ISO 04); 2,945 for controlling or handling objects and devices (ISO 24); 2,240 for domestic activities (ISO 15); 2,248 orthoses or prostheses (ISO 06); 2,147 for recreation and leisure (ISO 0); 1,904 especially related to worksite adaptation (ISO 28); 1,377 for education and training in skills (ISO 05) and 177 for improving the physical environment (ISO 27). In relation to the WHO APL (Assistive Products Priority List) the most numerous items appear to be manual wheelchairs (2,500 models, including 2,040 manual for active use, 705 manual assistant controlled and 223 with postural support) and electric wheelchairs (2,022 models), followed by chairs for shower/bath/toilet (1,937 models), pressure relief cushions (1,458) and mattresses (1,457), hand rails / grab bars (1,330), rollators (961) and time management products (895). Overall, about 25,000 products are estimated to fall within the APL.

Conclusions. The EASTIN system is designed in such a way to allow a potentially unlimited number of databases to plug in and be searchable through the EASTIN engine, independently of their technological platform. It is each partner's task to write, deploy and maintain the web-services interface that ensures communication between the database and the engine, according to the technical specifications publicly provided by EASTIN. It is therefore a good idea, within the GATE framework, that any other AT database established in any country worldwide considers joining the EASTIN network, thus collaborating to improve the information coverage on AT products worldwide. The prerequisite – from the EASTIN viewpoint – is that the database contents should be comprehensive, continuously updated and independent of commercial interest, as the EASTIN goal is to provide accurate and reliable information to serve the people's need.

Keywords

Information Databases, Assistive Products Provision, Global networks

Introduction

Information on available assistive technology products and services (AT) plays a key role in improving effective access to assistive solutions to those who need it. Recent studies identified the following information targets (1):

1. **End-users** (this term indicates persons with disabilities or elderly persons needing assistive products to carry out daily life tasks or participate in education or work or social life; it extends also to family members and any other informal or formal caregivers when they are involved in the usage of the assistive solution);
2. **Professionals** in health, social work and education, including not only at specialists but also general practitioners or community workers;
3. At **manufacturers and suppliers**, also including "makers communities" and solution integrators;
4. **Policy makers**, also including health/social services authorities;

5. **Scientists**, including academics, researchers and students; and
6. **General public**, as public awareness of it is also important to support any process in this field.

Today, Internet search engines such as Google are of great help in finding AT information in the Web. However, the vastness of the AT world – where products are described in the Web with varied terminology and different information structure, in various languages and in different contexts – makes it difficult to perform systematic searches of possible solutions to one individual's need, to get comprehensive answers, to distinguish between high and low-quality products, and to make comparisons that are useful to decisions (2).

What's more, assistive product information retrieved by Internet search engines is mostly produced by AT manufacturers and suppliers; however good the quality of this information may be, it is unavoidably driven by commercial interest. Conversely, end-users, professionals and all other actors involved need *super-partes* information (i.e. independent of commercial interest) to make sure that the most appropriate solutions to each individual case are chosen (2).

To address information need, public databases have been established in several countries over the years. Today, in these countries, citizens can rely on a comprehensive information source that helps make informed decisions on the assistive solutions needed for each individual person and – at policy level – to decide on appropriate measures to organize effective provision systems at national or local level.

These information systems are more than just databases: information is collected and stored according to standard structures, which makes comparisons possible among different products; search systems are designed so as to provide guided search paths, based on deep knowledge of audience information needs; the information provided often includes not only pure product data but also instructions on where the product can be purchased, suggestions on specialized centers which can provide expert consultation, fact sheets and documentation containing knowledge that helps take informed and responsible decisions.

In some countries, these information systems receive public funding, as those States recognize they help fulfil the citizens' right to access AT as highlighted by the UN Convention on the Rights of the persons with disabilities (see e.g. art. 20/b, that urges member states to implement measures "*facilitating access by persons with disabilities to quality mobility aids, devices, assistive technology and forms of live assistance and intermediaries*") (3).

Unfortunately, many countries have no such information and guidance service. The WHO GATE initiative calls for a global approach where the wealth of information available worldwide is put together to serve all countries. This article describes how EASTIN – the Global Assistive Technology Information Network – is contributing to this goal and provide data and facts about the AT products currently available worldwide as they emerge from the EASTIN information system.

Approach

The EASTIN network started in 2005, as the result of a collaborative project (partially funded by the European Commission) carried out by six Institutions based in the European Union. The initial objective was to provide comprehensive, accurate and unbiased information on AT products available in the European market to all citizens and stakeholders needing it. The network's name still reflects its original perspective, as the acronym "EASTIN" stands for "European Assistive Technology Information Network" (4).

More recently, the network evolved from a European to a global perspective, with the ambition to become gradually the worldwide AT information hub. The original acronym was maintained, as it had become in the years an internationally well-known brand; now the network identifies itself as "EASTIN – The Global Assistive Technology Information Network".

The network is operated by the EASTIN Association (a non-for-profit legal entity based in Italy) and is supported by its members through their annual membership fees. Each member serves as the EASTIN national contact organization for its country, and thus is responsible for the country's linguistic layer of the EASTIN website and for answering questions posted by citizens of that country through the website. This is the reason the network accepts only one member for each country (or one for each "linguistic culture" within a country where more language communities are present).

Two levels of participation in the network are possible:

- **Partners** (organizations that provide the core information of the EASTIN system through their national databases);
- **Affiliates** (organizations that have no national database but can use the central EASTIN repository to build one).

In addition to that, two levels of external participation is possible:

- External national contacts (organizations that volunteer to serve as national contacts for other countries but make use of an already existing linguistic layer)
- External thematic members (organizations that operate international databases on specific AT domains that can add useful information to the Eastin system).

The core of the network is the online information system www.eastin.eu, which provides – currently in 24 languages – information on AT products available in various countries, supplying companies and other useful material such as fact sheets, case studies and manuals. The EASTIN system is not a database in itself; it is a search engine, which aggregates the contents of several independent national databases, each running on a different technological platform.

The data comes from the seven national databases currently connected to the EASTIN engine and continuously updated through rigorous data quality control procedures: *SIVA (Italy)*, *HMI-Basen (Denmark)*, *REHADAT (Germany)*, *DLF-Data (UK)*, *HANDICAT (France)*, *VLIBANK (Belgium)* and *AT-AUST (Australia)*.

The SIVA database (Italy)

SIVA (www.portale.siva.it) (5) includes information on AT products available on the Italian market (10,864 – 3,845 of which recently updated), companies (overall, 1,751 companies, including manufacturers, primary suppliers and local resellers), AT expert centers (137) and ideas (630 hints on how to solve daily life problems). It also includes related documentation such as handbooks, lectures and articles (426). It works in both Italian and English. Product information is provided by the manufacturers or the Italian primary suppliers, through online structured input forms, and its accuracy is verified by the editorial team; each year this team also contacts the companies to make sure that any new product is entered in the database and existing products are regularly updated. The SIVA system is used mostly by health care professionals – especially those working in AT assessment centers – and by AT users throughout the country. In 2018 Google Analytics detected 132,522 visits / 181,464 sessions (i.e. average 363/497 each day). The SIVA database is funded and operated by Fondazione Don Gnocchi (a large Italian charitable NGO providing care and rehabilitation services to people with disabilities and elderly people) as part of a wider program, which also includes a network of AT assessment centers where expert teams can help the clients find the assistive solutions meeting their individual needs.

The HMI-Basen database (Denmark)

HMI-basen (<https://hmi-basen.dk>) (6) includes information on 31,376 assistive product series from about 1,200 primary suppliers on the Danish market (15,169 product series for sale + 16,207 discontinued product series). The information is collected from suppliers having online access to register and update product information. Besides product, and supplier information the database includes an integrated app search (retrieving information on apps from App Store and Google Play), 40 guides about specific product areas (rollators, powered wheelchairs, alarms for persons with epilepsy etc.), list of products for 14 specific target groups (e.g. dementia, children, incontinence, visually impaired), references to relevant principle rulings and templates for public procurement covering 27 broad product areas. Data from HMI-basen can be published in other websites as “free open public data” in TXT files and in a JSON web service. Data from HMI-basen through these services is used by Danish municipalities and hospitals for stock management and other administrative purposes related to the Danish service delivery system. HMI-basen is operated by Socialstyrelsen (The National Board of Social Services), a government agency under the Ministry for Children and Social Affairs. The interface works both in Danish and English and in 2018 Google Analytics detected 496,111 users / 950,361 sessions (i.e. average 1,359/2,604 each day).

The REHADAT database (Germany)

REHADAT (www.rehadat.de) (7) is the German national information system supporting the rehabilitation and participation of people with disabilities. It is funded by the Ministry of Labor and Social Affairs. Detailed information about various aspects of vocational

rehabilitation is available from databases and online-portals, designed for use by people with disabilities and health problems, elderly people and professionals. The Assistive Products portal (www.rehadat-hilfsmittel.de) is the most comprehensive and mostly used part in the REHADAT System. It is well known around the country by end users, experts and the AT industry. In 2018, Matomo detected more than 750.00 visits on this REHADAT-portal. Documenting more than 23,000 products, the database contains most assistive products that are available on the German market. The range of technical aids in this database covers all items listed in the ISO 9999 standard “Assistive products for persons with disability - Classification and terminology”. Each product is described in detail, with also Information on the manufacturer and the retailers. In addition to this market overview, information such as test reports and jurisdiction are provided. The database is bilingual and provides the information in German and English. At a technical level, REHADAT provides a service-oriented architecture (SOA) and offers standardized interfaces via web services.

The DLF-DATA database (UK)

DLF Data (<https://data.dlf.org.uk>) is the database which powers DLF’s popular websites www.livingmadeeasy.org.uk and www.asksara.org.uk attracting 1,291,478 unique visitors in 2018 (1, 473,123million sessions). The database features practical advice and guidance on a wide range of assistive technology – from coiled shoelaces to ceiling hoists). Over 950 suppliers and over 10,500 products are featured. Product information is provided by suppliers and then verified and sanitized by DLF Data Services team. The information is reviewed on a rolling basis every two years to ensure accuracy and availability, with regular contact with suppliers. New products and suppliers are solicited regularly. In addition, the database lists 1,100 retail outlets and stockists of assistive technology. DLF Data is a subscription database (from £75 for independent Occupational Therapists to £950 for large organizations). The database is used by health and social care professionals in community and acute settings and organizations of and for disabled people across the United Kingdom. The database is funded by DLF’s income generating services such as training and licensing of AskSARA (i.e. no government funding or Trust/Foundation support).

The HANDICAT database (France)

HANDICAT (www.handicat.com) is a French national resource on AT products available on the French market. It includes about 8,000 thousand products and over 1,000 manufacturers and national suppliers. Each product is described with technical details, price, funding, pictures and often additional pdf documentation. The possibility for users to comment and review the products has been recently added. Several searching methods are available: keyword search, usage search, ISO 9999 search, and advanced search with specified field search such as weight, speed and size. An assistance form is also available for complex searches where documentarists or occupational therapists answer all questions. 420,000 sessions and 314,000 unique visitors have been detected in 2018 by Google Analytics.

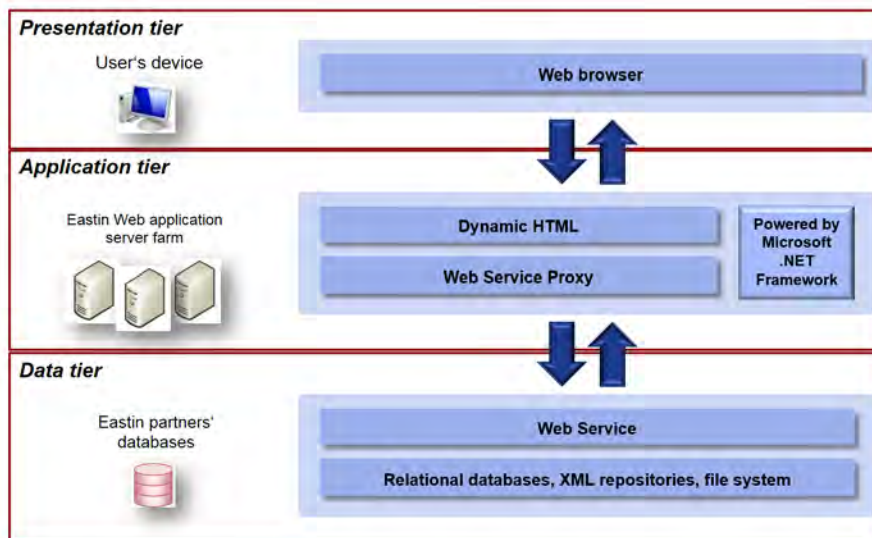
The VLIBANK database (Belgium)

Vlibank (www.vlibank.be) (8) is the Belgian (Flemish) database of AT products. The database contains continuously updated information on 9,436 (as of 15/05/2019) products available in the Flemish market. The database contains 2,751 addresses of manufacturers (Belgian and abroad), dealers and resellers. Each product record contains a digitized copy of the product brochure provided by the manufacturer or one of its dealers or resellers. Vlibank is only available in Dutch, however for interaction with the Eastin portal some of the content is translated into English. Vlibank is maintained by the Flemish Agency for Disabled Persons (VAPH). Since mid-2019, Vlibank is integrated in the website of VAPH, which gives information about the services for disabled persons in the Flanders Region. In 2018 Google Analytics reported 46,343 different users and 64,205 session (average 126/175 each day). 67% of the visits came from Belgium and 23% from the Netherlands. 20% of the visits were from a mobile phone, 10% from a tablet, the rest from laptop or desktop computers.

The AT-AUST database (Australia)

The AT Australian database, known as @Magic, holds around 10,000 products available in Australia and information on 2,950 suppliers of AT to Australia. Only products with complete information are uploaded to the website, www.at-aust.org. Within the website, people are able to search products by feature, use clipboards, compare products and find and contact a supplier close to their home. The database also contains 44 advisory documents and 2 booklets, (*Handbook for Memory Loss* and *Guide to Planning Bathrooms and Kitchens*) the latter of which is for sale only. When directly providing information and advice to almost 10,000 people each year, staff use an offline version of the @Magic database. During the last year, the database provided support to 399,138 unique visitors and provided 1,246,855 pages of information through the website. 30% of web database access is to people outside Australia, the top five nations represented are the USA, the United Kingdom, Canada, India and New Zealand. The database is operated by Assistive Technology Australia, an Australian registered charitable NGO, providing information and advice on AT and the built environment to those who need it. AT Aust is also a Registered Training Organization, accredited to deliver competency-based training within the Australia quality-training framework. AT Australia is supported by funding from the Australian Department of Health and Ageing and the NSW Department of Family and Community Services and by income generated through training and other activities.

Figure 1. Architecture of the EASTIN system

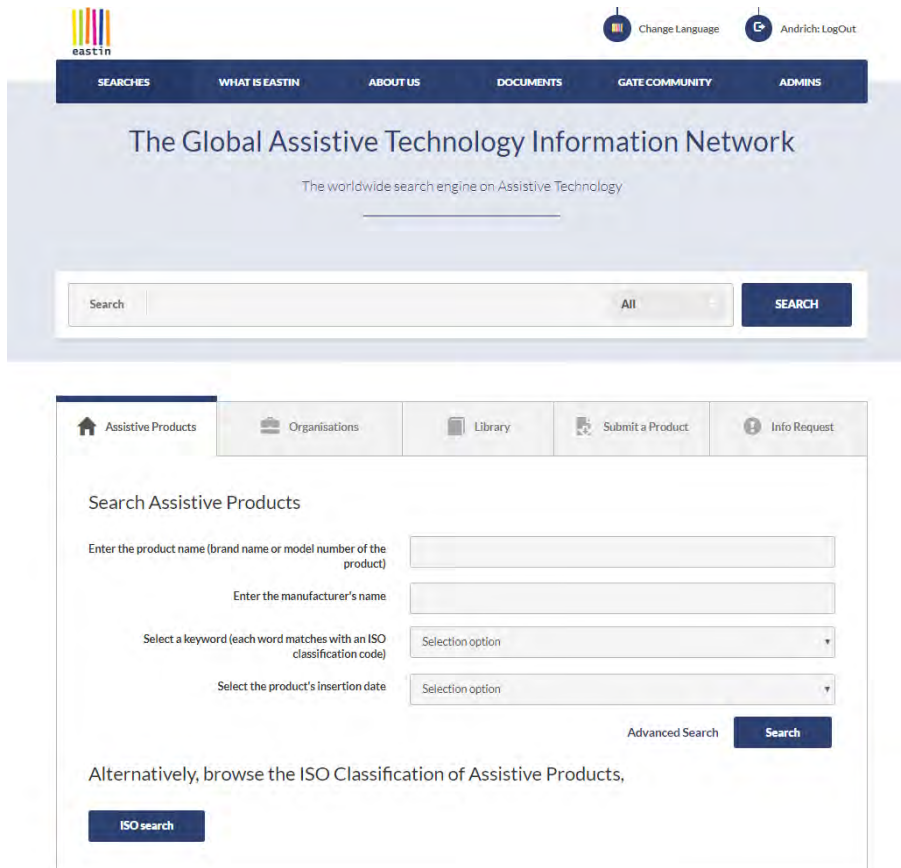


How does the EASTIN work

Technically speaking, the EASTIN system is based on a three-tier architecture (Figure 1) (9).

The upper layer (*presentation tier*) is the one that interacts with users, by means of their devices (PC or laptop or tablet or smartphone) and their Web browsers (Chrome, Safari, Firefox, Internet Explorer etc.). The home page (Figure 2) is automatically displayed in the user's Operating System language/culture or (if this does not correspond to any EASTIN linguistic layer) in a default language/culture named "English-International". From the home page, searches can be carried out of products (by ISO classification, by brand/model name, by manufacturer, by keyword, by insertion date), organizations (companies, service providers, projects) and related documentation (library). Users are also able to post questions (info requests) which will be answered by the selected EASTIN member or external national contact organization and manufacturers can alert EASTIN about new products that are not yet listed in any Partners' database and thus don't appear yet in the search results.

Figure 2. EASTIN Home Page, in "English International" language



Popular topics (main classes and subclasses of the ISO product classification) [What are ISO codes](#)

The middle layer (*application tier*) is the core of the EASTIN engine, that takes the search parameters from the presentation tier, activates the search into the partners' databases through its web service client software, gets the search results back from each partner's database, filters them according to agreed criteria (for instance, products whose last-modification date is older than ten years are excluded, in order to avoid obsolete information), sorts them according various criteria (the default sorting criterion is "first the most recently updated products") and sends the sorted results to the presentation tier to be displayed to the user in his or her preferred language. The engine is able to manage the possible temporary unavailability of any partners' server, in which case, the EASTIN search still works while alerting the user that there is missing information from that data base.

Finally, the lower layer (*data tier*) is composed of the partner's database, each communicating with the EASTIN web service proxy by means of a purposely-built piece of software (web service server) that "transforms" the requested data into the EASTIN scheme. The technical specifications for the partners to develop their web service server are publicly available (10). The data tier also includes a central repository which hosts all service data (language tables, classifications etc.) and a data upload tool for affiliate members to create their own products database which is visible to the EASTIN engine (11).

Any organization wishing to participate in the EASTIN network and connect their database into the EASTIN system should send an application to the EASTIN association. After verification that the candidate new member shares the EASTIN mission and goals, the database meets given requirements (comprehensiveness, reliability, national coverage etc.) and the candidate has the technical skills to develop the interface web service, the EASTIN Association arranges a plug-in technical test and - if successful – opens the procedure to become EASTIN partner.

Finally, it is worth mentioning that the EASTIN engine is also able to respond to machine-requests by other information systems, subject to IPR agreements and disclaimers that have to be agreed by all partners. Recently this facility has been experimented with, with the Global Public Inclusive Infrastructure (GPii) project (12) – an initiative promoted by a coalition of academic, industry and non-governmental organizations aimed at creating a global infrastructure that can deliver accessibility to every individual on any device they encounter. Within this project, the EASTIN sends information about some categories of assistive ICT products to a federated international database called Unified Listing (<https://ul.gpii.net/>) regarding solutions to ICT access (13). For each product retrieved by Unified Listing searches, the source database is acknowledged.

Findings

By searching the EASTIN information system, today we are able to get a picture of the range of AT products available on the market worldwide.

Overall figures about the Assistive Product categories available on the market

Currently the EASTIN system provides documentary evidence of 61,329 assistive products (see Table 1), whose data records have been updated recently or at least within the latest ten years. The most numerous class (referred to the ISO 9999:2016 standard classification) (14) is ISO 12 related to *mobility and transportation* (13,109 products). The other classes follow in decreasing numerosity: 10,471 for *self-care activities* (ISO 09); 10,109 related to *furnishing and fixtures* (ISO 18); 8,652 for *communication and information management* (ISO 22); 5,530 for *measuring, supporting or training body functions* (ISO 04); 2,945 for *controlling or handling objects and devices* (ISO 24); 2,240 for *domestic activities* (ISO 15); 2,248 *orthoses or prostheses* (ISO 06); 2,147 for *recreation and leisure* (ISO 0); 1,904 especially related to *worksites adaptation* (ISO 28); 1,377 for *education and training in skills* (ISO 05); 177 for *improving the physical environment* (ISO 27).

In order to avoid misunderstandings with the reported figures, one must consider that:

- In this context, “number of products” means “number of brand/models available”: it does not mean “number of items purchased”, as no EASTIN databases avails of this information;
- Only “off-the-shelf” products are considered (i.e. uniquely identified by a brand/model name): this doesn’t mean just ready-for-use objects but also products that need to be

configured / adjusted / tailored to the individual need, or components to be mounted to others to achieve an assistive solution; excluded are custom-made items which are individually built and thus don't exist as a brand/model;

- Products that are widespread on the international market are often present in more partners' databases, leading to product duplications in EASTIN searches.

In relation to the last point it is worth mentioning that – although the EASTIN includes a facility to “look for similar products”, based on a guess algorithm – no effective solution has been found so far to manage product duplications across the various databases. Here are some examples of difficulties encountered when trying to address the duplication issue: two products having the same brand/model in two different databases may not necessarily be the same product, as the version supplied in one country may differ from the one supplied in the other country due to different laws and regulations; a product may be supplied under different brands/models in various countries (or even within the same country) for marketing reason; the boundary between “different version” and “different model” is often blurred, so is differently managed in different databases.

Table 1 also shows how the contents are differently distributed among the source databases. While the products numerosness has similar distributions (in percentage of the whole contents) for classes 12, 09, 18 and 22, other classes show interesting differences: for instance, classes 06 (orthoses and prostheses) and 28 (products for worksite adaptation) seem to be comprehensively covered only by REHADAT.

Table 1. Number of assistive products models reported by each EASTIN database (search performed on June 15, 2019).

ISO Code	ISO 9999:2016 main class	TOTAL	SIVA (Italy)	HMI-BASEN (Denmark)	REHADAT (Germany)	DLF-DATA (UK)	HANDICAT (France)	VLIBANK (Belgium)	AT-AUST (Australia)
ISO 04	AP for measuring, supporting, training replacing body functions	5,530	333	1,508	1,777	790	299	338	485
ISO 05	AP for education and for training in skills	1,377	71	65	501	219	297	168	56
ISO 06	Orthoses and Prostheses	2,248	45	381	1,615	9	192	1	5
ISO 09	AP for self-care activities and participation in self care	10,471	491	3,036	2,288	1,571	350	1,364	1,371
ISO 12	AP for activities and part. relating to personal mobility and transportation	13,109	1,204	3,007	2,154	2,623	348	2,334	1,439
ISO 15	AP for domestic activities and participation in domestic life	2,660	99	877	319	385	184	337	459
ISO 18	AP supporting activities in indoor and outdoor human-made environments	10,109	504	2,336	1,459	2,567	345	1,464	1,434
ISO 22	AP for communication and information management	8,652	821	1,941	1,392	1,506	337	1,827	828
ISO 24	AP for controlling, carrying, moving, handling objects and devices	2,945	179	806	309	580	349	428	294
ISO 27	AP for controlling, adapting, measur. elements of physical environments	177	0	52	20	41	13	48	3
ISO 28	AP for work activities and participation in employment	1,904	12	168	1,286	42	214	22	160
ISO 30	AP for recreation and leisure	2,147	60	230	143	847	321	422	124
	Total	61,329	3,819	14,407	13,263	11,180	3,249	8,753	6,658

Figures about the WHO Assistive Products Priority List (APL)

Table 2 shows an estimate of the numerosity of the models existing on the market in relation to the 50 categories of the APL (15). As the EASTIN works based on the ISO 9999:2016 classification, the estimate can be made by mapping each APL item to the corresponding ISO categories. However, while most items can be precisely mapped, for some others any mapping is questionable. For instance:

- Item **APL 10** (Communication Software) corresponds quite precisely to ISO 22.21.12 (Face-to-face communication software);
- Item **APL 6** (Chairs for shower/bath/toiled) includes a wide range of products that fall within at least 3 ISO categories: 09.12.03 (Commode chairs), 09.12.12 (Raised toilet seats mounted on frame) and 09.33.07 (Shower chairs with and without wheels);
- Item **APL 8** (Clubfoot braces) is a very specific product that is “buried” within the ISO category 06.12.06 (ankle foot orthoses); actually, only one model was found in the EASTIN system by browsing one-by-one all 211 products retrieved in this ISO category. The reason may be that probably in the countries where the EASTIN databases are operated, this device may be not so popular, or is not available as a product with brand/model but is rather custom built by orthotists for each individual case. Whatever the reason may be, mapping is not applicable (n.a.) because this APL item is too narrow within a broader ISO category.
- Item **APL 14** (Gesture to voice technology) has no clear correspondence with any ISO category, although some products “buried” in ISO 22.36 (Input devices for computer) and ISO 22.39 (Output devices for computer) make use of this technology; thus mapping is not applicable also in this case.
- Item **APL 49** (Wheelchairs, manual with postural support) is dealt differently by the ISO classification, where wheelchairs designed with built-in postural supports are usually included among assistant-controlled wheelchairs, while postural supports that can be mounted on a wheeled basis are classified under 18.09.39 (Seating systems). Here we prefer to map this APL item to seating systems, as in the EASTIN databases the majority of manual wheelchairs with postural support tend to reflect the latter case.

Given the above, through the EASTIN system we can estimate the existence of about 25,000 products belonging to the Priority List. The most numerous APL items appear to be manual wheelchairs (2,500 models, including 2,040 manual for active use, 705 manual assistant controlled and 223 with postural support) and electric wheelchairs (2,022 models), followed by chairs for shower/bath/toilet (1,937 models), pressure relief cushions (1,458) and mattresses (1,457), hand rails / grab bars (1,330), rollators (961) and time management products (895). Overall, there are 14,065 APL product models for mobility, 4,245 for the environment, 2,279 for cognition, 3,203 for vision, 696 for hearing and 557 for communication.

Table 2. Estimate of the number of products (models) available for each item of the WHO Assistive Products Priority List (APL)

Code	APL Item	N. products	IsoMapping
1	Alarm signalers with light/sound/vibration	469	22.27.04 – 22.27.21
2	Audio players with DAISY capability	184	22.18.03
3	Braille displays (note takers)	77	22.12.21
4	Braille writing equipment/braille	130	22.12.12 – 22.12.15
5	Canes/sticks	505	12.03.03 – 12.03.16
6	Chairs for shower/bath/toilet	1,927	09.12.03 – 09.12.12 – 09.33.07
7	Closed captioning displays	17	22.18.21
8	Club foot braces		Not applicable
9	Communication boards/books/cards	137	22.21.03
10	Communication software	255	22.21.12
11	Crutches, axillary/elbow	255	12.03.06 – 12.0.312
12	Deafblind communicators	162	22.39.05
13	Fall detectors	586	22.27.18
14	Gesture to voice technology		Not applicable
15	Global positioning system (GPS) locators	240	22.27.24
16	Hand rails/grab bars	1,327	18.18
17	Hearing aids (digital) and batteries	117	22.06.12 – 22.06.15
18	Hearing loops/FM systems	73	22.18.30
19	Incontinence products, absorbent	540	09.30 – 09.31
20	Keyboard and mouse emulation software	170	22.36.18
21	Magnifiers, digital hand-held	718	22.03.18
22	Magnifiers, optical	762	22.03.09
23	Orthoses, lower limb	806	06.12
24	Orthoses, spinal	355	06.03
25	Orthoses, upper limb	544	06.06
26	Personal digital assistant (PDA)	33	22.33.06
27	Personal emergency alarm systems	586	22.27.18
28	Pill organizers	314	04.19.04
29	Pressure relief cushions	1,468	04.33.03 – 04.33.04 – 09.07.06
30	Pressure relief mattresses	1,451	04.33.08 – 18.12.18
31	Prostheses, lower limb	412	06.24
32	Ramps, portable	461	18.30.15
33	Recorders	184	22.18.03
34	Rollators	974	12.06.06
35	Screen readers	188	22.39.12
36	Simplified mobile phones	163	22.24.06
37	Spectacles (low vision, short/long distance, filters, protection)	82	22.03.03 – 22.03.06
38	Standing frames, adjustable	197	05.36.03

Code	APL Item	N. products	IsoMapping
39	Therapeutic footwear; diabetic, neuropathic, orthopaedic	366	09.03.42
40	Time management products	910	22.27.12 – 22.27.15 – 22.27.16
41	Travel aids, portable	44	12.39.06
42	Tricycles	723	12.18.06 – 12.18.09 – 12.18.15
43	Video communication devices	29	22.24.24
44	Walking frames/walkers	352	12.06.03
45	Watches, talking/touching	528	22.27.12
49	Wheelchairs, electrically powered	2,000	12.23.03 – 12.23.06 – 12.23.12 – 12.22.21
47	Wheelchairs, manual assistant-controlled	699	12.22.18 – 12.27.04
46	Wheelchairs, manual for active use	2,046	12.22.03 – 12.22.06 - 12.22.09 – 12.22.15
48	Wheelchairs, manual with postural support	226	18.09.39
50	White canes	236	12.39.03
-	Total	25,028	

Discussion

The EASTIN system is a unique information resource in the assistive technology domain. Currently it is based on seven national databases from seven countries, and most of the products included are in principle available worldwide. EASTIN is not conceived as an alternative to national information systems: it only deals with information of trans-national value (the existence of a product, the picture, a basic description and links to the product record in the source database) while each national system provides a wealth of information to guide the user to make choices and take decisions. Basically, EASTIN is a tool that helps to know whether assistive solutions that solve a problem are available somewhere in the world.

The ambition is that other databases from other countries join the endeavor, to have all products reachable by one single access point. For this reason, the EASTIN engine has been designed in such a way to allow a potentially unlimited number of databases to plug in and be searchable through the EASTIN engine, independently of their technological platform. It is each partner's task to write, deploy and maintain the web-services interface that ensures communication between the database and the engine, according to the technical specifications publicly provided by EASTIN.

It is therefore a good idea that any other AT database established in any country worldwide considers joining the EASTIN network, thus helping improve the information coverage on AT products worldwide. Obviously, this need on their side a solid motivation – the same as the seven current partners have – to invest in international collaboration. If assistive technology

information will be in the agenda of the GATE global collaboration, we expect there will be more reasons for them to join the network. Then they will experience – as the current partners do – that the efforts spent in plugging-in a national database and participating in the network are widely repaid by the opportunity to help each other to improve the contents quality and the data collection efficiency, and by their increased national profile due to being part of a global network. The prerequisite – from the EASTIN viewpoint – is that the database contents should be comprehensive, continuously updated and independent of commercial interest, as the EASTIN goal is to provide accurate and reliable information to serve the people’s need. For this reason, a detailed analysis is carried out before including any new partner.

Countries that do not have a national assistive technology database and have no resources to build one can also participate in the network as information providers: the EASTIN system offers software tools to upload information on locally manufactured products and related resources (suppliers, organizations etc.), which will be retrieved in EASTIN searches. This could be a useful facility especially for medium or lower income countries whose local product availability is limited: through the system, people can learn either what is available in the world or what is locally available.

The current fast evolution of the AT market and the even faster advancement in information technology greatly challenges all database providers and especially a global information system such as the EASTIN. These challenges – to mention a few - are related to **information contents** (e.g. how to address the emerging world of App-based AT solutions or makers communities), **information sources** (e.g. what contents should be considered of national/local interest rather than of global interest), **technical approach** (e.g. more user-friendly search strategies and tools) and **sustainability** in the long run. Only international collaboration can properly address these challenges; the collaboration within the GATE initiative is playing a strategic role in this endeavor, and work is in progress to work out the most appropriate roadmap.

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Procurement of assistive technology based on Norwegian experiences

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Abstract

Background and objectives: Procurement of assistive products, accessories, spare parts and related services are based on four strategic objectives: to procure the most appropriate, good quality, affordable assistive products; selection of reliable suppliers; ensure timely deliveries; achieve the lowest possible total cost. Moreover, the procurement is also based on core principles such as integrity, fairness and transparency; competition, economy and efficiency and available assistive products. The objective of my paper will be to show how these objectives are met by which actions in Norway. Norway has a public system for assistive product procurement and provision. Procurement is based on tendering and contracts for deliveries of assistive products, accessories, spare parts and related services for the whole country are entered with different suppliers. **Approach:** The writing of the paper is based on my experiences with the present Norwegian procurement system, which has been in operation since 2007. **Expected findings:** The main finding is that the objectives are achieved to a great extent, and that the core principles are followed throughout the procurement processes. **Best practices and recommendations:** I will recommend that procurement teams should be established and that these teams should be responsible (on behalf on a superior manager) for the procurement process, from quantification of needs and till the signing of the contracts. There could be national procurement teams or different teams for the different regions/districts of a country. The procurement teams should consist of experienced professionals like e.g. physiotherapists, occupational therapists, procurement professionals, engineers/ technicians. **Challenges and opportunities regarding greater access to quality, affordable AT for all:** The cost of the assistive products is one challenge for low-and-middle income countries. Another challenge is lack of qualified personnel in many of these countries. Lack of necessary funding is also a challenge in many countries, especially in low-and-middle income countries. There is a huge unmet need for assistive products throughout the world. This also means that there are huge market opportunities for manufacturers of assistive products. Lager volumes will perhaps reduce the prices and perhaps make the assistive products affordable for countries that do not afford to buy these products today. Competition among suppliers is also one way of reducing the prices of assistive products.

Keywords

Competition, transparency, reliable suppliers, affordability

The Global Accessibility Reporting Initiative: Helping consumers find devices with the features that best serve them

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Abstract

Introduction: GARI's mission is to inform consumers about existing accessibility solutions in the market today and specifically to help them identify devices with features that best meet their individual needs. This includes mobile phones with built-in screen readers, 'simple access' for persons who find today's user interfaces overwhelming, wearables with haptic feedback, Smart TVs that allow voice recognition for accessing features, or mobile apps that have been developed specifically to help overcome a barrier in daily life like finding accessible locations. GARI currently covers five product groups with information on the accessibility features of more than 1,500 individual devices in 18 languages. Objective: The objective of this paper is to provide information on this resource to an audience that can greatly benefit from knowing about the existence of accessibility features in mainstream devices and the central source of information that GARI constitutes. Approach or method: The data provided in this paper is partly the result of 4 Feature Reviews, in which a network of 80+ organisations of persons with disabilities and accessibility experts worldwide have been consulted for feedback on the use and usability of the GARI database and website. The rest of the data (use statistics, geographical distribution of users, uptake of accessibility features) has been gathered through tools implemented in the GARI backend as well as the use of Smarter Stats.

Keywords

Mobile accessibility, mainstream accessibility, accessible mobile devices, accessibility features, simple access, screen-readers, voice recognition, accessibility apps, usability.

What is GARI?

GARI was created in 2008 by the Mobile & Wireless Forum (MWF) to provide information on accessibility features in mobile phones and to help consumers identify devices that support these features. The GARI website (www.gari.info) features an evolving searchable database that currently has information on more than 300 accessibility features in over 1,500 devices in 18 languages.

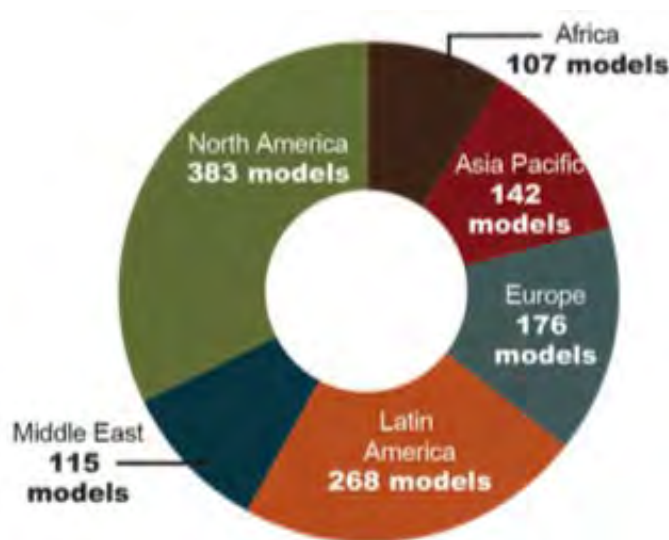
Five product groups and 1,500+ accessible devices

GARI started out as a simple spreadsheet listing accessibility features available in mainstream mobile phones. Since then, the database has grown to provide information on the accessibility of over 1,500 devices, including mobile phones, tablets, Smart TVs, Wearables and almost 500 accessibility related apps.

The GARI database is populated with new devices coming to the market.

By the end of 2018, the database listed information on almost 400 phone models in North America, around 270 phone models in Latin America, over 140 models in Asia Pacific, 115 models in Middle East and just under 180 models in Europe.

Figure 1. Over 300 accessibility features



The GARI database currently provides accessibility information on:

- 121 features for mobile phones;
- 67 features for tablets;
- 61 features for Smart TVs; and,
- 52 features for Wearables.

These features have been developed in collaboration with the disability community, accessibility experts, industry and national regulators.

The MWF has furthermore committed to regular reviews of the features that GARI reports on, in light of changes in the technology and customer needs. Every two years, stakeholders with an interest in mobile accessibility are invited to provide comments or suggestions on the features that they would like to see reported on by manufacturers.

In 2017, the MWF carried out the 4th GARI Feature Review involving more than 80 stakeholder organizations from around the world. As an example of the usefulness of this process, as part of that review the European Disability Forum (EDF), who represents the

interests of 80 million people with disabilities in Europe, suggested the addition of “Emergency Service & Location” as a feature to be reported on. This function within devices involves the automatic transmission of location data when placing an emergency call and while helpful for all users, has additional value for those with a disability.

The feature was indeed added to GARI in the beginning of 2018, and by the end of the year already over 100 devices in the database were reporting that they supported the function making it easy for users interested in this feature to find an appropriate device.

The 5th GARI Feature Review is currently underway.

Reporting that is in line with national regulations and standards

The MWF took care to match the features in the database against national regulations and standards such as Section 508 in the USA and EN 301 549 in Europe, as well as Australia’s Telephone Equipment Industry Code C625, in order to support companies in reporting on the compliance of their devices.

The main objective of GARI is to provide information about accessibility solutions that already exist in today’s devices to consumers that will benefit most from these features. These consumers include seniors, persons with disabilities, their family members and care givers. At the same time, GARI provides manufacturers with a way to provide this information to consumers that is in line with information requirements set out in national regulations and standards.

How many people are using GARI?

In 2018, the GARI website attracted on average over 59,000 unique visits and over 600,000 page-views per month. This data only covers the main project site and does not include information on usage from the many organizations that also use the underlying data via direct XML feed.

In addition to the public usage of the site there are many examples of how organisations and stakeholders around the world use GARI in different ways:

1. Mobile network operators link to GARI via the dedicated accessibility pages on their web-sites and invite their store personal to use GARI to search for appropriate devices when confronted with consumers that have individual needs (e.g. <https://www.telefonica.com.mx/rc-sostenibilidad/transparencia-y-dialogo/nos-importa-mexico>)
2. Organisations of persons with disabilities provide the link to GARI via their website as service to their members and publish regular updates about GARI’s progress in their newsletters (e.g. <https://www.hearingloss.org/hearing-help/technology/phones-mobile-devices/>)
3. National regulators integrate GARI into their websites to provide their visitors with information on accessible mobile devices and encourage mobile network operators to

actively use the GARI database as service to their customers (e.g.

http://www.ancom.org.ro/en/baza-de-date-telefoane-persoane-dizabilitati_5252)

4. Occupational therapists use GARI to inform their clients about available features in mainstream devices
5. Platforms such as Atvisor.ai (<https://www.atvisor.ai>), which is an AI-based digital platform for assistive technology consultation, for the shared use of healthcare professionals and their clients – people with disabilities and the elderly, integrate the GARI data via xml feed
6. Mobile network operators use GARI for the selection of accessible devices for their product portfolio
7. Consumer organisations provide information and a link to GARI as service for their members and to improve consumer information

By the end of 2018, the GARI database was being actively used by governments, regulators, civil society, universities and industry bodies in 26 countries around the world.

Where do GARI users come from?

In 2018, Latin America remained the region using the GARI database most intensively with 34.09% of searches via the web interface, followed by North America with 29.50% and Europe with 17.37% of searches. The remaining visitors to the site came from Asia, Africa and the Middle East.

Accessibility information in 18 national languages

As important as it is to provide information on the accessibility features in devices, it is equally important to provide the information in an accessible format. For this reason, the GARI website was designed to be usable with screen-readers and includes a collection of American sign-language videos that explain how to use the site. In addition, the GARI site has been translated into 18 languages allowing consumers to search the database in their preferred language irrespective of where they reside.

Languages currently supported on the site include Arabic, Chinese, Danish, Dutch, English, Finnish, French, German, Hungarian, Italian, Japanese, Korean, Norwegian, Polish, Portuguese, Romanian, Spanish, and Swedish.

The MWF is committed to expanding the range of languages that GARI is provided in and is happy to work with partner organizations to help bring this about.

Over 100 accessibility features – how to know where to look first?

A recurring theme is the need for better information on available solutions as well as the education of users and digital capacity building among persons with disabilities and older users.

In order to address this need, the MWF prepared a new information guide on the accessibility features in mobile devices – the *GARI Feature Guide (1)*. It explains what kind of features exist in today’s devices and what situation they might be helpful in.

Figure 2. The GARI feature guide



In addition, there is a useful overview table - *Accessibility Features at a Glance (2)*:

Figure 3. GARI Accessibility features at a glance

VISION

- Moderate visual impairment**
 - Screen Magnifier
 - High Contrast Mode
 - Display Characteristics - Color - Enhancement
 - Display Characteristics - Backlight for Display
 - Display Characteristics - Adjustable Contrast Control
 - Display Characteristics - Adjustable Brightness Control
 - Adjustable Font Size
 - Adjustable Font Style
 - Dedicated and clearly distinguishable volume keys
 - Backlight for Keypad
 - Key Identification
 - Web Browser Zoom
- Severe visual impairment**
 - Web Browser Zoom
 - Speed Dial
 - High Contrast Mode
 - Voice Output of Caller ID from Contacts List
 - Visual Menu
 - Audible Cues - Volume
 - Audible Cues - Calls
 - Audible Cues - Power
 - Audible Cues - Battery
 - Dedicated and clearly distinguishable key to lock the screen
 - Screen Magnifier
 - Display Characteristics - Adjustable Brightness Control
 - Display Characteristics - Adjustable Contrast Control
- Profound visual impairment**
 - Audible Cues - Enhancements
 - Audible Cues - Charging
 - Supports Accessibility APIs
 - Voice Output of SMS: Inbuilt
 - Ring Tone Variations
 - Personalized Shortcuts
 - Audible Identification of Keys - Functions
 - Audible Identification of Keys - Spoken
 - Standard Number Key Layout
 - Screen Magnifier
 - Web Browser Zoom
 - Display Characteristics - Adjustable Brightness Control
 - Display Characteristics - Adjustable Contrast Control
- Blindness**
 - Haptic Feedback
 - Screen Reader
 - Built-in Display Support
 - Voice Recognition for Dialing or Accessing Features
 - Automatic Features - Automatic Answer
 - Key Feedback - Audible
 - Key Feedback - Tactile
 - Tactile Key Marker - 'S'
 - Tactile Key Markers - 'P' and 'I'
 - Dedicated and clearly distinguishable volume keys
 - Personal Assistant / Voice Control

HEARING

- Mild hearing loss (lower end 25 to 40dB)**
 - Adjustable Maximum Volume Control
 - Ringer Volume - Adjustable
 - Mono Audio
 - Messaging Options - Email
 - Messaging Options - Text Messaging/SMS
 - Visual Indicators on Display - Missed Mail
 - Headset - plug connect
 - Hearing Aid or HAC Setting
 - Improved Call Quality
- Moderate hearing loss (40 to 70dB)**
 - Real-time-text capability
 - Call Logs
 - Key Feedback - Displayed
 - Messaging Options - Predictive Text
 - Visual Indicators on Display - Battery
 - Visual Alerts - Incoming Calls
 - Hearing Aid or HAC Setting
 - Ringer Volume - Adjustable
 - Adjustable Maximum Volume Control
 - Mono Audio
 - Ringer Volume - Adjustable
 - Improved Call Quality
- Severe hearing loss (70 to 95dB)**
 - Real-time-text capability
 - Adjustable Vibrating Alerts
 - Visual Alerts - Electronic Message
 - Key Feedback - Displayed
 - Video Conferencing
 - SMS Personalisation and Reuse
 - Visual Alerts - Other
 - Allows for sign language communication
 - Flashlight/Notification
 - Visual Alerts - Other
 - Allows for sign language communication
- Profound hearing loss/deaf**
 - Real-time-text capability
 - Allows for sign language communication
 - Flashlight/Notification
 - Front Facing Camera
 - Two-way Video Communications - using wireless LAN networks
 - Two-way Video Communications - using mobile networks
 - Vibrating alert
 - Visual Alerts - Other
 - Real-time-text capability
 - Supports Closed Captioning for Web Video or Streaming
 - Allows for sign language communication

SPEECH

- Speech disorder**
 - Real-time-text capability
 - Allows for sign language communication
 - Front Facing Camera
 - Two-way Video Communications - using wireless LAN networks
 - Two-way Video Communications - using mobile networks
 - Video Conferencing
- Language disorder**
 - Supports Closed Captioning for Web Video or Streaming
 - SMS Personalisation and Reuse
 - Messaging Options - Predictive Text
 - Messaging Options - MMS
 - Messaging Options - IM
 - Messaging Options - Text Messaging/SMS
 - Supports ability to install third party applications or apps

DEXTERITY

- Reduced gross motor skills (mobility)**
 - Personal Assistant / Voice Control
 - Device support
 - External Switch / External Support
 - Visible Focus Indicators
 - Voice Recognition for Accessing Features
 - Voice Recognition for Dialing
 - Automatic Answer
 - Device Coupling - Bluetooth/WLAN
 - Device Coupling - Infrared
 - Device Coupling - Cable
 - Display Characteristics - Screen Flicker
 - Personal Assistant / Voice Control
 - Supports Accessibility APIs
- Reduced fine motor skills (dexterity)**
 - Text-to-Speech / Dictation
 - Supports Gesture Based Navigation
 - Hand Movement
 - Easy to Press Keys
 - Guarded/Recessed Keys
 - Text Messaging Services Capable
 - Speaker-phone capable
 - External Keyboard Support
 - Layout Pin for key ring or Lanyard Strap
 - Ease of Opening for Clean Shell Flip Phone/Slide
 - Anti-slip Features
 - Automatic Features - Automatic Answer
 - Personal Assistant / Voice Control
 - External Switch / Voice Support
 - Visible Focus Indicators

COGNITION

- Mild cognitive impairment**
 - Differentiation of Function Keys
 - Voice Notes
 - Simplify Display
 - GPS Capability
 - Copy and Paste
 - Simple Instructions
- Severe cognitive impairment**
 - Emergency services and location
 - Assistance Instructions
 - Photo Associated Telephone Book
 - Simple Reminders
 - No Screen Timeout

DEAFBLIND

- Deafblind**
 - Dedicated and clearly distinguishable volume keys
 - Allows for sign language communication
 - Supports Closed Captioning for Web Video or Streaming
 - Adjustable Maximum Volume Control
 - Video Conferencing
 - SMS Personalisation and Reuse
 - Messaging Options - Predictive Text
 - Screen Reader
 - Screen Magnifier
 - Built-in Display Support
 - Web Browser Zoom
 - High Contrast Mode

MWF Mobile & Wireless Forum
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 Web: www.mwfai.org
 Twitter: @GARIupdates

GARI – a tool to help put accessibility policy into practice

Countries who have signed the UN Convention on Rights for Persons with Disabilities have committed to “enable persons with disabilities to live independently and participate fully in all aspects of life. [...] States Parties shall also take appropriate measures: [...] to promote access for persons with disabilities to new information and communications technologies and systems, including the Internet” (3).

Over the last decade, mobile devices have become the most popular means of accessing ICT services and with their widespread adoption and usage in conjunction with the many features that they offer, mean that these devices have become one of the more important gateways to a more accessible society for everyone.

While many devices today include a variety of accessibility features, a majority of users and in particular those who would benefit most from these features including persons with disabilities and older users, very often do not know about them. The need for better information on available solutions, education and digital capacity building is a recurring theme and highlights the need for a credible, central source of information on accessible devices that helps increase awareness, educates and demonstrates how the various features can be used and explains which devices support them.

The GARI database intends to serve this need. We work with governments and regulatory authorities around the world, providing them with a comprehensive overview of accessibility features available in today’s devices and offer them a platform where their citizens can learn about existing solutions and select a device best suited to their needs.

The MWF offers governments and organisations around the world the use of the GARI database, in order to inform their citizens and constituencies about the wide range of existing accessibility features in today’s ICT devices and help them find and select a device that best meets their needs.

Interested parties can link or reference GARI from their website or include the GARI dataset directly into their own website via a XML feed updated daily. The dataset is licensed under a Creative Commons License (4).

Several governments and regulatory authorities have chosen to utilise the XML feed including:

- Mexican Instituto Federal de Telecomunicaciones (IFT): http://movilesaccesibles.ift.org.mx/catalogo_desktop/app/web/busqueda.php
- US Federal Communications Commission (FCC): <https://ach.fcc.gov/resources-by-disability/blind-or-visually-impaired/>

As can be seen from the two examples above, using the GARI XML feed offers the ability to customise the presentation to fit national needs.

The MWF is happy to work with interested parties to identify the best way to implement and use the GARI database in their country and also provide additional support, such as guidance on how to promote mobile accessibility in general and the implementation of GARI in particular on a national level.

The links to many of the organisations already using GARI can be found on the “Examples of GARI in use” page: <http://gari.info/examples-of-gari-in-use.cfm>

Regular updates on the progression of GARI

Every year, the MWF publishes a report on the progress of the GARI project, summarizing the latest developments, usage statistics, trends and new features.

Figure 4. The GARI Annual Report 2018



The 2018 report can be downloaded from:

http://www.mwfai.org/docs/eng/MWF_GARI_2018AnnualReport.pdf

About the MWF

GARI is an initiative of the Mobile & Wireless Forum (MWF) - an international association of companies with an interest in mobile and wireless communications including the evolution to 5G and the Internet of Things. Its members include Alcatel OneTouch (TCT Mobile), Apple, Cisco, Ericsson, Huawei, Intel, LG, Motorola Mobility (Lenovo), Motorola Solutions, Qualcomm, Samsung and Sony. More information about the MWF and its activities can be found at www.mwfai.org.

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Interaction between functioning, disability and assistive technologies

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Abstract

Recommendations of assistive technology (AT) to a person depend on the factors that characterize a person and the environment. The research aimed at creating a simple tool to list of appropriate ATs for individual (re)habilitation programs based on the biopsychosocial model. Only disabling body functions were considered. Connections between impairments of body functions and structures, limitations of activities and participation, classified in the International Classification of Functioning, Disability and Health (ICF), were set. The selected appropriate ATs, classified in ISO 9999, and interventions can compensate these limitations. All findings were transformed into an electronic handbook called the Codifier of Disability Categories. Given approach enables defining AT to integrate a person into environment. Codes obtained as a result of formalizing the health conditions of a disabled person can be used to record (re)habilitation measures on a social card of a citizen electronically, to control the implementation of (re)habilitation measures, to analyze the needs in various types of ATs, to make budgets etc. Creating and maintaining the Codifier of Disability Categories greatly simplifies the development of individual (re)habilitation programs and improves their quality. It increases the skills of specialists, indirectly expanding their competence regarding to existing ATs and possibilities of their applications in specific cases. The Codifier of Disability Categories may be supplemented with extended information on AT suppliers. The manufacturer can position AT more accurately by describing impairments of the body functions and structures, limitations of activities and participation when AT can be applied. It helps to ensure greater access to quality, affordable AT for all who needs rehabilitation.

Keywords

ICF, assistive technology, Codifier of Disability Categories

Introduction

Sustainable Development Goal 10 emphasizes the social, economic and political inclusion of persons with disabilities (1). AT enables them to live more independently through the

application of specialized technologies that reduce or eliminate the impact of a disability. The Convention on the Rights of Persons with Disabilities (CRPD) obligates state parties to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost (Article 4 (g) (2)).

As in 2012 the Russian Federation ratified the CRPD (3), it is a duty of the state to provide social support and ATs to persons with disabilities. The Service of Medical and Social Expertise (MSE), which has a widespread system of bureaus around the country, evaluates needs of persons with disabilities in assistive devices and ATs. Recommended ones are written in individual (re)habilitation programs (IRPs). The Russian government in cooperation with the Fund of Social Insurance of the Russian Federation guarantees provision of the disabled with assistive devices and ATs according to the federal list of ATs (4). In some Russian regions, additional lists exist.

Selection of AT is a person-centered process to address individual's needs and a step towards making the link between AT and rehabilitation and requires highly qualified specialists. It is not always obvious which AT will suit a person in each particular case. This often does not depend on the diagnosis but is more related to the factors that characterize a person and the environment. Assistive products for persons with disability - Classification and terminology (ISO 9999:2016) significantly broadens the horizons of a specialist, but usually does not relate to a specific product (5). International Classification of Health Interventions (ICHI) allows selecting services (interventions) depending on the diagnosis, function, activities and participation (6), but there is no generally accepted bridge between categories of International Classification of Functioning, Disability and Health (ICF) (7) and ATs.

A group of experts from Albrecht Federal Scientific Centre of Rehabilitation of the Disabled completed research on development of the Codifier of Disability Categories in accordance with ICF (8). This Codifier of Disability Categories was differentiated according to the prior types of assistance that persons with disabilities require. The research aimed at creating a simple tool to develop IRP based on the ICF biopsychosocial model (7).

Methods and Materials

At the first stage the Codifier of Disability Categories was based on the ICF and the national standard of the Russian Federation: technical aids for rehabilitation of disabled persons (8) (analog to ISO 9999:2002), classification of rehabilitation services. The current concept is to map ICF, ISO 9999 and ICHI (5-7).

It was required to create software for implementing knowledge and approaches reflected in a number of the logically related but independent classifications. Until that moment, most of them were used mainly for statistical purposes.

The framework for the Codifier of Disability Categories consisted of the following assumptions (8). The analysis showed initial attributes that defined the need for assistance: impairments of body functions and structures, but the same dysfunctions could be caused by disorders of different body structures. Depending on the body structures impairments, different types of assistance had to be delivered. An impairment of a body function leads to limitations of activities and participation that can be decreased or eliminated by selection of appropriate ATs and (re)habilitation services (interventions)

The suggested structure of the Codifier of Disability Categories consists of independent records (codes) linked in chains and based on categories of the ICF domains with qualifiers, ISO 9999 and ICHI (5-7).

The Codifier of Disability Categories has 5 levels: the first level – category of disability, the second level – body functions + qualifier of impairment, the third one – body structures + qualifier of impairment, the fourth one – activity (execution of a task or an action by a disabled person) and participation (involvement of a disabled person in a life situation) + appropriate qualifiers; the fifth level – ATs and interventions (8).

The first level (the category of disability) is qualified by impairment of body functions leading to certain categories of disability connected with primary type of assistance (permanent, partial and/or situational) that a disabled person needs.

Each category of disability has its own letter code, which is written in the same way both in Russian and Latin alphabets (8):

- A) Needs permanent outside care (assistance, supervision) because of severe restrictions in mobility, self-care, domestic life to and/or orientation.
- B) Needs partial outside care (assistance, supervision) incl. at home because of severe restriction of mobility.
- C) Needs partial outside care (assistance, supervision) and guidance, including when outside, because of severe and moderate impairment of orientation (blind or visually impaired).
- E) Needs partial outside care (assistance, supervision), including when outside, because of moderate difficulty in self-care and domestic life.
- H) Needs partial outside care (assistance, supervision), including when outside and guidance by a person who implements care, because of moderate impairment of orientation and/or appropriate behavior.
- K) Needs partial outside care (assistance, supervision) and guidance by a personal care provident including when outside, because of severe impairment of orientation, difficulties in communication and interpersonal interaction (hearing, speech and vision impaired).

M) Needs professional assistance (sign language interpreter) in formal relationships (mainly outside) because of severe and moderate difficulties in communication and interpersonal interaction (hearing and speech impaired).

O) Does not need any outside assistance. In exceptional cases needs assistance from strangers (personal care providers) experiencing certain life situations when outside.

The second, the third and the fourth levels of the Codifier of Disability Categories (body functions + impairment qualifier; body structures + impairment qualifier, activities and participation + appropriate qualifiers) were defined in strict accordance with the ICF (7).

The fifth level of AT description mapped to ISO 9999 (5).

The structure of the Codifier of Disability Categories is a number (chain) of codes (8):

x/bxxxxx.x/sxxxxx.x/ dxxx.x/xx xx xx1/.../xx xx xxn1/xx.xx.xx.xx1 /... /xx.xx.xx.xxn2, where x is a code of disability category;

bxxxxx.x is a code of body function with ICF qualifier;

sxxxxx.x is a code of body structure with ICF qualifier;

dxxx.x is a code of activity and participation with ICF qualifier;

xx.xx.xx are the codes of ATs (ISO 9999);

xx.xx.xx.xx are the codes for interventions;

n1 is a number of ATs corresponding to the chosen body function with a qualifier, body structure with a qualifier, disability category, type of activity and participation.

n2 is the number of interventions corresponding to the chosen body function with a qualifier, body structure with a qualifier, disability category, type of activity and participation.

Using the Codifier of Disability Categories more than one hundred complex professional terms describing body impairments were grouped to 8 disability categories, which can be described with common language so that it can be used by those non-specialists in the field of disabilities.

Examining a person, with the help of the Codifier of Disability Categories one can fully define all the disabling impairments of body functions. The set of codes of these functions enables to create an individual profile of a disabled person, which can be also a basis for developing of IRP. After that it is analyzed whether the functions defined by the specialist coincide with those existing in the Codifier of Disability Categories. In case if the functions coincide, a specialist gets a list of ATs and interventions recommended from the Codifier of Disability Categories. The specialist makes decision on ATs and interventions in the specific case. In case if there are no coincidences, a specialist has to search weaker or more severe disabling impairments of body functions in the Codifier of Disability Categories and select ATs and interventions by himself/herself.

Findings

Expert from Albrecht Federal Scientific Centre of Rehabilitation of the Disabled developed guidelines on delivering assistance and communications with persons included in each of 8 disability categories (A, B, C, E, H, M, N, and O) in life situations.

In electronic form, a handbook (the Codifier of Disability Categories) was compiled on the correspondence of impaired body functions to the categories of body structures, activities and participation and ATs. The use of such an electronic handbook allows the specialist to offer the most appropriate AT while describing a person in the ICF categories.

Materials of the Bureaus of MSE on assessing the status of disability were taken from the archive. According to the documents, impairments of the body functions were described with use of ICF. Later the experts applied the developed handbook and made up new IRPs. Comparison of these new programs with previously developed ones showed a high degree of coincidence of selected ATs and interventions, about 60%. Programs developed using the Codifier of Disability Categories were more comprehensive.

The suggested approach that exists in the form of the Codifier of Disability Categories can be widely applied. Independent but logically connected classifications contain urgent knowledge and techniques.

Relying on comparison of severity of impaired body functions and structures, activities and participation of a person with disability before and after carrying out the rehabilitation measures one can analyze the efficacy of (re)habilitation of a person.

Thus, the health condition of a disabled person can be objectified both from the perspective of impairments of body functions and structures and from the perspective of activities and participation in life situations. Given approach allows defining prior types of assistance to integrate the person into environment. Codes obtained as a result of formalizing the conditions of a disabled person can be used to record measures on a social card of a citizen electronically, to control the implementation of (re)habilitation measures, to analyze the needs in various types of assistance, and make budgets etc.

Discussion

Creating and maintaining the Codifier of Disability Categories, which combines information about impaired body functions and structures, activities and participation, and ATs greatly simplifies the development of IRPs and improves their quality.

At a repeated medical-social expertise the evaluation of an individual's profile obtained with the help of the Codifier of Disability Categories provides the basis for evaluation of efficacy of the (re)habilitation measures.

As ICHI is being developed to provide a new common tool the current concept of the Codifier of Disability Categories is to map ICF, ISO 9999 and ICHI (5-7).

Besides this it improves the skills of specialists, indirectly expanding its competence regarding to existing ATs and possibilities of their applications in specific cases. It helps to ensure greater access to quality, affordable ATs for all who needs (re)habilitation. The Codifier of Disability Categories can be supplemented with extended information on AT suppliers.

The manufacturer can position AT more accurately by describing impairments of the body functions and structures, limitations of activities and participation when AT can be applied.

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Technologies to enhance quality and access to prosthetics and orthotics: The importance of a multidisciplinary, user-centred approach

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Abstract

This paper presents the story behind developing the Cambodia-United Kingdom prosthetics and orthotics (P&O) project 'LMIC Limbs'. We describe the methods employed in identifying and iterating the project scope, the principles underpinning our collaboration, and our reflections on the process. In the context of growing digital technology possibilities for P&O services (CAD/CAM, 3D scanning, and 3D printing or additive manufacturing), this set of principles addresses issues of: i) ensuring the project is defined by a technology pull, instead of a technology push, ii) objectively mapping project stakeholders and the value proposition, and iii) consulting these stakeholders on the potential benefits and disadvantages of these technologies, and the barriers and facilitators associated with their implementation. These issues are addressed simultaneously through approaching the project development by co-design of research with equal status partnerships across nationalities and multidisciplinary team professions. As such, the project deliverables are designed according to the definition of Appropriate Technology (1) in the context of UN Sustainable Development Goal 3: Good Health & Wellbeing (2). This study highlighted the importance of carrying out in-depth scoping and preparatory work in a user- and value-led framework before undertaking work to develop and introduce new technologies within an LMIC service. This enabled us to challenge our prior assumptions and redesign our project as co-researchers for far broader and sustained potential benefit, and potentially prevented unintended harm.

Keywords

Appropriate technologies, co-design, PPI, scoping work, stakeholder mapping, sustainable implementation, user needs.

Background

Approximately 100M people worldwide need prosthetic or orthotic devices (3). An estimated 80-90% do not have access to P&O services "due to a shortage of trained personnel, service units and health rehabilitation infrastructures" (4). P&O service access is particularly poor for people in Lower and Middle-Income Countries (LMICs), who are typically younger and have higher physical working demands than those in high income countries, for whom most prosthetics technology has been developed. The demographics of those affected also differs, with some LMICs having high levels of traumatic amputation from accidents, conflict and landmine injuries, and humanitarian crises (5). By contrast, the primary reason for amputation in high income countries is vascular compromise associated with diabetes, although the prevalence, predicted at 500M people by 2035, is growing fastest in LMICs (6). The United Kingdom government's Global Challenges Research Fund (GCRF) was launched in 2016 with £1.5Bn available over five years as part of the UK's Official Development Assistance, and in 2017 a GCRF 'Engineering and Healthcare Technologies' funding call was announced, specifically targeting Diagnostics, Prosthetics and Orthotics.

Figure 1: Improvised and self-repaired prostheses are sometimes used in situations where there is inadequate access to established P&O services.



There is a history of harm caused in LMICs by direct application of inappropriate technologies, or implementing technologies in the wrong way (7). The concept of appropriate technology has been defined in various ways, with key themes including compatibility with the "human, material and resources of the (local) economy", "with tools

and processes maintained and operationally controlled by the local population” (1). More recently, this has incorporated open source principles (8), and the concept focuses on implementation for sustained benefit.

In the absence of better alternatives, people may construct their own devices using local materials (Figur). While these offer some advantages (e.g. reparability), it is likely that they are both uncomfortable and sub-optimal from a functional perspective. One clear potential technology contribution to the 2017 GCRF call was the development of LMIC-specific P&O componentry, to complement the substantial improvements made in device design for LMICs through the International Society for Prosthetics and Orthotics (ISPO), supported by the International Committee of the Red Cross (ICRC) (4,9) and others (Figure 2). However, appropriate P&O componentry is only part of the access problem. An overwhelming patient-clinician ratio remains and "the development of the sector is too slow ... to meet existing needs or keep pace with the growing populations of people with disabilities" (4). Even with ISPO accredited training, in Southeast Asian LMICs it is estimated that three times the current number of clinicians are required to provide services for the affected population, based on current working practices (10).

Figure 2: In Cambodia, Non-Governmental Organisations (NGOs) provide replacement devices free of charge, and nation-wide standardisation across NGOs means that devices may be repaired quite locally even if a person migrates. However, access remains challenging for some of their clients like subsistence farmers or those who can only take time away from work after harvest is complete, even if the NGO reimburses them for travel and accommodation expenses.



Our team recognised that some of the access barriers mentioned above might be addressed by technology. The efficiency of clinicians could be improved through appropriate tools to enhance P&O data and uncover the meaning behind it, and to educate clinicians and service users, both in urban and rural community settings. The context of P&O services makes this

work challenging. Experience shows that particular care must be taken in delivering aid, healthcare and technologies in LMICs, especially if directly applying technologies developed in high-income countries. Considering P&O in particular, as well as users' different needs, their relationship with clinicians and prosthetics are different for complex cultural, social and environmental reasons. Therefore, we decided to frame our scientific research using an ethnographic study of P&O service providers and users, to evaluate the practicality of our project ideas. This paper describes the project's development, and the principles with which we established its scope.

Approach and Findings

Iteration 1: Developing Collaborations, Observations, and Reflection on Appropriate Technologies

In the context of growing adoption of Computer-Aided Design and Manufacturing technologies (CAD/CAM) in Europe and the USA, and interest in 3D printed P&O devices, we set out to form a project proposal around identifying appropriate technologies for a CAD/CAM prosthetic socket design and fabrication workflow for LMICs.

There is growing evidence that CAD/CAM methods can improve P&O services, from Europe and the USA (11,12), but fundamental questions remain due to limited research funding, capacity and culture. Prosthetic limbs comprise standard modules and a bespoke socket, designed by skilled prosthetists through plaster casting and rectification, and manufactured by technicians. CAD/CAM is used in a growing number of clinics. A 3D surface representation of the residuum's shape is captured and used to design the socket in a software environment (CAD). A Computer Numerical Controlled (CNC) carver can then be used to machine a mould from polyurethane foam (CAM), upon which the socket is vacuum-formed or 'draped'. The traditional plaster methods are subjective, time-consuming, and the design record is destroyed during fabrication. Many people are considering 3D printing as an alternative direct CAM fabrication method, although questions remain around the durability of available materials (13) and logistical issues around 3D printing in-house (14). Especially where clients are farmers and labourers, the mechanical reliability demands placed on their prostheses are high, and thicker walls may be required to achieve adequate strength. This may have an undesirable impact on cosmesis, if the brim of the socket becomes visible through the person's clothes. Proposed benefits of the CAD/CAM approach are a data-rich device design process with automated, repeatable fabrication, and therefore more efficient use of staffing resources. In principle, these are justifiable benefits for high and low resource economies alike. Whilst CAD/CAM is considered expensive versus plaster methods, recent developments in 3D scanners suggests that the shape capture element of the CAD/CAM process might become feasible with far lower-cost equipment (\$100s, vs. \$10,000s) (15), whilst retaining a clinically acceptable level of accuracy.

Figure 3: A key element in the sustainability of Polypropylene technologies is recycling off-cuts and used devices, at the Phnom Penh Orthopaedic Component Factory



Therefore, our first plan was to build a project proposal around identifying the requisite level of accuracy for clinical effectiveness and selecting appropriate scanners. Furthermore, research to enhance the CAD/CAM workflow would incorporate tools to survey residuum tissue compliance, sensitive points and regions at risk of damage, which is a fundamental part of the prosthetist's manual skill. We wanted to create an ethos of co-research and co-production from the outset (16), so prior to applying for a large grant we secured pump-priming funding to build collaborations and evaluate our project ideas. We used a Patient and Public Involvement (PPI) framework, as distinct from formal research, which includes service users and other stakeholders in the project's design in order to avoid predetermining research questions or solutions. As such, the research is carried out *with* and *by* its intended beneficiaries, instead of *about* or *on* them. We formed a collaboration with Exceed Worldwide, who provided extensive advice and cultural training, and in December 2016 we visited their school and three clinics in Cambodia, in Phnom Penh, Sihanoukville and Kampong Chhnang, to meet our potential collaborators and understand their work, environment and service delivery model. To better understand the manufacture of prosthetic components, we also visited the Orthopaedic Component Factory (OCF) run by Persons with Disability Foundation (PwDF) and the Ministry of Social Affairs, Veterans and Youth Rehabilitation (MOSVY), and the Artificial Leg Production and Rubber Processing (ALRP) Foot Factory. In addition, we joined community workers on visits to provincial service users' homes and places of work, to understand the technical, environmental, social and cultural service issues involved.

This work indicated that directly embedding a CAD/CAM prosthetic fabrication workflow would not have been an appropriate use of technology in the environment where the study was conducted. Pushing this technology directly on high volume plaster technique expert clinicians would have caused a period of reduced quality socket fitting. Whilst training would overcome this issue, we identified a greater barrier to sustainable implementation.

Available materials for mould carving would have been more expensive than plaster, and might increase non-reusable fabrication consumables, where extensive use of recycled materials as a critical aspect of present fabrication practices and the clinics' business model (Figure 3). Furthermore, with many LMIC P&O services using a charitable donation service model, the process for funding the maintenance and replacement of carvers or 3D printers was not clear. A worst-case outcome would be that this well-meaning project would result in the clinicians replacing their skills in manual plaster techniques with CAD/CAM expertise and becoming less able to deliver an effective service should their CAD/CAM technologies become unavailable, ultimately at the expense of their clients' comfort and quality of life. These findings do not preclude the use of CAD/CAM methods in the future, or in other environments, but demonstrated a need to redesign our project aims.

Iteration 2: Co-Design to Re-Focus on Data Technologies to Enhance Access

Based on these observations and our collaborative research planning, we pivoted, and co-designed the project with our new partners. The scoping work revealed that greater benefits might be offered by a simpler but broader approach using digital assessment technologies both to evaluate the effectiveness of P&O components and services and improve the efficiency of clinical practice at centres and in users' own communities. Our objectives were re-framed and focused on technologies with the potential to address these more fundamental challenges around tools to improve *access* to P&O service, train clinicians and optimise the efficiency of service funding use.

Figure 4: Infrastructures exist for community-based assessment, and community workers and travelling clinicians would be empowered by data-based technologies.



Whether national health and social care services are free at the point of delivery or privately funded, the sustainability of any health service relies on leveraging evidence of its effectiveness. Therefore, our revised objectives were motivated by the importance of data-led solutions towards addressing the UN Sustainable Development Goals, helping at a government level to evidence the effectiveness of health systems. This required technologies in two areas:

- Technologies involving digital measurement tools to assess a user's residual limb anatomy, typical daily prosthetic limb use, and measures of functional outcome and quality of life; and
- A robust and secure data architecture for prosthetists, physiotherapists and community workers visiting provincial areas to collect these data (Figure 4), which might also be used as a platform for evidence-based treatment for those in remote communities who cannot afford to travel.

A more portable P&O service may enable people to access provision, fitting, adjustment and repair of their prosthetics devices, whilst limiting social impacts such as time off work - essential where many service users are subsistence farmers, spending their day's earnings on the same day's food.

Figure 5: One way of assessing whether a low-cost scanner is an appropriate technology is its repeatability in comparison with the expert clinician plaster casting, but the associated sustainability issues are more complex.



On this foundation, a more detailed study was carried out in March 2017 to explore the potential benefits of data-based technologies within the Cambodian P&O service, and barriers to their use. We designed a mixed-methods exploratory study, to ensure the potential technologies for our final project bid would be beneficial within this specific context, and meet the needs of the user and wider stakeholders. We obtained approval from the University of Southampton institutional ethics board (ERGO25100) and the Cambodian National Ethics Committee for Health Research (073NECHR) for:

1. Qualitative semi-structured interviews with healthcare professionals working in P&O services, to gain a wide range of perspectives regarding the potential use of technologies to meet client and service needs, alongside additional PPI work with service users;
2. Retrospective analysis of client notes to provide requirements for documentation and rehabilitation outcomes; and
3. A cohort study focusing on reliability assessment of one example technology (3D scanners for residual limb shape capture), with comparison to manual plaster casting (Figure 5).

The following thematic trends around these technologies were identified in the PPI work and interviews, and subsequent collaborative discussions:

3D Scanning

Instead of proposing to use 3D scanning as part of a CAD/CAM workflow, or a central design and fabrication, the technology was identified as a potential limb assessment tool for people in provincial communities. Prosthetists and travelling community workers might collect scan

data to monitor residual limb volume and shape change to understand changes in socket fit over time, identify the optimal time at which to prescribe a definitive socket, and the optimal time of day and environmental conditions to cast when residuum volume and shape would be most stable. Their residuum and socket could be assessed quantitatively at their home or place of work, alongside a self-reported comfort score, so that unnecessary visits to central clinics might be avoided. The scan data can be post-processed to provide key metrics of residual limb size and shape (i.e. volume, length, perimeter), with high accuracy, which would normally be performed by hand using callipers and tape measures. In this way, the most highly trained clinicians could spend a greater proportion of their time on higher value-added work. The foundation would be in place for clinic- or community-based CAD and CAM at a central fabrication facility, once appropriate technology is identified, i.e. with a sustainable funding model.

Physical Activity Measurement

Our Cambodian partners identified additional challenges around the assessment of P&O device use in real community-based settings. Whilst advanced movement analysis methods such as motion capture offer detailed insights into gait quality, our partners reported a greater need to assess more general patterns of longer-term device use. People may receive training to use their devices in a clinic, but their continuing use after returning home is completely unknown, as is the potential change in physical behaviour which their prosthetic or orthotic device may enable. It can be argued that the true measure for any assistive device is the extent to which it is actually used in everyday life. Physical activity monitors are established (17), and they have been used in the field with proximity sensors to indicate activity and prosthesis removal (18). It was therefore hypothesised that these technologies might assist in the unobtrusive assessment of device use and activity classification, as a priority over more complex movement quality characterisation.

Our PPI work revealed that some people were concerned that physical activity monitors would use GPS to track their location rather than the intended more generic assessment of their level and types of activity whilst wearing their prosthetic device. Anecdotally we were informed that others had concerns that these devices might be used to check a person's work or personal activities. Others suggested concerns that individual judgements would be made on the basis of their activity level, fearing that low usage would be used to justify the removal of their device, and that this may lead to a reporting bias. This concern may be exacerbated by cultural issues and where, unlike any health intervention, these devices are provided free of charge. This demonstrated the need to reconsider how potential study participants are educated about the research objectives and technologies, in order to make an informed decision regarding consent. Taking into account these practical considerations, physical activity measurement in community settings offers valuable potential solutions to the third key issue we uncovered: what outcomes are meaningful to service users, and how can we measure them?

Meaningful Outcomes, and How to Measure Them

Perhaps one of the largest challenges is the complex connection between health and social support interventions, and quality of life. A very broad range of objective and subject P&O outcome measures is available, many of which are difficult to contextualise or compare. There is a lack of consensus around which measures should be used, and a high data collection workload on busy clinicians (19). This is indicative of a larger problem, as extensive research on how we measure outcomes might distract us from evaluation of what defines a meaningful outcome for the different stakeholders in P&O services.

The link between gross activity level and quality of life is almost certainly not simple. Actimeters may indicate changes in patterns and quantities of activity. For example, they could be used to quantify changes in activity enabled by provision of a device, gradual impairment arising from device wear or loss of adequate fit, and more marked changes due to injury, device breakage or psychosocial factors such as depression. If self-reported activity estimates provided by service users are subject to the same reporting bias mentioned above, actimeters used in a community setting may provide a measure of validity or allow these estimates to be scaled or corrected. However, the sensor technology also needs to be able to withstand the harsh environment more rural data collection might pose, and be minimally invasive to users. There are also challenges in retrieving logged data, particularly in rural areas where internet access is limited.

Further, physical activity monitoring data interpretation for LMIC users is highly complex: agricultural workers spend long periods standing and walking on uneven ground, and there could be challenges in identifying sedentary behaviour (20). The proprietary software associated with determining activity from sensor data often uses data from a healthy cohort to define parameters. The movement patterns of prosthetic limb users in rural areas of Cambodia are likely to be vastly different from a healthy European or American cohort, creating the potential for activity classification error, which will be addressed in this project.

Greater complexity arises because a positive health outcome is based on multiple factors, many confounding. Health is not monodimensional and an improvement in one domain, such as activity, does not necessarily transfer into the wider context of health or quality of life. For example, common clinical measures of mobility (such as the ability to walk for 10 meters, distance walked in 2 minutes, or number of steps per day) do not necessarily translate into the ability to stand in a market, factory or rice field, or get in and out of a car or ride a motorcycle, which may be far more meaningful to an individual. Little is currently understood about how patients define a successful recovery or outcome following amputation, although a growing body of research has sought to document the experience of amputation and prosthetic use from the service user's viewpoint (21). Our scoping work indicated that, although increased activity may indicate improvement in an individual's ability to work or social engagement, other important indicators include marital status and having children in education. These and other impacts may not be reflected in typically-used Quality of Life measurement tools, and may be achieved with no notable change in physical

activity. There would appear to be a benefit in identifying a minimal effective suite of measures, both in terms of LMICs and western populations. By employing the user-centred approach, we are considering whether an individual's perception of the value behind physical, psychology, social, cultural and economic activities could be different from our expectation as professionals working in health sciences and engineering. If we can evaluate their satisfaction compared to their perceived value and evaluate correspondence with the data from their physical activity measurement, we may be able to gain subjective understanding of their personal success after rehabilitation.

Data Digitisation and Management

Access to services also relies on patient data being available. While computer-based systems have been in use in clinics for decades, the main patient record was still paper-based. This means duplicate effort has to be put into recording episodes and patient data, and full record duplication when people make their first visit to a clinic in a different geographical location. This was highlighted as a particular issue presently in Cambodia, where migration is reported to be common: a young person living in an urban area might be injured in a road traffic accident, return to their family to recuperate, in a rural area, and return to the city after rehabilitation. Data exchange between different sites can happen sporadically, often relies on spreadsheet reports or paper forms, which may be insecure and prone to error due to factors such as handwriting or language skills. Electronic patient record systems are not typically designed for use in LMICs and do not address many of the issues that are specific to this environment:

- computer systems in rural locations are often not constantly connected, due to high cost and unreliable power supplies;
- because of the lack of connectivity, data are not held centrally as is the case in many modern patient management systems; and
- data may be sent via proxies, instead of synchronising directly.

Sharing patient data across clinics, organisations or even countries also brings up a question of privacy and whether adequate measures, such as encryption, have been taken. Furthermore, problems arise around consent, where patients may not understand the implications of distributed data and consequently are unable to give informed consent. As well as making careful culture-specific considerations for informing participants and obtaining their consent to participate in research (Figure 6), this is a requirement of by data protection regulations such as the gold standard General Data Protection Regulation (GDPR).

Figure 6: Challenges remain around obtaining genuinely informed consent for research, treatment and use of clinical data. We simplified and translated our photographic consent form into Khmer language, including an explanation for our PPI contributors about our reasons for requesting to document the work with photos. Despite this preparation, for some clients it was necessary for a community worker to read and explain the form, and some completed the form by thumb print – here in the community worker’s lipstick.



Raising our targets: sustainable approaches to stakeholder challenges

We are now applying business modelling and data science methods to ensure the technologies are cost effective and can be implemented sustainably, and to support their translation into other countries and services. Long term, we intend that the data collected using this project’s deliverables will enable providers to become more efficient and evidence-based, selecting more appropriate P&O devices and components, seeing service users on a data-informed basis rather than at predetermined dates, and making best use of limited budgets (22). However, as described there is a remaining challenge in the complex correspondence between health and social care interventions and the delivered changes in quality of life, further confounded by what is readily and unobtrusively measurable. Biological, physical, psychological and social measures, and an understanding of their complex dynamic and impact on a person’s ability to participate in society, are required for establishing meaningful health outcomes.

Health outcomes can be contextualised within the World Health Organisation’s International Classification of Functioning, Disability and Health (23). In Lower- and Middle-Income Countries (LMICs), poverty, sociocultural bias toward difference and environmental

factors all affect an individual's ability to access health services. To date, the global emphasis has been appropriately focused on improved access to services through inclusion initiatives and development strategies, such as the Universal Health Coverage, part of realising the UN Sustainable Development Goals (2) and WHO Rehabilitation 2030 strategy (24) covering both health and social inclusion. However, in order for these initiatives to be sustainable, we need to understand what 'success' looks like, and at the moment this is poorly understood (25). The challenge globally is to effectively manage inclusive access to - and assured quality of - health and social care systems, and ensure continuity between health and rehabilitation services, with data that supports both. Equitable access to sustainable, quality and meaningful health outcome data becomes the barometer for improvement, failure and success of those services, and ultimately translates into the quality of an individual's life through function, activity and participation.

Current P&O evidence is built on results from rather traditionally designed clinical studies, the majority of which are conducted in high income countries. This approach is arguably not fit-for-purpose, even for those populations: it is slow, where P&O technologies evolve faster than we can evaluate them using traditional methods, and the results cannot easily be generalised to LMIC populations. New approaches are needed that can improve quality of care, but also efficiency and quality of service, allowing for scale-up of services broadening their reach and impact. There is a global increase in ageing, chronic illness and non-communicable diseases illustrated through trends in demographic and epidemiological data (26), and these trends indicate that functioning will be a key indicator of population health (27) even though, as discussed, the mapping between function and health, wellbeing and quality of life is not simple.

As such, it is imperative to establish robust, meaningful and ubiquitous access to health outcome data. Data must be accessible and useable, and presented in a meaningful way for a diverse set of stakeholder profiles. For example:

- individually, service users may want to view data to compare their rehabilitation experiences, progress and problems against their peers;
- locally, clinicians and service providers want to understand the effectiveness of an intervention or expected/predicted outcome, with which to lobby for better or sustained resources;
- regionally, commissioners need to justify funding decisions based on evidence;
- nationally, the health of a population or group can be ascertained; and
- globally, healthcare systems can share standardised approaches and good practice, including sharing resources where possible and appropriate.

The Broader Context of Social Impact

While there are clear returns to private individuals from P&O processes, adopting a social impact lens allows us to see how they also can be catalytic in the advancement of not just individual capabilities but *collective* capabilities (28,29). These include household and

community level capabilities to enter parental labour markets and to liberate education opportunities for children who might otherwise have to work to compensate for labour market exclusion, and other forms of social exclusion. Such capabilities are particularly likely to be enhanced when women are service users, given that they are disproportionately burdened by poverty (30).

A social impact lens also helps us to apprehend the multi-dimensionality of poverty, such as the crucial interlinkages between SDG 3, SDG 5 (gender equality) SDG 8 (decent work and economic growth) and SDG 9 (industry, innovation and infrastructure).

Relatedly, such a social impact lens can help us build an added value chain to P&O processes which can not only enhance their effectiveness, but the identification of meaningful outcomes and sustainability which also help address multiple SDG objectives. Work Integration Social Enterprises (WISE) for example are potentially well suited models, since their primary aim is to provide employability and integration-related opportunities for those disadvantaged within, or excluded from, full access to labour markets. Including service users in the operation and delivery of P&O based WISE models allows them to move from passive beneficiaries to active co-producers and constitutes a form of community economic development (31), which consequent impact on community level capabilities.

Re-orientating our understanding of P&O processes from private healthcare investment to social investments, which broad ranging catalytic impact on a range of poverty and human development indicators allows us to place our interventions into a wider social impact context, and to think more ambitiously about the most appropriate organisational vehicles to scale and replicate them.

The Benefits of this Scoping Work, and a Value-Led Approach

The results from all four parts of this study provided a clear insight into the specific needs of the user and wider service, and were essential for developing the next stage of the work in three key ways:

1. Preliminary study of candidate technologies: healthcare professionals were observed, and their views of candidate technologies' usability, benefits and barriers were obtained, and used to change the project direction.
2. Remit of the future study: arising from this change to the study's technical objectives, specific infrastructure needs were identified, with the requirement to address the importance of sustainable implementation factors.
3. Working relationships: through scoping work we built relationships, rapport and trust, identified reciprocal factors, built capacity, and worked as co-researchers. We have since delivered training at each other's institutions, and co-authored scientific publication of our results.

Conclusions and Recommendations

This study highlighted the importance of carrying out in-depth scoping and preparatory work in a user- and value-led framework before undertaking work to develop and introduce new technologies within an LMIC service. This scoping work enabled us to challenge our prior assumptions and redesign our project as co-researchers with far broader and sustained potential benefit, and potentially prevented unintended harm.

P&O intervention investments are social investments, with collective benefits across families and communities. Engaging these stakeholders as co-producers in research empowers them, builds local capacity and embeds a network able to deliver further, broad and sustainable benefits. As a key PPI principle, we have an obligation to report back to the clinicians, community workers and clients who have contributed to the project. Empowering, inclusive and participatory technology research should have the professionals on tap, instead of the professionals on top!

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Sustainability of wheelchair service provision: Perspectives from service providers

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Abstract

In January 2016 the Sustainable Development Goals (SDGs) came into effect. These goals highlight the need for inclusion of all vulnerable groups including people with disabilities. Universal and equitable access to high quality and affordable assistive products must be prioritised by international and national development partners and governments, as an essential component of inclusive sustainable development. To achieve universal and equitable access, the provision of Assistive Technology (AT) must be sustainable. This paper explores the issue of sustainable wheelchair service provision through research carried out by the Motivation Charitable Trust in 2016. The research evaluated the sustainability of wheelchair services, using five key indicators, and identified the principle drivers and barriers from the perspective of the wheelchair service providers. Indicators were: facilities; product supply; service delivery; service management; and networks and national context. This research used both quantitative and qualitative methods and was conducted via a survey completed by 15 organisations from 12 countries across Africa, Asia and Eastern Europe, and follow-up semi-structured interviews with representatives from eight organisations. Overall, responses identified delivering the World Health Organization's (WHO) recommended eight steps of wheelchair service provision as a positive driver (or opportunity) which promotes the development of sustainable wheelchair services. Further positive drivers included: training of staff in wheelchair service provision; and having the necessary plans, systems, procedures and facilities in place. The principle barrier (or threat) to sustainability highlighted by responses, was accessing a consistent supply of wheelchairs, including the funding of wheelchairs and government support to provide resources for wheelchairs. Giving wheelchair services a voice has highlighted the complexity of wheelchair service provision where a range of factors influence sustainability. This paper suggests that there is need for a comprehensive and systematic approach to understanding, measuring and implementing best practice for achieving sustainable wheelchair services, and consolidating varied approaches to sustainability in the sector is vital if the SDGs are to be achieved.

Keywords

Sustainability; assistive technology; wheelchairs; service provision

Introduction and objectives of review

In January 2016, the Sustainable Development Goals (SDGs) came into effect and set the global target to 'leave no one behind'. In 2011 the World Health Organization (WHO) estimated that more than a billion people, or 15% of the world's population, live with some form of disability, and anticipated that this number would rise in future years (1). The WHO approximates that of the 15% of the global population living with a disability, 'there are more than 1000 million people who would benefit from one or more assistive products'. The WHO also projects that this number 'will rise above 2000 million by 2050' (2). However, the WHO asserts that only 10% of people requiring an assistive product have access to one (3). As Tebbutt et. al. emphasise, 'Achieving the SDGs and leaving no-one behind will not be possible if the people who need essential assistive products do not have access to them' (4).

People with disabilities can access assistive products through a range of stakeholders and facilities (5), and for the purpose of this report such stakeholders and facilities will collectively be referred to as service providers, or services.

With projects across Africa and Asia, Motivation Charitable Trust advocates for the rights of people with disabilities and aims to empower them to stay healthy, access education and employment, and to participate in their communities. Motivation works in line with the WHO 'Guidelines on the provision of Manual Wheelchairs in less resourced settings' (hereafter referred to as the WHO Guidelines), promoting the provision of appropriate wheelchairs through comprehensive services. As defined by the WHO Guidelines, an appropriate wheelchair is one that 'meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained and services sustained in the country at an affordable cost' (6). The sustainability of services is vital to providing appropriate wheelchairs and ensuring universal and equitable access to such assistive products.

In 2016, Motivation carried out a sustainability review of wheelchair service providers that had been supported in the past 25 years of the charity's operation. 'Sustainability means different things to different actors' (7) and the objectives of this review were to explore this from the perspectives of wheelchair service providers with the aim of providing valuable insight to enhance Motivation's future work.

Review approach and methodology

This review gathered qualitative and quantitative data through an on-line structured survey and semi-structured interviews to open initial discussions with service providers. The overall aim of the review was to document service users' perspectives on sustainability in order to evaluate the sustainability of the services, and to identify the drivers for and barriers to sustainability.

The WHO defines a sustainable wheelchair service as one which has ‘the capacity to provide appropriate wheelchairs through the eight steps of service to a consistent number of individuals over a significant period of time’ (8). The eight steps include:

1. Referral and appointment;
2. Assessment;
3. Prescription;
4. Funding and ordering;
5. Product preparation;
6. Fitting;
7. User training; and
8. Follow-up, maintenance and repairs (6).

The WHO also asserts that the sustainability of wheelchair services ‘requires continuous investments in product supply, trained personnel, space, and monitoring and evaluation systems’ (8).

Elaborating on the WHO definition of a sustainable wheelchair service, research methodology for this review was based around five key indicators for sustainability, devised to guide the evaluation of sustainability and open conversations with service providers.

Table 1 outlines these key indicators and topics covered.

Table 1. Sustainability indicators and topics covered

Indicator	Topics covered
Facilities	Longevity of organisation, type of organisation, service setting, clinical and technical space and resources.
Product supply	Wheelchair supply and consistency, funding for wheelchairs, types of wheelchairs available and the needs of target users.
Service delivery	Service setting and facilities, personnel and training, systems and record keeping, and WHO eight steps of service provision.
Service management	Annual planning and budgeting for wheelchair products and service provision
Networks and national context	National policy context and organisational knowledge of this, partnership with other organisations and advocacy initiatives

It must be recognised that this review was intended only to provide an initial exploration of sustainability from the perspective of service providers, and not set definitive indicators, attribute causality or explore the relationship between indicators.

Sample

The research population consisted of all organisations with which Motivation had worked over the previous 25 years to provide wheelchair services, regardless of duration of support, level of financial investment or type of support (such as training, capacity development, product development or provision of products).

Drawing on Motivation’s records, a total of 64 organisations were identified to form the sample population. 58% of organisations were in Africa; 38% in Asia; 3% in Eastern Europe; and 2% in South America. The regional distribution of the sample population distribution reflected the geographical spread of Motivation’s work.

A tiered sampling process was employed. Respondents could self-select to respond to the survey, and through a question at the end of the survey respondents were also given the option to self-select to participate in further semi-structured follow-up interviews.

From the sample population of 64 organisations, there was a 23% response rate to the survey; 15 organisations from 12 countries self-selected to respond. Eight organisations from eight countries self-selected from the survey respondents (including two from a pilot survey sent out to trial the questions) to participate in the semi-structured follow-up interviews. See Table 2 for the breakdown of countries represented in the survey and follow up responses.

Table 2. Countries represented in the survey and follow-up interview responses

Region	% of total survey responses	Countries represented in the survey	% of total follow up responses	Countries represented in the follow-up interviews
Africa	46.70%	Kenya, Malawi, Nigeria, United Republic of Tanzania, Uganda (2 organisations), Zambia	50.00%	Kenya, Lesotho, Uganda, Zambia
Asia	46.70%	Cambodia, India (2 organisations), Pakistan (2 organisations), Sri Lanka, Nepal	50.00%	Bangladesh, Cambodia, Nepal, Pakistan
Europe	6.70%	Romania	0%	None

The regional spread of the 15 organisations that responded to the survey, and the eight organisations that participated in the semi-structured follow-up interviews, was representative of the regions covered by the research population. The findings were not unevenly weighted to any one region, a distribution that reflected the geographical spread of Motivation’s work.

Methods

This review used a combination of quantitative and qualitative research methods which used the framework of the five sustainability indicators as outlined above in Table 1. The chosen methods facilitated rapid and cost-effective data gathering from a United Kingdom base, engaging directly with service partners and giving them a voice, but without the costs of face-to-face engagement.

Quantitative research

An on-line structured survey was designed to gather an overview of the sustainability of wheelchair service provision at each organisation. The survey was piloted with four organisations to trial the survey questions. The final survey included 40 closed-ended and multiple-choice questions to enable the surveys to be answered quickly and to gather factual information rather than value-driven opinions. This approach was designed to optimise objectivity where possible, given the knowledge that responses were self-reported by organisations and therefore susceptible to subjectivity and bias.

The survey consisted of questions that covered all five sustainability indicators. Questions were designed to elicit a range of responses on wheelchair services and organisations, which could also be triangulated to check for consistency of answers given and provide an indication of authenticity.

The survey was presented in English as an online survey, with a link emailed to the key contact at each of the 63 organisations of the sample population, inviting them to respond.

Qualitative research

Semi-structured follow-up interview questions were designed to gather qualitative data from representatives from the organisations, which self-selected via the survey to participate. In contrast to the survey, the purpose of the follow-up interviews was to gather subjective views and to provide a fuller understanding of sustainability from the perspectives of the organisations.

Six open-ended interview questions were set for the follow-up, which allowed for discussion to become participatory and develop organically. Interviews with key informants from the organisation were held in English over Skype/telephone (without video) and conversations lasted between 30 minutes and one hour. Detailed notes were taken during the interviews to record responses.

Analysis of data

A systematic approach was taken to the analysis of both quantitative and qualitative data.

Quantitative data gathered through the 15 surveys completed online was downloaded into Excel, where data was coded to be analysed according to the five sustainability indicators, with a number of questions providing potential for triangulation of information. The analysis used percentages to gain understanding of patterns in the data.

Qualitative data from the eight follow-up interviews was analysed through the mapping and categorisation of themes. Themes were correlated using Excel which facilitated further analysis of issues and concerns through graphical exploration of the themes.

Evaluation of review methodology

The nature of the data from a non-random (or non-probability) sample must be taken into account and an awareness of both self-selection bias and self-reporting bias in the findings

is important. Whilst self-selection and self-reporting produced valid data through directly engaging with the organisations, and giving them a voice, it carried the potential for social-desirability bias. Social-desirability bias may have involved the over-reporting of positive results by organisations, especially if the positive results were seen as favourable to Motivation as a United Kingdom partner. Conversely, under-reporting of positive results may also have arisen, if negative results were seen as potentially leveraging further support from Motivation. However, it has been noted that the online survey as a 'self-administered' method of data collection, could 'decrease the prevalence of social desirability bias' as the 'absence of the interviewer reduces the fear of receiving a negative evaluation' (9).

The remote nature of the survey could have contributed to more accurate data, however, there was also the risk of misunderstandings of the questions posed, arising from language use and/or cultural differences. In a face-to-face survey, misunderstandings could have been recognised and meanings could be clarified by giving explanations or re-wording in real time.

Whilst evidence suggests that a 24% response rate to the survey as an external survey is good (10), the reasons for non-response must be considered. Non-response may reflect organisations ceasing operation or wheelchair services, or could reflect limitations of the methods including:

- Responses required internet/email/Skype/telephone, time and available personnel;
- The length of the survey (40 questions in total) may have seemed to be too time consuming and difficult to complete;
- The contact details of organisations may have changed.

Finally, it must be noted that the survey responses and follow-ups were inevitably guided by the indicators and questions developed for this review and therefore by the purpose of the review and the researcher's own bias, as the researcher had previously worked at Motivation.

Ethical statement

All organisations that engaged in this review did so with the full understanding that there were no incentives or rewards for participation; conversely there were no disincentives for not participating. All were aware that findings would be used solely to advance Motivation's own internal learning and where shared more widely all data regarding named organisations will remain confidential.

Findings

The sample of organisations included in this review was representative of a range of providers with which Motivation works:

- **Regions:** Africa: seven countries; Asia: six countries; Europe: one country.

- **Longevity of wheelchair service:** 40% had been established between zero and 10 years (with the youngest established for three years) and 60% had been established 10 years or more (with the oldest established for 32 years).
- **Type of organisation:** 71% non-governmental organisations (NGOs); 21% Governmental; 7% Private.
- **Type of wheelchair service:** 79% ran integrated services (only 21% ran stand alone)¹; 50% ran both centre based and outreach services (43% running centre based only and 7% running outreach only) (2).

Sustainable services

To gain an overall impression of the sustainability of organisations from the survey responses, a total score was calculated for each organisation. The score used answers to a number of key questions in the survey that addressed the five indicators for sustainability and covered a range of topics as detailed in Table 1.

From this overall scoring, it appeared that none of the 15 organisations met all five indicators. This suggests that none had the potential to run fully sustainable services. However, progress towards sustainability was evident, with 73% of organisations meeting 50% or more of the indicators.

Additionally, when looking at individual questions in isolation, an overall positive response was given regarding delivering the WHO recommended eight steps of wheelchair service provision; 73% of organisations surveyed (or 11 organisations) self-reported that they were delivering all steps.

It is interesting to note that 73% of organisations (11 organisations) reported delivering all eight service steps and 10 of these organisations also met 50% or more of the indicators in their total score for sustainability. This suggests that whilst delivering the eight steps does not necessarily indicate sustainability, the eight steps and meeting criteria for sustainability are strongly linked. Following the eight steps suggests a positive correlation with knowledge and understanding of sustainability.

During follow-up interviews, when asked whether organisations felt their wheelchair service was sustainable:

- 43% of organisations said that their wheelchair services were **not** sustainable;
- Only 28% of organisations said that their wheelchair services were sustainable, but with the following stipulations: at current capacity (i.e. would not be able to expand at present) and if products were available;

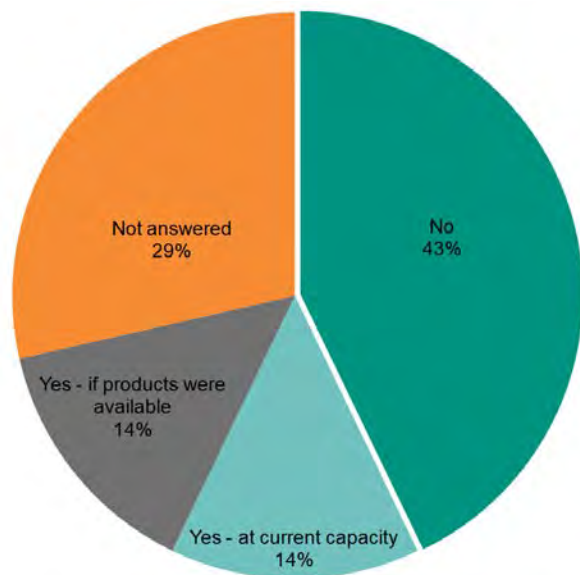
¹**Definitions: Integrated** - wheelchair service is integrated with activities of another service or services e.g. prosthetics and orthotics or physiotherapy; **Stand-alone** - wheelchair service is not integrated with activities of another service or services (8).

²**Definitions: Centre based** - wheelchair users travel to a permanent facility; **Outreach** - personnel either travel to wheelchair users' homes or to a central location in another district/region (8).

- 29% avoided answering the question (See Figure 1)

Responses from the survey and follow-up interviews indicate that criteria are being met for sustainability, or that drivers are present, however, key barriers inhibit sustainability.

Figure 1. Percent of organisations that felt their wheelchair services were sustainable



Drivers for sustainable services

Survey responses broken down by the five sustainability indicators revealed a positive response of 50% or more from organisations on key issues, as explored below. It was felt for the purposes of this review, a 50% or more positive response could be used as a benchmark; whilst services may not be meeting all indicators for sustainability, the positive responses suggest encouraging progress towards some critical elements of sustainability.

Facilities

50% of organisations surveyed reported having both clinical and technical space and equipment. The remaining 50% lack one or more of the required facilities, including clinical or technical space or equipment.

Product supply

Diversity of funding: Less than 10% of organisations reported being heavily reliant on any one source of funding for wheelchairs. Motivation considers that such reliance can be a barrier to long term sustainability. Additionally, over 60% of organisations reported that zero to 25% of funds for wheelchairs were sourced through payment by users and funds secured locally. Whilst this is a high number of organisations using these sources of funding, it appears that payment by users and local funds generate low levels of funding. This is to be expected when considering the socio-economic demographic that services generally target, and the known link between poverty and disability. However, it is positive to see that services are encouraging users to contribute to the cost of the wheelchair and from

experience, Motivation has learned that that this can increase the users sense of ownership and value of the wheelchair as a result.

Having required product types: 80% of organisations reported that they do have a sufficient range of wheelchairs to meet the needs of their target users. However, through triangulation of questions, comparing questions which provided descriptions of service users with questions which listed the types of products available, a lower positive result was given, with 55% of organisations having the required products to meet target users' needs. This could suggest that some organisations lack understanding of the criteria for appropriate wheelchairs to meet the needs of the users as per the WHO Guidelines, bringing into question the self-reported claims of 73% of the organisations to be effectively delivering the eight service steps.

Service delivery

Delivering the eight service steps for wheelchair provision: as noted above, 73% of organisations reported that they were delivering all eight steps of wheelchair service provision.

Having sufficient local staff: 53% of organisations reported they had sufficient staff in place to meet the needs of target users. 60% reported a high percentage of trained staff, with 75% to 100% of staff directly involved in wheelchair service provision having undergone relevant training. Additionally, 67% of organisations reported that they had a plan and budget in place for future training and/or mentoring of staff. Whilst these questions returned higher than 50% positive results, the responses potentially contradict other results from the survey that suggest that 73% of organisations are following the eight steps – since without more trained staff than the services reported, it could be argued that they organisations are unable to meet the guidelines. To provide a comprehensive wheelchair service, sufficient personnel and training in wheelchair service provision is paramount. It is also unclear from responses what training had been given, and what training was planned and budgeted for.

Having systems and procedures in place (including waiting lists): 80% of organisations reported that they keep a waiting list and 93% reported that they had documented systems/procedures in place. Whilst these are high positive results, it is not clear from the responses to what standard and accuracy records are kept.

Service management

Annual planning and budgeting: 53% of organisations reported that they have annual plans and budgets for wheelchair services. Whilst it is positive that half of the organisations are planning and budgeting for wheelchair services, it is equally concerning that half are not planning and budgeting. However, budgeting does not mean that funding is available and it would be useful in a future research study to look at the relationship between planning and budgeting and longevity of organisation or service, or sources of funding.

Networks and national context

Networks: 80% of organisations reported that they had agreements in place with two or more other types of organisation, indicating that generally the services are not working in isolation and are building on networks.

National context: All organisations reported that their government has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and 40% reported that government policies are in place for the areas of: Disability, Rehabilitation and Wheelchair service provision. A future study might look more closely at regional differences or the details of policies and their effect on sustainability.

Barriers to sustainable services

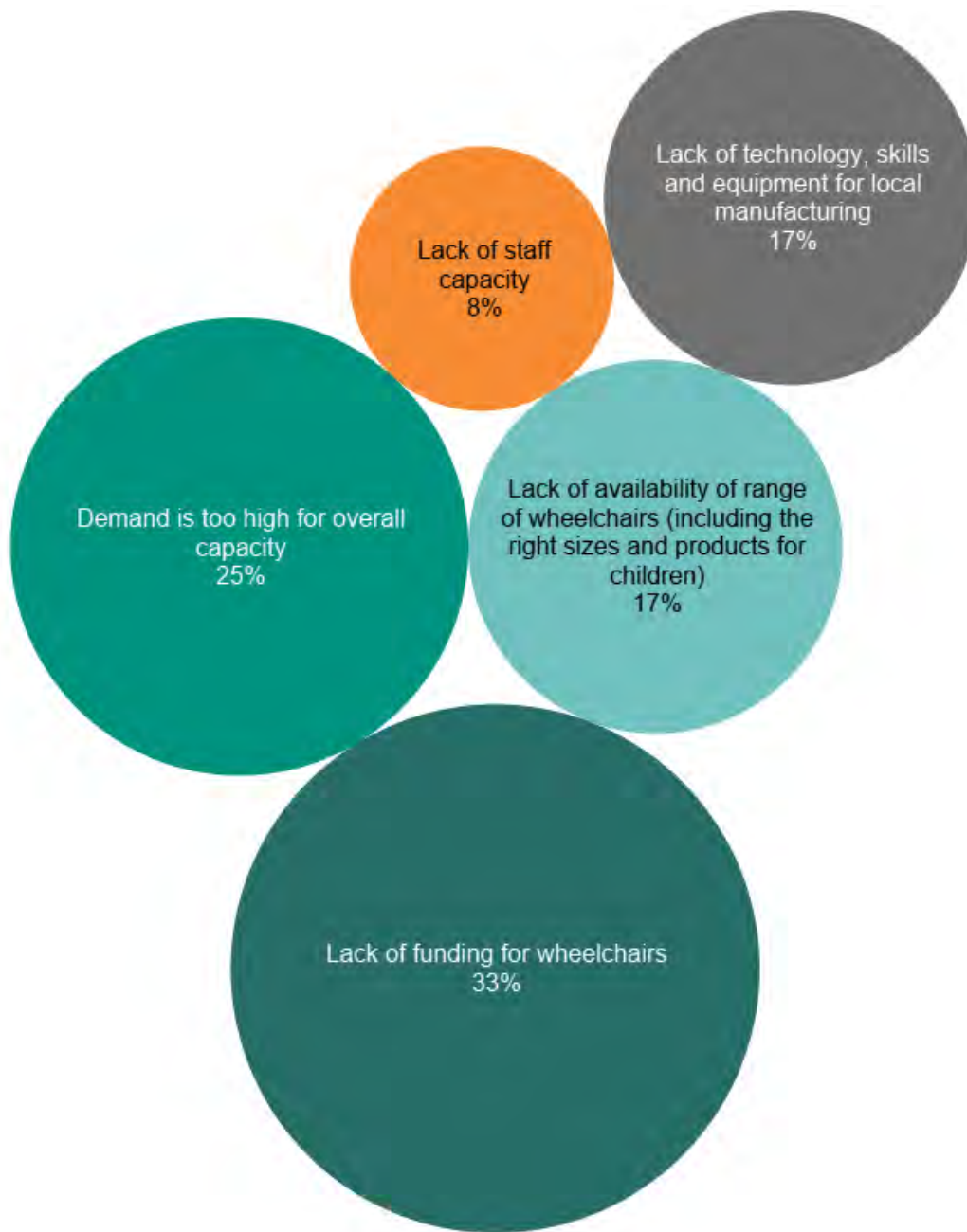
According to survey responses, the overriding barrier to sustainable services was accessing sufficient numbers of wheelchairs to meet local needs. 67% of organisations reported that they did not have a sufficient or guaranteed stock of wheelchairs to meet need.

Of all 12 reasons given in the surveys for not having the number of wheelchairs available to meet local need, lack of funding for wheelchairs was cited most often, (based on four organisations forming 33% of total responses and reasons given). See Figure 2.

In terms of sources of funding for wheelchairs, over 40% of organisations reported that they did not receive any funding from Government or other local organisations. This is a key point to highlight, as these sources, especially governmental, would, if in place, form a solid basis for sustainability. Conversely, as might be expected, a larger proportion of funds in total are sourced from an international donor or project partnership, which indicates that funding is potentially linked to funded projects which close at the end of their lifespan, a pattern which is not conducive to sustainability unless successfully built into the project plans.

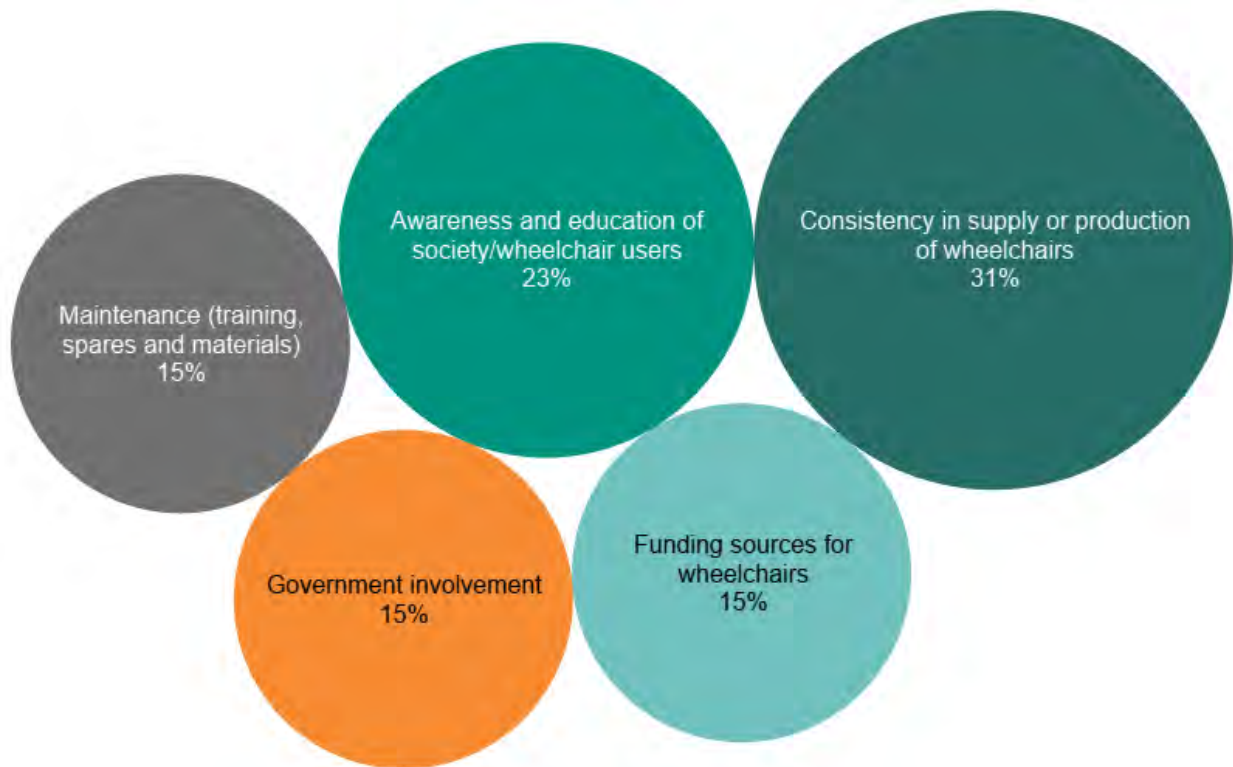
Issues of consistency in the supply of wheelchairs were also highlighted in survey responses; 60% of organisations reported providing over 100% more wheelchairs in the month of highest provision than in the month of lowest provision. Further exploration of this was made during follow-up and highlighted that differences in monthly provision could be the result of a range of factors, from religious festivals pausing services, to available funds and wheelchairs.

Figure 2. Reasons for not meeting the need for wheelchairs



Follow-up interviews also highlighted the consistency in supply or production of wheelchairs as the key issue to be addressed to support the sustainability of wheelchair services, with 31% responses raising this issue. Issues around government involvement, funding sources for wheelchairs and maintenance of wheelchairs, also represented a further 30%, further highlighting product availability as a key issue. (See Figure 3)

Figure 3. Issues raised which would support the sustainability of wheelchair services



Further comments in follow-up interviews also highlighted as barriers the lack of availability of spare parts for maintenance and materials for production. As one organisation explained, maintenance prolongs the wheelchair's life and in practice has much the same effect as sourcing another wheelchair. Good maintenance ensures that something can be kept 'as good as new', and therefore this is clearly more sustainable than discarding a worn out, damaged product (that might only need a few spare parts) and having the expense of, and potentially difficulty in sourcing, a whole new wheelchair.

Lack of awareness, education and government involvement seemed to be a secondary key barrier. This, however, formed less of a focus in the design of the survey, which focussed on the activities and situation of the organisation itself. It would therefore require further study. Staff retention was only raised by one organisation and is also an issue that was not fully captured by the survey.

Discussion

It is clear from this review that the five indicators for sustainability (facilities; product supply; service delivery; service management; and networks and national context) can be both drivers for and barriers to sustainability, depending on whether they are posing an opportunity or threat.

Some indicators also exhibited contradictory elements. For example, an overall positive response was given regarding the diversity of funding sources for wheelchair provision, however, an overall negative response was given regarding the level, consistency and

sustainable sources of funding. It is important to note that contradictions and possible inaccuracies of the results may have arisen from potentially less-informed survey and interview respondents, an element which would need to be unpicked through future study in terms of the level of awareness of global standards and the interrelated elements of service provision that are essential for sustainability.

Both the survey and follow-up highlight delivering the WHO recommended eight steps of wheelchair service provision as a positive driver (or opportunity) for the development of sustainability. Training of staff in wheelchair service provision and having the necessary plans, systems and procedures and facilities in place for following the eight steps of wheelchair service provision are also highlighted as drivers.

Both the survey and follow-up highlight the lack of supply of wheelchairs as a main barrier, including the funding of wheelchairs and government support to provide resources for wheelchairs. Lack of consistency in supply was also cited, and the difficulties of time-bound funded projects that create a demand and then close, or development partners who withdraw without follow-on plans. One organisation stated in the survey, that following the end of a project when it closed, 'support abruptly ended without availability of any local quality products'.

Levels of capacity for local production also featured as a key issue under the supply of wheelchairs, as was repair and maintenance (which can come under the banner of supply of wheelchairs). Clearly, with better repair and maintenance of wheelchairs, less new wheelchairs are required. Difficulties in meeting the volume of need was also noted as an issue when reaching isolated communities with services and repair and maintenance.

Finally, lack of support from government and lack of awareness of the need for ATs in society was raised as a barrier, or even a threat, to sustainability. This is interesting given the range of countries across Africa and Asia (and one in Europe) involved in the survey. A future study could look more closely at the nature of government support, where it exists, and explore how such support and awareness could support sustainability in different contexts.

What is clear from this review is that sustainability must be viewed as integral to the comprehensive system of service provision and dependent on a range of factors in different contexts. Wheelchair service provision is complex (11,12). Additionally, 'All areas of the globe have unmet AT needs, but they differ depending on climate and geography, available personnel and finances, policy directives, and so on.' (13).

Conclusion and recommendations

Giving wheelchair services a voice has highlighted the complexity of wheelchair service provision. It is evident that building the capacity of wheelchair services, including relevant training of personnel, and development of systems and facilities, needs to continue at an organisational level if we are to ensure access to quality, affordable AT for all. However, this

will not enable universal access if the supply of wheelchairs is neither sufficient nor consistent. All elements of the service must be valued and appropriately addressed.

Planning for long term funding of, and access to, a range of appropriate wheelchairs must be an integral part of programmes and policies within service models. This will be facilitated if national policies are in place, wheelchair services are integrated within other existing rehabilitation or assistive technology services, and there is engagement of a wider stakeholder group to influence both strategic investment in product supply and advocacy.

At an organisational level, for Motivation, future work might take a more comprehensive approach to sustainability. This could include ensuring that establishing a common vision of sustainability is central to the design of any partnership or project and taking into account all actors, specifically wheelchair users, using tools such as the Sustainability Analysis Process (7).

At a sector level, there is a need to consolidate the various approaches to sustainability and a comprehensive and systematic approach to understanding, measuring and implementing best practice for achieving sustainable systems through a validated tool. A validated tool would allow more consistent data comparison. Motivation has used the Motivation Wheelchair Service Monitoring and Evaluation Tool to enable service providers to evaluate change against WHO recommended best practice. Development of this tool to further identify benchmarks to assess key quality performance indicators would support research on the impacts and outcomes of service provision models and improve understanding of best practice for sustainability.

Global action is being carried out to address issues raised in this paper, since this research was carried out in 2016, including initiatives such as AT Scale and a framework for AT provision built through the Global Collaboration on Assistive Technology (GATE) and the Global Research, Innovation and Education on Assistive Technology (GREAT) Summit in 2018. The framework places AT users (or People) at the centre of an open system. Surrounding People is an inner circle of strategic drivers - Policy, Products, Provision and Personnel - and an outer circle of contextual elements - Procurement, Promotion, Place, Pace (14).

Adopting this framework of 10Ps globally across the sector may facilitate finding a common understanding of and approach to sustainability, and re-focussing our understanding of sustainability by placing users at the heart of service delivery and any conceptualisation of a sustainable system to ensure that no-one is left behind.

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A model to standardize the procurement and quality of assistive technologies in less-resourced settings

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Abstract

There remains a vast need for quality assistive technology (AT) around the world. The World Health Organization (WHO) estimates that 1 billion people need 1 or more assistive products and only 1 in 10 people have access to them, suggesting that the unmet need is approximately 100 million AT products. To address this need and improve the quality of life of people with disabilities specifically, the United Nations (UN) promotes the right to improved accessibility to appropriate assistive technology. Guidelines and policies published by UN and WHO have driven organization-led establishment of programs for improving wheelchairs, prosthetics and orthotics among all ATs. For instance, the WHO Guidelines on provision of manual wheelchairs in less-resourced settings has motivated funding agencies such as the United States Agency for International Development (USAID) to support several projects and initiatives to improve the availability of and access to appropriate, high-quality wheelchairs and trained wheelchair service providers in less-resourced settings (LRS). Two such initiatives are the Consolidating Logistics for Assistive Technology Supply and Provision (CLASP) and the International Society of Wheelchair Professionals (ISWP) that have activities focused on procurement and standards of high-quality, appropriate wheelchairs. In this paper, we propose a coupled CLASP-ISWP model that can be applied to ATs and implemented at national or local levels in LRS to improve AT procurement and quality.

Keywords

Assistive technology; design; procurement; quality; wheelchairs

Introduction

There remains a vast need for high-quality assistive technology (AT) around the world and this need will increase with time due to ageing, rise in noncommunicable diseases and increasing number of injuries from road traffic crashes, violence, falls, acts of war and natural disasters (1–7). Currently, more than 1 billion people need 1 or more assistive products and only 1 in 10 people in need have access to one (7). This need is overwhelming in less-resourced settings (LRS) as an estimated 80% of people with disabilities live there (8).

In such settings, there is a lack of reimbursement schemes and regulatory oversight of AT products and services, and consequently, when ATs such as wheelchairs are provided, they flow through multiple procurement channels such as donation, small-scale workshops, manufacturing, globalization and multi-modal. Because these channels are often informal and uncoordinated, it can lead to non-uniform product characteristics and quality (9). One of the common channels of provision in LRS is donation of a patchwork of different types of ATs by non-governmental aid and charitable organizations through camp-style distributions. This model of provision although known for providing AT and wheelchairs in large volumes, has been criticized by many experts who report that donated products lack necessary features, appropriate sizes and quality (10–12). Other channels provide products that are built locally, imported or refurbished products from another country through small-scale workshops, dealerships or wheelchair clinics (9,12). Irrespective of the procurement channel, the majority of the AT delivered in LRS is not appropriate for environments and use conditions which is linked to frequent product failures and breakdowns (13–17). Community studies conducted in LRS have reported AT products including walkers, canes, wheelchairs, tricycles and knee-ankle-foot orthosis (KAFO) to fail and be discarded within 3 months of use (14,15,17–19). Failures with these AT products are known to injure users, leave them stranded, and lead to significant secondary health conditions. For instance, without access to a reliable wheelchair, the user may need to stay in bed which increases the risk of pressure sores, drop foot, or spinal deformity and may cause premature death (12,20). Overall, the lack of regulations, funding and awareness has led to provision of inappropriate quality of AT models in LRS which is associated with adverse user consequences.

Improved accessibility to high-quality, appropriate AT to improve the quality of life of people with disabilities is a human right issue recognized by international guidelines and global stakeholders. The United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD) specifically mentions the importance of ATs in eight of its Articles (4, 9, 20, 21, 24, 26, 29, and 32) (8). Although there is widespread ratification of the UN-CRPD by as many as 177 countries, progress on its implementation is hampered by several challenges including a lack of appropriate community support services and guidance to support member states to implement the necessary changes (21). To accelerate the implementation of UN-CRPD initiatives globally, the WHO in 2014 initiated a program called the Global Cooperation on Assistive Technology (GATE) (22). As a part of this program, WHO recently published a Priority Assistive Products List (APL) that includes a list of minimum 50 AT products selected on the basis of widespread need and impact on people's lives (23). WHO, furthermore, has published guidelines for provision of manual wheelchairs in less-resourced settings and standards for prosthetics and orthotics that specify best practices and recommendations for design, testing, production and supply of these respective AT devices with a focus on increasing their quality (12,24). The WHO wheelchair guidelines define an appropriate wheelchair as one that meets the user's needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained and services sustained in the country at the

most economical and affordable price (12). Among all ATs available globally, wheelchairs, prosthetics and orthotics, have evolved significantly owing to the collaborative work of international organizations and global experts, and publication of guidelines and policies. This paper draws observations from activities that have been ongoing in the wheelchair sector with application to AT procurement and quality improvement, more broadly.

USAID Wheelchair Program

To support the recommendations in the WHO Guidelines, the United States Agency for International Development (USAID) and other U.S. Government agencies in collaboration with WHO have developed wheelchair service training packages, supported programs in 42 countries and provided over 70,000 wheelchairs (3). USAID has historically funded wheelchair programs that focus on five key areas: Research, Resources, Support Programs, Procurement and Professionalization (25). This paper focuses on specific activities that have been sponsored through the two USAID-funded projects the Consolidating Logistics for Assistive Technology Supply and Provision (CLASP) and the International Society of Wheelchair Professionals (ISWP) that address standardizing procurement and quality of wheelchairs.

Approach

CLASP, a distribution mechanism that consolidates a range of appropriate, high-quality wheelchairs (26) from various suppliers and promotes appropriate provision. ISWP, a global society that is strengthening wheelchair quality testing standards and disseminating resources on wheelchair design, testing and selection (27). CLASP and ISWP have developed and implemented project practices and procedures that may serve as models to standardize product procurement (*selection and distribution*) and operationalize quality standards of ATs in LRS.

CLASP as a Model to Improve Wheelchair Procurement

In 2014, the CLASP program was launched through a USAID-funded project implemented by UCP Wheels for Humanity (UCPW). The goal of CLASP is to improve the availability of and access to appropriate AT in LRS and to promote quality service provision. CLASP was conceived as a supply solution to ongoing challenges that wheelchair service provider organizations in LRS experience, including limited product variety, extensive lead times, and logistical burdens. CLASP streamlines distribution, expands marketing to ramp up global sales, promotes quality service provision through a network of CLASP Service Partners and promotes industry collaboration to advance a shared agenda.

To improve the availability of and access to AT, CLASP enables ordering of mobility products as listed in the GATE Assistive Product List through a web-based product catalogue (<https://www.clasphub.org/products/>). The selection of products in the catalogue is carried out through a bidding process guided by a Product Advisory Council (PAC) that comprises of wheelchair users, clinical, and technical experts from different countries with vast

experience in LRS. PAC members are selected through a nomination process and serve on a volunteer basis.

CLASP stocks adult and pediatric wheeled mobility devices that come with a standard set of promotion and support materials providing details of a product's performance specifications plus instructions on the proper use and care of the product. The goal of CLASP is for buyers, service providers, and other stakeholders to be able to purchase small-to-large numbers of a range of appropriate wheelchairs and non-wheelchair mobility products from a number of suppliers through a web-based product catalogue. Product sizes, specifications, intended users and support materials (*user guide and assembly manuals*) are provided on the product page. Spare parts and modification kits are also available. A wheelchair buyer, supplier and/or provider can request for a quote for appropriate products of interest directly through the CLASP on-line portal.

To date, CLASP has been successful at delivering high-quality mobility aids to more than 30 countries in some of the most remote regions in the world.

Multidisciplinary and Structured Selection of Products for CLASP Catalogue

The selection of products in the catalogue is carried out through a structured bidding and expert technical review process guided by the PAC. The bidding process begins with an announcement of an Invitation to Bid (*ITB*) for seating and mobility products based on product class. Eligible bidders are global wheelchair suppliers. Each bid is internally developed by CLASP's wheelchair experts with input from the PAC.

Products submitted in the ITB are evaluated through two phases of evaluation as below:

Phase I Evaluation

Interested bidders including wheelchair buyers, suppliers and providers are provided with product and operational requirements, divided by product class each with a corresponding rubric that transparently scores each requirement. A question & answer period allows CLASP to clarify bidder questions prior to embarking on submission. Initial scoring is split between threshold requirements and non-mandatory features. Bidders that meet threshold requirements are invited to Phase II. Threshold requirements are noted as-such within the evaluation rubric, based on the product class. Threshold categories fall under three review domains: product specifications, product quality, and business suitability.

Phase II Evaluation

Phase II review involves two additional review domains are included; product past performance and in-person product review. The review process solicits input from all PAC members who review and score products in multidisciplinary expert teams. Product review is conducted through a hybrid in-person and live streaming approach. The global multidisciplinary team spans time zones, which pose coordination challenges, but full in-person participation would be cost prohibitive. As such, the hybrid method has been a reasonable compromise.

During the in-person evaluation, the assembly, finishing, functionality and quality of each product are assessed. Group conference calls following in-person evaluations address any concerns and generate consensus. Throughout the process the bidder is asked for supplemental or absent information and clarification. A recommendations report developed and approved by PAC is submitted to CLASP. In the event of a dispute, PAC concerns or need for a tie-breaking vote, an ISWP expert is recruited.

Product selection is communicated to suppliers and over a 6-month period, new products are availed through the CLASP online catalogue.

CLASP Service Partners

The CLASP distribution mechanism promotes provision of appropriate wheelchairs through several mechanisms. One way is through selection and promotion of CLASP Service Partners. The Service Partners are selected through a competitive process in which they are evaluated to be in-line with the 8 steps for appropriate wheelchair provision stated by WHO. This includes the availability of trained service providers, range of product in stock, and organizational capacity to manage inventory and solicit funds. Service Partners are eligible for CLASP product donations and the partnerships are valid for a period of up to 3 years. As part of their responsibilities and commitment to appropriate provision, Service Partners have to register each newly provided wheelchair online with the accountability of responding to warranty claims, if any. Quarterly reporting on follow up is also required by Service Partners. This allows Service Partners, CLASP, and Suppliers to learn more about consumer satisfaction, and product performance. This feedback is critical to collect field performance of products and in turn, improve their design for better performance. Beyond Service Partners, CLASP buyers are provided information to register each individual wheelchair upon fitting to the end user, encouraged to conduct follow-ups and use CLASP's user feedback form to contribute to the understanding of context-specific product performance.

ISWP as a Model to Improve Wheelchair Quality:

USAID supported several programs and organizations around the world to professionalize wheelchair services and promote greater access to affordable and appropriate wheeled mobility devices and services. The discrete nature of these supported programs across different regions resulted in a wide variety of standards, norms and quality of service (28). To address this issue, in 2015, USAID funded development of the ISWP with the aim of coordinating the wheelchair sector and developing product and service standards. ISWP initiatives are directed by an Advisory board and while the activities have evolved over time, there is a strong emphasis of sector-wide collaboration that has been coordinated through working groups, with focuses on 1) Training; 2) Policy/Advocacy; 3) Product Standards; and 4) Evidence-based Practice. The focus of this paper is to highlight the activities of ISWP's Standards Working Group (SWG) in improving product quality through guideline and standards development. The SWG is composed of representatives from United States,

United Kingdom and South Africa with significant field experiences in LRS and expertise in wheelchair design and manufacturing, procurement, and large-scale purchasing. The SWG was established as an open group, where additional members can join at any time, and all meetings are open for participation from the wider community.

The group began their operations in early 2015 with biweekly group discussions via web conferencing. These group discussions were centered around wheelchair failures frequently encountered in the community but not predicted by the published ISO-7176 international wheelchair quality testing standards which include a suite of stability, dimensional evaluation and durability testing methods (13,29). The SWG experts provided informal evidence for the discussion by sharing pictures of broken and inoperable parts that they had collected through their work to demonstrate the types of failures common in adverse environments witnessed in LRS and rural areas of resourced settings. In parallel with these discussions, a literature review was conducted by a part of the SWG to determine the scope of the evidence regarding wheelchair quality in LRS and the application of ISO or other relevant standards. The review concluded that the current suite of ISO test methods is suitable for testing wheelchair products used in urban environments but not for those used in adverse environments where rough terrains, debris and elevated temperatures are common (13). The SWG then carried out a series of discussions to identify and prioritize additional tests that are required to predict wheelchair reliability in adverse environments. The outcome of these discussions was a list of tests methods that should be developed for wheelchairs used in adverse environments. The group then investigated whether test methods were already published (*for example for similar products*) through major standards organizations (*e.g. ISO, ASTM and MIL-SPEC*) that could be used as-is or could be a basis for new ISWP test methods. The priority for developing test methods was determined based on parts that fail most often and their related risk to the user's health and safety (13). Based on this effort, four test methods were prioritized for development: 1) Castor durability testing; 2) Rolling resistance testing of rear wheels and castors; 3) Corrosion testing and 4) Whole-chair durability testing.

In addition, the SWG highlighted the need for a best-practices document for wheelchair design to be used by designers to avoid the pitfalls common in wheelchair design. Part of the SG undertook the activity for drafting the best practices document based on their respective expertise. Wheelchair part and human anatomy drawings were sourced from one of the SWG members and added to the draft. ISWP castor testing outcomes informed some of the castor design guidelines. Once the draft was compiled, feedback was sought from 5 independent wheelchair experts through an in-person meeting. These expert reviewers were nominated by SWG members and other wheelchair experts affiliated with the ISWP. Following review, the draft was revised significantly based on comments and compiled for publication.

Castor Durability Testing

Rough terrains, shocks and corrosive environments cause castors to fail frequently with multiple failure modes, most of which are not simulated on ISO 7176 tests (18,19,30–35). An evidence-based approach (Figure 1) was followed in which evidence available from the three data sources of community, expert review and testing results was iteratively triangulated to develop the test equipment (Figure 2) and testing protocol (36). Validation of the protocol to community data has led to failures from the community strongly correlate with the representative failures seen on the laboratory-based test (36,38). The equipment and protocol are consistent with ISO/AWP 7176-32 which is a castor standard under development (37).

Figure 1: Evidence-based approach for development of testing standards

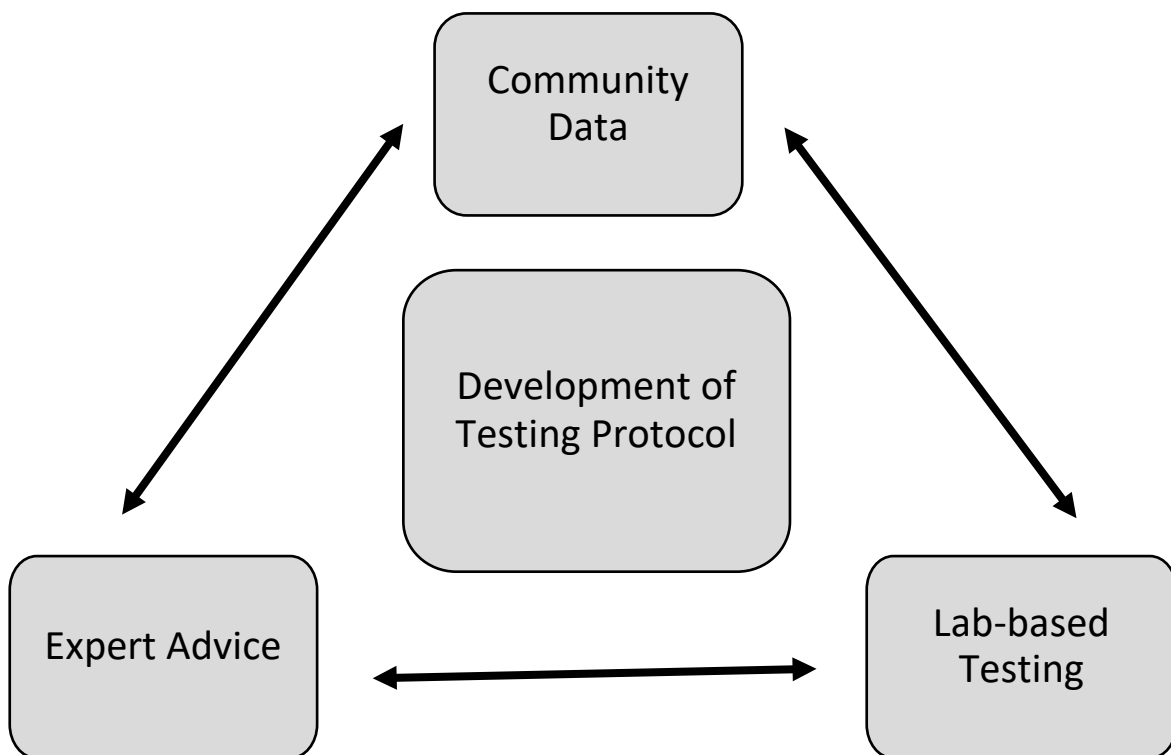


Figure 2: ISWP Castor Testing System also called as ISWP Chakra



Rolling Resistance Testing of Rear Wheels and Castors

Wheelchairs used in adverse environments are found to be heavy and difficult to roll (12). Wheels, tyres and castors perform differently and differ in rolling resistance depending on tyre's tread design, type of tyre (pneumatic versus solid), camber level, toe-in/toe-out, type of spokes, and play in the axle hub bearings. These conditions are not included in ISO testing. The ISWP Rolling Resistance Test (Figure 3) evaluates the resistance of wheels and castors. Results from the tests allow manufacturers and service providers to select an appropriate design based on use conditions.

Figure 3: Rolling Resistance Testing System



Corrosion Testing

Corrosion of wheelchairs is a universal issue wherein several wheelchair parts such as brakes and bearings lose their operational ability after being corroded. Although ISO testing includes testing in hot and cold environments, it does not test for corrosive, humid conditions to simulate exposure to rainwater or waterlogged in ditches. Hence, corrosion evaluation of specific chair parts is recommended. The ISWP Corrosion Test (Figure 4) includes testing wheelchair parts according to the ASTM B117 standard and evaluating them as per MIL-SPEC and ASTM standards. Such testing assists in evaluating the corrosion resistance of painted and coated parts (36).

Figure 4: ASTM B117-based salt fog chamber for corrosion testing



Whole-chair Durability Testing

The SWG recognizes that wheelchairs suffer from mechanical impacts and shocks, and effects from environmental factors. Environmental factors include different ground surfaces, temperature, humidity, and dirt that are not included in the standard wheelchair test methods. The SWG in collaboration with Free Wheelchair Mission (*FWM*) is developing a whole-chair test which consists of a 20-foot treadmill that exposes wheelchairs to shocks and drops as seen in the community (Figure 5). Similar to the castor test, the validation of the shock conditions was conducted using acceleration and stress data collected in Kenya (39). To improve product quality, *FWM* has been continuously testing their products and offering testing services to evaluate other wheelchair designs and components.

Figure 5: Whole-chair Durability Testing System at FWM



ISWP Testing Outcomes

ISWP has tested multiple wheelchair models (*with ISO testing*) along with testing of wheelchair products with ISWP tests to screen inappropriate products. The outcomes from the ISWP testing work are as follows:

1. Development of wheelchair design and selection guidelines for manufacturers, suppliers, designers, clinicians and users in LRS (36).
2. Design modifications provided to manufacturers and suppliers for improving product quality and reliability (36,39).
3. ISWP plans to publish wheelchair testing standards under development as international standards through the International Organization for Standardization (ISO) (40).
4. Test improvement suggestions for ISO wheelchair testing standards to enable simulation of field-representative failures (36).

ISWP Design Considerations

While developing standards, the ISWP-SWG has published a Design Considerations document to guide wheelchair designers, manufacturers, providers, users and their caregivers on best design practices for wheelchairs used in adverse environments (41). Manufacturers, designers and technicians can apply the design practices for building appropriate mobility products and improving the quality of current designs for LRS. ISWP has been disseminating the guidelines to stakeholders and providers with the hope that more users will receive appropriate, high-quality wheelchairs, enabling them to actively participate in their communities.

ISWP Product Testing Documentation

There are very few independent wheelchair product quality testing laboratories internationally. To raise the wheelchair testing capacity around the world, ISWP has been publishing product testing documentation. Manufacturers and providers can set up test labs to conduct testing of local and imported products to determine their appropriateness and quality. The documentation packets consist of operational checklists, schematics and design

drawings. The documentation has been published as open-source and is also being disseminated through the ISWP Resource Hub (27). Documentation is currently available for the ISWP Castor Test, ISO Multi-drum and Curb Drop Test, and Test Dummy (42-45). Further, the SWG plans to develop a Wikipedia of testing methods which will further assist development of wheelchair testing laboratories.

Discussion

A lack of controls and viable markets in LRS often result in low-quality, inappropriate ATs including wheelchairs being procured and provided that rarely meet the needs of the recipient (12). This has led to poor user outcomes and AT abandonment (14,15,19). To improve the quality of life for wheelchair users, the USAID-funded projects – CLASP and ISWP are helping to standardizing wheelchair procurement and quality internationally. They are generating evidence, standards and resources that have the potential to inform decision-making on design and supply of appropriate wheelchair products globally. These two approaches support each other to improve wheelchair procurement and quality of wheelchairs internationally.

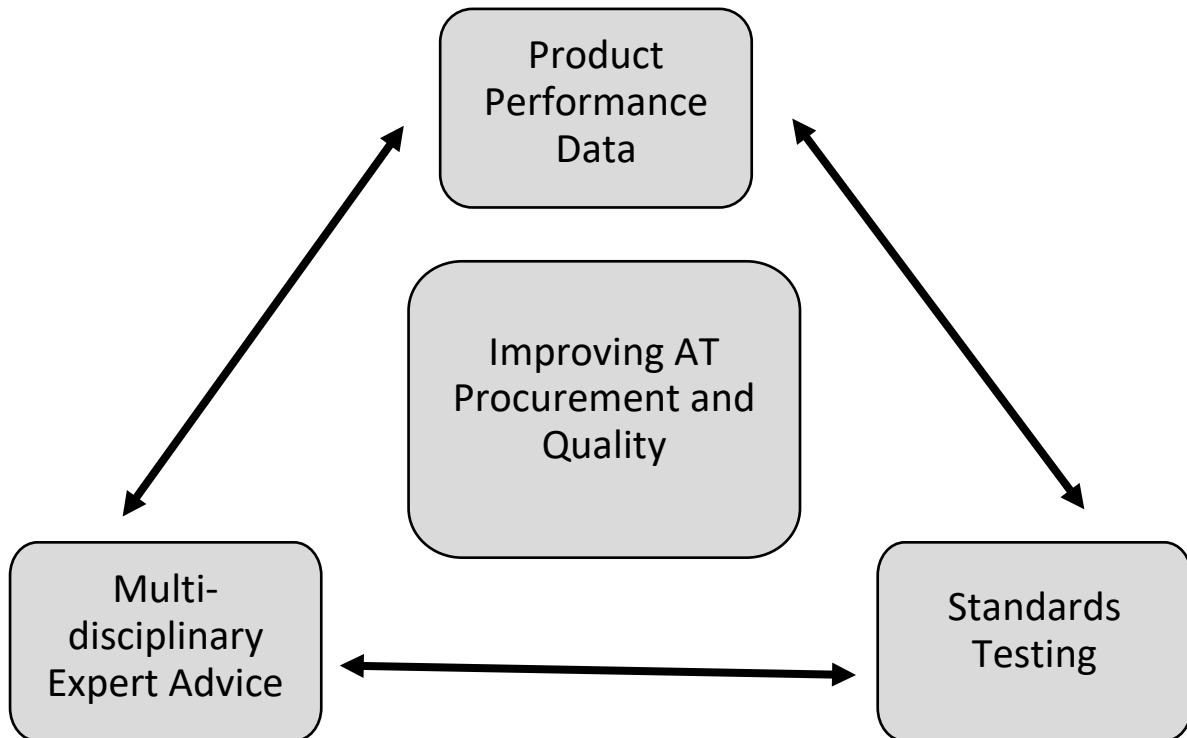
For instance, CLASP relies on the ISWP guidance on the standardized testing (*e.g. ISO and ISWP tests*) that should be used as part of the product screening during their ITB evaluations. Since ISWP supports standards development for adverse environments, wheelchairs procured through the CLASP catalogue should be high-quality and reliable for use in LRS. CLASP through their relationships with product suppliers can promote the ISWP-recommended tests protocols that support the uptake of the tests into global testing facilities.

Through ongoing monitoring of customers, CLASP collects data on product failures, warranty repairs and replacements in LRS which has been difficult due to lack of programs and provision systems that encourage follow-up, repair and related data collection. Such data can then be used to inform product standards development activities (*see Figure 2*). For instance, the ISWP SWG as well as ISO working groups develop testing methodologies based on product failure in the community, and CLASP's data can then directly be used to inform and strengthen standards development.

Recommendations for Greater Access to Appropriate AT

The wheelchair sector-specific CLASP and ISWP models can be coupled, adapted, and implemented as a national strategic approach to standardize the procurement and quality of AT in LRS (Figure 6).

Figure 6: The CLASP-ISWP model to improve access to appropriate AT



A multidisciplinary expert steering committee like CLASP's PAC and ISWP's SWG can be formed to develop evidence-based standard testing methods and enforce the standards for product qualification during procurement. The committee shall consist of experts including AT users, development practitioners, service providers, production, and quality assurance and manufacturing. A strategic plan can be drafted to develop and implement the CLASP-ISWP model for AT products in the country after a thorough review of national AT policies, programs and services. The plan shall focus on developing a centralized system like CLASP or programs at partnering service providers and rehabilitation centers for collecting product performance data and developing a database. This data collection can provide information on usage, performance and failures of currently used AT devices in the region. Using this information, an AT product testing matrix can be developed similar to the ISWP approach (13). ATs like walkers, KAFO, tricycles and crutches that have been found to fail as frequently as once per month can be prioritized for test method development. In case wheelchairs are prioritized, wheelchair product testing resources disseminated by ISWP can be utilized for developing wheelchair testing capacity in LRS. Product testing results shall be iteratively correlated with the product failures and performance to inform the committee regarding improvements in testing methods. Test methods should be benchmarked for desired product performance in the community. Once test methods are fully developed, they can be proposed to national standard bodies for development and publication as a national standard. Testing outcomes shall be reported to manufacturers and providers for product quality improvements and development of new, appropriate AT designs. Testing outcomes and product performance data can be used to put together a Design Considerations

document for ATs which can be referred to by manufacturers, stakeholders and committees in other LRS.

In parallel with standards development, the body in charge of AT procurement may collaborate with the expert committee to develop a bidding process for ATs that are significantly needed in the context. The two-phase evaluation process standardized by CLASP can be followed by the expert committee for screening products. AT testing standards developed by the committee and other testing standards (*ISO, ISWP*) can be suitably adopted in the screening process. Qualified AT products can be included on an online catalogue with product documentation, testing information, and product performance data with user feedback. This will promote informed decision-making during selection and procurement of appropriate locally manufactured and possibly, imported AT products. The CLASP-ISWP based AT provision model may benefit all the AT-sector stakeholders including users, product developers, procurement agencies, service providers, among others. It is important to note individuals who use AT have a protagonist role in this model as they serve in the expert committee and their experiences with the AT products will be the drivers of product quality improvement.

Challenges

This paper outlines a model for improving AT quality and procurement in LRS. The model's implementation can be challenging depending on existing systems, infrastructure and resources. The authors encourage national AT programs to adopt the proposed product procurement and quality model for their coordinated action to insure access to AT. This effort can be initiated with suitable support and funding from governmental and nongovernmental organizations.

Opportunities

Implementation of CLASP-ISWP model in LRS can open new possibilities like product innovation and competition. Since AT products will be reviewed against relevant testing standards and criteria, manufacturers in the AT sector will be compelled to innovate and compete to gain recognition in the marketplace. Local manufacturers and providers can team up with international manufacturers to gain competitive advantage by knowledge sharing on cost-effective, manufacturing practices, building products from local materials and context-appropriate parts, and sale of quality AT at affordable prices.

Conclusion

There is an overwhelming need for appropriate, high-quality assistive technology globally and majority of this need is concentrated in LRS. Lack of regulations, funding and awareness has led to provision of inappropriate AT models through various procurement channels. To standardize procurement and quality of wheelchairs, USAID has supported two project initiatives – CLASP and ISWP. Coupling the CLASP-ISWP approaches can provide a model with a national strategic approach to streamline procurement and improve AT quality. Using

this model proposed in the paper, a multidisciplinary expert committee can lead the development and adoption of evidence-based standard testing methods appropriate for LRS, which can be used to qualify products during procurement. With suitable support from governmental and non-governmental organizations, the expert committee and AT users are encouraged to play a vital role in the implementation of the CLASP-ISWP model which has the potential to standardize procurement and quality of AT products in LRS.

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Telemedicine as assistive technology for rehabilitation of children with cerebral palsy or musculoskeletal disorders

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Abstract

Background and aims. The solution to the problem of disability is connected with the creation and development of a system of comprehensive rehabilitation and habilitation aimed at reducing severe health limitations. It is important to provide availability and quality of rehabilitation services to the population. This issue is particularly acute in remote areas of Russia, as highly qualified specialists are usually concentrated in research centres and large clinics in cities. **Methods.** In order to improve the quality of rehabilitation services for children, in the framework of the Russian-Norwegian project we organized work on establishment and implementation of a consultative network. The project is based on telemedicine technology. The target group is specialists who work with children with cerebral palsy (CP) and with disorders of the musculoskeletal system and families with children with these disorders. The project involves seven Russian regions that belong both to the Russian North-West Federal Division and the Barents Region. It was planned to build a consultative network “specialist-specialist” with Albrecht Federal Scientific Centre of Rehabilitation of the Disabled. The specialists of the centre, who possess great experience, can provide high-quality consultations to the North-Western regions, conduct lectures and master classes improving the quality of rehabilitation services by raising the skills of local specialists. **Results.** The project started in July 2018. It has two main directions: the establishment of a consultative network and building informational courses on CP and musculoskeletal disorders. Now we do preparative work to launch the network and courses. **Conclusions.** The building and use of a consultative network for rehabilitation and habilitation will help both qualitatively and quantitatively expand rehabilitation services, improve quality and efficiency, improve the availability of rehabilitation and habilitation measures in medical institutions, social sphere and during individual consultations.

Keywords

Telemedicine, training, cerebral palsy, musculoskeletal disorders, ICF Core Sets.

Introduction

According to the Federal State Statistic Service, the population of the Russian Federation is 146,8 million people (1), 3,5 million of whom live in Russian part of Barents region in rural area in conditions of arctic desert (on islands), cold desert (tundra) and dense forest and about 2 million people live in Leningrad region in small towns and rural areas. According to the Federal Register of Disabled people over 11 million people (57% - women, 43% - men) are disabled, and only one million of them live in Moscow and a half of the million live in St. Petersburg (2). Moreover, due to specific of work in Barents region (rotating scheme) a part of population structure changes constantly. It means that the need in rehabilitation, especially, after work accidents is a priority.

It is important to provide equal access to rehabilitation services and assistive technologies to the population in cities and rural areas of Russia. It is known that highly qualified specialists are usually concentrated in research centres and large clinics in cities. Therefore, rehabilitation of disabled people of high quality is urgent in rural areas.

From another side, eHealth diplomacy was initiated in 2016 - 2017 in the Russian Federation. Currently there are two important laws in the legislation system of the country on eHealth and telemedicine technologies: Federal law № 323 of 21/Nov/2011 with amendments of 29/May/2019 "On the basis of the protection of public health in the Russian Federation" and Federal law № 242 of 29/July/2017 "On making amendments to the selected legislative acts of the Russian Federation on issues of information technology application in the sphere of health protection" (3, 4). Moreover, the Ministry of Health is developing the project passport "eHealth" (5). It shows the big interest of the Government to new technologies in healthcare.

Information and communication technologies (ICTs) can be considered as rapidly developing assistive technologies that can affect services, researches and health-related activities and provide the sustainable system that covers the need of the whole country. ICTs can help solving this problem through eHealth (6), using electronic communication technologies for health needs: examining and treating patients, training specialists and monitoring public health trends (7).

Albrecht Federal Scientific Centre of Rehabilitation of the Disabled is a unique organization in the country that is responsible on the spread of knowledge and methodology on rehabilitation of disabled people on the territory of the whole country and provides all aspects of rehabilitation to Russian citizens equally without priority to particular regions.

The solution to the problem of disability is connected with the creation and development of a system of comprehensive rehabilitation and habilitation aimed at reducing severe health limitations. It is important to provide availability and quality of rehabilitation services to the population. This issue is particularly acute in remote areas of Russia, as highly qualified specialists are usually concentrated in research centres and large clinics in cities.

The aim of the study is to improve the quality of rehabilitation services of children with disabilities via consultations and trainings with help of telemedicine tools, by attracting a team of highly qualified specialists and implementing International Classification of Functioning Disability and Health (ICF) Core Sets. The work has several objectives:

- to collect the information about specialists who work with children with cerebral palsy (CP) or musculoskeletal disorders in the particular regions;
- to collect information about the amount of equipment for telemedicine, especially, for remote consultations and possible remote trainings: availability of speakers, high quality cameras, screens and computers with update software and licenses for Skype for Business, WebEx, Zoom, etc.
- to create a closed consultation network of the type specialist – specialist;
- to create informative courses for families (relatives) with children with CP or musculoskeletal disorders;
- to provide consultations for specialists from particular regions of Russia, constant supervision of complex cases, when it is necessary;
- to create forms of feedback for using website with consultation and informative courses for families (relatives) with children with CP or musculoskeletal disorders and for receiving consultations;
- to collect and process statistics with popularity and quality of consultation network and courses;
- to disseminate information about the project results.

Methods

In July 2018, Federal State Budgetary Institution “Albrecht Federal Scientific Centre of Rehabilitation of the Disabled” of the Ministry of Labour and Social Protection of the Russian Federation in St. Petersburg and University Hospital of North Norway in Tromsø set up the Russian – Norwegian project “Establishment of the consultation network in framework of rehabilitation and habilitation” with support of the Royal Norwegian Ministry of Health and Care Services. The project is being implemented in the regions of Russian Federation that are included into Barents region (5 territorial entities are included: Arkhangelsk region, Murmansk region, the Republic of Karelia, the Komi Republic, and the Nenets Autonomous area). In addition, two more territorial entities were added due to Albrecht’s Centre location, they are St. Petersburg and Leningrad region. Target groups of the project are specialists from these regions who work with children with CP or musculoskeletal disorders and families (relatives) and families.

The project consists of two main blocks of activities. The first one is development of consultation network between specialists of Albrecht’s Centre and specialists from regions of the Russian Federation (Barents region and Leningrad region) to provide on-line / off-line consultations on the issues of CP and musculoskeletal disorders. The second block is

creation of informative educational courses for families with children with CP or musculoskeletal disorders.

In addition, Albrecht's Centre is a WHO Collaborating Centre on the Family of International Classifications (WHO FIC CC) and it works with International Classification of Functioning, Disability and Health (ICF) and ICF Core Sets since 2014 (8, 9). Therefore, the base for the project also is scientific researches on development of methodological recommendations for Russia to use ICF Core Sets for musculoskeletal disorders (2013-2015) (10); ICF Core Sets for CP (2016-2018) (11, 12). These researches were set down by the Ministry of Labour and Social Protection of the Russian Federation and completed by Albrecht's Centre specialists.

It was considered to develop a website that has both open and closed layers. Open one contains informative courses on CP and musculoskeletal disorders for families, specialists and for all interested people, also there are forms for feedbacks. The closed layer is a consultative network including registration and authorisation for specialists from the regions described above to receive consultations from Albrecht's Centre specialists.

Consultations are based on telemedicine technology that is one of the components of eHealth (13).

Findings

Currently, the project is in process. On the first step of creation of consultation network we identified 11 coordinators from regions with help of the Governors of these regions (North-West of Russia / Barents region). In their turn they made lists of specialists who would like to be involved into consultation network and informed these people with details of the project. As it appeared that some responsible persons also would like to participate as specialists from regions and receive consultations, currently we have 31 specialists for the network. They work in hospitals, clinics and different rehabilitation centres. The specialists from regions had a survey and provided the information about the equipment for teleconsultations. All organizations have meeting/consultation rooms with computer, camera and speaker, but only 30% ever used Skype for Business, WebEx or Zoom.

At the same time, we analysed the need for telemedicine services. Specialists of marketing department collected statistic data for 2017-2018 years on the basis of requests that came to Albrecht's Centre call service via phone calls and emails. The statistics showed rapidly growing demand for teleconsultations and patients were ready to receive rehabilitation services immediately rather than send a request with already prepared and attached documents. The latest would mean that they are ready to come to Albrecht's Centre themselves for operations or other kinds of treatment. For example, only half of email requests for rehabilitation came with already prepared documents in 2018. According to the statistical data, the maximum number of requests for tele-consultations in 2017 was 16 (in December 2017), while by the end of 2018 this amount grew up to almost 100 requests. Moreover, the average number of calls was 3800 in 2018 and only quarter of them became medical appointment booking. The rest of them can be potential tele-consultations.

In framework of website development, the content for informative educational course on CP has been elaborated. The course provides information for families that have children with CP. Moreover, there are blocks on ICD-10 (14), basics of ICF (8) and ICF Core Sets for CP (11). Their usage is explained in brief form and easy for understanding. The informative course on musculoskeletal disorders is under development.

In the process we discovered the need to organize and conduct the distant training for specialists from regions. It is considered to contain two parts. The first one is a technical module that explains how to work in consultation network of rehabilitation and habilitation using telemedicine tools and website platform for the consultation network. The second part is the use-case specific module aimed at implementation of ICF in rehabilitation children with CP. It contains basics of ICF, using the rehabilitation and habilitation guidelines based on the ICF Core Sets for children and youth with CP and multidisciplinary approach to rehabilitation and habilitation. The course is planned to be conducted in September 2019.

In July 2019, the website (15) that is a platform for consultation network and informative courses is being tested. Currently, it is on Russian only, but also there is information about the project itself on Albrecht's Centre official website on both Russian (16) and English (17) languages. The consultation network was developed with open technologies such as OPENUIS, NodeJS, MongoDB. The OPENUIS framework (an open framework from SAP Company) was used for custom web applications. The framework allows you to run applications on your computer and on any mobile device (18). The server part was developed using the NodeJS application development platform and the MongoDB database (19, 20). The application is implemented using a single programming language that is JavaScript, which simplifies the process of its support and development.

The consultation network is aimed at specialists from regions and support consultations of the type "Specialist - specialist". To work in the network, a specialist has to log in and create a request for Albrecht's Centre. The request contains basic information about a patient (age, disorder, short description of a case, etc.). Then, the administrator of Albrecht's Centre appoints a specialist and refers the request to him or her. There is possibility to choose necessary topic of request (CP, musculoskeletal disorders and other), to indicate the date of online consultation or to have a chat between specialists. The consultation network provides two possible type of consultations: online and offline. If online consultation is necessary, it is possible to be provided with Skype for Business in newly equipped meeting room.

Speaking about feedback forms to assess the quality of the website, it has been integrated into the structure of the website and can be transformed into Excel document to collect statistics.

Discussion

In 2019 it is planned to expand topics of informative online courses and consultations up to ASD (with use of ICF Core Sets for ASD) and early childhood interventions. ICF Core Sets on

CP, musculoskeletal disorders and ASD is basis to elaborate the programme of consultations. Provision of consultations and supervision of cases will be constant during next two years of the project. As a result of the project, the network can be expanded on other territories of Russia or other countries.

Moreover, one of the objectives of the project is to elaborate a universal feedback form for consultations. It is important to develop such feedback form that can allow collecting essential information and showing problem elements of the website, network and consultation or informative course quality. Also, it is planned to use the tool Yandex Metrika (21) to collect statistic data on user actions at the website.

If legislation on eHealth develops fast, it will facilitate the project process. Also, it is important to protect patients' data inside the network and while discussing on online consultations. From legislation side, there is a federal law № 152 of 27/July/2006 "On personal data" with final amendments of 2019 that contains points on confidence of patient's data (22). From technical side, it is necessary to use data protected channels of communication such as Skype for Business for online consultations.

The use of ICT and ICF Core Sets in rehabilitation will improve the quality of life and work in regions. The network platform, online courses and universal feedback forms can be duplicated into other spheres in future. The consultation network and courses will increase the common level of rehabilitation services on the territory of North-West of Russia, especially, in rural areas in the North. The project will help both qualitatively and quantitatively expand rehabilitation services, improve quality and efficacy, improve access to rehabilitation and habilitation measures.

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Community-based rehabilitation workers' role in wheelchair service provision

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Abstract

Background: Shortage of rehabilitation professionals and other contextual barriers in low-income contexts prevent access to services and utilisation of wheelchairs. Community-based rehabilitation workers (CBR) workers may strengthen wheelchair service delivery, but the exact nature of their contribution requires understanding. **Objectives and approach:** This descriptive, qualitative study explored what CBR workers perceived as challenges to wheelchair provision and use, the contributing factors, the role they could play and what was needed. Three wheelchair services and 21 CBR workers in Uganda were purposively selected to participate in three focus group discussions. **Findings:** CBR workers reflected on challenges to mobility and participation due to historical and societal influences on attitudes, limited availability of appropriate products, weaknesses or absence of service provision, unimplemented and misunderstood policies and too few trained personnel. CBR workers suggested strategies consistent with the CBR matrix to support and enhance utilisation of services and participation of wheelchair users. They need wheelchair-specific training. Their role should be formalised. **Conclusion:** Wheelchair-service provision in Uganda could benefit from engaging with the CBR sector to identify wheelchair users, make referrals and facilitate access to services, support wheelchair services by providing contextually appropriate information, train and support wheelchair users and caregivers, and assist with follow up and maintenance.

Keywords

Wheelchairs; low income settings; community-based rehabilitation; wheelchair service provision; wheelchair service steps; Uganda; empowerment; inclusion; assistive device.

Introduction

Personal mobility is a right mandated by the United Nations Convention on the Rights of Persons with Disability (1). The right wheelchair can be a steppingstone to achieve personal health, development and participation in society (2,3). However, only 5%–15% of wheelchair needs are met in low- and middle-income countries (LMIC) (4). Reasons are multifaceted

and include the lack of appropriately trained personnel (5-8). Rehabilitation professionals are in short supply in many resource-constrained settings (9,10). Consequently, services are located in cities and large towns, impeding access for people from remote and rural communities (4). Financial constraints, inaccessible transport, and lack of service information – together with widespread attitudinal barriers – limit uptake of available services (9,11). Additionally, centralised services may not be responsive to specific contextual factors, affecting provision of an appropriate wheelchair (5,12,13). Despite an appropriate wheelchair, meaningful participation and inclusion may be challenged by prolific environmental including attitudinal barriers (12,14-17).

The need for assistive products, including wheelchairs, is rising due to aging populations and an increase in non-communicable diseases (18). Assistive products, including wheelchairs, are crucial in achieving the Sustainable Development Goals (19,20) and require a systems approach to understand and navigate the complexities of developing and scaling up provision, particularly in under-resourced contexts (21). An assistive-technology system refers to ‘the development and application of organized knowledge, skills, procedures, and policies relevant to the provision, use and assessment of assistive products’ (21). The WHO GATE initiative recommends a focus on five interlinked areas – people, policy, products, provision, and personnel – to ensure a dynamic, quality-focused, and expanding sustainable system (21,22). Towards effective provision of wheelchairs, WHO constructed a comprehensive service model, developed the Wheelchair Service Training Packages (WSTP) to equip wheelchair service personnel with skills and knowledge (23), and included four categories of wheelchairs in the WHO Priority Assistive Products List (19).

Uganda has committed itself to the strengthening of wheelchair services by launching a revised ‘Code of practice for design, production, supply and distribution of wheelchairs and tricycles’ in 2015 (24). Wheelchair service provision is integrated in the health and social development system, which includes community-based rehabilitation (CBR). However, substantial gaps and challenges remain (25,26) and is the focus of national and international organisations such as Motivation Charitable Trust (27). By exploring the perspectives of CBR workers crucial for understanding and tackling such complexities (7,28), the first author, employed by Motivation Charitable Trust, hoped to develop a better understanding of the situation, and gather and stimulate suggestions to improve practice.

The research objectives were to determine what CBR workers perceive as:

- the challenges with wheelchair provision and use
- the factors contributing to these challenges
- the role they can play and what they need to achieve this.

Method

A descriptive, qualitative design was applied within the transformative paradigm and using a participatory methodology (28). Ethical clearance was obtained from Stellenbosch

University Health Research Ethics Committee (S14/10/210) and permission obtained from the Uganda National Council for Science and Technology (SS3687).

Three wheelchair services in Uganda (Figure 1) with WSTP-trained personnel were purposively selected. These hospital-based services in the central, western, and northern regions were active less than 18 months each and integrated into rehabilitation departments. CBR workers working within the collaborative CBR programs were purposively sampled. Participants had to have worked in the geographical area for at least six months with a minimum of 10 wheelchair service beneficiaries.

Participants completed an individual questionnaire in their preferred language and participated in a focus-group discussion (FGD) exploring the following questions (29):

- What are the challenges for people who need or use wheelchairs in your community?
- What are the reasons for these challenges?
- What can you do about it?
- What do you need to achieve this?

Questionnaires were summarised (Table 1). FGDs were audio-recorded, transcribed verbatim, and thematically analysed for each area and across areas. Inductive analysis revealed themes for the first group, which were used for deductive analysis of the other two groups, including new emerging themes (30). Data were triangulated across the three groups. Participants verified the researcher's summaries of the focus-group discussions.

Figure 1. Kisubi (Central), Kasese (West), and Gulu (North) from where participants were recruited



Table 1. Profile of focus-group participants

	1. Centre	2. West	3. North
Description of location	Kisubu, rural and urban, north of the Kampala.	Kasese, rural and remote, mountainous	Gulu, predominantly rural
Total no's (female + male)	Total: 7 (6f + 1m)	Total: 8 (3f + 1m)	Total: 6 (2f + 1m)
Disability status	3 PWD (1 wheelchair user)	2 PWD (1 wheelchair user)	4 PWD
Professional qualifications; CBR training & experience (years)	1 occupational therapist; 1 physiotherapist; 1 social worker with additional CBR training. 1 CBR qualification. 3 no training Experience: 3 – 6yrs	5 CBR training (COMBRA) Experience: 1 - 9 yrs	1 social worker, 1 CBR qualification, 1 CBR training (COMBRA) 4 short courses Experience: 1 - 10 yrs
Details of wheelchair training	4 x 3 days formal course by the wheelchair service (2015). 1 x 1 day in 2013	4 x training ranging from 2 hrs to 2 days in 2014 by the wheelchair service	1 x wheelchair orientation

Findings

There was a high level of agreement between the three groups for all items discussed.

Perceived challenges with wheelchair provision and use and the contributing factors

The International Classification of Functioning, Disability and Health (31) and wheelchair service steps (referral and appointment, assessment, prescription, funding and ordering, product preparation, fitting, user training, and follow-up maintenance and repair) (2) were used to analyse objectives one and two.

An inadequate supply and limited availability of appropriate wheelchairs were identified. Although wheelchairs provided through the services were viewed positively, the range was limited and the supply inconsistent:

North: 'This one issued at the hospital has lot of adjustment and modification before one receives one. They are good.'

North: 'There are times when wheelchairs get finished. People need to wait.'

The low quality and inappropriate design and materials of especially locally-manufactured wheelchairs or those provided through mass donor distributions reportedly resulted in rejections.

North: 'But the ones that are made locally are really unstable.'

North: 'There are so many products for adults in the community. They are out of use; they can fill 2 rooms.'

Other contextual factors contributed to disuse:

Central: 'They keep it outside their room. It wears off very fast.'

North: '...members of the communities, stealing their spare tyre, even their pump, especially to use on their ordinary bicycle.'

CBR workers felt both government and service provision systems failed to understand the magnitude of the need, resulting in many PWD, especially the most rural, not being identified and not receiving information about available services and products.

West 'Those people who don't reach into the community think there's not many disabled persons. Most of these parents hide their children in houses. We as CBR workers know about these people because we've been deep in the village to search for them.'

Having been previously disappointed by services and products provided through political and charity distribution models, many users were hesitant to believe the new wheelchair service would be different. Furthermore, simultaneous on-going distributions conflicted with the new approach, confusing users and continuing to disempower them.

Central: 'Some organisations say I've got 50 wheelchairs. If it fits you – good! If it doesn't fit you, you still have it.'

Being positioned within the health system, fear of hospitals limited access to services. One CBR worker explained how he is pressurised to provide wheelchairs rather than refer people to the hospital.

North: 'If one is afraid [of the hospital], this means they won't turn up for the wheelchair even if they are in need.'

Others were uncertain about the impact of a wheelchair, such as on a child's potential to learn to walk, and their ability to manage the device, affecting their openness to new opportunities.

Conflicting information and expectations amongst both PWD and CBR workers about the right to mobility and the new systems resulted in poor service access.

North: 'People are against the idea of paying [they] are used to the culture of free things.'

North: 'Our situation is not that we have very few wheelchairs – the wheelchairs are there – or that the need for the wheelchair is not there – it is there. But they are not given out as fast as possible because people think it has to go for free.'

CBR workers who accompanied users to the wheelchair services reflected on the perceived benefits for those who received appropriate, individually set-up wheelchairs. Though they appreciated the complexity and technicality of the work required, they warned that the

duration and the multiple visits that were often required, deterred users, and impeded the numbers of beneficiaries.

North: 'You may need to travel to the hospital, maybe twice or even three times to access the chair. Most of the parents give up.'

The CBR workers additionally identified low service capacity, insufficiently trained service providers, inadequate time, and challenges in bringing the services closer to service users.

North: 'They say they are few and their workload is high, particularly for wheelchairs. They are only allocated one day per week.'

West: 'Transporting those wheelchairs, [...] and two technicians from [the service] to outreach is difficult.'

Inadequate user training reportedly resulted in problems with participation and sustained use of wheelchairs. Problems with user training included not having received training, not retaining what had been taught, and not training the main user or all appropriate persons.

West: 'The toolbox might be there but there is only a grandmother - don't even know a spanner - you need someone who has a skill.'

North: 'Each time we go for a home visit, you'll find that they don't have skills of how to care for the wheelchair.'

Furthermore, unavailable and inaccessible follow-up and repair services, together with costs, contributed to small technical issues resulting in dilapidated or abandoned products and health risks, which in turn resulted in more serious complications. A CBR worker explained how a child with complex needs was positioned in the wheelchair all day:

West: '[The] caretaker will just assume that [this is] now a comfortable place.'

Manmade and natural barriers limited accessibility, participation and integration, reportedly demotivating and disempowering users.

Central: 'They find it very tiresome using it every day. They find themselves forgoing it some days.'

North: 'We don't use the road, we use the path, it is very narrow. At times we have to cross the river, there is no bridge. You have to carry the wheelchair on your back or on a bicycle.'

Traditional beliefs, negative attitudes, lack of knowledge and commitment, and the nature of accommodation in the community additionally challenged user participation and independence and increased the caregiver burden.

Central: 'She stopped over six taxis, but they were all leaving her because she had a wheelchair.'

West: 'If this child has to be wheeled to school, [and] the mother has so many other commitments, he won't attend school; because she's the only person to wheel the boy.'

Central: 'At first some teachers were willing [help], but then their attitude changed – I think because he was new. But after he had stayed for a year, it feels like it's a lot of work for them. Now no-one feels interested to do so.'

Some users experienced health risks as they became more active with their appropriate wheelchairs, such as traveling on the road or going to a school lacking appropriate toileting facilities.

Central: 'Kids who are using wheelchairs have to transfer from a wheelchair and then use their hands and enter in a latrine which is already very dirty.'

The wheelchair was also said to increase visibility of the user, potentially exposing females in particular to abuse.

North: 'Many, especially the females, have been objects of sexual abuse. Many will want support from their parents or close relative. Most parents are very protective of the girl child.'

Gaining confidence, becoming empowered, and developing a greater belief in their capability was challenging for wheelchair users due to a lack of role models.

North: 'Most disabled children that have had limited exposure and mentorship from adult disabled person look at themselves as valueless. For them to gain self-esteem it requires lots of support by the community like teachers, adult disabled person and parents.'

Perceived role of CBR workers and facilitators required to fulfil this role

The CBR matrix and wheelchair service steps were used to analyse objective 3.

CBR workers believed that they had an important role in transferring information, explaining disability, combating misconceptions, and improving uptake of available wheelchair services. For this, they required a comprehensive understanding of the wheelchair services and the context, a flexible approach, and ability to move around and spend time in the community.

West: 'You find that a caretaker can say that this child of mine was cursed. Changing him from that belief to the actual belief takes long.'

North: 'You explain that you pay some small amount of money [for the wheelchair]. If they have understood, then people will start paying.'

Advocacy, information and empowering of users were thought to possibly result in an increased demand on services and potential unmet expectations.

West: 'We shall get problems if we mobilise people and they don't get wheelchairs.'

CBR workers suggested that formalising and recognising their role and function was essential to legitimise their work in the community, but also for interacting with the

wheelchair services. They play a critical role in facilitating logistics and communication between services and disempowered users, enabling them to access and reach services.

West: 'We talk to [the users to see if they] are able to afford the transport. Then we talk to the technician. If all are agreed it is on that day, then we access that service.'

They supported users to engage with unfamiliar service personnel.

West: 'If the CBR worker is well known to the parent, [...] then the parent will feel [...] at home. Then he can be able to elaborate more.'

It was suggested that more users may benefit from the services if CBR workers were trained to assist in aspects of service provision.

West: 'If we are trained in that technicality, then you can help the service to reach all the people that have come.'

Home and community visits were seen as opportunities to follow up, identify challenges, advise on maintenance, problem solve, or refer to services. To be responsive they needed enough time to be available and accessible.

North: 'Those mothers can have enough time to ask what they don't know, and you also have enough time to explain and demonstrate.'

These activities were seen to benefit advocacy efforts.

Central: 'It helps you to assimilate how people are living in wheelchair – appreciate the challenges – so when you are lobbying for service delivery you know the issues you are talking about not like guess work.'

Furthermore, they suggested how they could empower wheelchair users, facilitate integration and participation, and create awareness of environmental barriers by educating and informing communities, service providers, and community leaders. A CBR worker shared how he accompanied a child to their new school to educate management, teachers, and pupils about the wheelchair and disability, advise on accessibility, and train school representatives on use and care of the wheelchair. Identifying and empowering peer role models and support groups and engaging them to uplift wheelchair users and influence communities was discussed as a crucial technique.

To be effective, CBR workers emphasised the need for knowledge and skills to ensure understanding of and support for the wheelchair service and users. Their knowledge was limited, with only half having received training on wheelchairs, ranging from two hours to three days, and they expressed concern about their practice.

North: 'What I know is there is a need for capacity building. We may be doing different things.'

However, implementing their role required financial resources which were mostly lacking and, in many cases, depended on what the CBR worker could contribute.

West: 'If you feel that you have something [to] donate then you can go with him [to the service]; but if you have an empty pocket, you just send him.'

West 'If we are really empowered with the facilitation [funds] we can train more people within their localities.'

This led to unequal support to users in different areas, placed pressure on CBR workers who themselves were often also poor, and demotivated them, leading to discontinuation of their roles.

Discussion

The results are discussed in terms of people, policy, products, provision, and personnel (21).

People

Due to their previous experience, many wheelchair users in this study were disempowered and reluctant to access the new wheelchair services. Person-centred services exploring wheelchair users' needs are required to empower users (3,21), and agency is further affected by fears of negative treatment in health establishments, additional attitudinal barriers, and poverty (9). When accessing new wheelchair services, historically disempowered users and communities benefitted from support of a trusted CBR worker to help dispel misunderstandings and fears, provide impetus for users to take up new offers, and to enable a collaborative consultation with service providers (6,9).

Assistive technology (AT) should be the interface between users and the life they wish to lead (3). Similar to other studies in LMIC, a vast range of barriers affected participation, leading to a high need for personal support (9,12,14,15). CBR workers identified a role for themselves in equipping and supporting appropriate and changing support systems to prevent social isolation (14,15). CBR workers identified the lack of role models as contributing to users' disempowerment. Role models could influence individuals' and communities' perceptions of their potential and capability, affecting their beliefs and decisions (32).

The diverse activities of CBR workers over multiple sectors can help empower users who face complex daily challenges in communities where few people understand wheelchairs (12). The true impact of a wheelchair can only be measured by how it is used, meaning this support is essential for monitoring the effectiveness of the wheelchair-provision system (3).

Policy

Policy was not well understood, implemented, or integrated in services in the study context. Inconsistent and conflicting messages from government, wheelchair services, politicians, and non-profit organisations shows lack of effective policy implementation and further disempowers users, exacerbating challenges and increasing distrust between users and those trying to support them (8). The policy environment should support a multi-sectoral, long-term, rights-based focus in which wheelchairs are available, affordable, and accessible

(18). Although both rehabilitation professionals and CBR workers were identified as wheelchair-service role players in the Uganda Wheelchair Code of Conduct (24), only the professionals were formally engaged in service delivery. Due to limited capacity, they would however be unlikely to meet the service demands (24).

Products

CBR workers in this study reported how inadequate supply and inappropriate wheelchairs perpetuated dependency and limited wheelchair users from accessing their rights. Inappropriate products, poor maintenance, and limited access to follow-up and repair services led to poor product durability and life span (13,15).

Preventative strategies such as better and repeated training and more regular check-ups have been shown to have an impact on product durability and safety of the user (17). In this study, these were identified as an area in which CBR can contribute.

Provision

Provision includes everything that is required to ensure anyone in need of a wheelchair can access and receive what they require (16). Similar to the findings of Smith and colleagues (6), CBR workers suggested wheelchair services were not available or accessible (particularly for those in the rural areas), were fragmented, had insufficient personnel, limited time, and too few resources to effectively provide their service to more than a few. Decentralised services would facilitate access and contextual appropriateness (13). CBR workers described how they could facilitate outreach activities.

CBR workers noted the detrimental impact of inappropriate service delivery and products delivered through donation programmes and the negative impact on user attitude and trust in services, making their future advocacy more challenging (15). CBR workers' observations furthermore emphasised the detrimental impact of fragmented services. Smith and colleagues reported that provision systems most commonly focus on assessment and prescription without fully understanding whether the whole system, including referral and follow up, is effective (6). The weaknesses with step one (referral and appointment) and step eight (follow up, maintenance, and repair), as identified in this study, negatively affected wheelchair users' quality of life, dignity, independence, and participation. CBR workers also identified a need for ongoing user and caregiver training. Despite limited wheelchair knowledge, CBR workers played a pivotal role in enabling access to services.

Supporting wheelchair users and caregivers in the community through their grassroots exposure and knowledge about wheelchairs could facilitate a responsive service and supplement the service knowledge to plan and monitor a contextually appropriate system (5,13,17).

Personnel

Ensuring a skills mix of human resources in a well-coordinated system is necessary to develop and expand effective and efficient provision (3). This includes task shifting (3,7,16),

which was already initiated in this study. CBR workers could facilitate under-resourced wheelchair services and support wheelchair users in LMIC. Their knowledge of local conditions and needs, their availability and accessibility to PWD and other stakeholders, combined with their diverse strategies could ensure an important grassroots link, enable a responsive and preventative approach, and facilitate a person-centred system (9,16).

To achieve this, their role should be defined, they should be better equipped with knowledge and financial resources, and have clear referral pathways (3,7,11,28). A standardised module of minimum competencies could supplement the WSTP (7,14).

Passion, commitment, and determination to fulfil their suggested role was found specifically with those who had attended the wheelchair services. By deliberately involving CBR workers and mentoring them through jointly-arranged outreach services, this technique may help mitigate common challenges experienced by CBR workers, such as isolation and compassion fatigue (28). Confirming earlier studies (11, 32), the creativity of the CBR workers, - along with good communication skills, and cultural and historical understanding - are necessary attributes to enable the CBR worker to be an informed and trusted part of the system (7).

Summary and conclusion

Wheelchair-service provision in Uganda could benefit from engaging with the CBR sector. The scope of CBR workers enabled them to see opportunities in identifying potential wheelchair users, make referrals and facilitate access to services, support wheelchair services by providing contextually appropriate information, train and support wheelchair users and caregivers, and assist with follow up and maintenance. Their potential role would be enhanced by wheelchair-specific training and should be formalised.

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Accessible Centers for Children for Empowerment and Sustainable Services: Service delivery models for children with disabilities within 7,100 islands of the Philippine archipelago

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Abstract

Background: A multidisciplinary approach is crucial in the holistic care of children with disabilities (CWD). This includes regular consults with developmental pediatricians, ophthalmologists, otorhinolaryngologists, physiatrists, in conjunction with physical therapists, occupational therapists, speech and language pathologists, audiologists, optometrists, prosthetist-orthotists, and wheelchair professionals. To avail of these services, caregivers have to independently bring their children to different centers with varying capacities to deliver the services. Lack of awareness, geographic barriers, caregiver availability and transportation costs are some of the identified barriers to compliance with and utilization of these services by CWDs despite the Philippine Health Insurance (PhilHealth) CWD Benefit Packages for Vision, Hearing, Developmental and Mobility Impairment. To enhance access to assistive technology and rehabilitation services for CWDs, the project envisioned A.C.C.E.S.S. (Accessible Centers for Children for Empowerment and Sustainable Services) models, which are responsive & relevant to the targeted CWD community. The medical, allied health & assistive technology services will be made available through infrastructure renovation, equipment provision, assistive technology supplies start-ups and assistance in the establishment of staffing and service delivery network operations. This study aims to discuss the development and pilot sites of the ACCESS model. **Method:** The project sites selected were strategic government facilities around the Philippines. The United Nations Children's Fund (UNICEF) and Physicians for Peace Philippines (PFPP) partnered with the University of the Philippines Philippine General Hospital (UP-PGH) for Luzon; Eastern Visayas Regional Medical Center (EVRMC) and the Municipal Government of Mapanas in Visayas, and Southern Philippines Medical Center (SPMC) in Mindanao. ACCESS hubs are analyzed by the research team through a comparative based on the key areas of the ACCESS model. The key areas include types of services available, location of ACCESS hub, catchment area/referral network, service delivery, and operationalization. All three ACCESS hubs in the Philippines were included in this study. **Results:** The project led to the establishment of a one-stop-shop ACCESS model for UP-PGH in Luzon, community-linked

ACCESS model for EVRMC in Visayas, and, integrated regional ACCESS model in SPMC. All the ACCESS models were developed based on the ideal service delivery network that will ensure utilization by CWDs and comply with the multidisciplinary and holistic requirements of CWD rehabilitation and assistive technology provision. **Summary and Recommendations:** Service Delivery Models for ACCESS centers are customized in accordance to the targeted community's needs and barriers identified in terms of compliance with and utilization of services. A multidisciplinary approach is advocated in the planning stages of each ACCESS model. Stakeholders from all medical and paramedical fields must be consulted in the planning. Other stakeholders indirectly involved in the establishment of ACCESS centers, including architects, engineers, interior designers, sound engineers, and network infrastructure specialists, must likewise be included.

Keywords

Assistive Devices, Service Delivery, Disability, Health Facility

Introduction

Participation, that is, the involvement in daily situations and activities including self-care, mobility, socialization, education, recreation and community life, is a crucial part of the development of children as it lays the foundation to develop skills and competencies necessary for social involvement, improving their overall quality of life. However, children with disabilities (CWDs) face more restrictions in participating as compared to their peers, a gap that further widens as children become adults (1). One way of closing this gap is through the use of assistive devices, which enable disabled children to maintain or improve their functioning and independence and prevent developmental delays (2).

This presents a problem in low-middle income countries where there are limited resources and an already stressed health systems. In the Philippines, the United Nations Children's Fund (UNICEF) estimates that one out of seven Filipino children, which translates to about 5.2 million, are living with disabilities which may range from hearing, visual, mobility to developmental impairments (3). From this population, about 1.5 million require the use of assistive devices such as hearing and visual aids or prosthesis and orthosis to assist in activities of daily living (4). However, only 5% of them receive the necessary support.

Access to health services are also often restricted by the limited understanding about the needs of CWDs. A multidisciplinary approach is crucial in the holistic care of CWDs, which includes regular consults with developmental pediatricians, ophthalmologists, otorhinolaryngologists, physiatrists, in conjunction with physical therapists, occupational therapists, speech and language pathologists, audiologists, optometrists, prosthetist-orthotists, and wheelchair professionals. This makes it difficult for the disabled to avail these services as caregivers have to independently bring their children to different centers with varying capacities to deliver the services.

A survey in 2017 among families with children with disabilities in southern Philippines showed that while 79% have access to specialized medical services, only 68% have assistive devices, mostly coming from donations. Moreover, among these families, only 60% sought consult after seeing the need to refer their child, while 83% of healthcare costs is shouldered by families as out-of-pocket expenses. Despite the heavy burden of the problem in the Philippines, an initial facility survey indicated overwhelming gaps in the capacity of the health facilities to provide health services and rehabilitation to PWDs, including service delivery system and referral network (5).

To address this need, in 2016, the Philippine Health Insurance Corporation (PhilHealth), in collaboration with UNICEF and the Physicians for Peace Philippines (PFPP), introduced four separate benefit packages covering the provision of assistive devices and rehabilitation of CWDs with hearing, visual, mobility and developmental disabilities. With these packages, the health sector hopes that these will improve financial risk protection, enhance access to necessary health services and improve the lives of CWDs through functioning and participation.

Complementing this endeavor, the collaboration envisioned A.C.C.E.S.S. (Accessible Centers for Children for Empowerment and Sustainable Services) models which are responsive & relevant to the targeted CWD community to enhance access to assistive technology and rehabilitation services for CWDs. The medical, allied health & assistive technology services will be made available through infrastructure renovation, equipment provision, assistive technology supplies start-ups and assistance in the establishment of staffing and service delivery network operations. This paper discusses the ACCESS service models developed to support the implementation of the PhilHealth benefit packages for children with disabilities.

Methodology

Individual hubs for children with disabilities developed around the country were designed based on the concept and goals of the ACCESS model. However, as regional rehabilitation hubs, the development of ACCESS hubs were developed in consideration on the local context of each region and the capacity of stakeholders to provide services. The scope and service delivery model of each hub are based on the directions identified by regional committees based on an initial assessment of the regional health system.

In this paper, ACCESS hubs are analyzed by the research team through a comparative analysis based on the key areas of the ACCESS model. The key areas include types of services available, location of ACCESS hub, catchment area/referral network, service delivery, and operationalization. All three ACCESS hubs in the Philippines were included in this study.

Results

The first ACCESS hub established is at the Philippine General Hospital which is widely considered as the end-referral facility in the Philippines. The second ACCESS hub was

established in Southern Philippines Medical Center in Davao City, Mindanao. Lastly, the third ACCESS hub is currently being established in Eastern Visayas Regional Medical Center in Visayas, where a pilot child-centered community-based rehabilitation will be established in a municipality which is considered a Geographically Isolated and Disadvantaged Area (GIDA).

PGH ACCESS

The Philippine General Hospital (PGH) is a tertiary state-owned hospital administered and operated by the University of the Philippines Manila, the University of the Philippines System's Health Sciences Center. It is the largest government hospital administered by the university and is designated as the National University Hospital.

Based on initial facility assessment, assessment services, rehabilitation services, and assistive devices for mobility impairment are available in the health facility. Assistive devices for visual impairment are limited since not all devices indicated in the benefit packages are provided. On the other hand, hearing aids are currently not provided in PGH. Patients with hearing impairment are referred to stand-alone hearing aid centers outside the health facility to avail of hearing aids. Furthermore, services for CWDs in PGH are delivered in separate departments. *Table 1* summarizes the availability of services for persons with disabilities in PGH.

Table 1. Availability of services for persons with disabilities in PGH.

Services	Vision	Hearing	Mobility	Developmental
Assessment Services	Available	Available	Available	Available
Assistive Devices	Limited	Not Available	Available	-
Rehabilitation Services	Available	Available	Available	Available

The PGH ACCESS Unit was envisioned to be a one-stop shop for the PhilHealth Children with Disabilities Package. A Technical Working Group (TWG) composed of representatives from several hospital departments was formed to direct the process. To support the provision of services for CWDs, a one-stop-shop ACCESS hub shall be established at the Philippine General Hospital. The establishment of ACCESS hub in PGH shall ensure the availability services located in one center with capability to provide assessment and diagnostic services, assistive devices, and rehabilitation services for CWDs.

During discussions with representatives from PGH, the technical working group agreed on the creation of a separate unit which shall have all services in one area at the health facility. As a requirement for the establishment of the hub, the department of ophthalmology and the department of otorhinolaryngology worked on the procurement process for consignment of assistive devices to ensure that all services are available in the hub.

Planning for the physical renovation of the hub and construction of an elevator began in the latter months of 2016. A pre-construction survey was done by the TWG and the contractors to identify the needs of each department. Renovation activities were conducted in the first quarter of 2017 and was completed in the second quarter. A disability accessibility consultant was employed in the early phase to ensure a universally accessible set-up.

Upon completion of the renovation, the TWG worked on the operational guidelines of the hub which described the pathway of care, guidelines in referral, and human resource requirement of each department. As the end-referral facility in the Philippines, PGH ACCESS was not linked directly with regional and local government institutions. Instead, PGH ACCESS was linked with other ACCESS hubs and committed to provide technical and capacity building support to other ACCESS hubs.

At present, PGH ACCESS already caters to patients with developmental disability and mobility impairment. PGH is currently working on the procurement of assistive devices for hearing and visual impairment. At the same time, PGH recently signed a memorandum of agreement with Philhealth to implement the benefit package for developmental disability. The contract agreement between PGH and PhilHealth shall guide the implementation of benefit packages and copayment of patients. To track implementation, assess outputs systematically, and measure the targets of the hub, the technical working group developed a monitoring and evaluation plan. This will aid in assessing whether services are efficient and effective and if the objectives of the hub are achieved. Management and evaluation began during the start of operations and continue throughout the duration of the hub to serve as guidance for further improvement.

SPMC ACCESS

The Southern Philippines Medical Center is a Department of Health (DOH)-retained hospital in the Davao Region, Mindanao. It caters primarily to patients in the Davao region, in collaboration with the Davao Regional Medical Center, with an estimated population of 4.9 million in 2015.

In April 2016, an assessment of key public hospitals and health facilities in Davao Region showed that SPMC as the most strategic facility in providing complete services for children with disabilities. Based on the assessment, SPMC is the most capable and ready to cater to children with vision, hearing, mobility and developmental disabilities and provide them with assistive devices and rehabilitation services. Upon consultation with regional stakeholders including, DOH Regional Office Non-Communicable Disease Department personnel and key personnel from SPMC, the following were identified to be the priorities of the ACCESS hub:

1. Deliver integrated health services for children with disabilities;
2. Reduce the chronic disease burden through correct diagnosis and early intervention;
3. Enhance functionality of children with disabilities by provision of assistive devices; and,
4. Implement the PhilHealth package for children with disabilities

Based on the assessment of SPMC, assessment services, rehabilitation services, and assistive devices for mobility impairment are available. Hearing aids are currently not being provided at SPMC, while only few assistive devices for visual impairment are available. *Table 2* summarizes the availability of services for persons with disabilities in SPMC.

Table 2. Availability of services for persons with disabilities in SPMC.

Services	Vision	Hearing	Mobility	Developmental
Assessment Services	Available	Available	Available	Available
Assistive Devices	Limited	Not Available	Available	-
Rehabilitation Services	Available	Available	Available	Available

To guide the establishment of an ACCESS hub, a programme management committee was created with representatives from the Department of Health Regional Office, Regional Council for Disability Affairs, Department of Social Welfare and Development Regional Office, Health Facility Representatives (Davao Regional Medical Center and Southern Philippines Medical Center), and representatives from the city health offices of local government units. The programme management committee decided to develop an ACCESS hub in SPMC, but instead of creating a separate unit which will provide services together in a specific area, services in SPMC for CWDs will be implemented by different departments in the hospital. Moreover, a coordinator will be assigned to manage the documents, records, and assist patients in availing services under the benefit packages for CWDs.

In 2017, the DOH Regional Office issued Order No. 2017-0053 or the Implementing Guidelines on the Operational Plan for the Service and Rehabilitation Hubs for Children with Disabilities in Davao Region. Through the memorandum, DOH aims to strengthen its role to ensure access to and provision of health care services for children with disabilities. The memorandum describes the composition of the service delivery network, while identifying the roles of community workers and public health workers in screening and referral of children with disabilities.

Recently, Philhealth and SPMC signed a memorandum of agreement authorizing SPMC to implement the benefit package for developmental disability, becoming the first hospital in the Philippines to be contracted as a package implementor. At present, SPMC is in the process of applying to be a contracted health facility to implement the benefit packages for other types of disabilities.

EVRMC ACCESS

Eastern Visayas Regional Medical Center (EVRMC) is a DOH retained regional hospital located in Tacloban City, Eastern Visayas. It is a tertiary level teaching and training hospital with an authorized bed capacity of 500 beds. As a regional hospital, the Eastern Visayas Region is the primary catchment area of EVRMC, with an estimated population of 4.4 million

in 2015. Eastern Visayas is composed of the islands of Samar, Leyte and Biliran and its surrounding small islets. In the first semester of 2018, the Philippine Statistics Authority (PSA) recorded a poverty incidence among families of 30.40% for the region (6).

There are several reasons for the choice of the third CWD Hub site. From an equity lens, Region VIII or the Eastern Visayas region has the highest level of poverty incidence in the Visayas and ranks third nationally (6). The region is also extremely vulnerable to disasters that renders its persons with disability population more vulnerable to a vicious cycle of deprivation. Meanwhile, from an efficiency argument, the region has benefited from a lot of initial groundwork on Community Based Rehabilitation from the Haiyan Recovery efforts in 2015 and this initiative will be complementary to those initial efforts by the humanitarian and development community.

The initial assessment of EVRMC indicated limited availability of assessment services, rehabilitation services, and assistive devices for mobility impairment while, assistive devices for visual and hearing impairment are not available. *Table 3* summarizes the availability of services for persons with disabilities in EVRMC.

Table 3. Availability of services for persons with disabilities in EVRMC.

Services	Vision	Hearing	Mobility	Developmental
Assessment Services	Limited	Limited	Available	Available
Assistive Devices	Not Available	Not Available	Limited	-
Rehabilitation Services	Available	Limited	Available	Limited

Discussions with EVRMC administration were focused on establishing an ACCESS hub in the health facility since they are currently working on construction of a trauma center which will cover the rehabilitation medicine unit. The site selected for the hub is beside the rehabilitation medicine unit.

At present, renovation activities are currently being conducted in EVRMC. The hub is expected to be completed and operational by August 2019. After renovation, the immediate next step for EVRMC is to work on ensuring the availability of assistive devices for hearing and visual impairment. Moreover, discussions on the operationalization of the hub will be conducted within the next few weeks.

For EVRMC ACCESS, the project team included the pilot implementation of a child centered community-based rehabilitation in Mapanas, Northern Samar. The municipality of Mapanas is considered as a GIDA and is located six hours away from EVRMC. The child centered community-based rehabilitation has five core components:

1. Screening and Early Detection
2. Early Intervention and Referral Mechanism

3. Advocacy and Sensitization
4. Disability Prevention
5. Information and knowledge management

Through these, a case-finding mechanism will be established in the municipality of Mapanas, while ensuring that early interventions can be provided in the community and a referral mechanism to EVRMC is established. An assessment of potential referral facilities between EVRMC and Mapanas revealed that EVRMC is the best next level referral facility because of the unavailability of services for CWD at secondary level facilities along the way.

The EVRMC ACCESS hub partnership with the Municipal Government of Mapanas is a pilot model of linking tertiary services to one model LGU where CBR can be operationalized and services linked to the referral facility and including the provision of basic child health services for the CWDs within the ACCESS hub.

ACCESS Hubs in the Philippines

At present, three ACCESS hubs are being developed in the Philippines. The three ACCESS hubs are envisioned to be able to contracted as package implementer for all four benefit packages. At present, PGH and SPMC are working on Philhealth contracting for mobility and developmental, while working on completing the requirements for vision and hearing packages. EVRMC is still working on the renovation of the ACCESS hub area, while completing the requirements for contracting.

In summary, all ACCESS hubs are intended to provide all services for CWDs mandated by the benefit packages. PGH has a national level scope of implementation as the end-referral facility, while SPMC and EVRMC are focused on regional operations. In terms of services, the PGH and EVRMC hub models aims to deliver services in a single one-stop-shop center for children with disabilities. The SPMC hub model delivers services through the different departments in the hospital, through the support of a z-benefit package for CWDs coordinator. Lastly, as the end referral facility, the PGH hub has regional operational guidelines for a single region. Moreover, as the first established ACCESS hub, PGH also provides technical support to other ACCESS hubs if necessary. SPMC and EVRMC hubs are envisioned to be regional rehabilitation centers which caters to referrals from the entire region. Moreover, EVRMC ACCESS hub has a direct partnership with the municipality of Mapanas which refers directly. *Table 4* shows the current status and details of the three ACCESS hubs.

Table 4. Current status and details of the three ACCESS hubs.

	PGH	SPMC	EVRMC
Philhealth Contracted (as of July 2019)	None	Developmental	None
Services to be offered	Hearing, Vision, Mobility, Developmental	Hearing, Vision, Mobility, Developmental	Hearing, Vision, Mobility, Developmental
Location	Manila City, Luzon island, northern part of the country	Davao City, Mindanao Island, south of the country	Eastern Visayas Region, central part of the country
Catchment Area/Referral Network	National (End-Referral)	Regional	Regional
Services	ACCESS hub providing all services for CWDs	Services are provided different departments	ACCESS hub providing all services for CWDs
Operationalization	Single facility; Provides technical support to other ACCESS hubs	Regional operationalization	Regional operationalization; has direct partnership with remote areas implementing community-based rehabilitation

Discussion

One of the main reasons for the establishment of ACCESS hubs is the need to establish tertiary level facilities capable of providing all services for children with disabilities, while integrating the service delivery network of its catchment area. At the same, the implementation of benefit packages allows patients to avail of services for free or at minimal cost. Moreover, Philhealth reimbursements paid to health facilities due to package utilization can be used to support the operations of the ACCESS hubs, facilitating sustainability.

During the development of ACCESS hubs, the project team encountered difficulties in different areas. In terms of structure and accessibility, not all hospitals can be considered as universally accessible for persons with disabilities. Currently, the most common accessibility feature complied with by hospitals are the presence of ramps and handrails. However, tiles with tactile stimulation for visually impaired are not available in most facilities. On the other

hand, fire alarm systems in health facilities are not compliant with strobe light requirements for people who are hearing impaired. Furthermore, not all health facilities have accessible toilets.

In terms of availability of services, several health facilities in the Philippines are not capable of providing assessment services and assistive devices. Most of the time, this is due to the unavailability of equipment, supplies, and specialized personnel who delivers services. Allied health professionals which are relatively new in the Philippines, such as certified prosthetist and orthotist, wheelchair professionals, and audiologists, do not have government posts in health facilities yet.

Most government facilities are not providing assistive devices because of the customization it requires per patient and limitations in the procurement process. Since assistive devices such as prosthesis and hearing aids are customized based on the needs of each patient, health facilities cannot order several items ahead of time. This result to longer waiting times before patients would be able to receive assistive devices. Furthermore, current provision is out-of-pocket expense from the patient and is coursed through informal purchase through doctors. This requires a consideration of how assistive devices can be effectively provided using current or new policies and mechanisms.

The concept of a one-stop-shop center was considered in the project because of the difficulty going around the entire health facility for children with multiple disabilities. Through the one-stop-shop ACCESS hub, children with multiple disabilities can avail of health services in one area. However, in establishing one-stop-shop ACCESS hubs, the first challenge encountered is the availability of an area is usually encountered. Moreover, since services should also be delivered in the hub, health facilities are required to procure additional equipment and supplies and hire additional human resources to support the operations of the hub.

In summary, development of service hubs requires a lot of planning and work from different fields. These include management and health service operations, clinical areas (rehabilitation, developmental pediatrics, ophthalmology, otorhinolaryngology, pediatrics), infrastructure and design, finance, procurement, information system and referral/ network management. The challenge is that the entire process requires time and several teams, hence collaboration is difficult. The reality is, such level of planning is actually a form of service innovation and is not usually funded in developing countries.

Conclusion and Recommendations

ACCESS hubs are developed to ensure that services for children with disabilities are available, service delivery networks are integrated, and health financing mechanisms are established. Service Delivery Models for ACCESS hubs are customized in accordance to the targeted community's needs and barriers identified in terms of compliance with and utilization of services. A multidisciplinary approach is advocated in the planning stages of each ACCESS model. Stakeholders from all medical and paramedical fields must be

consulted in the planning. Other stakeholders which are indirectly involved in the establishment of ACCESS centers, including architects, engineers, interior designers, sound engineers, and network infrastructure specialists, must likewise be included.

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Capacity building

Development of the World Health Organization's Package of Rehabilitation Interventions: The importance of assistive technology

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Abstract

Rehabilitation is a core health service for individuals with health conditions throughout the life course and across the continuum of care. The provision and the training in the use of assistive technologies is an essential component within rehabilitation. It is critical that WHO Member States are equipped with technical guidance to establish and strengthen rehabilitation service delivery in line with population needs. The Package of Rehabilitation Interventions (PRI) will be a WHO resource containing evidence-based rehabilitation interventions and assistive technologies related to these interventions. As such, the PRI will support Ministries of Health to plan the integration of rehabilitation interventions in their national health services. The development of the PRI takes an evidence-based approach. The WHO Rehabilitation Programme is leading the development of the PRI with extensive stakeholder involvement and support of WHO's Guideline Review Committee Secretariat. The development process comprises different steps: (1) Health conditions have been selected based on global prevalence estimate, associated years of living with disability, as well as proposals from rehabilitation experts working in low- and middle-income countries. (2) Technical Working Groups will identify the evidence from high-quality clinical practice guidelines. Evidence from Cochrane Systematic Reviews will complement the information on evidence-based rehabilitation interventions. (3, 4) Development Groups composed of rehabilitation experts from different world regions and different health professions will approve identified interventions, define the areas of service delivery (primary, secondary and tertiary care) for the interventions, and describe the required resources workforce, assistive technologies, equipment and consumables.) (5) Peer Review Groups will review the first draft of the PRI. (6) After the production of the first Alpha version, the PRI will be (7) tested in countries and (8) finally published as an open source web-based tool and print version. (9) Different dissemination strategies will be used to raise awareness on the PRI.

Global survey of the World Health Organization's Standards for Prosthetic and Orthotic Services

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Abstract

Background: The WHO Standards for Prosthetics Services were developed by WHO in collaboration with the International Society for Prosthetics & Orthotics (ISPO) and funded by USAid. The Standards have 60 recommendations which are grouped in 4 parts representing the 4 Pillars (4 Ps) of the Report – Policy, Products, Personnel & Provision of Services. The Standards are applicable worldwide. As part of the implementation it is critical to assess the current services, the deficiencies and the different priorities. **Objective:** The objective is to assess the current services and their compliance with the WHO P& O standards. **Approach:** A Survey tool was developed by Mr Bengt Soderberg, a past president of ISPO and in conjunction with the Mahidol University in Bangkok, Thailand. The survey tool consists of a questionnaire completed that is completed on-line. Each respondent is requested to give information regarding their professional qualifications, employment and geographical location. The questionnaire contains 3 questions for each of 60 Standards relating to the current services and the priority perceived by the person or organisation completing the questionnaire. The questionnaire was divided into 4 parts in line with the 4Ps. Each of the four parts needed to be answered independently. The results were analysed by each part and then by each standard, but only some of the standard analyses have been included in this report. Some of the standards were also analysed according to differences in geographic regions. **Results:** A total of 371 responses were received for part 1 on policy, at the time of writing this report. For part 2 on products 210 responses were received. The personnel (part 3) of the survey had 193 responses and the fourth and final part of the survey on the standards relating to provision of services received 171 responses. The demographic information of the respondents is presented from the 371 responses to part one of the survey. **Discussion:** This study included an adequate sample size with good geographical spread. The overall mean scores for each of the parts lie between 3.5 and 4.0, indicating that there still is a lot of work to be done to implement the standards. The gap between the current situation score and the importance and relevance score demonstrate the need for further improvement. **Conclusion:** This study underpins the importance of developing standards, measuring against the standards and then developing services to meet the standards.

Keywords

Prosthetic and Orthotic, services, standards

Background

The WHO Standards for Prosthetics Service (1) were developed by World Health Organisation (WHO) in collaboration with the International Society for Prosthetics & Orthotics (ISPO) and funded by the United States Agency for International Development (USAID). The standards were launched at the ISPO World Congress in Cape Town, South Africa in May 2017 and subsequently published and promoted widely.

Prostheses (artificial legs and hands) and orthoses (braces and splints) enable people with physical impairments or functional limitations to live healthy, productive, independent, dignified lives and to participate in education, the labour market and social life. The use of prostheses or orthoses can reduce the need for formal health care, support services, long term care and caregivers. Without access to prostheses or orthoses, people who need them are often excluded from society, isolated and locked into poverty, which increases the burden of morbidity and disability (1).

To improve access to prosthetics and orthotics services, WHO, in partnership with ISPO and USAID, has prepared global standards and an implementation manual to assist Member States in setting up, improving or transforming their systems for delivering these services. One aim of the document is to ensure that prosthetics and orthotics services are integrated into health services and systems, as they are often provided at the same time as other health services. WHO believes that this document will promote greater access to these services globally, as another step towards strengthening universal health coverage and achieving the Sustainable Development Goals (SDGs) (1).

The Standards document consists of a set of standards and a manual for implementation to support countries in developing or improving high-quality, affordable and adequate prosthetics and orthotics services. It brings promise, by ensuring that everyone in need, everywhere, has access to prostheses and orthoses: that no one is left behind. Its aim is to ensure that prosthetics and orthotics services are people-centred and responsive to every individual's personal and environmental needs (1).

The Standards have 60 recommendations which are grouped in 4 parts representing the 4 Pillars (4 Ps) of the Report – Policy, Products, Personnel & Provision of Services.

Policy points out the responsibility of Member States to promote the availability and use of prostheses and orthoses at a cost that is affordable to users or the State. It recalls that governments should assume a leading role in or delegate responsibility for the governance of nationwide prosthetics and orthotics services and should involve a range of stakeholders in planning, developing and monitoring services. A guiding framework, consisting of legal acts, policies, strategic plans, standards, rules and regulations, should be in place to guide the

design of affordable, accessible, effective, efficient, safe services of high quality. The section states that funding of prosthetics and orthotics services must be included in moving towards universal health coverage. Access to prostheses and orthoses can be greatly increased by appropriate financing, especially through national health and/or social insurance. The argument is made that money spent on these services is not an expense but an investment that generates both social and economic returns (1).

Products emphasizes that prosthetic and orthotic products and working methods should be appropriate to the setting in which the products are fabricated, fitted, used and funded. Establishment of a national list of priority products helps to create public awareness, mobilize resources, guide product development and procurement and stimulate competition to make the products available at an affordable cost. The section proposes that prosthetic and orthotic materials and components and the tools, machines and equipment used in the services be exempt from import taxes and customs fees in order to ensure that they are affordable and accessible. It urges national and international stakeholders, including the private prosthetics and orthotics industry, to develop alternative, affordable products made of cost-effective, good-quality, context-appropriate components (1).

Personnel identifies the requirements to be considered in planning, developing and promoting professional recognition of the workforce. It stresses the importance of training various types of prosthetics and orthotics personnel to meet nationwide demand and urges the promulgation of State regulations to ensure that service users are protected from malpractice and poor-quality services. Prosthetics and orthotics clinicians should be recognized as independent health professionals with a distinct professional title, profile and job description. The section states the importance of a multidisciplinary team approach in prosthetics and orthotics, especially for people with severe or complex physical impairments (1).

Provision of services emphasizes the importance of people- or user-centred prosthetics and orthotics services. Users must be regarded as equal members of the treatment team and be given the necessary information to empower them to make decisions about their care and final selection of a product. They should be consulted and involved in policy development and in planning, implementing, monitoring and evaluating services. The section positions prosthetics and orthotics services as an integral part of health services, closely related to medical, surgical and rehabilitation services. It raises the importance of coordination with other sectors, such as labour, social welfare and education, for overall health and rehabilitation outcomes. The section outlines standards for referral, service delivery and service unit management (1).

The current phase is the Implementation of the Standards. As part of the implementation it is critical to assess the current services, the deficiencies and the different priorities. The Standards are applicable worldwide. It is recognised that different services around the world are at different stages of the development of their prosthetic and orthotic services, some countries may have a good national service while in other parts of the world the service may

be non-existent. Unfortunately, the priorities may also be different from country to country. A global survey is essential to be able to assess the current situation in each country and around the globe and to be able further improvement in the service over time. It is envisaged that ISPO will work with the WHO to develop a standardised assessment tool which can be utilised globally. As the development of a standardised, globally acceptable tool will require considerable time and resources, the executive board of ISPO is conducting a global survey using their world-wide network and a more basic assessment tool which has been developed by Mahidol University.

ISPO has over 3000 members represented in about 100 countries and has a National Member Society in 70 countries. This provides an excellent platform to gain an overview of the global picture.

Objective

The objective is to assess current compliance with the WHO P&O standards around the globe.

Method

A Survey tool was developed by Mahidol University in Bangkok, Thailand in conjunction with Mr Bengt Soderberg, a past president of ISPO. The tool was modified by ISPO to include some questions regarding some characteristics of the survey responder including their profession, their current main job, their region and country and which national member society of ISPO they belong to.

The survey tool consists of a questionnaire that can be completed on-line.

The questionnaire contains 3 questions for each of 60 Standards. For each of the standards the basic question was a rephrasing of the standard in a positive statement. For example, for Standard 1 which states that "Governments should assume a leading role in the development and coordination of national prosthetics and orthotics service provision" the question was phrased as "The government takes a leading role in developing and coordinating the national prosthetic and orthotic service provision."

The three questions on each standard enquire into the current situation regarding that standard; the relevance and importance of that standard to the country and the applicability of that standard to that country or region. The rationale for the including these three questions is that involvement of the government is a measure of the government to lead and ensure implementation of that standards, the relevance or importance is a measure the significance of this standard contributing to P&O service delivery and the applicability is a measure of whether this standard could be achieved given sufficient governmental and other support to comply with that standard. In more simplistic term the three dimensions measure what is being done, what should be done and what could be done.

A rating scale with values 0 to 6 was used for each of the questions. The scale was labelled as absolutely disagree at the left end and absolutely agree at the right end of the scale. For each standard the definitions of the scores were listed immediately following the text which defined the standard. Each individual descriptor was listed on a separate line as follows:

Please indicate level of agreement with the following statements:

6 = Absolutely Agree

5 = Strongly Agree

4 = Agree

3 = Neutral

2 = Disagree

1 = Strongly Disagree

0 = Absolutely Disagree

A score of 3 was therefore exactly in the middle signifying neither agreement or disagreement with the particular statement for the particular standard. As the questions were always phrased in a positive statement, a higher rating or a higher level of agreement indicates that there is a higher degree of current compliance with this standard.

An initial explanation regarding the importance of this survey from the President of ISPO was sent to all individual members of ISPO. Multiple further prompts to complete the survey were sent to the individual members over a period of three months period. Some of the prompts coincided to new postings of the survey in different languages. The survey was translated into French, Spanish, Arabic, traditional and simplified Chinese.

The results were collated in Microsoft Excel (2010) worksheets. The worksheets were exported into Medcalc (2) statistical software package for statistical analysis.

For the results of each of the four parts of the survey the collated in order to give an overall summary score of that component of the standards. This was done by combining the values of all the scores for each of the three questions related to each standard. The results were then presented in summary scores for each of the four parts of the survey followed by presentation of some of the individual scores. The presentation of the results for each part is similar in a table where the first column of the table lists the variable in each row. The values presented always start with the lowest value, then the highest value, then the arithmetic mean, then 95% confidence interval of the arithmetic mean and then the median. The lowest and the highest value were included to give an indication of the spread of the values. The arithmetic mean and the 95% confidence interval of the mean were included to give an impression of the mean scores for responses and allow easy comparisons across the three questions of each standard (or parts) and across the different standards. The 95% confidence interval (CI) for the mean was calculated by calculating the Standard error of the mean (SEM) and set as the population mean $\pm t$ SEM, with t taken

from the t-distribution with $n-1$ degrees of freedom and a confidence of 95%². The median was included to give an indication of the skewness of the sample particularly when read in conjunction with the mean.

Following the collated results selected individual standard results are tabled to give a detailed understanding for the presented standards. An indicative sample of the standards were selected for inclusion in this report based on having the highest or lowest means for that part or in a few cases having a higher discrepancy between the current situation and the relevance and importance/applicability scores in each of the sections.

Results

As the survey was structure along the same format as the P&O standards there were four parts to the survey. These four parts required the individual to link in separately into each part. The result of this structure was that there was a differential response rate for each part of the survey. The highest rate of responses received was for policy which constituted the first part of the survey with a total of 371 responses at the time of writing this report. Of the 371 responses, 14 were received to the French survey. There were 2 responses to the Spanish survey, but no responses to the Arabic or either of the two Chinese language versions of the survey at the time of writing this report. Only the English and French responses were included in this report. For part 2 on products 210 including 12 French responses were received. The personnel (part 3) of the survey had 193 responses including 12 from the French survey. The fourth and final part of the survey on the standards relating to provision of services received 171 responses including 12 French responses.

The demographic information of the respondents is presented from the 371 responses to part one of the survey.

The main job/current appointment in decreasing order the respondents included: 171 Prosthetists and Orthotists, 27 educators, either professors and lecturers, 26, Orthotists, 24 Prosthetists, 22 administration directors, 21 administration managers, 18 physicians, 12 researchers, 10 engineers, 8 physiotherapists, 5 surgeons, 5 pedorthists, 4 occupational therapists and 17 others including some students and retirees.

The respondents had a wide geographic distribution (86 countries and areas) and included in decreasing order 31 from Canada, 30 from South Africa, 21 from Sweden, 12 each from Namibia and Nepal, 11 from the United Kingdom, 10 each from Australia and Columbia, 9 from Ethiopia and Kenya, 8 each from Uganda and the USA, 7 each from Germany, India, Nigeria and Afghanistan, 6 each from Cambodia, the United Republic of Tanzania, Togo, and Tunisia, 5 each from Argentina, the Republic of the Congo, Ghana, Haiti, Japan, Sudan, and Turkey, 4 each from France, the Islamic Republic of Iran, Peru, Rwanda, Tonga, and Zambia, 3 each from Burundi, the Democratic Republic of the Congo, Djibouti, Myanmar, Norway, Pakistan, Portugal, Sri Lanka, Russia, Thailand, and the Netherlands, 2 each from Bangladesh, Benin, the Plurinational State of Bolivia, Czech Republic, Greece, Hungary, Indonesia, Israel, Morocco, Philippines, Senegal, North Macedonia, and 1 each from Albania,

Belgium, Bhutan, Cameroon, Cost Rica, Denmark, Ecuador, Eswatini, Finland, Hong Kong SAR, Iceland, Iraq, Ireland, Italy, Kiribati, Latvia, Madagascar, Malawi, Mexico, Papua New Guinea, Poland, Scotland, Serbia, Seychelles, Slovakia, Somalia, Switzerland, Samoa and Zimbabwe.

For the policy part of the survey the collated results are listed in Table 1. The mean score applied to the current implementation of the policy standards is 3.7, the relevance and importance of the policy criteria has a mean score of 4.9 and the mean applicability score for the policy criteria is 4.7.

Table 1. Collated mean ratings for the Policy Standards

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.7	4.9	4.7
95% CI for the Arithmetic mean	3.6 to 3.7	4.8 to 4.9	4.7 to 4.8
Median	4	5	5

For the products part of the survey the collated results are listed in Table 2. The mean score applied to the current implementation of the products standards is 3.5, the relevance and importance of the products criteria has a mean score of 5.2 and the mean applicability score for the products criteria is 5.0

Table 2. Collated mean ratings for the Products Standards

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.5	5.2	5.0
95% CI for the Arithmetic mean	3.4 to 3.6	5.2 to 4.3	5.0 to 5.1
Median	4	6	5

For the personnel part of the survey the collated results are listed in Table 3. The mean score applied to the current implementation of the personnel standards is 4.0, the relevance and importance of the personnel criteria has a mean score of 5.4 and the mean applicability score for the personnel criteria is 5.2.

Table 3. Collated mean ratings for the Personnel Standards

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.0	5.4	5.2
95% CI for the Arithmetic mean	3.9 to 4.1	5.35 to 5.4	5.2 to 5.3
Median	4	6	6

For the provision of services part of the survey the collated results are listed in Table 4. The mean score applied to the current implementation of the provision of services standards is 3.9, the relevance and importance of the provision of services criteria has a mean score of 5.1 and the mean applicability score for the provision of services criteria is 5.0

Table 4. Collated mean ratings for the Provision of Services Standards

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.9	5.1	5.0
95% CI for the Arithmetic mean	3.9 to 4.0	5.0 to 5.1	5.0 to 5.1
Median	4	6	6

WHO Standard Number 4 states: “There should be a national guiding framework for prosthetics and orthotics service provision.” The summarised results for this standard are listed in Table 5. The mean score is 3.4, the relevance and importance of the criteria has a mean score of 4.9 and the mean applicability score for the criteria is 4.8.

Table 5. Mean ratings for the National Guiding Framework Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.4	4.9	4.8
95% CI for the Arithmetic mean	3.2 to 3.6	4.7 to 5.0	4.7 to 4.9
Median	4	5	5

WHO Standard Number 11 states: “Prosthetics and orthotics services should be an integral part of universal health coverage.” The summarised results for this standard are listed in Table 6. The mean score is 4.4, the relevance and importance of the criteria has a mean score of 5.1 and the mean applicability score for the criteria is 4.9.

Table 6. Mean ratings for the Universal Health Coverage Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.4	5.1	4.9
95% CI for the Arithmetic mean	4.2 to 4.6	4.9 to 5.2	4.8 to 5.0
Median	5	6	6

WHO Standard Number 14 states: “A national prosthetics and orthotics database should be established to identify total need, types of need and unmet need.” The summarised results for this standard are listed in Table 7. The mean score is 3.3, the relevance and importance of the criteria has a mean score of 4.9 and the mean applicability score for the criteria is 4.7.

Table 7. Mean ratings for the National Database Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.3	4.9	4.7
95% CI for the Arithmetic mean	3.0 to 3.5	4.7 to 5.0	4.6 to 4.9
Median	3	5	5

WHO Standard Number 16 states: “An appropriate range of prosthetic and orthotic products should be available in countries to suit local needs and realities.” The summarised results for this standard are listed in Table 8. The mean score is 4.1, the relevance and importance of the criteria has a mean score of 5.3 and the mean applicability score for the criteria is 5.1.

Table 8. Mean ratings for the Range of Products Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.1	5.3	5.1
95% CI for the Arithmetic mean	3.9 to 4.4	5.1 to 5.4	4.9 to 5.2
Median	4	6	5

Table 9. Mean ratings for the Range of Products Standard by region

	Africa excluding South Africa	Africa including south Africa	Asia	Europe	North America
Sample size	61	70	30	45	33
Lowest value	0	0	0	2	0
Highest value	6	6	6	6	6
Arithmetic mean	3.2	3.5	3.2	5.3	4.8
95% CI for the Arithmetic mean	2.8 to 3.7	3.0 to 3.9	2.7 to 3.8	5.0 to 5.7	4.3 to 5.4
Median	3	4	3	6	6

WHO Standard Number 17 states: “A national list of priority prosthetic and orthotic products should be drawn up, respected and updated regularly.” The summarised results for this standard are listed in Table 10. The mean score is 3.0, the relevance and importance of the criteria has a mean score of 4.8 and the mean applicability score for the criteria is 4.6.

Table 10. Mean ratings for the Products list Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.0	4.8	4.6
95% CI for the Arithmetic mean	2.7 to 3.3	4.6 to 5.0	4.4 to 4.9
Median	3	5	5

WHO Standard Number 20 states: “Reuse of prosthetic and orthotic components should be regulated by a designated authority or group of experts with no conflict of interests and involve proper quality control and documentation.” The summarised results for this standard are listed in Table 11. The mean score is 2.8, the relevance and importance of the criteria has a mean score of 4.1 and the mean applicability score for the criteria is 3.9.

Table 11. Mean ratings for the Reuse of Components Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	2.8	4.1	3.9
95% CI for the Arithmetic mean	2.5 to 3.1	3.8 to 4.4	3.7 to 4.2
Median	3	4	4

WHO Standard Number 28 states: “Training in prosthetics and orthotics should be available at various levels to fully meet national needs.” The summarised results for this standard are listed in Table 12. The mean score is 3.9, the relevance and importance of the criteria has a mean score of 5.1 and the mean applicability score for the criteria is 4.9.

Table 12. Mean ratings for the Training Availability Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.9	5.1	4.9
95% CI for the Arithmetic mean	3.5 to 4.2	5.0 to 5.4	4.8 to 5.2
Median	5	6	6

Table 13. Mean ratings for the Training Availability Standard by region

	Africa excluding South Africa	Africa including south Africa	Asia	Europe	North America
Sample size	57	71	23	39	29
Lowest value	0	0	0	0	0
Highest value	6	6	6	6	6
Arithmetic mean	3.1	3.3	3.7	4.6	4.8
95% CI for the Arithmetic mean	2.6 to 3.7	2.8 to 3.8	2.8 to 4.6	3.9 to 5.2	4.2 to 5.4
Median	3	3	4	6	6

WHO Standard Number 30 states: “Continuing professional development should be compulsory in prosthetics and orthotics professional practice.” The summarised results for this standard are listed in Table 14. The mean score is 4.5, the relevance and importance of the criteria has a mean score of 5.2 and the mean applicability score for the criteria is 5.1.

Table 14. Mean ratings for the Continuing Professional Development Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.5	5.2	5.1
95% CI for the Arithmetic mean	4.2 to 4.8	5.0 to 5.4	4.9 to 5.3
Median	5	6	6

WHO Standard Number 33 states: “A strategy to retain prosthetics and orthotics personnel should be in place.” The summarised results for this standard are listed in Table 15. The

mean score is 3.1, the relevance and importance of the criteria has a mean score of 5.0 and the mean applicability score for the criteria is 4.8.

Table 15. Mean ratings for the Workforce Retention Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.1	5.0	4.8
95% CI for the Arithmetic mean	2.8 to 2.4	4.8 to 5.2	4.6 to 5.0
Median	3	6	5

WHO Standard Number 38 refers to: “Service users and their representatives should be involved in policy-making, planning, implementing, monitoring and evaluating prosthetics and orthotics services, take part in decision-making at all levels and be represented on relevant committees.” The summarised results for this standard are listed in Table 16. The mean score is 3.3, the relevance and importance of the criteria has a mean score of 5.0 and the mean applicability score for the criteria is 4.7.

Table 16. Mean ratings for the Service User Involvement Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.3	5.0	4.7
95% CI for the Arithmetic mean	3.0 to 3.5	4.8 to 5.2	4.4 to 4.9
Median	3	5	5

WHO Standard Number 40 states: “Prosthetics and orthotics services should be accessible to all the people who need them: girls, boys, women, men and older adults.” The summarised results for this standard are listed in Table 17. The mean score is 4.3, the relevance and importance of the criteria has a mean score of 5.4 and the mean applicability score for the criteria is 5.2.

Table 17. Mean ratings for the Service Accessibility Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.3	5.4	5.2
95% CI for the Arithmetic mean	4.0 to 4.6	5.2 to 5.5	5.0 to 5.4
Median	5	6	6

Table 18. Mean ratings for the Service Accessibility Standard by region

	Africa	Asia	Europe	North America
Sample size	60	19	38	28
Lowest value	0	2	0	1
Highest value	6	6	6	6
Arithmetic mean	3.5	4.5	5.4	4.9
95% CI for the Arithmetic mean	2.9 to 4.0	3.8 to 5.3	5.0 to 5.8	4.3 to 5.4
Median	4	45	6	5

WHO Standard Number 41 states: “Prosthetics and orthotics services should be part of the health sector or be closely linked to it.” The summarised results for this standard are listed in Table 19. The mean score is 4.8, the relevance and importance of the criteria has a mean score of 5.4 and the mean applicability score for the criteria is 5.3.

Table 19. Mean ratings for the Linkage to Health System Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.8	5.4	5.3
95% CI for the Arithmetic mean	4.5 to 5.0	5.2 to 5.5	5.2 to 5.5
Median	5	6	6

WHO Standard Number 42 states: “Prosthetics and orthotics services should be delivered in a three-tier system, at primary, secondary and tertiary levels, with established links and two-way pathways for referral and follow-up.” The summarised results for this standard are listed in Table 20. The mean score is 3.1, the relevance and importance of the criteria has a mean score of 4.8 and the mean applicability score for the criteria is 4.6.

Table 20. Mean ratings for the Referral System Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	3.1	4.8	4.6
95% CI for the Arithmetic mean	2.9 to 3.5	4.6 to 5.0	4.4 to 4.8
Median	3	5	5

WHO Standard Number 43 states: “Maintenance and repair services should be an integral part of a prosthetics and orthotics service delivery system.” The summarised results for this

standard are listed in Table 21. The mean score is 3.1, the relevance and importance of the criteria has a mean score of 4.8 and the mean applicability score for the criteria is 4.6.

Table 21. Mean ratings for the Maintenance and Repair Standard

	Current situation	Relevance and importance	Applicability
Lowest value	0	0	0
Highest value	6	6	6
Arithmetic mean	4.8	5.2	5.2
95% CI for the Arithmetic mean	4.6 to 5.1	5.0 to 5.4	5.0 to 5.3
Median	5	6	6

A full list of data on all standards is available from the authors.

Discussion

This study gives a useful preliminary understanding of the current implementation of the WHO P&O standards. An adequate sample size was achieved with excellent geographical spread around the globe.

The summary values for each of the four parts of the standards give an overview of the current situation on both a global geographic basis but also from the whole of P&O service point of view.

A score of 3.0 indicates that one is neutral to that this standard has been addresses and 4.0 demonstrates agreement that this standard has been addressed. The overall mean scores for each of the parts lie between 3.5 and 4.0, indicating that there still is a lot of work to be done to implement the standards. An average score of 3.5 indicates that there would be many places where the standards have not been implemented.

The gap between the current situation score and the importance and relevance score clearly demonstrate and quantifies the need for further improvement to adequately address the standards.

The differential score between the importance and relevance and the applicability, with applicability being consistently scored slightly lower indicates that while the individuals rate the importance of a standards, they do not always consider that is equally relevant and/or achievable in their local situation.

For each part of the standards, the results for the lowest and highest mean in that part are presented separately to give a more detailed insight into some of the standards and two they are applied internationally currently.

For three standards, the results are also presented by region. This clearly demonstrates the regional variation which is consistent across the three exemplars. Not all standards could be presented by regional groupings for the purpose of brevity of this report. Further analysis by

regional and even sub regional or country level will present a more detailed understanding of the variations. This is currently not possible as the number of responses per country is generally too small to allow country by country comparison. However as further contributions to the results become available this can be done.

Limitation of the study include that the survey was primarily sent to members of ISPO. While this is a limited number of individuals, it is at the same time a significant and active proportion of individuals who provide prosthetic, orthotic and mobility device services to patient. In contrast, as the membership of ISPO is multidisciplinary the responders are also from a multidisciplinary background as outlined in the results, giving a broad cross-sectional opinion about the service provided. This gives the opportunity for a potential subgroup analysis by professional category at some stage.

The responders are self-selected, and this may introduce a bias into the results. More detailed analysis of the response could be carried out looking for significant outliers either from the regional or country means, if this were felt to be a significant problem.

Another potential limitation is that the majority of the responders responded in English although many of the responders do not use English as their primary language. This has been partially addressed by having the survey available in multiple languages. At the time of writing this report only 14 non-English survey responses were available to be included in the analysis.

The limitations of language and numbers have prevented more detailed analysis on a country by country basis. To address this limitation, we have left the survey open on our internet page and are encouraging more members to respond to the survey. Potentially non ISPO members and service users or potential service users could also complete the survey (with minor modifications) to boost the numbers and give a representative view of the adherence to the standards on a country by country basis.

The best practice that we recommend is the WHO Standards itself. We understand that the full global implementation standards is unrealistic at this stage. Hence the base line in formation to be gathered by this survey is a critical pre-implementation task.

National Member Societies with significantly large number of members can use the same Questionnaire when planning services in their own countries. ISPO could identify the countries with scores of 3 or less to initiate Planning services. A Report anonymised can be sent to NMSs with their only own findings/scores identified thus giving them an idea of where they are placed in comparison to other services.

The results will also be shared with any further project for implementation of the WHO Standards by any official organisation e.g. ISPO Global Partnership Exchange members.

We felt that a significant challenge would be a lack of participation in completing the questionnaire. Our normal established communication channel is that the individual members in our society to be informed through the national member societies. However,

we have deliberately taken an exceptional approach in sending the questionnaire to the individuals directly from our Head Office with numerous reminders of the importance of this survey and regular updates as the various languages became available. Despite this we received only 1 response from 30 countries and while it is possible that they were responding on behalf of the national member society it would be preferable to have more individual responses.

We have demonstrated that there are considerable challenges in implementation of the Standards, and this emphasises the importance of the development of the Standards, against which one can measure. The Standards are an important document anyone in the field can use and start the well-established process for discussion in changing or improving the service. Users, professionals or decision makers can initiate this process with these Standards. Having established the Standards, and now disseminating the standards and giving appropriate supports, gives the opportunity to develop services in a more cohesive and coordinated way ultimately resulting in significantly improved access and quality of service delivery.

Conclusion

This study underpins the importance of developing standards, measuring against the standards and then developing services to meet the standards.

Further work needs to be done to measure against the standards and then developing implementation plans to improve P&O service delivery.

ISPO will continue to work with the Standards and would be delighted to work with other partners to improve service delivery for those in need of assistive technology, in particular mobility, prosthetic and orthotic devices.

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International education standards for prosthetics and orthotics occupations

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Abstract

Background and objectives: One billion people are known to need assistive products worldwide. The World Health Organization (WHO) estimates that by the year 2050, this number will grow to two billion people. Figures from WHO also recognize a global shortfall of appropriate service providers in the field of prosthetics/orthotics. An important contributor to the shortfall is the limited number of appropriate education programmes, with many low/middle-income countries having no training programmes. The result of this and other barriers is that only 1 in 10 persons who require prosthetic and orthotic (P&O) care have access to appropriate services. The need for health professions to transform and expand their training to better serve the needs of persons with disabilities and the ageing population is evident. For users of prosthetic and orthotic services, the skill mix within training programmes⁴ is vital to ensure both sustainable education programmes and sustainable P&O services. The International Society for Prosthetics and Orthotics (ISPO) has provided the education standard of reference for prosthetics and orthotics since its first standards were released in 1992. These standards have been used to establish, develop, and evaluate programmes around the world. This process of quality assurance has been instrumental in programme improvement leading to quality providers of P&O care. To update terminology, better reflect changing models of education, and encourage a better understanding of the range of professionals within the prosthetic and orthotic occupational structure, ISPO launched new education standards in 2018. The new standards offer a systematic framework for programme development and evaluation. They are designed to encourage ongoing development within institutions and their graduates, with the aim of ensuring that users have access to appropriate prosthetic orthotic services regardless of their setting. The objective is to describe the process involved in developing education standards for prosthetic orthotic occupations and provide guidance on the implementation of education standards for prosthetic orthotic occupations. **Approach:** A narrative approach would be used to describe the development of the International Society of Prosthetics Orthotics (ISPO) Education Standards and use the data sets collected by ISPO to describe the

current status and trends in prosthetic orthotic education. In addition, a literature review will demonstrate best practices, challenges and opportunities. **Expected findings:** This manuscript will discuss the process, lessons learned, and outcomes for the development of the ISPO education standards. Implications for workforce planning related to education and training will be discussed to help frame the importance of structured plans for education that meets the needs for assistive technology services. Equally important is the aim to report on the current status and trends in education for prosthetic orthotic occupations and their value in achieving sustainable services for users. **Best practices and recommendations:** Best practices in education for prosthetic orthotic occupations will be described in this chapter. In addition, this chapter would demonstrate alignment between ISPO Education Standards and the recent World Health Organization Standards for Prosthetic Orthotic Service Provision. **Challenges and opportunities regarding greater access to quality, affordable AT for all:** A description of common challenges in developing appropriate education programs such as compliance with standard, barriers associated with setting, and funding. Opportunities for aspects related to prosthetic and orthotic standards will be described such as advocacy and collaboration.

Keywords

Prosthetic/orthotic education standards, prosthetic/orthotic workforce

Introduction

The World Health Organization (WHO) estimates that one billion people are in need of assistive products and expects this number to double by the year 2050 (1). In prosthetic/orthotic services an important factor in the limited access to services is the recognized shortfall of appropriate service providers and education institutes around the world. WHO reports that access to prosthetic/orthotic services will remain inadequate, uncertain or even at the point of crisis unless there is an effort to increase the number of personnel providing prosthetic/orthotic services (2). At present only 1 in 10 persons who require prostheses or orthoses have access to these services (2) which highlights the urgent need to scale up access to services. It should be noted that these figures only speak to access and do not necessarily address the quality of service available.

The shortfall in the number of prosthetic/orthotic education programmes worldwide with many low/middle-income countries having no formal training programmes at all (3) presents an important barrier to developing appropriate and sustainable services.

The need for health professions to transform and expand to better serve the needs of persons with disabilities and the ageing population is a recognized and growing problem. One important factor is the need to expand the workforce by increasing the quality and quantity of trained professionals. Increasing the number of formal programmes should include diversity in the level of training programmes to ensure an appropriate skill mix (3).

Globally ISPO has been working to improve access to appropriate prosthetic/orthotic services since its inception and has specifically targeted education standards as a key method of advancing this agenda. ISPO education standards have been the international standard of reference for prosthetic/orthotic occupations since they were first released in 1992.

The ISPO standards have been used to establish new programmes, develop and improve existing programmes and evaluate education programmes around the world. This voluntary process of quality assurance has also been instrumental in cultivating collaboration between ISPO, education institutes and policy makers while simultaneously improving access and the quality of prosthetic/orthotic care.

In 2018 ISPO launched new education standards to update terminology, better reflect changing models of education and encourage improved understanding of the range of professionals within the prosthetic/orthotic occupational structure.

The new standards offer a more systematic framework for programme development and evaluation. They are designed to encourage ongoing development within institutes and their graduates, with the aim of ensuring users have access to appropriate prosthetic/orthotic services regardless of their setting.

The following text will describe the process undertaken by ISPO to develop their education standards and the resulting effort to harmonize the competencies of entry level professionals globally.

Background

Historically prosthetic/orthotic professions have been trained in an apprenticeship model. The need for programmes to be established at the level of higher education was recommended in the late 1960's and early 1970's through a series of international and national meetings. Although this initiative improved the availability of qualified faculty, institutes were still reluctant to expand programmes with small numbers of students and high tuition that had limited resources or government support (4). In the 1976 book *The Advance in Orthotics* by George Murdock (ed), Murdock conclude that there was a great need for individuals requiring services and noted that many governments were already heavily invested in providing inadequate services (5).

In many parts of the world prosthetic/orthotic education and subsequent service have progressed since that time, however the challenges that existed in the 1970's often persist today. High level of need, low level of access and resource constraints mean it is not always possible to achieve all that is needed to supply appropriate services.

Data and evidence related to prosthetic/orthotic services is lacking. Research is reported to be needed in prosthetic/orthotic governance, sector planning, monitoring and finance, among others (2). Despite this recognized need, it appears that contribution to the body of

knowledge is unlikely to arise from a multidisciplinary landscape, and therefore must come from the prosthetic/orthotic professionals.

In studies of graduates from ISPO recognized programmes in less resourced settings, investigators found prosthetist/orthotists were more likely to take on complex clinical cases as well as teaching, mentoring and management roles than others in the occupational structure (6). This suggests that competencies related to decision making and leadership are of importance playing a decisive role in the sustainability of programmes and services.

A USA based multidisciplinary white paper aimed at determining orthotic prescriber authority agreed that physicians of all specialties had a greater burden of knowledge in current practice settings. They reported that physicians had less time and opportunity to gain a working knowledge of prosthetics/orthotics than in the past. The white paper concluded that orthotists had the most applicable education and training to contribute to determining the orthotic treatment plan. The authors recommend that the Centres for Medicare and Medicaid Services guidelines should recognize the level of expertise of orthotists and their role in provision of timely, safe and effective orthotic devices (7). This recommendation indicated that even in highly resourced settings prosthetist/orthotists role continues to expand and requires skills sufficient to take on a leadership role within the multidisciplinary team.

With the evolving impetus for prosthetic/orthotic professionals to take an active role in leadership, evidence-based practice and research, ISPO identified that related competencies should be seen as a priority for entry level professionals to ensure prosthetic/orthotic professionals can contribute to the field at an appropriate level.

Approach

In 1991 WHO and ISPO began establishing guidelines for training of three professional prosthetic/orthotic occupational Categories. Produced by ISPO and endorsed by WHO these standards have become the guiding principle for many quality programmes. By 2015 ISPO reported that 38 schools in 26 countries had voluntarily adopted the guidelines and successfully completed the process to be recognized by ISPO (8).

Since the inception of ISPO Education Standards, there have been more than 4900 graduates from ISPO accredited programmes working in over 120 countries, demonstrating the broad impact of the standards.

The ISPO Education Standards have always had a strong basis in specific and practical curriculum content as well as roots in traditional education models. Over the course of 30 years the standards have been regularly reviewed and updated to ensure they reflect current best practice and continue to encourage development in the field.

By 2010 there was an increasing demand from programmes who wanted to become ISPO recognized institutes. This placed a high demand on the organization and its volunteer auditors. Coupled with changing education models and increasing awareness of the unmet

need ISPO perceived there was a need to review its education standards to ensure the standards were a facilitator of access to quality prosthetic/orthotic services and not a barrier to innovation in learning models.

The ISPO Education Committee – Standards and Guidelines Sub-committee were tasked with reviewing the standard and recommend changes that might enhance the outcome, impact and accessibility of the standards.

Following consultation with internal experts and other stakeholders the sub-committee surveyed ISPO membership and prosthetic/orthotic educators to understand their knowledge, integration and impact of the current standards. Following analysis of the collected data the Education Committee convened focus groups at the Global Educators Meeting in Kobe, Japan. To ensure a balanced view of the need for change, the subcommittee also completed a comprehensive literature review and consulted a range of stakeholders including those beyond the education sphere.

Findings

Once data from all sources was collected and analyzed the Sub-committee set about determining the type of change that was needed to update and enhance the ISPO education standard. The following describes the results of this process.

From the survey results the Sub-committee identified that there was a real, and perceived limitations to the understanding of the unique ISPO system of categories for classification of prosthetic/orthotic occupations. Focus groups with educators in Kobe confirmed this finding. Participants made clear that a range of education models were being used successfully around the world, and that in spite of differences in how outcomes were achieved prosthetic/orthotic programmes expected graduates to achieve similar competencies regardless of their setting (9).

The literature review and consultation with stakeholders confirmed that ISPO needed to align its classifications and competencies with more commonly used systems if prosthetic/orthotic occupations were to be understood at policy level. Coordinating with transnational frameworks was also considered of importance in ensuring that ISPO could communicate its standards and advocate for access to quality services (9).

The process of review identified three key areas for ISPO to consider in developing their education standards;

1. Occupational Classification
2. Education Frameworks
3. Documenting and Communicating Standards

Occupational Classification

The art and science of prosthetic/orthotic services requires diversity in its workforce. The WHO identifies two main groups within the prosthetic/orthotic workforce, clinical

(prosthetist/orthotist and associate prosthetist/orthotist) and non-clinical (technicians and support staff). The ISPO Education standards provide the framework for competencies expected in each of these classifications where specialized prosthetic/orthotic knowledge is mandatory. ISPO does not detail competencies of support staff as this role is varied and may or may not require prosthetic/orthotic competencies.

The volume and ratio of professionals are other critical components for access to service. The WHO recommends that a ratio of at least 5-10 clinicians per million population, and that at least one prosthetist/orthotist should be available in each service unit. This ratio is often greater in high income countries (15-20 per million) and lower in less resourced settings (1 per million). They further recommend developing the role of technicians to reduce the bottleneck in service caused by lengthy manufacturing processes inherent to the profession. This usually requires a ratio of at least 1:2 clinicians to non-clinicians but varied depending on the setting, rising to 4-5 non-clinicians to increase production or lowering to a 1:1 ratio in specialist clinics (10). The effectiveness of these ratios in ensuring access to appropriate services depends on personnel working within their scope of practice and in appropriate supervision structures.

The expected competencies and supervision structures of each occupational classification are clearly defined by ISPO through its Education Standards. However, the review process revealed that the standards set forth by ISPO were not well incorporated in other global standards.

Although occupational classifications were considered of importance for monitoring and planning services, the review process identified a lack of clarity not only with the unique ISPO system but also within the International Labour Organization classification. In spite of distinct differences in the competencies and role of various professionals the International Labour Organization had failed to differentiate the prosthetic/orthotic professions within their ISCO-08 Volume I - International Standard Classification of Occupations (11) and other global bodies have followed suit. The lack of clarity in the unique classification of categories shows similar trends to the miss-classified details in the ISCO-08, however it is unclear which established the trend.

In addition, this miss-classification of prosthetic/orthotic professions within global occupational structures may not be limited only to prosthetic/orthotic professionals. In the 433 pages of ISCO-08 Volume I the terms Assistive Technology, Assistive Device do not appear, hearing aids and orthotics have only a limited appearance and are classified into Unit Group 3214 Medical and Dental Prosthetic Technicians with occupations such as Dental Mechanics and Prosthetists among others. The term wheelchair appears only within Unit Group 7234 Bicycles and related repairers (11). This suggests that although one of the main objectives of the ISCO-08 is to provide contemporary, relevant and comparable information in the realm of occupations, individuals engaged in the Assistive Technology workforce are likely being overlooked in the statistics that aim to monitor workforce and/or may be miss-classified. Furthermore, these classifications do not align with the WHO recommendation

that prosthetist/orthotists should be classified to correspond with that of physiotherapists and occupational therapists owing to their similar level of responsibility (2).

The lack of monitoring for prosthetic/orthotic occupations and services was evident in the paucity of national level data available during the reviews and consultations. Through follow up with ISPO National Member Societies, national/regional governing bodies and key informants ISPO was able to determine that while some countries have reliable data describing their prosthetic/orthotic workforce, others have a complete absence of data. Many countries do not monitor these occupations or report how users access services.

Within the limited data available key informants from 47 countries report that prosthetic/orthotic workforce in those countries is about 75,000 individuals in various prosthetic/orthotic occupations. This represents a range of settings, educational levels, in some instances this data may or may not include service providers with little or no formal training.

As baseline information is typically the foundation of planning, absences and omission of data collection about the workforce results in a diminished ability to plan and implement safe, effective and sustainable services.

Education Frameworks

The United Nations reports that transnational education frameworks are increasingly common (12). These frameworks aim to improve the mobility of graduates and clarify the knowledge, skills and competencies of various levels of training for policy makers, funding agents and other stakeholders (9). For these reasons ISPO has developed its standards to align with common transnational frameworks (see Table 1 for example alignment). The standards establish the minimum competencies for entry level personnel established by ISPO.

ISPO selected the European Qualification Framework as a reference framework as it includes a range of education models and economic settings. In addition, the European Qualification Framework has been reported to be influential in other transnational frameworks (12).

Table 1. Summary of Prosthetic/Orthotic Occupational Classification with Alignment to Sample Qualification Framework (9).

ISPO Occupational Classification	Sample (European) Qualification Framework	Summary Description
Prosthetist/Orthotist	Minimum Level 6	The training level aimed at the full breadth of clinical service, leadership, advancing models and/or methods of service delivery.
Associate Prosthetist/Orthotist	Minimum Level 5	The training level aimed at general clinical service delivery.
Prosthetic/Orthotic Technician	Minimum Level 4	The training level aimed at technical design and fabrication of devices without providing clinical intervention.

Documenting and Communicating Standards

Among its findings ISPO confirmed that training models for prosthetic/orthotic occupations had diversified. While traditional colleges and universities were still the most common model of training, blended learning, upgrading or stacked/ladderized approaches were appearing in prosthetic/orthotic education programmes (9). These approaches allowed for more entry and exit points within the occupational pathway (9) and often appear to have developed in response to unique barriers in specific settings.

In less resourced settings the impact of graduates from various training models has been assessed and investigators found that no statistically significant difference in the quality of prosthetic/orthotic devices was evident based on the model of education (6) between ISPO recognized programmes.

While these innovative education solutions appear to have a positive impact on the clinical services, some were a challenge to fit with standards aimed at traditional education models.

Therefore, ISPO investigated alternative frameworks for consideration with the new iteration of the standards.

Ultimately ISPO determined that an outcomes-based structure for the competencies of entry level personnel would be a more appropriate structure. Outcome based education is considered less prescriptive, applicable in a range of settings, allows for innovation, and includes auditable quality indicators (13). These attributes met the criteria ISPO had established, allowing various models and pathways to be assessed against the same criteria no matter how the competency was reached. Opening opportunities for innovation in education models without risking fairness and transparency necessary for quality standards.

In its review, ISPO also determined that the overall quality of an education programme was not exclusively determined by curriculum content. Leadership, faculty profile, policies and

governance were considered to be of equal importance. Having these elements in place better ensures that programmes meet the minimum standards, have the ability to evolve in step with the profession and address the needs of the service users. Furthermore, education programmes that are comprised of these elements are often better aligned and have more effective communication with policy makers, funding agents and other stakeholders.

Therefore, the standards were developed to include these aspects and align with WHO and other education standards (14,15). The new standard explicitly requires evidence of compliance in five domains;

1. Entry-level Personnel
2. Institutional/Programme Requirements
3. Programme Curriculum
4. Faculty
5. Programme Admission (9)

From these five domains were developed 15 education standards and supporting evidence statements to clarify the essence of each standard.

Discussion

The new education standards were launched at the ISPO Global Educators Meeting in Gottingen, Germany in September 2018 (16). These standards provide a comprehensive framework for programmes to use as a tool for self-assessment, programme development and to demonstrate compliance with the global standards. The following will highlight some of the key aspects of inclusion in the standards and their accompanying process.

The Standards

The attributes of a profession begin with student attainment of competencies during training programmes. Therefore, ISPO has sought to ensure that its new standards carefully define and describe the outcomes of education programmes. Following is a description of some of the salient additions to the new standards that aim to ensure prosthetic/orthotic personnel can meet the needs of their society.

It is of importance that the prosthetic/orthotic workforce contribute to the body of knowledge and formal research initiatives to ensure evidence-based standards for care and ongoing professional development are rooted in a prosthetic/orthotic specific context. If research is to be used to improve access, ensure quality of care and manage the cost of services, prosthetic/orthotic professionals must possess the competencies necessary to contribute to such initiatives. As such these competencies have an increased focus in the new standards.

The lack of data within the field suggests a need for subject matter experts in prosthetics/orthotics to be better consumers of research and to contribute to the collection of data and research. Education standards ensure that graduates possess competencies

that equip them to matriculate into environments (both academic and clinical) that encourage evidence-based practice and/or research.

Advances in science and technology associated with prosthetic/orthotic services raise the demand on service providers and increases costs associated with that same service. This highlights the need for prosthetic/orthotic personnel to possess competencies in self-directed learning that is ongoing throughout their career. As such ISPO has included standards to ensure this competency is addressed in programmes.

The expanding role with the multidisciplinary team and increased demand for services suggest that the workforce must be of sufficient capacity to allocate responsibilities and accomplish tasks. Whether by necessity, efficiency or effectiveness, task shifting is reported to result in improved cost effectiveness and achievement of higher quality care than physician centred models. This is considered an important element in increasing access to services. Therefore, there exists a need for graduates of prosthetic/orthotic training programmes to possess appropriate competencies for task shifting that equip the workforce with the appropriate skill mix to achieve benefits in the quality and cost of care for prosthetic/orthotic services.

The standards also recognize and address the profile of leadership and faculty to ensure that subject matter experts have high level input to programmes and operations. Recognizing the push from general education standards to increasingly enhance academic standing at the cost of subject matter expertise ISPO have specified the attributes that should be considered a minimum level clinical expertise and continuous professional development for educators and programme leadership.

Education programmes that align occupations at an appropriate level with disciplines of similar responsibility are perceived as enhancing retention and ensuring the benefits of investment in training (2). By aligning the standards with recognized frameworks and establishing the minimum standard, ISPO aspires to ensure that graduates will begin their career from a place that allows them to grow within the profession and be retained within the field.

Collectively, under the new education standards, the level of training for the prosthetist/orthotists, associates and technician is more transparent and better defined. The outcomes expected at each level of training are more clearly communicated to programmes and stakeholders.

The Procedure

As the update to the standards was underway a concurrent effort was undertaken to revise the existing accreditation process. As part of this undertaking the ISPO programme reporting tool was updated to reflect the changes in the education standard and to transition the document from paper to an online format. Initial feedback indicated that the online reporting tool was more user friendly than the previous narrative format.

Strategically placed instructions embedded in the tool made it easier to clarify the type of evidence the standard required. The format of the online tool encourages a concise statement of how a programme meets the standard with the opportunity to up-load more detailed documents as needed. This streamlines the documentation while allowing the full breadth of evidence to be presented. The tool generates a report that is easier to navigate for programmes, auditors and the ISPO committee that review reports.

In addition to the programme reporting tool, ISPO undertook an overhaul of the audit process and accompanying auditor training process.

Historically lengthy narrative reports were required of audit teams. These reports often caused delays in accreditation, were burdensome to administer and monitor over time. In the new process, lengthy narratives have been replaced with a more efficient online auditor reporting tool. The 2018 version of auditors report better specifies level of programme compliance with the standards and allows for programmes to see more readily where improvements are needed.

In the past ISPO auditors had various levels of auditor specific training. Many were long-time committed volunteers with extensive experience in education and as auditors. As the demand for audits increased the ability of this group to manage the volume of on-site inspection and reporting was becoming impractical.

Under the new process, auditors must still possess the relevant experience and work with more experienced auditors to ensure they understand the standards and the process. In addition, auditors are required to complete specified training modules to ensure they understand the standards and the accreditation process. Accompanying resources have also been developed in various forms (handbook, webinars, online training) to offer the auditors and programmes faculty additional support in preparing for and engaging in the audit process. The process of implementation is still in early stages, however thus far the results are promising.

Barriers

While the revision of the standards has been largely positive, many barriers arose during the process that are worthy of note. Time and changes outside the control of ISPO were the most impactful, for example;

- The duration of the project extended over nearly 8 years and as such there were multiple occasions when changes to regulations, process, or procedures required a change in strategy or project planning.
- The vast majority of the work was done through the volunteer efforts of subject matter experts. As the work spanned multiple biennium for the organization it was not uncommon for the team members to change and commitment to vary.

- It was also common for key informants outside the organization to change roles midway through a process. Leaving ISPO to either formulate new relationships or develop a new plan.
- Owing to the lack of data readily available, ISPO often had to regress or suspend primary project work in order to develop sub-research projects and gather subsequent data to make an informed decision.

These barriers represent only a snapshot of the challenges encountered, however with patience and perseverance those barriers were successfully managed and often overcome.

Opportunities

Many perceived barriers eventually evolved into opportunities allowing ISPO to develop more sound rationale and strategies that may not have been available had the planned path not been obstructed, for example;

- Implementation of the survey of members and educators had the unexpected effect of providing invaluable information about ISPO stakeholders and in guiding the competencies later outlined in the standards.
- ISPO has built a better understanding of other global actors that affect prosthetic/orthotic education and services through an indirect route, such as the influence of the International Labour organization on occupational classification.
- The new process is more rigorous and transparent.
- The process also appears to be more efficient and clearer for stakeholders.
- The stricter format results in collection of more comparable data.

ISPO is still in the early days of implementation and anticipates that more barriers and opportunities may yet present themselves.

Had ISPO not undertaken the task of developing new education standards and updating the accreditation process it is unlikely that ISPO would have been able to sustain its accreditation. Based on the increasing number of programmes worldwide that are seeking ISPO accreditation, ISPO would not have been able to effectively meet the demands of the education programmes. In all likelihood there would have been more delays in the accreditation process ultimately leading to programme dissatisfaction. As it stands now, ISPO is well-positioned to meet the growing demand for ISPO accreditation and encourage appropriate services through the quality of education programmes around the world.

Conclusion

Education standards should be seen as the foundation of any profession. They establish the competencies of graduates who should in turn be expected to evolve into leaders, advocates and compassionate providers of care.

The process of review of the ISPO Education Standards began as what appeared to be a simple task to review and revise standards that were both well accepted and effective in

monitoring the quality of prosthetic/orthotic education programmes. This simple task evolved into a process of discovery that would allow ISPO to step back and look beyond the landscape towards the horizon.

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Regulation of assistive technology practitioners to drive workforce training and retention

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Abstract

The World Health Assembly identified the need to increase access to Assistive Technology (AT) for the one billion people around the world who require AT to improve their function, participation, independence and well-being (1). Through resolution WHA71.8, the World Health Assembly called upon the World Health Organisation (WHO) to produce a Global Report outlining approaches to increase access to AT (2). The Global Report will be guided by contributions to the *Global Report on effective access to Assistive Technology* (GReAT) Summit, including extended reports and presentations by academics, practitioners, policy makers and AT users. The GReAT Summit objectives outline nine themes for exploration including theme number six, 'good practices in AT workforce training and retention'. In order to develop good practices in AT workforce training and retention, appropriate regulation of AT practitioners is key. Regulation ensures that AT is provided by suitably trained practitioners who have the requisite skills and knowledge to provide a safe and effective service. In addition, regulation supports recognition of an occupation and therefore contributes to workforce growth and retention which, in turn, increases access for AT users. The authors of this contribution have expertise in self-regulation, education and training, and workforce development for the orthotic/prosthetic occupation. We are honoured to submit this report to the WHO which investigates current regulation of the orthotic/prosthetic occupation internationally and captures the experience of developing regulation of a national association in Australia. Based on the findings of this report, we recommend the establishment of an international professional body with the express purpose to build the regulatory capacity of national orthotic/prosthetic associations. As detailed at the end of this report, such a model could address the financial and expertise barriers that currently hinder the development and growth of a workforce with the skills and competencies to provide a safe and effective service for the growing number of people that require orthoses/prostheses and other types of AT.

Introduction

The World Health Organization (WHO) estimates there are currently more than one billion people around the world who require some form of Assistive Technology (AT) (1) to improve

function, participation, independence and well-being. This number is expected to double in the coming decade given the ageing population and the prevalence of communicable diseases (3).

Only about 1 in 10 people currently have access to the AT they need (1), which limits participation in education, employment, and activities that bring joy and meaning to life. The majority of people who lack access to AT live in *low-* and *middle-*income countries and are more likely to experience poverty (4, 5) partly due to a lack of access to AT (6). People living with disabilities face barriers to participation in education and employment which increases the burden of disability for themselves, their families and the broader community in which they live. Access to appropriate AT can reduce the barrier to participation experienced by people living with disability (7), and therefore it is not surprising that increasing access to AT is a priority of national governments (8), the WHO and the AT community (3, 7, 9).

If we are to increase access to appropriate AT it is essential that we build a suitably trained AT workforce with the requisite skills and knowledge to provide safe and effective services (10-12). Regulation of practitioners is key to building a suitably trained workforce, which applies core standards and uses ongoing monitoring and compliance of practitioners to ensure the delivery of safe and effective services appropriate for the local setting (6, 13). Regulation of AT practitioners must provide sufficient oversight without being unnecessarily burdensome (14) or creating barriers that limit access (13, 15).

Given that AT workforces in many countries are small, under resourced, and lack recognition as health care providers by Government (12, 13, 16), regulation is often the responsibility of national associations who autonomously establish and enforce the core standards (15, 17, 18). This form of regulation is known as self-regulation (19) and is often difficult to establish given the limited financial resources and expertise available (15).

Despite the barriers to establishing self-regulation, it provides significant benefits that help ensure safe and effective AT provision, whilst minimising regulatory burden and administrative cost (14-16). It also allows small occupations to take responsibility for setting standards appropriate to the needs of their unique setting (16). Setting specific standards are particularly important in low-income countries where the cost and administration of complex regulation may further impede workforce training and development (14). Self-regulation, therefore, offers an appropriate regulatory model for small and under-represented occupations (19) where regulatory cost and administrative burden are likely barriers.

Given the barriers that exist to self-regulation, the establishment of an international professional body that could provide regulatory support in the form of guidance and expertise, would improve regulation and strengthening regulatory capacity (18). While international professional bodies offer regulatory support to national associations in many allied health occupations, such as physiotherapy and occupational therapy, currently none exist to specifically support regulation of professionals providing AT (15).

A prudent first step to understanding the regulatory oversight of AT practitioners would be to take a closer look at a single occupation as a case example. We propose that the

orthotic/prosthetic occupation may serve as an appropriate exemplar given that the entire scope of clinical and technical services - the provision of orthoses (external braces or splints) and prostheses (artificial limbs) – is about the provision of AT. While other professionals do provide AT, it is often a comparatively small component of the scope of practice of physiotherapy, occupational therapy, audiology, and speech pathology, and therefore less insight would be gained.

Given this background, this document reports the findings of two environmental scans:

- an investigation of national regulation of the orthotic/prosthetic occupation, and
- an investigation of international professional bodies in allied health providing regulatory support to national associations.

The following subsections of the document report the method and results of the environmental scans and discuss what we might learn from the examples identified. Findings will inform recommendations about appropriate forms of national regulation, and opportunities for international professional bodies to provide regulatory support to build regulatory capacity and guide the training and retention of a suitably trained AT workforce.

Introduction to regulation

Regulation plays a vital role in ensuring services are safe and effective by establishing standards that define the requirements to begin practice (entry-to-practice standards) and maintain practice (ongoing practice standards). Entry-to-practice standards set requirements to ensure only those people with appropriate training/qualifications and competency can provide services. Ongoing practice standards outline the requirements to ensure practitioners maintain the competencies to provide safe and effective services, or to extend their competencies appropriate to more senior or new roles. Together, entry-to-practice and ongoing practice standards help ensure the community receives safe and effective AT services.

Regulation uses entry-to-practice standards, such as competency standards, to define the knowledge and skills essential to the delivery of safe and effective services (20-22), which must be acquired through practitioner training programs. This ensures the content of practitioner training programs is aligned with the needs of the workforce and AT users in a particular national setting (13, 21-24). If training programs are not fit-for-purpose or contextualised to the national setting, then graduates are unable to deliver safe and effective services. Standards such as course accreditation provide the required monitoring and compliance to ensure the competencies are being acquired by the future workforce (23, 25). Therefore, regulation supports the development of an appropriately trained workforce for a particular national setting which contributes to improving access to AT.

Training alone will be insufficient to meet the rising demand for access to AT (12, 16) and as such, it is important that issues with practitioner retention be addressed (26). Regulation contributes to the retention of a suitably trained workforce through increasing recognition of the occupation (23), and the development of career pathways (16), thereby increasing job satisfaction. When an occupation is recognised, and its contribution is understood and

respected, government agencies are more likely to establish defined roles and career pathways, such as positions in government hospitals (16). The establishment of defined roles and positions provide the occupation with access to higher salaries, greater employment stability and future promotion opportunities (16, 26, 27). This is evident when we look at occupations without formal training requirements or a defined occupation scope (23), such as orthotic/prosthetic technicians in Australia: a non-clinical workforce supporting the manufacture of orthoses and prostheses. This occupation is undefined and without standards or representation, thus unrecognised in the public health system. As a result, salaries are low and opportunities for career progression are limited. It is therefore not surprising that retention in this occupation is also low, with orthotic/prosthetic technicians seeking employment in other sectors that offer greater pay, more stability, and career progression. Regulation provides a vehicle for the recognition of an occupation, which in turn supports the establishment of career pathways and increased employment satisfaction, therefore valuably contributing to workforce retention.

Method

The aims of this project were to:

- Investigate the regulation of the orthotic/prosthetic occupation globally;
- Investigate the provision of regulatory support by international allied health professional bodies to their national member associations.

To achieve these aims, two environmental scans were conducted using a defined set of core regulatory standards.

Core regulatory standards

To underpin the environmental scans, nine core regulatory standards (Table 1) were defined using the Australian Health Practitioner Regulation Agency (AHPRA) health practitioner standards (28). AHPRA is acknowledged as a leading regulator for the health workforce as recognised by the WHO Collaborating Centre (29). This well-established health regulatory system is linked to education, roles and responsibilities of the occupation, and the certification of individuals to practice (18). Given this, we believe the AHPRA health practitioner standards represent a sound basis to investigate national regulation of the orthotic/prosthetic occupation and the regulatory support provided by international allied health professional bodies.

Table 1. AHPRA nine core health practitioner regulation standards which include three of the AHPRA core standards (28) and a further six standards common to the 14 profession-specific boards overseen by AHPRA (30). AHPRA’s criminal history standard and professional indemnity insurance requirements were considered to be setting specific and therefore excluded from the core standards that underpin this report (28).

Regulatory Standard	Definition and purpose of regulatory standard
Minimum training/qualification	The minimum training and/or education level required for individuals to practice in the occupation. This standard communicates the minimum training requirements to practice to the community, external stakeholders and training institutions.
Entry level competency standards	An outline of the minimum skills and knowledge that must be demonstrated by individuals to practice in the occupation This is an assessable standard which is used by training institutions to determine the required training content. It is also used by authorities responsible for assessing competency to determine whether international practitioners can practice in the occupation.
Scope of practice	A guidance document which describes the role and activities a practitioner is permitted to undertake based on their training and qualifications This guidance is used to ensure the community and external stakeholders are aware of the boundaries of practice for an occupation. It is commonly used to promote the services of an occupation, but also to support disciplinary processes as working within one’s scope of practice is typically a component of a code of conduct.
Code of conduct and/or ethics	Describes the conduct expected of practitioners in providing a health service and/or the values and principles required to be upheld by a practitioner. This code defines the behavioural and ethical expectations to which the community can hold a practitioner to account. The code is commonly used in complaint and disciplinary processes and therefore each component must be assessable.
Course accreditation	A standard that training institutions must meet to be accredited by the national body for the education of practitioners Course accreditation ensures that training programs deliver practitioner education in line with the competency standards and scope of practice for the profession and therefore ensure the future workforce meets the needs of the population and the health system.
Continuing Professional Development	Describes the minimum requirement for ongoing education typically on an annual basis. This standard ensures that practitioners education journey is life-long and appropriate to their area of practice. It provides protection of the public by ensuring practitioners knowledge and skills are current.
Language requirements	National language requirements define the level to which a practitioner can adequately speak the language of the client or the primary language of the country. This requirement supports consumer safety by ensuring services are delivered by practitioners that can sufficiently communicate, or where language is a barrier, that alternative safe guards, such as translators are used.
Recency-of-practice	Describes the minimum amount of time that a practitioner can be absent from the occupation before a return to practice program must be completed. This standard provides protection to the public by ensuring services are delivered by practitioners with current knowledge and skills.
Return-to-practice	Describes the pathway to return to employment after a period of absenteeism from the occupation, as defined by the recency-of-practice standard. This standard ensures that practitioners are sufficiently current before returning to practice, thereby supporting retention in the workforce, whilst simultaneously ensuring services are delivered by practitioners with current knowledge and skills.

Environmental Scan One: National-level regulation of the orthotic/prosthetic occupation

Environmental scan one was conducted to investigate the regulation of the orthotic/prosthetic occupation at the national level.

The *Health Regulation Worldwide* database (Health and Care Professions Council HCPC) was used to generate a list of all countries that had an orthotic/prosthetic national association (31). A national association was defined as an organisation established by members of an occupation and acted nationally in the interests of the occupation (18). Additional internet searches using *Google*, and social media sites were undertaken based on the name of country in combination with the following terms and their synonyms:

- National
- Alliance, Association, Society, Union, Council
- Orthotist/prosthetist, orthotics/prosthetics, orthopaedic technologist, orthopaedic technician

An exploration of publicly available information was conducted for all identified national associations to determine whether the orthotic/prosthetic occupation was self-regulated, or Government regulated and determine whether the nine core regulatory standards were 'in place' or 'absent'. Where it was unclear, or we were unable to find the information publicly, email communications were utilised to ensure records were as accurate as possible. Where no response was received, publicly available information was used.

Given financial resources are a known barrier to the establishment of regulation, we also categorised each country by income status. We used the World Bank database (32) to classify income based on the Gross National Income per capita and thereby categorise countries into one of the following: High-, Upper-Middle-, Lower- Middle-, and Low-Income countries (33). Countries and national associations were de-identified in the tabulation and analysis of data.

Environmental Scan Two: International-level allied health professional bodies that provide regulatory support

The second environmental scan investigated the regulatory support provided by international allied health professional bodies.

We operationally defined *international allied health professional bodies* based on the following two criteria:

- in the absence of an agreed international definition, allied health occupations were defined as those recognised by, and members of, *Allied Health Professions Australia* (AHPA); the peak body for allied health occupations in Australia (34),
- an international professional body was defined as an organisation with an international purpose related to a specific occupation(s) where membership consisted of independent national associations or entities. Given this definition, international professional bodies with individual practitioner memberships (e.g., International Expressive Art Therapy Association) or a purpose related to a health service and not a specific occupation (e.g., the International Society of Prosthetics and Orthotics) were excluded.

The Health Regulation Worldwide Database search function was used to identify the international professional body for each of the allied health occupations (31). Further to this, we searched *Google* using the occupation name and combinations of the following search terms and their synonyms:

- World, Global, International
- Council, Federation, Confederation, Alliance, Association, Society, Union

If an international professional body was identified, we documented the number of national associations and the provision of regulatory support relating to the nine core regulatory standards, which were considered to be 'in place' or 'absent'.

Results

Environmental Scan One: National-level regulation of the orthotic/prosthetic occupation

This scan investigated the regulation of the orthotic/prosthetic occupation at the national level, including the identification of countries with orthotic/prosthetic national associations and investigation of the presence of the nine core regulatory standards for the occupation.

Countries with national associations for orthotist/prosthetists

Of the 195 countries identified via the Health Regulation Worldwide Database (31), 36 were identified as having a national association for orthotic/prosthetic practitioners (Table 2). Nearly half of these were classified by the World Bank as High-Income countries (n=17) with the remaining classified as Upper-Middle-Income (n=6), Lower-Middle-Income (n=8) and Low-Income (n=7)

Presence of regulatory standards for orthotist/prosthetists

In nearly 80% of the 36 countries, self-regulation was undertaken by the national association (n=28) rather than the Government (n=8) (Table 2). In some countries responsibility for regulation was mixed, with Government regulation present for some standards (e.g., minimum education/training), but not all (e.g. Code of Conduct).

The following results describe the presence of the nine core regulatory standards for orthotic/prosthetic practitioners in each country, in both Government and self-regulation models.

There was large variation in the number of regulatory standards in place across the 36 countries (Table 2). Eight countries had all nine standards in place. Eighteen countries had more than six standards in place, whilst seventeen countries had three or fewer standards in place.

High- and Upper-Middle-Income countries had more standards in place than Lower-Middle- and Low-Income countries. For example, more than 70% of High- and Upper-Middle-Income countries had implemented six or more standards, compared with 20% of Lower-Middle and Low-Income countries. Of the 17 countries with three or fewer implemented standards, nearly three quarters (73%) were Lower-Middle and Low-Income countries (Table 2).

Thirty countries (83%) had standards for minimum education/training (Table 2). Course accreditation was in place in 21 countries (72%), noting that seven countries did not have in-country training programs. Code of conduct (n=21), competency standards (n=19) and language requirements (n=19) were implemented in more than half of the countries (Table 2). Mandatory continuing professional development and recency of practice standards were present in 15 countries, with scope of practice and resumption of practice in place in 13 countries (36%).

Environmental Scan Two: International-level allied health professional bodies providing regulatory support

This scan investigated the provision of regulatory support of the allied health occupation at the international level including: the identification of international allied health bodies, and the extent to which they provided regulatory support against the nine core regulatory standards.

Allied health occupations with international professional bodies

Twenty allied health occupations were identified (Table 3). Fourteen had international professional bodies that met the eligibility criteria (Table 3). Six allied health occupations did not have an international professional body that met the eligibility criteria including the occupations of: genetic counselors, creative art therapy, perfusion, rehabilitation counselling, exercise physiology, and orthotics/prosthetics.

Provision of support on core regulatory standards

No allied health profession had an international professional body that provided regulatory support for all nine core regulatory standards (Table 3). The profession with support for the largest number of standards was physical therapy, with the *World Confederation for Physical Therapy* (WCPT) providing support for eight of the nine core standards. Occupational therapy was supported by the *World Federation of Occupational Therapists* for five standards. Speech therapy/audiology and social work was supported by the *International Association of Logopedics and Phoniatrics*, and the *International Federation of Social Workers* (IFSW) respectively, for which four standards were in place. The remaining 10 occupations received regulatory support from their international professional bodies for three or fewer standards (Table 3).

The minimum education and training standard was supported by more than three-quarters of the international professional bodies, (n=11, 79%). A code of conduct (n=8, 57%), competency standards (n=6, 43%) and scope of practice (n=6, 43%) were supported by approximately half of the international professional bodies. Guidance on implementing the return-to-practice standard was not provided by any international professional body. The only occupation receiving guidance on implementing standards for continuing professional development and recency-of-practice was physical therapy (Table 3).

Table 2. Presence of a sub-set of nine regulation standards for orthotist/prosthetist by country and income category (High-Income, Upper-Middle-Income, Lower-Middle-Income and Low-Income)

Income Level	Country ID	Presence of Government regulation	Minimum training/ education	Entry level competency standards	Scope of practice	Code of conduct	Course accreditation	Continuing professional development	Language standard	Recency-of-practice	Return-to-practice
High-Income Countries (n=15, 42%)	1	-	X	X	X	X	X	X	X	X	X
	2	-	X	X	X	X	X	X	X	X	X
	3	X	X	X	X	X	X	X	X	X	X
	4	X	X	X	X	X	X	-	X	X	
	5	X	X	X	X	X	X	X	X	X	X
	6*	-	-	-	-	X	N/A	X	-	-	-
	7	X	X	-	-	-	N/A	-	-	-	-
	8	-	X	X	X	X	X	X	X	X	X
	9	-	X	X	-	X	-	X	X	-	-
	10	X	X	X	X	X	X	-	X	X	-
	11	-	X	-	-	-	-	-	-	-	-
	12*	-	X	-	-	-	X	-	X	-	-
	13*	X	X	X	X	X	X	X	X	X	X
	14*	-	X	X	X	X	X	X	X	X	X
	15*	-	X	X	X	X	X	X	X	X	-
Upper-Middle-Income Countries (n=6, 17%)	16	-	X	X	X	X	X	-	-	X	X
	17	-	X	X	X	X	X	-	X	X	X
	18	-	-	-	-	X	-	-	-	-	-
	19	-	X	X	-	X	X	X	-	X	-
	20*	-	X	-	-	-	X	-	X	-	-
	21	-	X	X	-	X	X	-	X	X	X
Lower-Middle-Income	22	-	X	X	X	X	X	X	X	X	X
	23	-	-	-	-	-	X	X	-	-	-
	24	-	X	-	-	-	-	-	-	-	-
	25	-	X	-	-	-	-	-	-	-	-

Income Level	Country ID	Presence of Government regulation	Minimum training/ education	Entry level competency standards	Scope of practice	Code of conduct	Course accreditation	Continuing professional development	Language standard	Recency-of-practice	Return-to-practice
Countries (n=8, 22%)	26	-	X	X	-	X	X	-	-	X	X
	27	-	X	-	-	-	n/a	-	-	-	-
	28	-	X	-	-	-	-	-	X	-	-
	29	-	X	-	-	-	-	-	-	-	-
Low-Income Countries (n=7, 19%)	30	-	-	-	-	-	n/a	X	-	-	X
	31	-	-	-	-	-	n/a	-	-	-	-
	32	X	X	X	-	X	X	X	X	-	-
	33	X	X	X	-	X	X	-	X	-	-
	34	-	-	-	-	-	n/a	-	-	-	-
	35	-	X	-	-	-	n/a	-	-	-	-
	36	-	X	-	-	-	-	-	-	-	-
	Total	8	30	19	13	21	21	15	19	15	13
	%	28%	83%	53%	36%	58%	72%	42%	53%	42%	36%

Notes: Of the 36 countries included in the scan, the asterix represents those where we unable to verify the scan data. Bolding indicates countries with all nine core regulatory standards in place.

Table 3. International allied health professional bodies and presence of regulatory support provided for nine core regulatory standards

Occupation, name of international body and number of member organisations (n)	Minimum training/ education	Entry level competency standards	Scope of practice	Code of conduct	Course accreditation	Continuing professional development	Language standard	Recency-of-practice	Return-to-practice
Physical Therapy World Confederation for Physical Therapy (n=120)	X	X	X	X	X	X	X	X	-
Occupational Therapy World Federation of Occupational Therapists (n=101)	X	X	X	X	X	-	-	-	-
Speech and Language Therapy (inc Audiology) International Association of Logopedics and Phoniatrics (n=63)	X	-	X	X	X	-	-	-	-
Social Work International Federation of Social Workers (n=123)	X	-	X	X	-	-	X	-	-
Dietetics International Confederation of Dietetic Associations (n=50)	X	X	-	X	-	-	-	-	-
Osteopathy Osteopathic International Alliance (n=10)	X	X	X	-	-	-	-	-	-
Music Therapy World Federation of Music Therapy (n=26)	X	-	-	X	-	-	-	-	-
Psychology International Union of Psychological Science (n=89)	X	X	-	X	-	-	-	-	-
Medical Imaging	X	-	-	-	X	-	X	-	-

Occupation, name of international body and number of member organisations (n)	Minimum training/ education	Entry level competency standards	Scope of practice	Code of conduct	Course accreditation	Continuing professional development	Language standard	Recency-of-practice	Return-to-practice
International Society of Radiographers and Radiological Technologists (n=80)									
Optometry World Council of Optometry (n=unknown)	-	X	X	-	-	-	X	-	-
Orthoptics International Orthoptic Association (n=16)	X	-	-	X	-	-	-	-	-
Chiropractic World Federation of Chiropractic (n=88)	X	-	-	-	-	-	-	-	-
Audiology International Society of Audiology (n=unknown)	-	-	-	-	-	-	-	-	-
Podiatry International Federation of Podiatrists (n=31)	-	-	-	-	-	-	-	-	-

Discussion

The exploration of the orthotic/prosthetic occupation as an illustrative example of AT practitioner regulation shows that, for the vast majority of countries, the occupation is unregulated. Only eight countries had the full suite of regulatory standards in place. Nearly half (n=17) had three or less regulatory standards in place, and we anticipate there to be little-to-no practitioner regulation in the remaining 159 countries. Given the population of these 176 countries, our results suggest that the provision of orthotic/prosthetic service is largely unregulated for approximately 50% of the world's population; confirming observations made by at least one other author (23). Given the important role regulation can play in improving access to AT, there is an urgent need for regulatory support to be provided to national associations to address the absence of regulation for the orthotic/prosthetic occupation in many countries.

Exploration of orthotic/prosthetic regulation: a national example of self-regulation

Whilst eight countries have in place all nine core regulatory standards, it is our intimate knowledge of regulatory changes introduced by the Australian Orthotic Prosthetic Association (AOPA) that allow us to talk with some authority about the transition from limited regulation to full regulation in Australia. In describing this transition from limited to full regulation, we hope to illuminate the barriers and the real-life benefits of self-regulation; in particular: how the recent establishment of regulation has impacted Government policy and workforce growth, and how self-regulation might be realised in other countries wishing to make a similar transition.

By way of background, AOPA was established in 1975 as the peak professional body for orthotist/prosthetists with a role to represent and regulate the occupation in Australia. In 2013 AOPA determined it would establish self-regulation of orthotist/prosthetists in line with other allied health professions in Australia and implement all nine core regulation standards. This decision began a five-year journey that was completed in 2018.

Strengthening AOPA's regulation increased external stakeholder confidence in the occupation and resulted in improved recognition of both the occupation itself, and the clinical services provided by orthotist/prosthetists. By way of example, in 2017 the Australian Government Department of Immigration recognised the occupation of orthotist/prosthetist, and established a need for a larger workforce. The occupation was added to the Skilled Occupations List which allowed skilled migration based on practitioners meeting the regulatory standards applicable to the occupation. Based on the strength of AOPA's regulatory standards and associated assessment processes, the Australian Government appointed AOPA as the authority for conducting assessments for skilled migration. Therefore, the Government's recognition of the occupation, and confidence in AOPA's regulatory capacity, allowed a substantial shift in workforce policy necessary to meet the rising demand for AT.

In addition to workforce policy changes, in 2018 the Australian Department of Veterans Affairs, as well as the private health insurance industry, undertook substantial funding policy changes that recognised orthotist/prosthetists as allied health practitioners. Based on confidence in the regulation of the occupation, formal funding schedules were established allowing orthotist/prosthetists to deliver services autonomously. In turn, this improved access to the occupation and made AT services more streamlined for users given they no longer require AT prescriptions from a medial specialist. These significant national-level policy changes resulted in workforce growth through improved immigration pathways and increased employment opportunities as new funding models increased access to AT services for people with disabilities.

Financial resources were a major barrier to AOPA initiating its regulatory journey. As an organisation with a relatively small membership and limited financial resources, the cost to develop, implement and maintain the full suite of regulatory standards was high. Successful funding applications to four rounds of Government grants allowed AOPA to employ staff to develop the entry-level competency standards (22, 35), course accreditation standards (36) and the associated entry-to-practice assessment processes.

In addition to the financial barriers AOPA also identified a lack of expertise as a barrier. To overcome the lack of expertise in regulation, AOPA sought support from the *National Alliance of Self-Regulating Health Professions* (NASRHP). NASRHP is a peak organisation that represents and supports the establishment of self-regulation for the allied health occupations (i.e., those occupations not Government regulated in Australia) including speech pathology, dietetics, social work, and orthotics/prosthetics. NASRHP provided regulatory support and promoted peer-to-peer mentoring between allied health associations to build regulatory capacity. Peer-to-peer mentoring reduced the time and cost burden to develop new standards and procedures, and helped AOPA learn from the experiences of our allied health colleagues. Without financial support from Government and the regulatory support offered by NASRHP and our allied health colleagues, AOPA would not have achieved full self-regulation or obtained the associated benefits for the workforce and people requiring AT services.

We believe the barriers AOPA experienced are not limited to Australia. In fact, the experience is likely similar world-wide given the small numbers of orthotic/prosthetic practitioners in many countries and indeed the small number of practitioners who provide AT services around the world. These barriers are likely exacerbated in countries categorised as lower income because of the relative immaturity of the health care services in those countries and the poor recognition of many AT occupations (16, 37). Indeed, our results suggest that for orthotic/prosthetic regulation, countries categorised as higher income have implemented more regulatory standards than those categorised as lower income, and the standards most commonly implemented are those where assistance has provided by external organisations, such as course accreditation (38) and service practice standards (16) supported by the International Society of Prosthetics and Orthotics (ISPO) and the WHO.

The model of regulatory support provided by NASRHP highlights a solution to the regulation challenge where external support removes expertise barriers, and resource sharing reduces the financial burden. This approach to regulatory support was identified in the international scan, and is in-line with the WHO Workforce Report 2030 (39), whereby international professional bodies assist national associations to build their regulation capacity. Unfortunately, our environmental scan did not identify an international body with the express purpose for supporting and building regulatory capacity of the orthotic/prosthetic occupation.

While some may argue that ISPO is such an international body, it is important to recognise that ISPO is a multidisciplinary organisation *dedicated to improving the quality of life for persons who may benefit from prosthetic, orthotic, mobility and assistive devices* (40). The society's mission is not to explicitly support and build regulatory capacity for practitioners providing AT. This is not to undervalue the work of ISPO given their long standing administration of international course accreditation that addresses one regulatory standard, nor their long standing collaboration with the WHO to establish international best practice standards for orthotic and prosthetic services (16). While these practice standards recommend increased support for national regulation, they do not describe a method for how this can be achieved (16), where the responsibility for this support lies, nor is the development of this sort of regulatory capacity in keeping with the mission of ISPO.

Without explicit international support to build regulatory capacity, the vast majority of national associations are attempting to establish orthotic/prosthetic self-regulation alone. Unfortunately, for many, the barriers will be too great to overcome in a timely manner, and benefits to workforce training and retention out of reach.

Exploration of regulatory support: an international allied health example

Given the need for an international body whose mission is to support the development of regulatory capacity in orthotics/prosthetics at a national level, it is appropriate to consider what we might learn from international allied health professional bodies

Results from the international-level environmental scan highlight the presence of international bodies in a number of allied health occupations that have a distinct purpose to provide regulatory support of their occupations by building regulatory capacity at the national level. The WCPT provides an excellent exemplar of an international professional body providing comprehensive regulatory support across eight of the core regulatory standards to its 120 member associations. Further to this, the WCPT makes clear the role that national regulation plays in building confidence in the occupation and ensuring the delivery of safe and effective services .

“WCPT encourages member organisations to work towards a system of regulation that focuses on the public interest. Such a system will promote trust and confidence in the profession” (41).

“ . . . in some countries, the profession is regulated by physical therapists meeting membership criteria for the professional organisation . . . In many cases, effective regulation can be achieved by embedding standards of professional education, performance, conduct and competence within the system of regulation. These standards, together with mechanisms to monitor and foster practitioner compliance and manage non-compliance, provide the means by which the profession can protect the public interest.” (41).

Other international professional bodies also demonstrate the value of regulatory support through formal mentoring programs to support emerging regulation. For example, the IFSW has a mentor program, known as “twinning” (42, 43) where a mature national association with well-developed regulation provides support to a national association just beginning its journey (44)

“The Moroccan association AMAS (Association Marocaine des Assistants et Assistantes Sociales) is still young, just like social work education in Morocco . . . Now both social work associations have decided to start twinning; to inspire each other. The still young association can be supported from the Netherlands, and Dutch social workers can learn from work in different circumstances and how to set up initiatives where governmental support is lacking or only providing a part of what is needed.” (43).

Recommendations

Based on the findings of the two environmental scans, we recommend the establishment of an international professional body for the orthotic/prosthetic occupation to provide support and build the regulatory capacity of national orthotic/prosthetic associations.

Drawing on the findings from the international-level scan, we recommend the following:

- Establish an international orthotic/prosthetic professional body with the express purpose to support national-level regulation of the orthotic/prosthetic occupation,
- Limit membership to the international orthotic/prosthetic professional body to national associations for the orthotic/prosthetic occupation; acknowledging that many national associations may not currently be legal entities, but can demonstrate working towards formalisation,
- Provide leadership to establish expectations for the regulation of the orthotic/prosthetic occupation through the development of position statements for each of the nine core regulatory standards (e.g., position statement stating the conduct and ethical behaviour expected of orthotic/prosthetic practitioner and the requirement for a national code of conduct to be in place),
- Remove the expertise barriers that hinder the *development* of the nine core standards by writing example documents for each the nine core regulatory standards, knowing they can be adapted for the national setting (e.g., example code of conduct for the orthotic/prosthetic occupation),

- Remove the expertise barriers that hinder the *implementation* of the nine core standards by providing guidance documents that describe the required policies and procedures, including exemplars where possible, that underpin the standards (e.g., implementation of a national code of conduct requires policies and procedures pertaining to complaint handling and disciplinary action as well as the formation of a committee that can oversee such complaints effectively),
- Establish formalised programs that support peer-to-peer relationships where national associations with expertise in standards implementation can support emerging associations (e.g., a ‘twinning’ program),
- Establish a register of orthotic/prosthetic national associations for the purpose of communicating regulatory efforts for the occupation to the international community and collecting data to support a greater understanding of regulatory status and progress,
- Remove the financial barriers to establishing regulation by creating opportunities for financial support (e.g., grant funding) for national associations through engagement with international organisations (e.g., WHO) and national stakeholders (e.g., national Governments and Ministries of Health) that wish to support the development of effective national-level regulation.

We hope the recommendations paint a clear picture of the need to establish an international professional body and the functions it would serve for the orthotic/prosthetic occupation. We believe these same recommendations would be applicable to other occupations looking to improve the regulatory support that helps ensure the provision of safe and effective AT services for the growing number of people that require AT.

We encourage a thoughtful approach to building such an international organisation, whereby those with demonstrable expertise can provide leadership. We would highlight the expertise and experience that already exists among the eight countries that have all nine core regulatory standards in place and suggest these organisations are well placed to lead or guide these next steps.

Limitations

We acknowledge the limitations of the data obtained by using an environmental scan methodology. The presence of regulation was determined by identifying publically available information. It is possible that for some countries there may be organisations and regulation in place that may not be publically available, or were not available in English, and therefore were not identified. Attempts were made to contact in-country representatives, with 83% confirming the presence of the regulatory standards (Table 2). Further to this, our methodology for the national-level scan assumed the orthotic/prosthetic occupation to be largely self-regulated and therefore the initial search focussed on the identification of national associations. It is possible that Government regulation of the occupation may exist, without the presence of a national association.

Whilst the selection of nine core regulatory standards of AHPRA may bias the outcome of the national-level scan in favour of AOPA as a regulator in the same country, we highlight many other regulatory systems in similarly developed countries that also have these same standards in place. We hope to have engendered confidence in the rigour with which the core regulatory standards of AHPRA were developed and that they are highly regarded as best practice regulatory standards in keeping with other countries such as the United Kingdom.

This report describes the experience of AOPA's journey as an example of an orthotic/prosthetic national association that has made the transition from limited to full regulation over a number of years. We acknowledge that many other organisations have also made this transition, but we are unable to speak to the detail of their experiences with authenticity and hope that the illustrative example of AOPA's experience illuminates some of the barriers and facilitators to this transition.

We have been deliberate in withholding details about the countries identified in the national-level environmental scan. The intent was not to determine countries that were successful or unsuccessful in the implementation of regulatory standards, but to provide a snap-shot of the extent of orthotic/prosthetic regulation internationally.

Notwithstanding these limitations, we feel the data presented in this report supports the recommendations and conclusions drawn, and thereby facilitate further discussion among policy makers attending the GREAT Summit 2019 and inform the Global Report 2021.

Conclusion

Health practitioner regulation is a valuable mechanism to ensure the delivery of safe and effective AT services, whilst simultaneously supporting workforce training and retention. Establishing robust regulation of the occupations responsible for the provision of AT is one key step in supporting global access to these vital services. The orthotic/prosthetic occupation is largely unregulated and therefore many of the benefits of regulation are yet to be realised in many countries. Increased regulatory support is required to remove barriers for many orthotic/prosthetic national associations in low-income countries with small workforces. An international body, modelled on existing successful international professional bodies, could provide the required regulatory support to reduce these barriers.

There are opportunities for an international professional body to support and build the regulatory capacity of orthotic/prosthetic national associations which in turn, will support workforce training and retention and increase global access to appropriate, safe and effective AT for the growing number of people living with disability.

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Capacity building approaches to assistive technology human resource development in low- and middle-income countries: Preliminary findings from a scoping review

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Abstract

Purpose: Human resource development and credentialing frameworks focused on assistive technology (AT) education, research, and training for competent practice are needed to support key international health initiatives. This review focuses on capacity building approaches to human resource development applicable to AT provision in low-and-middle-income countries (LMICs). **Methods:** A scoping review of scientific and grey literature published from 1993 to 2019 was conducted, using a stepwise search strategy. The first step focused on empirical literature indexed in the following electronic databases: MEDLINE, PsycINFO, Human Resources Abstracts, EMBASE, Scopus, and Cochrane Library. The second step identified grey literature relevant to the topic through database, search engine, and website searches. Content analysis was used to extract emergent themes in the literature. **Results:** The literature on AT-specific, competency-based training frameworks for use in LMICs remains limited but has been growing in recent years. The search yielded 12 unique publications from the empirical literature that met our inclusion criteria. Content analysis suggested the following three themes on efforts to: (1) clarify competence and skill domains, (2) establish sustainable education and training frameworks, and (3) facilitate maintenance of AT skills and retention of the LMIC rehabilitation workforce. **Conclusions:** Capacity building and human resource development is central to international efforts to increase access to effective AT services worldwide. Synthesizing the information gathered through this review with literature on related topics, several recommendations for developing an AT-focused competency-based training framework emerge. Emerging frameworks need to be sustainable and scalable in de-centralized care models in LMIC settings where task-shifting is often necessary.

Keywords

Capacity building; human resources

Introduction

Access to assistive technologies (AT) is often necessary for people with disabilities to be able to secure or maintain employment, attend school, and generally participate in community activities. In 2017, the World Health Organization (WHO) published a document on *Rehabilitation in Health Systems* that affirmed multi-disciplinary rehabilitation as an aspirational model for effectively managing chronic and disabling health conditions (1). However, significant barriers to the development of the multi-disciplinary workforce and, more specifically, human resource in AT sectors exist (2,3). These barriers, which include high financial costs and limited availability of trained healthcare professionals, are particularly apparent in low- and middle-income countries (LMIC) where approximately 80% of all people with disabilities reside (2-10).

The rehabilitation and disability-related human resource gap in LMICs, including those specific to AT service provision, has been well documented (2). Cook and Polgar (11) provided a set of principles to guide AT provision: (a) the process is person centered rather than product centered, (b) increased participation in desired activities is the target outcome, (c) the process is evidence-informed, (d) ethical provision is an imperative, and (e) provision is occurring in a sustainable model. Despite longstanding efforts aimed at identifying of guiding principles for AT provision and increasing availability of health workers as well as the recent emergence of research identifying potential barriers and facilitators of AT access, the explication of specific training models for AT competency development appears to be in its early stages. As a result, identification of potential approaches to rehabilitation human resource development has emerged as a global priority in recent years (12).

Capacity building approaches to human resource development have shown broad promise for enhancing disability and rehabilitation services in LMICs (13-15). The United Nations Development Programme defines capacity building as “*the process through which individuals, organizations and societies obtain, strengthen and maintain the capabilities to set and achieve their own development objectives over time*” (16, p5). By this definition, capacity building may be conceptualized as emphasizing a *process* used to support a range of efforts from education and training to increasing access and inclusion through institutional and systemic strengthening. Indeed, the potential utility of these approaches for facilitating sustainable development of disability and rehabilitation workforce has been reflected in the WHO’s longstanding promotion of community-based rehabilitation (CBR) (17) and in its rehabilitation call to action for the upcoming years (18).

Parameters for AT-focused education, training, and credentialing for LMIC health workers are unclear, particularly given that curricula must be flexible enough to address the unique needs of people with disabilities who navigate multiple environmental systems within local contexts (1,4). Moreover, processes for developing human resources with a core set of skills that can be applied across a range of AT products to address complex interactions between person and environment inherent to disability remain undifferentiated. In order to identify

best practices for sustainable increases in the global AT workforce, synthesis of the current empirical and qualitative research literature with emerging theoretical frameworks for human resource development in LMICs will be needed.

Objectives

The purpose of the current study is to provide a scoping review of the scientific and grey literature on capacity building approaches to human resource development applicable to AT. The aim of the review was to identify the state of the science regarding best practices for work force training and retention. The findings of the review will be interpreted within the context of relevant training frameworks and conceptual models for the sustainable development of trained health personnel (e.g., task shifting, skill mix, train-the-trainer, community-based rehabilitation).

Methods

Search strategy

A systematic approach was taken to conduct this scoping review. In order to scope the literature related to AT-related human resource capacity development in LMICs, multiple search strategies were adopted to locate a wide range of scientific and grey literature. The search was conducted in July 2019 using a two-step approach. Results were then combined to generate preliminary themes.

The first step was a detailed database search of scientific literature using the following electronic databases: MEDLINE, PsycINFO, Human Resources Abstracts, EMBASE, Scopus, and Cochrane Library. A list of keywords relating to AT and human resource capacity building in LMICs were identified by conducting a preliminary literature review. Keywords and MeSH terms used in various combinations and refined via Boolean operators. Search terms were selected with the aim of capturing a breadth of literature.

In the second step, we identified and reviewed the grey literature relevant to AT-related capacity building in LMICs via Google searches and key websites. These included the WHO Library Database (WHOLIS) and regional indexes, including: African Index Medicus (AIM), the Eastern Mediterranean Region Library Network (EMLIBNET), Europe (EURO) publications, Pan American Health Organization (PAHO) Library Institutional Memory Database, Index Medicus for South-East Asia Region (IMSEAR), and Western Pacific Region Index Medicus (WPRIM). The initial grey literature search was conducted using the same keyword combinations for the scientific literature search.

Titles and abstracts of all articles retrieved through searches of the scientific and grey literature were initially reviewed for relevance to the screening questions and inclusion criteria described below. We also reviewed reference lists to identify any additional relevant studies or publications not captured through the computerized searches. The following screening questions were used: (a) does the publication address AT as a primary topic? (b)

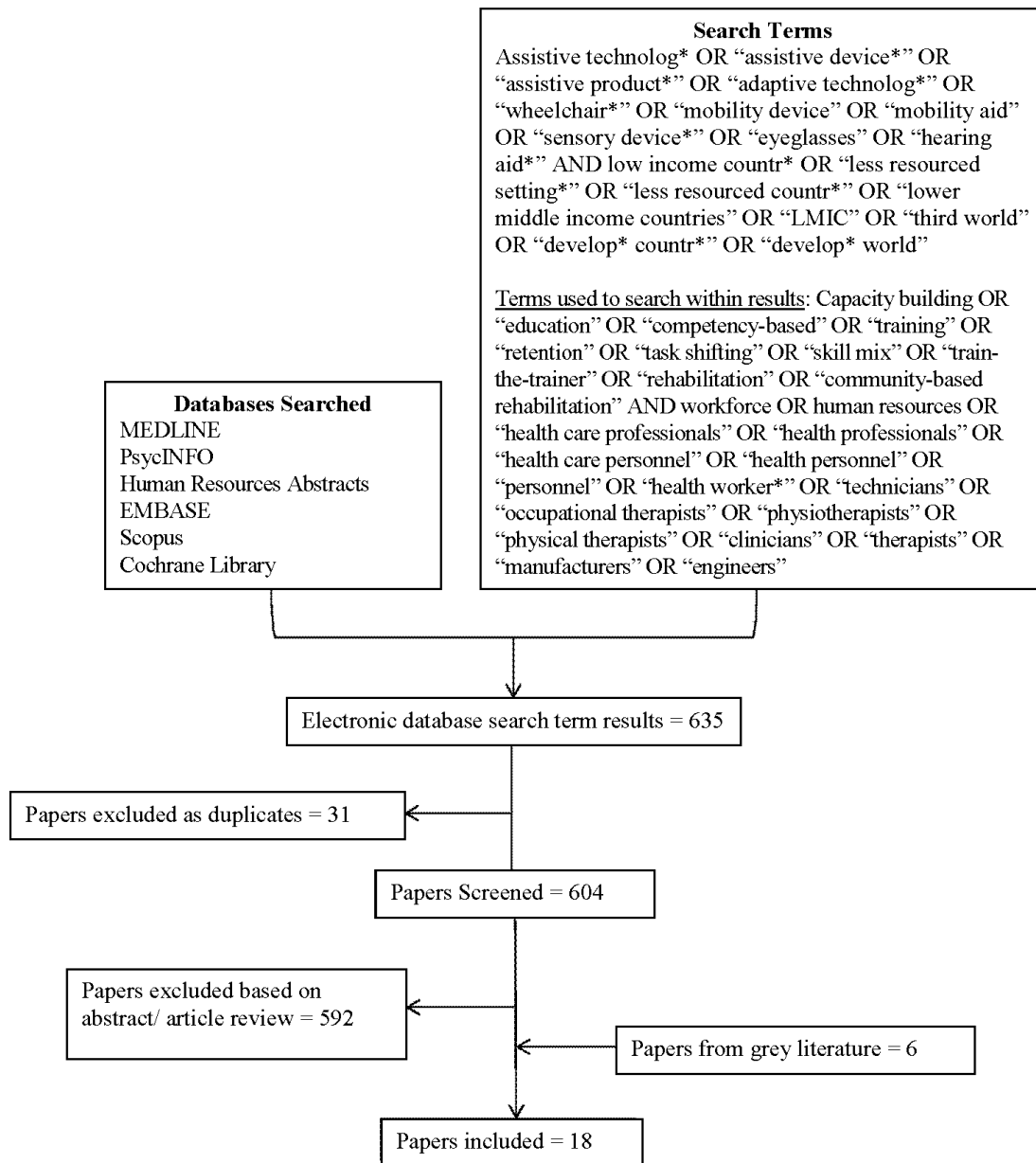
does the publication focus on LMICs?, and (c) does the publication pertain to disability-related human resource capacity building?

Inclusion and exclusion criteria

Retrieved publications were assessed using the following inclusion criteria: (a) articles published between 1993 to July 2019, capturing the time period following the adoption of the UN's Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993 (19), (b) published in academic and peer-reviewed journals, research reports, government reports, or other grey literature, (c) studies that elicited an affirmative responses to all three screening questions, and (d) sources available in the English language. One reviewer initially screened all publications. In order to assess reliability, a second reviewer also screened 10% of records.

Publications were excluded if they did not specifically pertain to AT-related training and skill/ competency cultivation among health workers in LMIC contexts. As a result, many publications on topics pertinent but not specific to the review (e.g., non-AT competency training or development in CBR; overarching capacity building frameworks) were excluded but subsequently used to inform interpretation of findings and generation of recommendations. Example of such sources included studies that identified facilitators and barriers of AT provision in LMICs, compared effectiveness of care provision models, outlined capacity building models outside the AT sector, or those that otherwise yielded a 'yes' response on only one or two of the screening questions. Duplicates were also identified and excluded. Figure 1 provides a PRISMA summary of the various stages of the data screening process.

Figure 1. Flowchart of Selection and Review Process



Data extraction and analysis

Data were examined using a content analysis approach, which is based on an iterative process of extracting and coding themes using a data charting form (20). Grounded in ethnography and consistent with cross-cultural research principles, content analysis was chosen over other methods of data analysis as it better allows for generating theory and developing hypotheses relative to other approaches (21). One benefit of this approach in the context of the current study is that content analysis provides more flexibility when applied to various source types, from qualitatively and quantitatively oriented research studies to grey literature. In the current review, the research team thoroughly analyzed the

documents and extracted themes using a charting form. The research team consulted and debriefed to ensure reliability and agreement on the extracted themes.

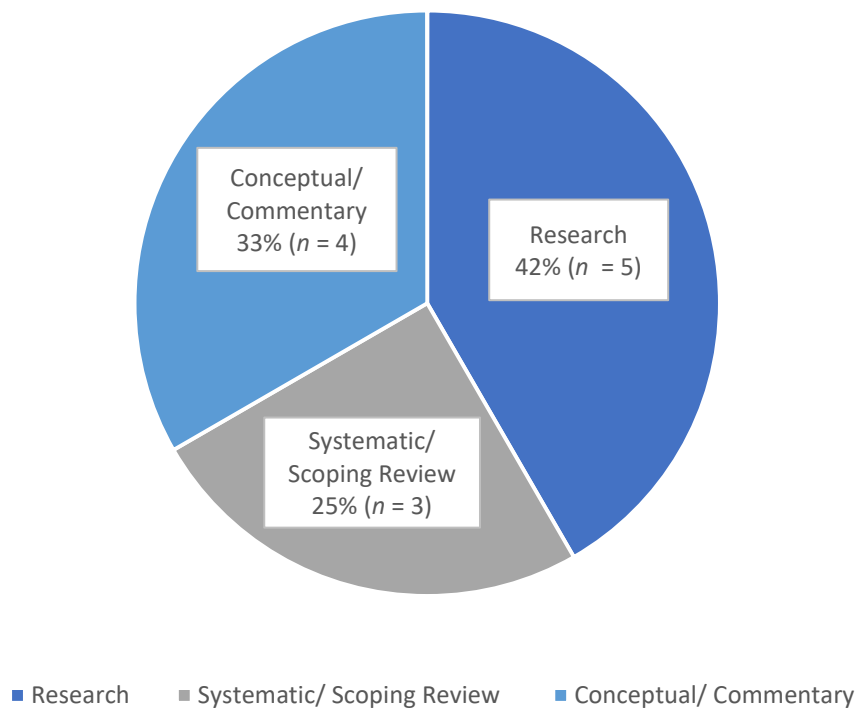
Findings

Results of scoping search

The first step of the scoping search yielded 13 papers published in peer-reviewed scientific journals. However, a pair of those papers represented two parts of the same scoping review and, as a result, were considered as a single publication source for the purposes of this review. Therefore, the final number of unique scholarly products captured in the first step of the review focused on scientific literature has been listed as 12. With regard to grey literature, six additional sources were identified through database and website searches of international agencies and relevant professional organizations. The total number of sources included through steps 1 and 2 of the review process was 18.

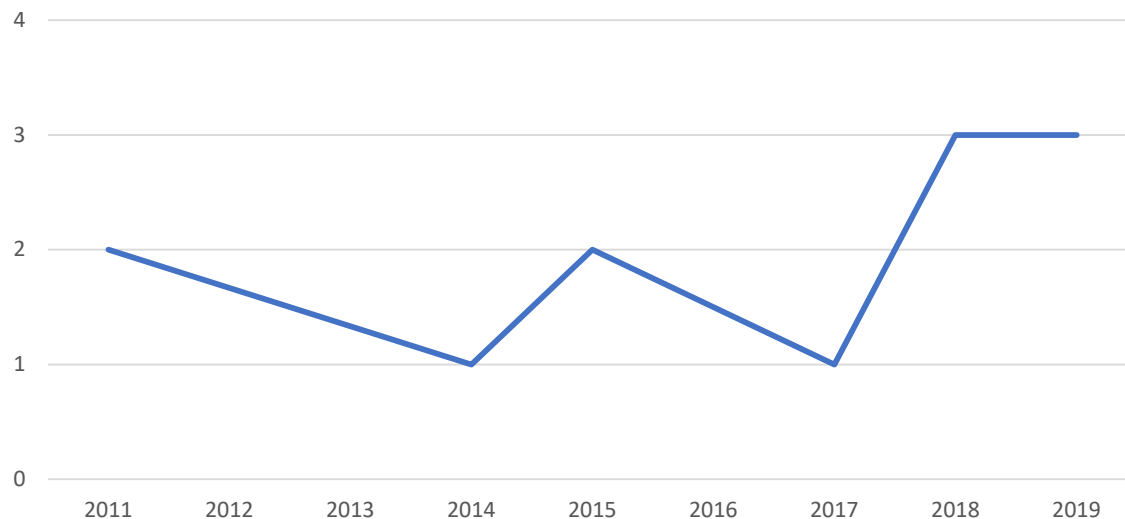
Figure 2 shows the distribution of publications by study design, with original research (e.g., cross-sectional quantitative ($n = 2$); qualitative ($n = 3$)) being the most common. No randomized controlled trials, nonrandomized comparative, case-control, crossover trial, controlled before-after, repeated measures designs were found. Of the reviews, including a two-part scoping review of orthotic and prosthetic provision (22, 23), two of the reviews focused on device-specific education and provision *considerations* (24) while the remaining article utilized a rapid review to assist with conceptual model development (25).

Figure 2. Scoping review results from scientific literature by publication type (n = 12)



A summary of the distribution of scientific papers by year of publication has been provided in Figure 3. All of the papers that met our inclusion criteria were published between the years 2011-2019, and half ($n = 6$) were published between 2018 and July 2019.

Figure 3. Number of scientific publications by year



Content analysis

The following key themes emerged through the content analysis: (a) clarification of competence and skill domains, (b) establishment of sustainable education and training frameworks, and (c) maintenance and retention of AT skills in the LMIC rehabilitation workforce.

Clarification of competence and skill domains

Identification of skill and competency domains was identified as a priority in CBR in general and in health workers' interface with AT in particular (26,27). For example, a survey of 40 CBR health workers identified provision of AT, aids, and devices as one of the most frequently used skills for the promotion of participation among people with disabilities (26). A study of rehabilitation professionals in LMICs found AT skill varied based on personnel type, with physiatrists and other medical practitioners most likely to report prescription of AT as a core skill (28). Establishment of training mechanisms related to the appropriate prescription, procurement, and maintenance was recognized as a priority across several studies. One conceptual development paper outlined a competency-based model that included AT as a core practice domain for health and rehabilitation human resources (29).

Establishment of sustainable education and training frameworks

Several papers summarized and/ or presented models of AT provision in LMICs (22,23,30-32), but information on frameworks for rehabilitation training and education was sparse. A subset of papers advocated for approaches that simultaneously work to enhance skills and competencies of already established rehabilitation practitioners while also using task-shifting to facilitate growth in community-based workforces in rural and economically

impoverished settings (25,33-35). Within this theme, there was an observable dialectic between training of rehabilitation professions and task-shifting approaches focused on skill-mix rather than personnel type. These papers also often invoked, either explicitly or implicitly, systems-based frameworks that promote sustainability by attending to inter-relationships and intersections among multiple entities, stakeholders, sectors, and environmental levels (e.g., individual; caregiver; occupational; political) (25,27,35).

Maintenance of AT skills and retention of the LMIC rehabilitation workforce

Several papers noted the importance of developing mechanisms for continued maintenance of AT skill and retaining rehabilitation workforce in understaffed communities (28-30,34). Countries that have financially invested in developing and maintaining in-country health and rehabilitation workforce (e.g., Brazil; Ghana; Mexico; Thailand) were cited as examples of enhancing equitable population health and reducing socioeconomic health disparities (29). Overall, however, few papers directly addressed the topic of personnel retention and none provided detailed recommendations for retaining personnel who have accrued AT knowledge, skills, and experience.

Discussion

The lack of AT trained healthcare workforce in LMICs remains a concern given how integral AT is to social participation for many persons with disabilities. The empirical and grey literature on AT-specific workforce training and retention in LMICs was limited in breadth and depth. However, our review indicated that the number of publications related to establishing and supporting AT competencies among health workers and personnel in LMICs has been burgeoning in recent years. A content analysis suggested three primary themes about efforts to clarify competence and skill domains, establish sustainable education and training frameworks, and facilitate maintenance of AT skills and retention of the LMIC rehabilitation workforce. Documenting trends in the scope of the literature and associated limitations provides a means of establishing future directions relevant to international initiatives on disability, rehabilitation, and AT.

In the following paragraphs, we will integrate our findings with related capacity building literature in an attempt to summarize potential best practices for competency-based frameworks for education and training in AT, supporting skill development among existing healthcare personnel and community health workers in AT, and incentives and other mechanisms for retaining personnel. Finally, we will provide general recommendations regarding AT training and credentialing based on the available evidence and predominant theory.

Establishing competency-based frameworks for education and training in AT

The findings from this scoping review point toward the importance of developing sustainable competency-based training procedures to support human resource growth in LMICs. To date, no AT competency frameworks have been established specifically for LMIC

environments. In order to meet the needs of people with disabilities in financially limited and rural communities, according to the emerging themes in the existing literature, the competence structure should be flexible enough to be feasibly applied across the continuum of care from highly trained rehabilitation providers to community settings requiring a decentralized task-shifting approach. Jesus and colleagues (29) proposed a competency-based model for health and rehabilitation workforce. Their classification system provided an important contribution by identifying potential categories of specified practice domains and competency levels, with expected competencies varying in relation to rehabilitation task complexity and context-specific regulatory mechanisms (e.g., legislation; educational accreditation, licensing, or credentialing structures). The competency framework proposed by Jesus et al. has been developed for implementation across the skill spectrum, including task-shifting to community health workers. However, additional work will be needed in order to evaluate the feasibility or applicability of such a framework to LMIC environments with a high degree of reliance on task-shifting in traditionally specialized practice domains like AT.

In constructing competency-based training and certification procedures with attention to scalability, the international rehabilitation and AT community will benefit from drawing from other disciplines using a train-the-trainer dissemination model. Such models build capacity for access to health services by training up leaders from local communities to train others on a specific knowledge and skill set. Shifting training tasks from healthcare professionals to already trained lay leaders has the potential for creating local efficacy in not only delivering competent services but also preparing others to do the same. This approach contrasts dissemination models reliant upon ongoing expert involvement, which can be expensive and unsustainable in some LMIC contexts. The train-the-trainer methodology has shown promise for extending treatments for individuals with psychiatric disabilities to areas lacking human resources (36), and holds potential for reducing costs, increasing local knowledge, and providing a self-sustaining mechanism for up-scaling human resources and access to interventions while also reducing perpetual reliance on ‘experts.’

Considered within the context of Cook and Polgar’s (11) heuristic principles for AT provision described above, the papers included in the current review argue for a systems theory perspective that emphasizes a person-centered approach with formative and collaborative stakeholder involvement, particularly from people with disabilities and their caregivers. This emphasis appears particularly noteworthy given that competency-based frameworks by definition focus on skill cultivation among healthcare personnel. Careful attention to the person-centered ethos must be given in the development or refinement of training and certification programs in order to ensure involvement of people with disabilities at all levels and focus on implementation of AT solutions as a means to a prioritized participation end. Utilizing a systems perspective would also enhance the translation of the competency framework for preparing human resources across multiple dimensions including but not limited to the provision of person-centered care, engaging the interaction between

participation goals and corresponding type of AT to be utilized, health systems infrastructure, and public-private sector interactions.

Supporting skill development among existing healthcare personnel and community health workers in AT

Studies included in this scoping review provided a sub-theme related to the need to bolster AT skill and competency development across a spectrum, from existing rehabilitation personnel to health workers embedded in communities. Our review of grey literature sources yielded potentially relevant service delivery criteria. As an example, Table 1 summarizes the general AT service delivery quality criteria put forth by the Association for the Advancement of Assistive Technology in Europe (AAATE) (37). Though constructed with European contexts in mind, these criteria appear broadly consistent with the findings of the scoping study and thus may be applicable if modified for specific LMIC contexts. These criteria intersect with competency frameworks and their inherent skill domains and identify a wide range of indicators to be considered for developing human resources in specific settings.

A growing body of literature provides insights into potential structures for facilitating partnerships aimed at administering programs focused on AT competency development. For example, university partnerships have emerged as viable mechanisms for bridging North/South, public/private sector, and high-income/ low-income country distinctions (14,15,38-40). These partnerships may be oriented to any educational level, from basic level certification (35) to integration in post-graduate degree programs (15). Despite growth in the availability of partnerships and toolkits for facilitating inter-institutional global health mentorship and capacity building, a recent review found that only three such toolkits were developed specifically for the LMIC context and none specifically addressed adaptation to local contexts (41). Narrowing these gaps appears imperative in order for these partnerships to realize their full potential as it relates to establishing mechanisms for enhancing and maintaining institutionalized AT expertise relevant to local environments.

Establishing models for supervision and support will be an important component to supporting AT skill development and maintenance. AT skills are frequently used in task-shifting schemes such as CBR (26,42). Therefore, competency-based training programs should develop explicit policies and practices regarding supervision in order to support a high standard of care. In a task-shifting paradigm, identifying and facilitating appropriate referrals when an individual's needs require a more acute level of care may be one of the core competencies of interest. In order for supervision to be effective, training models must also include education and mentorship on competent provision of supervision for those serving in supervisory capacities. Many practicing supervisors have never received training on evidence-based approaches to providing supervision, thereby potentially limiting their effectiveness in the role (43). The inter-institutional approach described above may present a model for building capacity and infrastructure for providing effective supervision to the growing AT workforce in LMICs.

Table 1. The Advancement of Assistive Technology in Europe's criteria for quality AT service delivery

Criteria	Indicators
Accessibility	<ul style="list-style-type: none"> - Information about assistive products, the service delivery system, and how to access them is widely available - Services are driven by user needs - Appropriate AT solutions are easily obtainable without unnecessary delays - No one is discriminated against or excluded from needed AT services - Details about user costs are interpretable and funds are allocated to remove financial barriers to access
Competence	<ul style="list-style-type: none"> - Personnel must have the requisite knowledge, skills, and experience to effectively serve users of AT - Components include: educational requirements for personnel, opportunities for continued education, implementation of established protocols and standards, access to information, and opportunities to learn from feedback
Coordination	<ul style="list-style-type: none"> - Services are coordinated on several levels: (1) care provision with an individual, (2) during discreet phases in the care process, and (3) in accordance with policies and processes related to AT and other supports available to the individual
Efficiency	<ul style="list-style-type: none"> - AT solutions should be able to reach the highest number of users possible by leveraging available resources for time-efficient and low-cost interventions
Flexibility	<ul style="list-style-type: none"> - Delivery systems must be responsive to diverse user needs, have the ability to easily adopt new technologies - Researchers and developers have mechanisms to support and coordinate the full scope of their work with users, designers, and producers
User influence	<ul style="list-style-type: none"> - People who use AT should be involved in all aspects of a service delivery system and in their own usage process - Indicators include: involvement of users at a policy level, active collaboration in the service development and delivery process, and identifiable influence on decisions

Creating mechanisms for personnel retention

The topic of workforce retention was addressed in several of the publications, usually as a secondary or tertiary consideration. When considered in relation to the other themes that emerged in the scoping review, it appears that mechanisms for retaining trained AT personnel should become a primary sustainability consideration in the development of competency frameworks applicable to LMICs. Given the utilization of community-based and task-shifting, the extant literature on health workforce retention can be used in the early phases of development for AT training and credentialing (44,45). Integration of lessons learned from these related areas of study will enable frameworks and programs to

anticipate potential challenges and opportunities while drawing from an existing evidence base. Workforce retention strategies likely need to be tailored to the local environment as financial incentives, for example, may not be optimal or even feasible in many LMICs (46). One component of a retention strategy may be considering how to leverage mobile health (mHealth) technologies, as recent research has identified potential opportunities for mHealth to facilitate performance and retention of community health workers (47). As Källander and colleagues (47) mention, the successful integration of mHealth into training and retention processes will be facilitated through multi-systemic partnerships between AT stakeholders (e.g., governments, technologists, non-governmental organizations, academia, industry).

Recommendations

There are numerous opportunities to establish AT training paradigms that span the workforce continuum from hospital- to community-based services. A summary of recommendations extending from this scoping review can be found in Table 2. With regard to competency-based training, we recommend approaches that promote AT training competencies related to person-centered care provision that also tailor to the unique demands of the local environment. People with disabilities should be involved in decision making at all levels in the process of establishing local needs assessments and the development of competency-based training curricula. A multi-level AT training structure (e.g., from lay-led to post-graduate certification) integrated into both the health system and community-based models of care, and facilitated by inter-institutional partnerships, will likely facilitate long-term sustainability and scalability. Furthermore, the use of education and research programs that promote dialogue amongst regional and national stakeholders about AT and a tiered infrastructure oriented around long- and short-term training initiatives as well as engagement with local policymakers (14,15). Rather than focusing on discipline-specific training (e.g., physical therapy; occupational therapy), it is recommended that the focus be on skill and competency development across personnel backgrounds.

Limitations

One limitation of this scoping review is that only a few academic databases were searched to identify potential publications for inclusion, thus it is possible that publications from other sources were missed. Only articles published in English were screened and considered for inclusion in the review, thereby limiting potential sources written in other languages. Additionally, our screening process and inclusion criteria were intentionally established to narrowly focus on capacity building for AT training and education in LMICs. This approach may have placed artificial divides between overlapping areas of research (e.g., capacity building, AT, integration of rehabilitation in health systems). However, we interpreted our findings in reference to information gathered from pertinent fields of study when generating recommendations and conclusions. Another limitation was that one reviewer screened all articles, with only 10% of records screened and extracted by a second reviewer.

Though there was perfect agreement between reviewers on the dual-screened papers, we are not able to ascertain the level of concordance for the remainder.

Table 2. Recommendations for Development of Sustainable AT-related Competency Frameworks

1. Actively involve people with disabilities and caregivers in the formation of the framework
2. Utilize a systems perspective in establishing and administering competency frameworks to ensure multi-sectoral stakeholder engagement
3. From the earliest stages of development, center the framework on community-based and task-shifting models of care and expand from there to more centralized provision systems
4. Consider train-the-trainer models for reducing reliance on ‘experts’ and increasing scalability
5. Proactively incorporate plans for workforce maintenance and retention as primary considerations for training, competence development, and credentialing procedures
6. Establish flexible structures within the competency framework to be malleable across the wide-ranging skill mix, AT type, and local environment spectrum
7. Integrate modules for specialized competencies required for specific AT modalities and products
8. Prioritize feasible supervision mechanisms to ensure competent practice in the field
9. Emphasize training in competent provision of AT supervision for those in supervisory positions
10. Develop a range of competency-based credentialing mechanisms to maximize skill base, for those with minimal prior health training and post-graduate degrees alike

Conclusion: Increasing access to quality, affordable AT for all

Rehabilitation personnel working in LMICs must develop a varied knowledge base and skillset including extensive training on pathology and relevant rehabilitative strategies, and well-refined diagnostic, problem-solving, clinical decision-making, and communication skills. Yet, training programs for healthcare workers rarely include disability-specific education and even less often explicitly focus on AT. Without established research and training infrastructures, some health-care providers may be unfamiliar with and/ or feel uncomfortable discussing potential AT interventions, and clinical decision-making may therefore be influenced by negative attitudes and assumptions about disability. Development of competency-based AT training and certificate programs can make explicit the knowledge, skills, and attitudes necessary for effectively meeting the needs of the individual.

The findings of this scoping review, and the recommendations generated from it, correspond well with a position paper focused on AT personnel published by a working group convened at the 2016 Global Research, Innovation, and Education in Assistive Technology (GREAT) Summit (34). Building frameworks may be most effective and sustainable if they focus on competencies across the AT provision process, incorporate

systems-based and person-centered principles, span a range of skill mix related to varied AT products, emphasize the provision of competent supervision, and are developed with de-centralized care models including task-shifting as the center for skill application. Existing frameworks provide a foundation but may need to be substantively re-oriented to support sustainability in de-centralized care models in LMIC settings where task-shifting is often necessary.

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Building sustainable and effective assistive technology provision in partnership: Lessons from the Pacific

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Abstract

The Blue Pacific is home to multiple small island nations, a number of which are the most isolated states in the world, making access to assistive technology (AT) a challenge. The Blue Pacific values regionalism and embraces its diverse geography, demography, cultures and economic development through collective action and sharing of institutions, resources and markets. Through the lens of Pacific AT stakeholders, this paper draws on existing data and Pacific perspectives to share the region's story about how and for whom access to AT has improved in the period from 2008 to 2019, as well as the factors that influenced the change. We show that sustainable, local and reliable access to AT is reliant upon the right mix of ingredients. Our findings highlight the benefit of: strong advocacy, genuine partnership and growing informed demand from the People who need and provide AT; a Product range suited to each context and funders willing to support procurement; Provision opportunities to integrate AT services into existing government and non-government services; effective and consistent local training for Personnel through the availability of an appropriate training package, training provider and funding support; as well as the global, regional and national Policy frameworks that support increased actions to make AT more readily available. The Blue Pacific journey offers the global AT community unique practices and innovations for meeting AT demand and supply and strengthening sustainable local sector capacity in less resourced settings.

Keywords

Pacific, Partnership, Collaboration, Assistive Technology, Stakeholders, Sustainability, Local Service System, People who use AT (user), Workforce, Procurement.

Introduction

The Pacific

The Pacific is home to multiple small island nations, many of which are considered Small Island Developing States. With the notable exception of Papua New Guinea, which has a population of 8.2 million, populations range from 1,499 (Tokelau) (1) to 885,000 (Fiji) (2). Together these nations, which are home to over 11 million people, comprise a land area of only half a million square kilometres scattered in the world's largest ocean. Distance is a key feature of Pacific life, with a number of Pacific Island Countries (PICs) being recognised as the most isolated states in the World (3).

PICs are diverse in their geography, demography, cultures and economic development. PICs also share similarities including small populations and geographical size; remoteness from each other and to global markets; limited scope to exploit economies of scale; and exposure to global environmental and economical challenges (3). Regardless of this acknowledged diversity, a key defining characteristic of the region is a common sense of identity and purpose. Pacific Island Forum Leaders and its people embrace Pacific regionalism and the 'Blue Pacific' identity as the core driver of collective action to advance the Pacific vision. Within this vision is the progressive sharing of "institutions, resources, and markets, with the purpose of complementing national efforts, overcoming common constraints, and enhancing sustainable and inclusive development within Pacific countries and territories and for the Pacific region as a whole" (4).

The Pacific Island Countries and Areas World Health Organisation (WHO) Cooperation Strategy 2018–2022 highlights the achievements by PICs in the development of health services in recent years. At the same time, WHO and Pacific leaders recognise the continued triple burden on health service delivery created by the unfinished communicable disease agenda; a rapidly rising noncommunicable disease epidemic; and climate change (5). This context has particular relevance to assistive technology (AT), as the need becomes increasingly relevant to an increasing section of the population.

Objectives and method

The authors of this paper represent stakeholders in AT across the Pacific including service providers, government, disabled persons organisations (DPOs), people using AT and development partners. We have tasked ourselves with reviewing work towards building more sustainable, consistent and effective AT services in the Pacific in the past decade, choosing as a base-line the year 2008. This was the year of the first Motivation Australia mobility device feasibility studies, the second Pacific Disability Forum Conference, the first Pacific ratification of the Convention on the Rights of Persons with Disabilities (CRPD) (6) and the year the Australian Government led consultations in the region to inform its first ever disability inclusive development strategy Development for All 2009-2014 (7). We have each been directly involved in the Pacific AT journey in different ways and believe that in

working together in drafting this paper, we bring a richer, better informed and more nuanced response to our task.

Our objective is to reflect on our shared AT journey, to draw and share conclusions of value for both the Pacific and global GATE community in increasing access to AT. Using the framework of **People, Provision, Personnel, Policy and Products** as well as the precursors to and ingredients of sustainable development, we specifically seek to identify from our shared perspective:

- How and for whom access to AT has improved in the Pacific since 2008
- What may have influenced this change

Our approach included:

- Mapping of data including published and unpublished reports, papers, project documentation and statistical data sets from Motivation Australia; other grey literature and publications; national and regional disability, health and legislative documents; and formally published work (see reference list).
- Mapped data from 2007 – 2012 was grouped to inform our baseline and documents later than 2017 used to present the picture of access to AT in the Pacific today.
- Review and analysis of data to identify characteristics of the status of access to AT approximately ten years ago, the situation today, and evidence of change facilitators.
- Concurrently with the above actions, authors completed a set of reflective questions (see Appendix) to contrast and deepen understandings of the data and illuminate and synthesise change factors.

Authors acknowledge many other individuals and organisations who have driven change in the AT space in our region, which may not be captured in this paper due to limitations in time, availability of published AT literature relevant to the region, access to written documentation, opportunity to consult and word limit. We also note that although our collective experience encompasses a range of different AT, much of the literature available for this paper focuses on mobility devices. An important step in progressing this work would be to engage with other stakeholders who may also have chronicled their journey through internal documents, around increasing access to (for example) hearing, vision and Information and Communication Technology (ICT) AT. This would deepen the overall understanding of the development of access to AT in the Pacific and to ensure important lessons are not missed.

A journey in accessing AT

AT provision in the Pacific today

The CRPD has been well socialised across PICs, and as of August 2019, 15 countries in the region have signed and 13 have ratified this international treaty. PICs Governments have also prioritized empowering persons with disabilities as one of the issues requiring collective

attention in the Pacific Roadmap for Sustainable Development (8) and through the Pacific Framework for the Rights of Persons with Disabilities (9).

In 2018 the Pacific Disability Forum (PDF) highlighted in their SDG-CRPD Monitoring Report the importance of AT as a pre-condition for inclusion (10). The same report also recognises that while there exist pockets of success in increased access to AT, there remain significant gaps “with regards to availability, accessibility, affordability and quality”.

Successful AT provision in a number of PICs is driven by collaborative and individual efforts of governments, non-government organisations (NGOs), disabled persons organisations, development partners and an emerging private sector. An increasing number of physiotherapy personnel are trained in basic level wheelchair service delivery and provide basic mobility devices such as walking aids and wheelchairs through their departments when stock is available. A number of ophthalmology departments in the region support provision of prescription glasses when stock is available, private opticians offer services in a few locations, and there are some small-scale initiatives supporting the use of low vision and blind AT (11). Hearing aids are provided in a few PICs through visiting missionary programmes and in one country there has been some exposure to cochlear implants. Government health services in Fiji, Kiribati, Papua New Guinea, Samoa and Tonga offer integrated prosthetics, orthotics and wheelchair services; and the Solomon Islands will soon add prosthetics and orthotics to existing wheelchair services. Also, of note, is the development in Papua New Guinea of National Guidelines for the Provision of AT (12) addressing training, personnel and priority products for people with mobility, hearing or vision impairment. These are the first AT specific guidelines developed in the Pacific region.

While progress has been made, a 2019 Pacific AT Procurement Study (13) led by Motivation Australia in partnership with the Pacific Disability Forum and Nossal Institute for Global Health, drew together a snapshot from ten PICs, identifying consistent patterns of AT access, including:

- Low levels of awareness of AT amongst people using services, service personnel and policy makers. This was less marked in mobility AT compared to AT for self-care, communication and cognition.
- Minimal representation from those who need and use AT in the planning, service delivery and evaluation of AT initiatives. One study informant noted *"Honestly, people with disability don't have any choice, they get what they are given."* This is particularly an issue for people with deafblindness, as well as intellectual and psychosocial disabilities who may benefit from AT use.
- Significant variance in the availability of AT depending on the type of device. Mobility devices were found to be most readily available, followed by glasses and hearing aids. AT for people with low vision or blindness was limited, while devices for self-care, communication and cognition are largely unavailable.

- Significant inequity in access to AT. Informants and data highlights that children, older people, those living furthest from services and with less resources are less likely to access AT than others. Additional Pacific research indicates that girls and women also face access barriers (14-15).
- Where people have accessed AT, they are unlikely to have all the AT they need.

The study highlighted issues impacting on the availability of appropriate AT in PICs as being: limited rehabilitation and AT capacity, human resource constraints, lack of required facilities, competing priorities for health financing, supply and procurement challenges associated with the context of PICs, and donations of poor quality and in-appropriate devices.

What was the situation like a decade ago?

Between 2008-2012 Motivation Australia carried out mobility device feasibility studies in five PICs, in partnership with national agencies the Community Based Rehabilitation Unit (Solomon Islands); Te Toa Matoa and the Tungaru Rehabilitation Service (Kiribati); the Vanuatu Society for People with Disabilities (Vanuatu); Nuanua O Le Alofa, Disability Advocacy Organisation (Samoa); and the Naunau 'o e 'Alamaite Tonga Association (Tonga).

A review of these five reports (16-20) and a report of disability service and human resource mapping by the CBM Australia Nossal Institute Partnership in 2011 (21) provides some perspective on the status of AT provision in the Pacific at that time.

Amidst a background of active processes underway in the region and at national level to raise awareness of the CRPD, rehabilitation and AT services were limited. Despite a long history in most PICs of government or non-government physiotherapy and/or community-based rehabilitation services, these services were largely under-funded, under-staffed and reliant upon ad-hoc second-hand donations of AT. Furthermore, there were very few personnel in the region with formal training in AT provision.

Focused on mobility device services, the studies noted above explored access to wheelchairs, walking aids and prostheses. In each country there was no formal service delivery for wheelchairs and walking aids. In the region, prosthetics and orthotics services were available only in Kiribati and Papua New Guinea. The mapping report (21) highlights mobility devices (mainly wheelchairs and walking aids) as the most commonly available, although *“informants raised concerns about the suitability of the devices provided for the Pacific context. For example, the Vanuatu Society for Disabled People received a donation of wheelchairs that were not suitable for the island terrain.”*

The mapping report further notes services and assistive devices for people with hearing impairments as rare, with a notable exception of a cochlear implant project initiated in Samoa by a local non-government organisation and the support of the Australian Government. Other AT mentioned in the report includes some vision aids such as white

canes, all donated, with no systematic service provision. There is no mention of AT to assist with communication, cognition, and self-care (21).

What has changed?

The Pacific AT study (13) completed in 2019 highlights considerable current gaps in access to AT across the Pacific. However, comparison between the findings of this study and that of a decade ago illuminates specific areas of improvement. This data, as well as authors' responses to a series of reflective questions (see Appendix) and a similar question answered by managers of nine mobility device services from five PICs during an evaluation workshop in April 2019 (22), reflect change in three areas.

Awareness and demand

There is strong evidence of growth in awareness of the need for an appropriate and diverse range of AT, with a corresponding increase in informed demand for appropriate AT services with trained personnel. DPO representatives, service providers and other stakeholders are increasingly specific in their advocacy and direct requests for appropriate AT inclusive of service delivery, training for people using devices and follow up. This is evidenced by the highlighting of AT as one of three pre-conditions for inclusion in the PDF SDG-CRPD Monitoring Report accompanied by a list of recommendations for increasing access to AT in the region (10). There is also more known about who needs AT, for example through growing census data (6, 23-24); who is accessing AT; and who is likely to be missing out, which is also key in understanding and expressing demand. This is also critical information to identify and ensure the voice of those missing out inform and increase demand in future.

Services, personnel and products

The number of AT services and personnel with formal AT training has increased. This increase is most marked in the area of mobility device products and services. Where ten years ago there were no systematic wheelchair services in the Pacific, and prosthetic and orthotic services only in three countries, there are now mobility device services in seven PICs, five of which offer integrated services inclusive of walking aids, wheelchairs, prosthetic and orthotic devices. There are personnel trained in the clinical and technical aspects of wheelchair service delivery, and this is recognised as a requirement for the safe and effective provision of wheelchairs. All physiotherapists trained in Fiji and employed across the region in the past six years have had training in basic level wheelchair service delivery as well as all of the community-based rehabilitation workers who have graduated in the Solomon Islands since 2012. The number of trained prosthetist orthotist clinical personnel has increased from five in the region with some formal training in 2008 to 15 trained to an internationally recognised standard as of August 2019.

Furthermore, the range of devices has increased. From almost universally orthopaedic style (often second hand) wheelchairs, there are now a range of different adult and paediatric products being consistently provided through the established wheelchair services (25).

Likewise, the range of prostheses has increased, through the introduction of polypropylene technology.

Findings indicate there has also been growth in access to vision and hearing AT. However, evidence suggests this is less marked, has occurred in fewer locations, and is less comprehensive in terms of addressing the need for local services, personnel and product solutions (13).

Policy environment

The policy environment is increasingly supportive of a systematic approach to the provision of AT as an integral component of health services, and as a precondition for inclusion for many. A review of a sample of disability policies, national and health action plans current between 2008-2012 (26-28) compared to those current in 2019 (29-36) reveals increased content and specificity of goals and actions supporting rehabilitation and AT. Many of these goals and actions align with and have reciprocally informed WHO commitments focused on rehabilitation and access to AT.

What helped create change?

People

Advocacy: The past decade has seen rapid growth in formation of DPOs and strengthening of the disability movement in the Pacific. This has been facilitated by the leadership of PDF as the peak body for the region, the CRPD and advocacy training of DPO leaders, as well as national government, development partner and donor support. A stronger DPO network has driven increasingly effective and informed advocacy for progressive realisation of the CRPD, inclusive of enablers such as access to AT. DPOs have been active in diversifying representation within their movement and advocating for programmes to implement a variety of AT services. For example, Nuanua o le Alofa (NOLA) in Samoa were particularly influential in lobbying for Government and donor investment in mobility device and hearing services (37) as well as greater investment in accessible ICT (11).

Service providers have also been strong advocates for strengthening rehabilitation and AT services. For example, the Tongan DPO Naunau 'o e 'Alamaite Tonga Association Incorporated (NATA) and the national physiotherapy department were both active in advocating for existing services to be expanded to include provision of mobility devices (38).

Multi-stakeholder collaboration: Alongside the growth of the DPO network has been a deliberate strategy in the Pacific to encourage multi-stakeholder dialogue in all issues related to realising the rights of people with disabilities. There are multiple examples of national and regional workshops and meetings that have been inclusive of all key stakeholders including DPOs, service providers, government representatives, donors and development partners attending and working together to address and solve issues. Such collaboration saw the establishment of the Pacific Community Based Inclusive Development Network in 2012. A strength in the region, "unique and fruitful regional and multi-

stakeholder collaboration” was recognised in the PDF CRPD-SDG monitoring report [10] as a key factor in overall progress.

Full and effective participation in society by a person using AT is dependent on many factors. AT stakeholders recognise that increasing their engagement across sectors is a critical advocacy strategy for influencing improvements in accessible infrastructure and transport as well as access to the same opportunities as others such as education, employment, justice and political participation.

Information about the people who need AT, and those who are accessing it: Establishment of practical service data systems, enabling tracking of services provided and to whom, has been a consistent component of the establishment of mobility device services in the region (39-40). To date there are over 4,000 people registered across seven service databases (25). The use of qualitative surveys has further strengthened available information about people who use AT, their experiences of accessing services and the impact on their lives (41-42).

This growing body of information is an important contributor to change. Active analysis of service data and qualitative surveys for example has led to more information about the demographics and perspectives of people using services, helping to identify and respond to issues such as service quality, suitability of products and equity of access.

Additionally, the region is set to benefit from increased information about who may need AT, through the inclusion of, for example, the Washington Groups Questions in the national census, which have been used in six PICs (10) in recent years.

Products

Availability of products appropriate to the context: Improvement in access for more people to a greater range of wheelchairs has been one of the most significant AT developments in the Pacific. A critical success factor is the availability of a range of affordable wheelchairs suitable for the Pacific context coupled with training for service personnel in the provision of this range (43).

When systematic wheelchair service delivery began in the Pacific, the region benefitted from over a decade of innovation in wheelchair design for settings with comparable conditions elsewhere. In addition, large scale production of these designs was underway, making it feasible to procure bulk orders of ‘flat packed’ wheelchairs that could be locally assembled. This availability of appropriate designs and/or technology has also been an advantage in the introduction of prostheses, with the Pacific being able to utilise polypropylene technology developed elsewhere, however well suited to the capabilities of PIC services and the needs of people accessing them. There are no notable similar examples in other product domains, and identification and procurement of appropriate products was a common challenge identified by informants to the Pacific AT Procurement Study for other types of AT (13).

Product trials: Trials of new products are important in order to confirm whether products and their specifications are appropriate to a given context (44). Trials are also important to socialise new technology and build local confidence in both prescription and use. As new wheelchairs were introduced into the Pacific, trials were carried out with the support of national service providers, initially in Papua New Guinea (45) and then the Solomon Islands [46]. Critically, these trials and others (42) were active in securing feedback from both service personnel and service users to fully understand how well different products performed. Further product evaluation activities in the region have capitalised on the expertise of DPOs and their members, engaging them as data collectors to gather feedback from service users (41). There is good evidence to suggest these local trial opportunities have assisted in the successful introduction of these new technologies. In contrast, the Pacific AT Procurement Study highlighted a lack of trials of hearing aids introduced in the Pacific and reported high levels of abandonment (13). These issues could be better understood, and results improved with context specific trials and systematic gathering of service user feedback.

Consistent supply of products: To enable reliable access to AT, a constant supply of stock is required, which requires consistent funding. At 2019, no PICs have national, consistent annual recurrent budgets for AT (13). Again, wheelchair services have had an advantage not seen in other areas, through steady support from the Latter-day Saints Charities (LDSC). A major donor of appropriate wheelchairs into the region, LDSC support has grown from 666 wheelchairs donated into one country in 2009 to 2,746 wheelchairs and walking aids donated into six countries in 2018. This has supported recipient service providers to offer a more consistent wheelchair service. LDSC has also been responsive to increasing their range from one wheelchair design to a range as personnel were trained and the capacity of services to absorb and work with a broader range of products increased. Other donors and a few PICs have also supported procurement of wheelchairs, utilising a now established supply chain for wheelchairs.

Provision

Funding: The establishment of new services, or increasing the scope of a service, requires an initial investment to provide training for personnel as well as to equip services with facilities, tools, equipment and service systems. It also requires absorption by government and ongoing recurrent government budget to ensure the service continues. Availability of development programme funding has been a driver of change in the Pacific, with some notable examples of support from the Australian Government in accordance with the Development for All Strategy 2008-2012 (7) and 2015-2020 (47) addressing mobility device services specifically. This has included the first mobility device service pilot in the Solomon Islands (48), establishment of the new mobility device service in Samoa (39), the re-building of the Tungaru Rehabilitation Service (after a fire) in Kiribati, expansion of rehabilitation services in Tonga (38) to include mobility device services, and similar expansion of services to encompass mobility device provision in Vanuatu. Without these investments, delivered

through a development partner with relevant technical experience alongside national service partners, the gains recognised in mobility device services would not have been possible. Continued advocacy for recurring government budgets for AT and associated services is a priority moving forward.

Sustainable, local solutions: Given the constraints under which health services operate in PICs, the ongoing success of AT provision relies on services being locally owned, valued and affordable. Mobility device services in the region have been driven by local demand. Implementation has focused on building local ownership and capacity and systematic use of service data has helped demonstrate the value of the services. Technology introduced has been suited to the context, appropriate to the skills of local providers and relatively affordable. These are all viewed as factors contributing to success, in contrast to initiatives relying on visiting teams with less local involvement. Additionally, effective coordination between stakeholders can increase service efficiencies. Vanuatu offers an example of effective coordination between government health and non-government service providers that has helped drive improvements in the reach of walking aid and wheelchair services (49).

Integrated services: Integrating the provision of different mobility devices within one service has been a cost-efficient strategy in the Pacific. These integrated services share physical and human resources, service systems and referral networks to provide a 'one stop shop' for mobility device users, providing a more holistic service that can address the overall mobility needs of individual clients (39).

Personnel

Viable and practical training: The increase in personnel trained in wheelchair service delivery in the Pacific was facilitated by the WHO Wheelchair Service Training Package (WSTP), a resource that enabled local delivery of a standardised and relevant training for health and other personnel. WSTP was introduced into the region as a pilot in 2010 by Motivation Australia in partnership with WHO and the Solomon Islands Rehabilitation Division (48). There have since been over 340 participants of WSTP basic, intermediate, management and refresher training across the Region (50) (noting that some individuals have been counted more than once as they progressed through training). In 2012, a collaboration between Motivation Australia, the Solomon Islands National University and Fiji National University, saw the integration of WSTP into the curricula for community-based rehabilitation workers (Solomon Islands) and physiotherapists (Fiji) (51). Through this project and other initiatives, there are now national trainers of the WSTP in Fiji, Papua New Guinea and Kiribati.

Training of existing workforce: A success factor in increasing the number of personnel trained in provision of AT and in a position to use their skills has been a focus on training an existing workforce, coupled with effective service delivery support (43). In the Pacific this has largely involved up-skilling community-based rehabilitation workers, physiotherapists

and nurses. It should be noted this has been accompanied with a slow increase in staffing numbers overall and in some instances new Government positions (for example more prosthetist-orthotist positions).

Policy

Regional policies and frameworks: After the completion of the Asian and Pacific Decade of Disabled Persons, 1993-2002, the Biwako Millennium Framework for Action (2003-2012) was the first key regional policy document supporting fundamental change for people with disabilities, including increasing access to information, communications and assistive technologies as one of seven priorities. The CRPD reinforced impetus gained by the Biwako Millennium Framework. It has had significant impact in the Pacific, providing a foundational human rights platform that has supported all efforts since in realising the rights of persons with disabilities. In 2012 the Incheon Strategy (52) was embraced by Pacific leaders, inclusive of a target specific to increasing access to AT. The Sustainable Development Goals have also played an important role, reinforcing AT as a precondition to ensure that no-one is left behind in the global development agenda. This has been further reinforced by the WHO AT Resolution (53) and other WHO rehabilitation and disability frameworks (54).

Together, these high-level documents, supported at implementation level by the Pacific Regional Strategy on Disability (2010-2015) (55) and the Pacific Framework on the Rights of Persons with Disabilities (2016-2025) (9) have supported PIC Governments to promote, protect and fulfil the rights of persons with disabilities. They have also driven and informed national policy documents such as disability policies and health strategies; and provided powerful advocacy and bench-mark tools that have been used effectively by the DPO network and others. At a national level, the increased acknowledgement of the need for AT and specificity regarding how this should be provided seen in current national policies and planning documents is both change in itself and also a driver for further change. Overall, the policy environment is considered by Pacific stakeholders as a key factor in increasing awareness, demand and support for disability specific services such as provision of AT (22). Pacific stakeholders want to see greater resourcing of these policies to ensure sustainability of AT provision.

Conclusions

Our findings suggest a range of factors, systems and development approaches underpin pathways to increasing access to AT, in particular in less resourced settings. These include (and are not limited to):

- A supportive policy framework and political commitment
- Genuine multi-stakeholder partnership and quality collaboration between DPOs, people who use AT and their families, service providers, government, development partners and donors

- Building of awareness, knowledge and capacity within local agencies including DPOs, service providers and government, as well as people using AT, to plan, prioritise, advocate for, implement and evaluate AT local solutions
- Availability and opportunity to access, evaluate locally and utilise context appropriate and affordable AT, training approaches, service and data systems
- Embedding AT services within the existing health system, including training existing groups of personnel and integrating services for groups of AT (such as mobility devices) to maximise the workforce and resources, and streamline referral pathways.

Most importantly, sustainable and reliable access to AT is reliant upon the right mix of ingredients across the domains of People, Products, Provision, Personnel and Policy. Our findings highlighted the most significant improvement in access to AT over the past ten years has been the increase in access to mobility devices, and most notably wheelchairs. Wheelchairs have had the benefit of strong advocacy and growing informed demand from the People who need and provide such devices, the availability of a Product range suited to the Pacific and funding mechanisms to support procurement. Provision opportunities have been facilitated by the integration of wheelchair service delivery into existing government and non-government services, as well as the ability to provide effective local training for Personnel through the availability of an appropriate training package, training provider and financial support. At the same time, global, regional and national Policy frameworks have increasingly supported increased actions to make AT more readily available.

Pacific stakeholders remain positive about future progress with plans to ensure existing services continue to strengthen, that a diversity of voices inform the demand and availability of an increasing range of appropriate AT provision, and that governments fulfil their policy commitments by ongoing resourcing of AT.

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Appendix

Author's reflection questions

1. Compared to ten years ago, has there been an increase in the capacity of Pacific service providers to provide more and better AT services?
2. If AT service capacity has increased, in what areas has capacity increased? A useful framework is to consider capacity in these areas:
 - Human resources
 - Technical resources
 - Service systems (which includes data, service forms, referral pathways etc.)
 - Policy

Also consider if there are differences in capacity across different areas of AT (e.g. mobility, vision, hearing, communication, cognition, communication).

3. Compared to ten years ago, is it easier for Pacific Island people to access AT? Does the answer vary depending on:
 - The type of AT a person needs? Are some types of AT more readily available than others?
 - The country in which a person lives?
 - The part of a country in which a person lives?
 - A person's age (child, adult, older person)?
 - A person's gender?
 - A person's level of education?
 - A person's socio-economic situation?
4. What key events (e.g. project, activity, meeting, policy, global commitment or other) have occurred in the past ten years that had a positive influence on increasing access to AT in the Pacific? For each event, how did that event help increase access to AT?
5. How important (if at all) have the following been in helping to increase access to AT:

- Partnership and collaboration (if yes, what partnerships and collaboration)
- Access to AT that is appropriate for the Pacific (if yes, what AT specifically)
- Activities that increase awareness of AT
- Activities that support users of AT and their representatives (e.g. DPOs) to advocate for AT
- Activities that support training of national personnel
- Activities that support system development for AT provision (e.g. data tools, service forms etc.)
- Activities that support improvements in infrastructure (facilities, tools, equipment)
- Activities that strengthen policies, national and regional planning and/or frameworks that support AT provision

Identifying a set of core skills to enable the provision of priority assistive products

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Abstract

Introduction: Only 1 in 10 people globally has access to assistive products, in large part because of the shortage and unbalanced mix of appropriate skills of the health workforce. WHO is calling for better optimization of health personnel skills, and the development of competency frameworks that effectively respond to the changing needs of the population.

Objectives: The scope of this research was to explore which skills are considered most relevant by health professionals for the provision of seven assistive products: manual wheelchairs, lower limb prostheses, reading glasses, vision magnifiers, hearing aids, pill organizers and commode chairs. **Methods:** An online survey with open-ended questions was used for data collection. The target population consisted of health professionals, researchers and managers experienced with the provision of the selected assistive products. Data was analysed with SPSS. **Results and Discussions:** A total of thirty (n=30) surveys were completed. Sufficient data was gathered for meaningful analysis relating to manual wheelchairs, lower limb prostheses and commode chairs. Core skills emerged from the study include the ability to conduct a multifactorial assessment, bodily measurement, trying out different products and selecting the most appropriate, ordering and preparing the product for use, fitting, referring to other services, as well as providing training and instruction. **Conclusions:** A set of core skills for the provision of assistive products can be identified and described. More research is needed to define a comprehensive set of skills to establish a competency framework, as well as understanding how these skills can be developed optimally, and the potential impact of community-level training programs to impart these skills.

Keywords

Assistive technology, health workforce, provision of assistive products, competency frameworks, skill-mix.

Introduction

Assistive products such as wheelchairs, prescription glasses, and hearing aids, as well as products such as calendars and communication boards for cognitive function are essential components of Universal Health Coverage and are fundamental to the achievement of the 2030 Agenda for Sustainable Development (1). However, access to appropriate assistive products remains limited, especially in low and middle-income countries (2).

The World Health Organization (WHO) estimated that almost 50% of the world's population does not have access to basic health services, and only 1 in 10 persons (5% to 15%) in need has access to assistive technology globally (3). Causes of this global unmet need include the global shortage, imbalanced mix of skills and competencies and uneven geographical distribution of existing cadres of the health workforce. The shortfall of health workers is projected to reach 18 million by 2030 (4).

Skilled health personnel are key to ensuring effective access to assistive products. However, professionals involved in the provision of assistive products such as physiotherapists, speech therapists and occupational therapists are virtually non-existent in some countries and are often a neglected component in national human resources policies (5). To achieve and sustain Universal Health Coverage and enable effective access to health services, WHO is calling for better alignment of health personnel competencies and skills with populations' health needs, as well as adopting a diverse, fit-for-purpose and sustainable skills mix (6).

Many countries have addressed the challenges of the health workers shortfall by delegating some clinical tasks to cadres (e.g. community-based health workers) with either less training or narrowly tailored training (7). This process of workforce optimization has proved to be effective in increasing coverage and ensuring access to basic services at primary health care level. There is literature on the effectiveness of the role of community-based health workers to deliver interventions for HIV and infectious diseases, maternal and child health, non-communicable diseases, trauma and surgical care as well as mental health (8-12).

Recommendations for effective workforce optimization and task shifting include conducting a comprehensive analysis of the skills required to perform the work (13), developing and scaling up competency-based curricula, as well as shifting education models away from narrow specializations (6). With regard to assistive products, there are currently no competency-based curricula or frameworks describing a set of core clinical skills necessary in the safe and effective provision of assistive products. Despite the availability of guidelines and service delivery models, there is a need to better understand the skills and competencies needed within the workforce, define frameworks for products selection and explore the perspectives of providers and users (14). As the technical content for competency-based curricula for assistive technology are not self-evident, more research is necessary to identify which competencies are essential for assistive technology professionals and how these skills can be developed optimally (15).

This research was therefore motivated by the current research gaps in assistive technology and aimed to make a contribution towards the identification of core clinical skills to inform curricula for primary care personnel involved in assistive products provision. The purpose of this study was to address one of the priority questions within the GATE Priority Research Agenda¹⁵ and, broadly, the need to identify effective clinical skills to be shared at the community and primary health-care level (13).

Research objectives

The objective of this study was to identify the most frequent and relevant clinical skills currently used by health professionals when providing.

Objectives

The research objectives were:

1. To explore which skills are used by health professionals when providing the following 7 pilot assistive products selected from the APL: *manual wheelchairs, lower limb prostheses, commode chairs, reading glasses, vision magnifiers, hearing aids and pill organizers*, and
2. To explore how these skills are ranked by respondents in terms of relevance.

Definitions

Manual wheelchair refers to a device providing wheeled mobility that is propelled by the user or pushed by another person. A *lower limb prosthesis* (referred to as *prosthesis*) is an externally applied device used to replace wholly, or in part, an absent or impaired lower limb. A *commode chair* consists of a waterproof chair, on wheels, with a seat designed to facilitate positioning and use over the toilet or in the shower. *Reading glasses* are spectacles intended for near-vision acuity, while a *hearing aid* is intended as a digital device to compensate for mild to moderate hearing loss. *Vision magnifiers* refer to devices used to enhance vision, supported and positioned by the user's hand (optical or digital). A *pill organizer* is a special container for storing scheduled doses of medication. *User* refers to a person using an assistive product to maintain or enhance body functions (physical or psychological), to perform activities and prevent participation restrictions (16).

Clinical skills (CSs) are defined as "discrete and observable acts within the overall process of patient care". CSs performance learning has the primary purpose of improving patient's/service user's health outcomes and/or quality of life (17). Despite considerable research, there is little consensus on which domains are included within the definition of CSs (18). For this research, CSs crossing various domains (assessment skills, practical procedures, communication skills, attitudinal and management skills) were all considered eligible.

Effective provision of assistive products refers to the extent to which the provision process can ensure optimal outcomes. There are several frameworks defining AT outcomes (19). For

this research, outcomes include optimal person-technology match, quality of life, person's satisfaction and discontinuance rate.

Methodology

Ethical approval

This study proposal was reviewed by the Health Policy and Management and Centre for Global Health Research Ethics Committee (HPM/CGH REC) of Trinity College, Dublin. The ethical approval was received on March the 13th, 2017.

Survey design

An online survey was created for data collection. The survey featured an initial page with the information about the study and the informed consent. Successively, multiple choice questions were displayed to gather demographic information such as gender and professional profile. Seven open-ended questions referring to each of the pilot assistive products were then used to investigate clinical skills mostly used by professionals when providing assistive products. Participants were asked to rank five (n=5) clinical skills according to time spent using them. Rank 1 corresponded to clinical skills most used, whereas lower ranks indicated less frequently used skills. Clinical skills within higher ranks were therefore deemed as more relevant for the provision of assistive products. Asking participants to describe clinical skills used in their job was considered more appropriate than requiring them to respond to researcher's closed questions based on preconceived ideas of what these skills might be. This methodology was already effectively used in previous research to identify a set of core clinical skills for community based rehabilitation settings (20).

Selection, access and recruitment of participants

The approach was to assess existing evidence-based practices among professionals in countries where provision of affordable and high-quality AT is widespread. Italy was chosen as the primary location for data collection.

Relevant Italian AT networks were initially selected using a purposeful sampling method (21). A snowballing sampling method was then applied to reach participants within and across different AT networks (22).

Eligible participants were health professionals, academics or managerial staff involved in the provision, research or curricula development related to one or more pilot assistive products. The participants had to be fluent in Italian or English.

Participants were accessed and recruited through email. They were sent the survey link which included the information leaflet. The online survey was anonymous, therefore signed consent was not collected. Participants agreed to take part in the study by reading the information and completing the survey. The consent form, information leaflets and survey

were originally written in English to obtain approval by the HPM/CGH REC, and then translated into Italian.

Data analysis

The data from the survey was analyzed using content analysis. Open answers were first translated into English, then coded and grouped into clinical skills.

Firstly, the frequency of each clinical skill emerged from the content analysis was calculated as the percentage of the survey participants who reported that skill, irrespective of the rank assigned. The clinical skills were regarded as of high frequency when reported by at least 50% of participants, of upper-medium frequency when reported by at least 30% of participants, lower-medium when reported by at least 10% of participants, and of lower-frequency when reported by less than 10% of participants.

Successively, the mean ranking was computed from the ranks assigned to a specific clinical skill. The standard deviation (SD) was also calculated to ascertain the variation from the mean. Skills with a mean ranking of 1 (highest rank) to 2 out of 5 (lowest rank) were considered of higher relevance; clinical skills whose mean ranked between 2.1 to 3 were considered of upper-medium relevance; mean ranking of 3.1 to 4 was deemed of lower-medium relevance and skills which ranked a mean of 4.1 to 5 were considered of lower relevance. Skills with a SD of less than or equal to ± 2 were identified as having reached sufficient consensus across survey respondents. Clinical skills mentioned by at least 30% of the participants, or clinical skills whose mean ranked between 1 and 3 were considered core for provision of the assistive product. The Statistical Package for the Social Science (SPSS) was utilized to calculate the frequency of the clinical skills' appearance in each of the five ranks, as well as the mean ranking and SD of each clinical skill. Bar charts showing the frequency of appearance of each task within the 5 ranks were created with Microsoft Excel.

Results

Survey respondents' profile

A total of fifty-three (n=53) surveys were collected. The survey was closed when a total of thirty (n=30) fully completed questionnaires was reached.

Among the respondents, seventeen (n=17) were females and thirteen (n=13) were males. Ten (n=10) respondents had attained a Master's degree, while the remaining twenty (n=20) participants had a Bachelor Degree. Most of the participants were involved in the provision of more than one product.

Figures 1 and 2 illustrate the professional profile of the respondents and the number of answers obtained for each product. Around 70% of the respondents were physiotherapists, mostly involved in the provision of manual wheelchairs, commode chairs and prostheses.

Figure 1. Professional profile of survey respondents

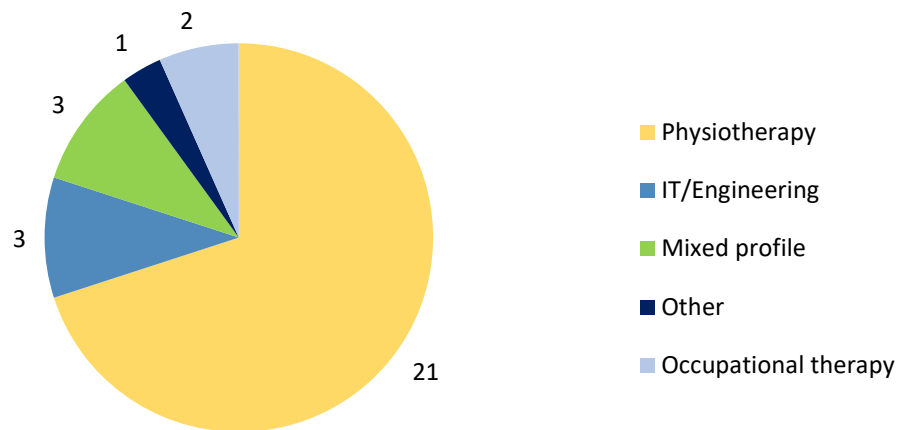
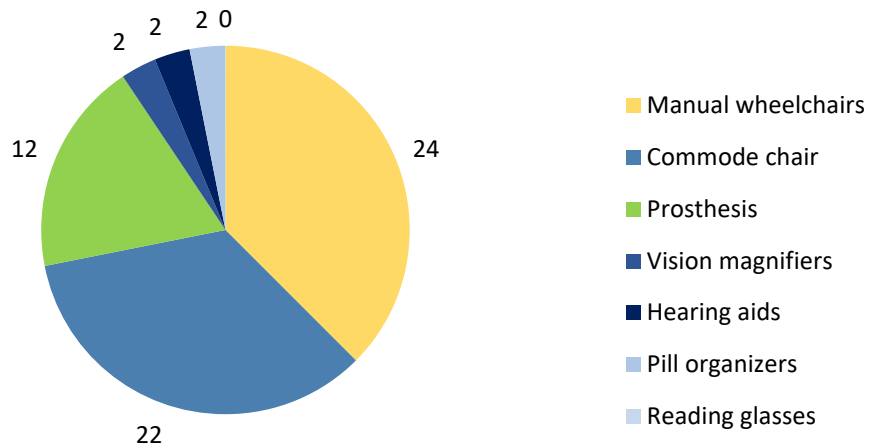


Figure 2. Number of completed survey per product



Clinical skills emerging from the survey

The responses collected for the vision magnifiers, hearing aids, pill organizers and reading glasses were insufficient in number to carry out meaningful analysis. Therefore, only data relating to manual wheelchairs, commode chairs and prostheses are presented in this section.

The responses were content analyzed and collated into groups of clinical skills. For manual wheelchairs, a total of twenty-four (=24) clinical skills were identified, twenty (=20) for commode chairs, and fifteen (=15) for lower limb prostheses. The skills emerging across the three products together with examples of answers referring to that skill, are presented in Table 1.

Table 1. Clinical skills emerging for manual wheelchairs, commode chairs and prostheses

Manual wheelchair (=24 clinical skills identified)
1. Assessment of person's needs (<i>includes in-person and phone interview</i>)
2. Functional assessment (<i>includes assessment of person's abilities, motor skills and functional capacity</i>)
3. Assessment of the environment (<i>includes where the person lives, works, and wants to go</i>)
4. Cognitive and psychological assessment
5. Activities of Daily Living (ADL) assessment
6. Assessing need for additional products (<i>including the need for table or pressure-relief cushion</i>)
7. Measurement (<i>includes body measurements and anthropometric measurements</i>)
8. Selecting the product (<i>includes choosing the product with the person, advising on choice, helping the person to select the product</i>)
9. Trying different products (<i>includes trying different products available, trying different models</i>)
10. Funding and ordering (<i>include filling in the request form, searching suppliers, doing a cost analysis, ordering-delivery</i>)
11. Referral (<i>mostly to national health service, to rehabilitation specialist</i>)
12. Product preparation (<i>includes testing, and checking that the product is appropriate</i>)
13. Fitting (<i>includes adjustments of wheelchair's parts and removal items</i>)
14. Positioning (<i>includes detecting pressure areas and making sure person has the correct posture</i>)
15. Training and instruction for use (<i>includes general mobility training and instructions, such as indoor and outdoor mobility and exercise</i>)
16. Transfers training (<i>includes transfer to and from bed/wheelchair</i>)
17. Team work (<i>includes choosing the best solution as a team, and ordering-delivery with the auxiliary personnel</i>)
18. Maintenance (<i>includes wheel inflation and brakes adjustment</i>)
19. Instruction on maintenance
20. Caregiver training
21. Environment adaptations
22. Supervising modifications (<i>refers to modification of the existing wheelchair</i>)
23. Follow-up and monitoring (<i>include getting feedback from the person and monitoring that the product suits the person over time</i>)
24. Problem solving
Commode chair (=20 clinical skills identified)
1. Assessment of environment (<i>includes toilet facilities and bathroom</i>)
2. Functional assessment (<i>includes evaluating the level of assistance required, and autonomy of the person when using the product</i>)
3. Assessment of person's needs (<i>includes needs appraisal and needs assessment</i>)
4. Selecting the product (<i>includes advice on different products available</i>)
5. Trying different products (<i>includes trying products that are appropriate for the context and simulation</i>)
6. Measurement (<i>refers to taking measurements of most suitable product</i>)
7. Funding and ordering (<i>include technical aspects for provision and final report</i>)
8. Product preparation (<i>refers to testing the product and making sure it is appropriate</i>)

9. Fitting (*refers to adjusting the product to suit person's size*)
10. Training and instruction for use (*includes education on correct use and instructions on assembly*)
11. Transfers training (*from bed/wheelchair to chair*)
12. Caregiver training
13. Environment adaptations (*refers to bathroom modification*)
14. Referral (*includes referral to NHS and rehabilitation specialists*)
15. Instruction on personal hygiene (*includes showering and performing tasks for personal hygiene*)
16. Maintenance
17. Team work (*refers to working with the orthopedic technician to assess the person*)
18. Instruction on maintenance
19. Follow-up and monitoring
20. Problem solving

Lower limb prosthesis (=15 clinical skills identified)

1. Measurement (*includes checking height and limb measurement*)
2. ADL assessment
3. Stump assessment
4. Selecting the product (*refers to product proposal*)
5. Product preparation (*includes assembling the prosthesis and testing the product*)
6. Funding and ordering (*include cost analysis and search suppliers*)
7. Fitting (*includes checking congruence and evaluation of tolerance*)
8. Training and instruction for use (*includes stump and socket management, correct use, instruction about break-in time and how to wear prosthesis*)
9. Rehabilitation
10. Walking and stairs training
11. Instruction on maintenance
12. Balance and transfers training
13. Repairing
14. Team work (*refers to collaboration with the P&O*)
15. Follow-up and monitoring

Frequency of clinical skills

The full list of clinical skills that emerged and their frequency for the three products is reported in Table 2. The Table shows the percentage of participants who reported a clinical skill, irrespectively of the rank assigned to that skill.

Table 2. Frequency of clinical skills emerged for the three assistive products

Frequency	Manual wheelchair	Commode chair	Prosthesis
High frequency (reported by no less than 50%)	<ul style="list-style-type: none"> • Training and instruction for use • Functional assessment 	<ul style="list-style-type: none"> • Funding and ordering • Assessment of environment 	<ul style="list-style-type: none"> • Training and instruction for use • Walking and stairs training
Upper-medium frequency (reported by no less than 30%)	<ul style="list-style-type: none"> • Assessment of the environment • Assessment of person's needs 	<ul style="list-style-type: none"> • Functional assessment • Training and instruction for use • Product preparation 	<ul style="list-style-type: none"> • Product preparation • Measurement • Fitting
Lower-medium frequency (reported by no less than 10%)	<ul style="list-style-type: none"> • Funding and ordering • Fitting • Follow-up and monitoring • Product preparation • Measurement • Selecting the product • Trying different products • Transfers training • Team work • Positioning • Maintenance • Assessing need for additional products • Referral 	<ul style="list-style-type: none"> • Selecting the product • Trying different products • Transfers training • Follow-up and monitoring • Assessment of person's needs • Caregiver training 	<ul style="list-style-type: none"> • Funding and ordering • Instruction on maintenance • Balance and transfers training • Repairing • Team work • Rehabilitation
Low frequency (reported by fewer than 10%)	<ul style="list-style-type: none"> • Cognitive and psychological assessment • Instruction on maintenance • Caregiver training • ADL assessment • Environment adaptations • Supervising modifications • Problem solving 	<ul style="list-style-type: none"> • Environment adaptations • Referral • Fitting • Instruction on personal hygiene • Maintenance • Measurement • Team work • Instruction on maintenance • Problem solving 	<ul style="list-style-type: none"> • ADL assessment • Stump assessment • Selecting the product • Follow-up and monitoring

Relevance of clinical skills

Participants were asked to rank the skills according to their relevance. Rank 1 corresponded to skills mostly used/relevant, whereas rank 5 corresponded to least relevant skills. Figures 3, 4 and 5 provide a visual description of how clinical skills were ranked by participants. Table 5, 6 and 7 in the appendix summarize the number of respondents who assigned a specific rank to each of the skills.

Figure 3. Manual wheelchairs: skills emerging from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used)

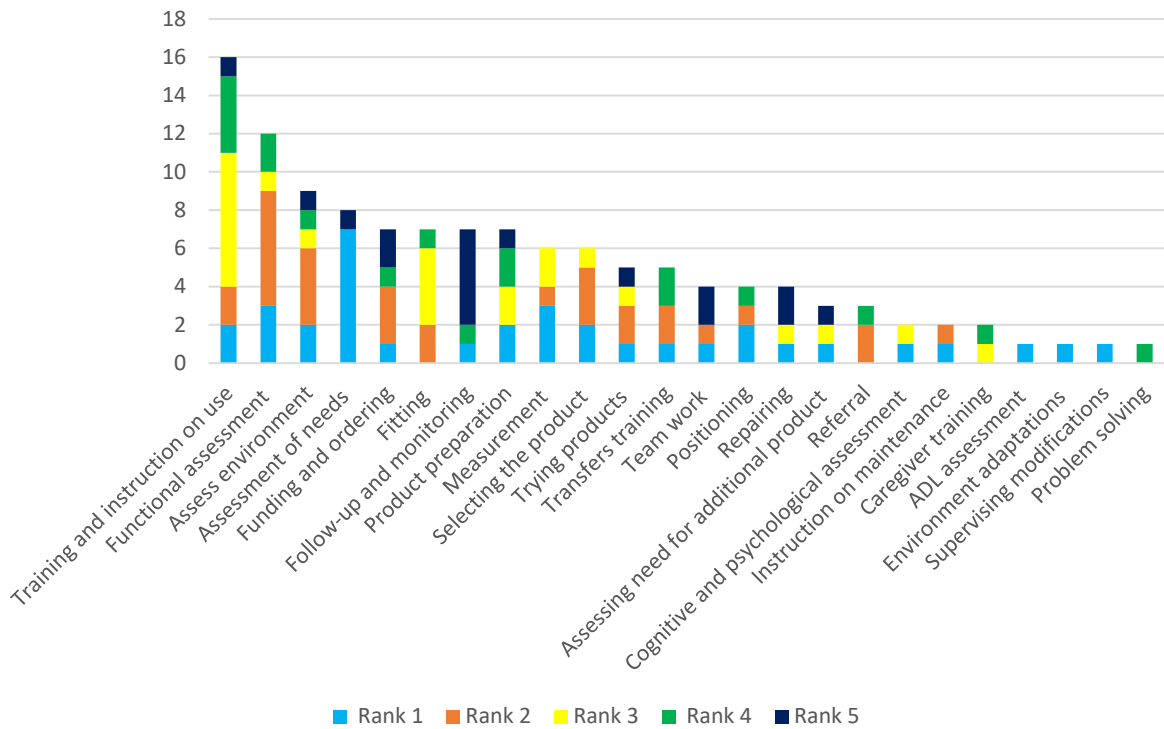


Figure 4. Commode chairs: skills emerging from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used)

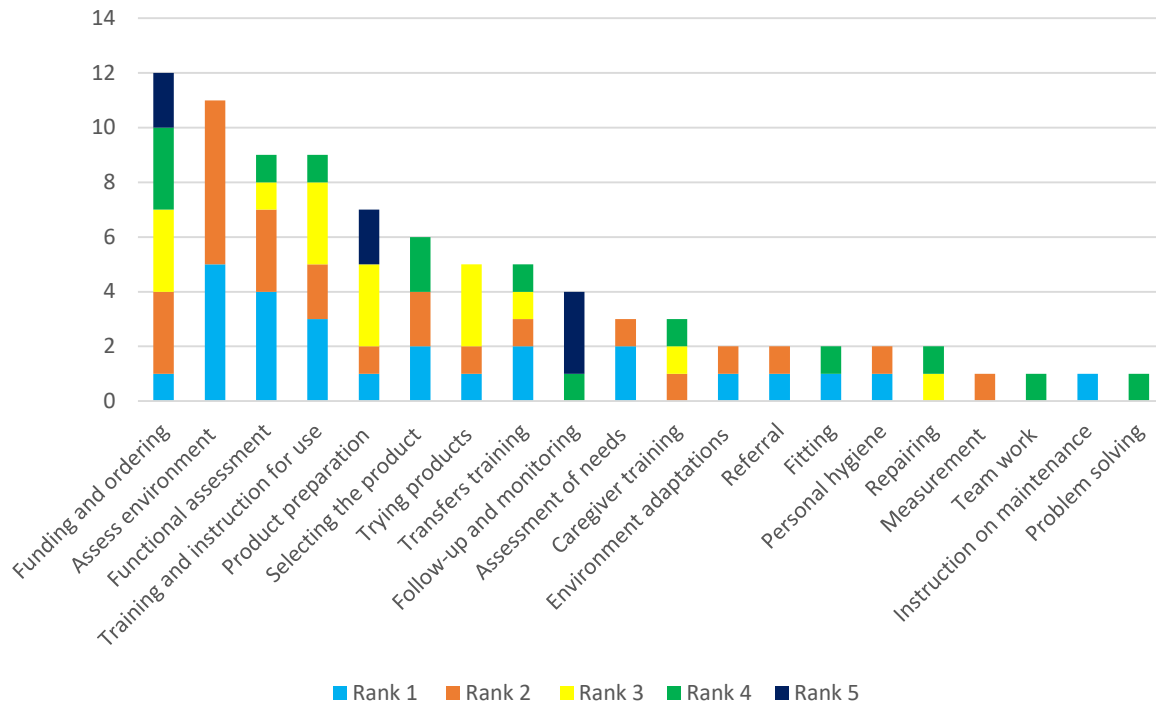
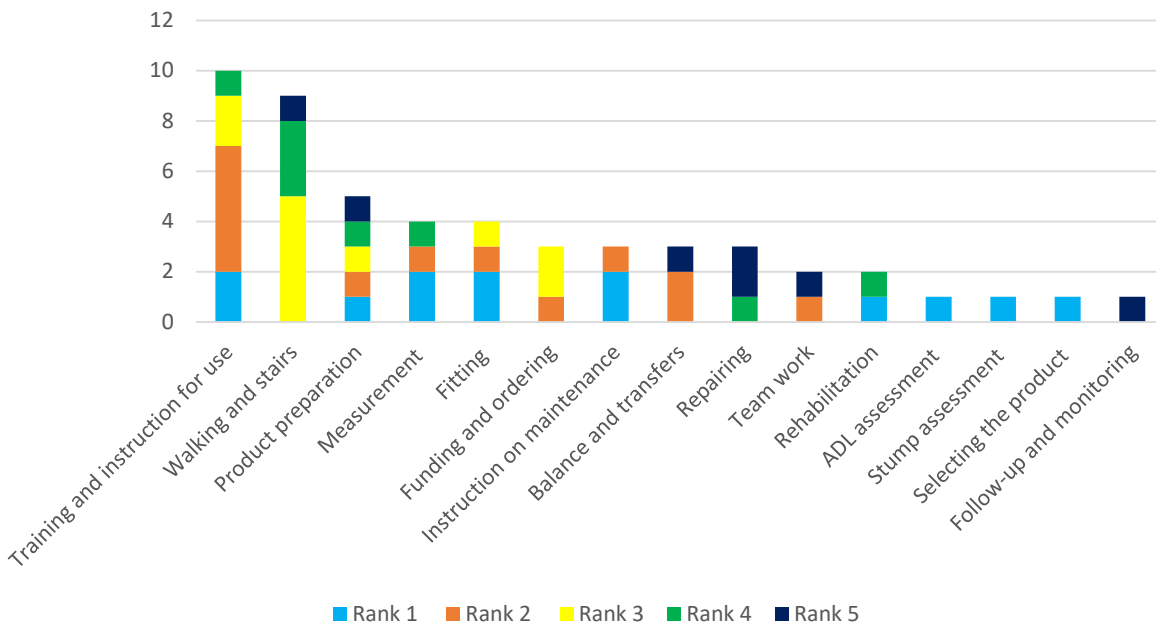


Figure 5. Prostheses: skills emerging from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used)



Most skills reached sufficient consensus in terms of relevance. Table 2 shows the mean ranking of the skills that presented a standard deviation of less than or equal to +/-2. The table also shows those skills for which consensus was not achieved (standard deviation more than +/-2), or for which it was not possible to calculate the mean ranking (usually skills reported only one time).

Table 3. Mean ranking of clinical skills emerged for the three products.

Mean ranking	Manual wheelchair	Commode chair	Lower limb prosthesis
1 to 2 (high relevance)	<ul style="list-style-type: none"> • Assessment of person's needs • Measurement • Selecting the product • Positioning • Cognitive and psychological assessment • Instruction on maintenance 	<ul style="list-style-type: none"> • Instruction on personal hygiene • Assessment of person's needs • Environment adaptations • Assessment of environment • Functional assessment • Referral 	<ul style="list-style-type: none"> • Instruction on maintenance • Fitting • Measurement
2.1 to 3 (upper-medium relevance)	<ul style="list-style-type: none"> • Functional assessment • Assessment of environment • Trying products • Transfers • Referral • Fitting • Training and instruction on use • Funding and ordering • Assessing need for additional product 	<ul style="list-style-type: none"> • Transfers training • Training and instruction on use • Selecting the product • Trying different products • Fitting • Caregiver training 	<ul style="list-style-type: none"> • Training and instruction on use • Rehabilitation • Funding and ordering • Product preparation • Balance and transfers training
3.1 to 4 (lower-medium relevance)	<ul style="list-style-type: none"> • Product preparation • Repairing • Caregiver training 	<ul style="list-style-type: none"> • Product preparation • Funding and ordering • Repairing 	<ul style="list-style-type: none"> • Walking and stairs training • Team work
4.1 to 5 (lower relevance)	<ul style="list-style-type: none"> • Follow-up and monitoring 	<ul style="list-style-type: none"> • Follow-up and monitoring 	<ul style="list-style-type: none"> • Repairing
Consensus not achieved (SD more than +/-2; or not possible to calculate mean)	<ul style="list-style-type: none"> • Team work • ADL assessment • Environment adaptations • Supervising modifications • Problem solving 	<ul style="list-style-type: none"> • Fitting • Measurement • Team work • Instruction on maintenance • Problem solving 	<ul style="list-style-type: none"> • ADL assessment • Stump assessment • Selecting the product • Follow-up and monitoring

Summary of core clinical skills for provision of three assistive products

Clinical skills mentioned by at least 30% of the participants, or clinical skills whose mean ranked between 1 and 3, were considered core for provision of assistive products. Table 3 reports the core skills that emerged from our analysis for each of the three pilot assistive products.

Table 4. Summary of core skills for the three assistive products

Manual wheelchair	Commode chair	Lower limb prosthesis
<ul style="list-style-type: none"> • Assessment of person's needs • Functional assessment • Assessment of the environment • Assessing need for additional product • Cognitive and psychological assessment • Measurement • Trying different products • Selecting the product • Funding and ordering • Fitting • Training and instruction for use • Positioning • Instruction on maintenance • Transfers training • Referral 	<ul style="list-style-type: none"> • Assessment of person's needs • Functional assessment • Assessment of environment • Trying different products • Selecting the product • Funding and ordering • Product preparation • Fitting • Instruction on personal hygiene • Environment adaptations • Referral • Training and instruction for use • Transfers training • Caregiver training 	<ul style="list-style-type: none"> • Measurement • Funding and ordering • Product preparation • Fitting • Training and instruction for use • Walking and stairs training • Balance and transfers training • Rehabilitation • Instruction on maintenance

Discussion

Discussion of findings

This research was carried out to investigate the skills most used by health professionals during the provision of particular assistive products. The findings suggest that a range of skills for the provision of assistive products can be identified and described. They include the ability to conduct a multifactorial assessment, bodily measurement, trying out different products and selecting the most appropriate, ordering and preparing the product for use, fitting, referring to other services, as well as providing training and instruction.

Skills deemed as core in the provision of assistive products include assessment of a person's needs, their functional abilities and the environment where they live and work. These skills were consistently ranked high among respondents, especially for the provision of manual

wheelchairs and commode chairs. The results suggest that a service provider should be able to carry out a holistic and multifactorial assessment to ensure positive outcomes. This is in line with previous studies (23-25) as well as existing frameworks such as the WHO Guidelines for the provision of manual wheelchairs in less-resourced settings (26), and the RESNA Wheelchair Service Provision Guide (27). For commode chairs, the importance of the clinical skills which emerged, such as home observation, assessment of functional abilities and environment adaptations, is consistent with previously published articles (28).

Assessment skills for the user and their environment for the provision of prostheses were reported less frequently and were less prominent compared to the other two assistive products. This could be because survey respondents might not be involved in the actual assessment, but in different steps of the provision process. On the other hand, the 'measurement' of body parts was one of the most frequently reported and relevant skills according to the respondents and this is a key element of prosthesis fitting.

The results confirm that selecting the appropriate product, together with the person, is a key skill within the provision process. Letting the person try different products and involving them in the selection and decision-making process was regarded as a core aspect within provision. These findings are in line with previously published articles, which highlight person-preferences and personal factors as essential aspects in the selection of appropriate assistive products (23).

'Funding and ordering' included skills such as reporting, filling out a formal request, cost analysis, search for providers and comparison. Although these skills were frequently reported, their distribution is more spread across the 5 ranks, with a lower mean ranking compared to other skills. This might depend on the amount of time respondents usually allocated to such administrative and bureaucratic tasks, which may well differ across different services. However, ordering-related tasks are indeed relevant for providing the correct product, as suggested in existing frameworks (26,29) previous studies (30).

Product preparation was regarded as a relevant clinical skill for both commode chairs and prostheses. Respondents providing commode chairs indicated product testing as one of the most used skills in their daily work. The relevance of performance testing in commode chairs was outlined by previous studies, which indicated the need to address the numerous safety concerns in certain service user populations (28). Respondents involved in prosthesis provision also reported the importance of congruence and testing.

Fitting has been identified as a core skill across the three products. For manual wheelchairs, fitting included adjustments of the product parts (such as seat and footrest) as well as support elements (e.g. table), to make it comfortable for the person. Positioning emerged as a relevant skill for manual wheelchairs as well. This finding is consistent with previous studies, where inadequate fitting and poor posture among wheelchair users have been associated with increased discomfort, complications and poorer use outcomes (31). For the provision of prostheses, fitting referred to skills such as checking congruence between

stump and socket. Fitting skills are fundamental in lower limb prosthesis provision, since poor practices increase the chance of product rejection and secondary complications (32,33).

Training the person in the use and providing instruction also emerged as a core skill in the provision of assistive products. The importance of instruction, as well as specific mobility and self-care skills training have been reported in previous studies. For manual wheelchairs, training is a widely acknowledged step within provision (34). Core mobility skills for wheelchairs emerged from the survey mostly referred to transfers. Previous studies reported that training in rehabilitation centers often does not go beyond fundamental skills like transfers, propulsion and basic maneuvering. While these skills address basic mobility and safety issues, more advanced training sessions might increase participation, quality of life and reduce the need for assistance (35).

Skills training for commode chairs included transfers, personal hygiene tasks and general instruction on use. These findings are supported by the work of Friesen et al., who identified nine activities mostly performed by commode chair users with spinal cord injury (14). Commode chair providers also mentioned and ranked caregiver training as a relevant aspect of the provision process.

For prostheses, five out of the nine skills emerging for this product referred to mobility skills and training. These included walking, stairs, balance and transfers, general rehabilitation and instruction on use. The researcher can speculate that physiotherapists (who represented almost 70% of the respondents) might be more involved in rehabilitation and training, which would explain the high frequency and relevance of this skill. Gait training in different settings, as well as load transfers and balance have been highlighted as frequently used skills in prosthesis training. Studies on the topic reported the benefits of such exercises on gait performance, confidence and prevention of secondary physical conditions (32,36,37).

Instruction on maintenance, identified as core, particularly for wheelchairs and prostheses, have also been previously identified as a precondition for the effective use of assistive products (38).

Follow-up was one of the least frequent and the lowest ranked skills across the three products in the survey. Some respondents providing manual wheelchairs and commode chairs indicated that they were involved in monitoring the person while using the product. On the other hand, some respondents specified that follow-up was rarely done in their service. The reason might be because respondents worked in assistive technology and rehabilitation centers in Italy. Existing literature reports that, to date, a formal follow-up mechanism for assistive products in the country is not in place (30). Given the importance of follow-up in determining the effective use of the product (38), many facilities in Italy have started building in monitoring operations to evaluate the use of complex product such as electric wheelchairs and stair lifts (30).

Responses about skills such as ‘team work’ and ‘problem solving’ were also inconsistent. These skills were mentioned by few participants, and the mean ranking and frequency of the skills reflected lower relevance compared to other skills. This could be for several reasons. While respondents might often use skills such as ability to work in a team and problem-solving in their daily job, when conducting an assessment, fitting a product to suit the person’s needs or providing training/instruction; some service providers might focus on the technical aspects of the provision process and might not regard these skills as relevant. The importance of “soft skills” (e.g. interpersonal skills and communication) in healthcare and their integration within practice has been acknowledged in many studies (39,40). In assistive technology, the role of ‘soft’ technology skills (such as the ability to conduct a multifactorial assessment) in achieving best health outcomes have been reported in previous studies (25).

Limitations of the study

The study has several limitations. Firstly, the authors recognize the challenge of recruiting sufficient respondents involved in the provision of all seven pilot assistive products. Time constraints, different types of professionals involved in the provision of different products, fragmentation of service provision and networks were considered the main challenges related to the data collection. Secondly, the sample included mostly physiotherapists. Skills used by this cadre might differ from the ones used by occupational therapists and other professionals involved in provision of assistive products. Furthermore, not all participants filled the five ranks in the survey. This factor reduced the consistency within the responses. Also, some respondents might have ranked skills according to the sequence of the provision steps, rather than their relevance. Finally, another limitation is related to the translation. Even though the lead researcher (GO) has translated the surveys and interviews (Italian to English) to the best of her knowledge, some translations might be open to interpretation. In terms of validity, the data was collected in Italy and skills used by Italian professionals might differ from skills used in other contexts.

Recommendations

While this study did not aim to comprehensively address the research gaps in standards and training development, the research shows that a set of common competencies and skills which are relevant across the selected products can be identified and described. Core skills which emerged from the study include the ability to conduct a multifactorial assessment, measuring, trying different products and selecting the most appropriate, ordering and preparing the product for use, fitting, referring to other services, as well as providing training and instruction.

These findings constitute a contribution to our initial understanding of clinical skills performed by professionals involved in the provision of assistive products and represent an important starting point for future research. This study has demonstrated a methodology that can identify both some AT-specific and some AT-generic skills that may inform the

development of a competency framework with associated skill for the provision of AT. Such a framework may allow for the development of specific skill sets that meet identified local or national needs, without the constraints imposed by the human resources for health crises regarding provision of conventionally trained health professionals. Where such professionals are however available they may have a key role in AT provision and/or in the guidance and support of cadre with the sort of specific AT skills described here.

Further studies should be conducted to identify the skills used by assistive product providers with diverse backgrounds and working in different geographical/socio-economic contexts. More research is needed to explore the importance of skills such as follow-up and monitoring, team work, interpersonal skills, problem-solving and their impact on assistive products provision outcomes. Moreover, further studies should be carried out to assess how these skills can be developed optimally, as well as the effectiveness of community-based training programs based on competency frameworks. Research should ultimately focus on whether this approach can increase community-level access to assistive products, as well as incorporating the perspectives of service users.

Opportunities

Developing locally relevant competency frameworks to inform workforce skills development is crucial in ensuring community-level access to priority assistive products. Matching the workforce mix of skills to the needs of the population would better enable more than 1 billion people to access assistive products through appropriate services. The development of competency-based training programmes for health personnel is essential in order to achieve Universal Health Coverage, move the 2030 Agenda for Sustainable Development forward (6) and to realize the resolution Improving access to assistive technology (41): GATE's vision, a world where everyone in need has access to high-quality, affordable assistive products to lead a healthy, productive and dignified life.

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Appendix

Table 5. Manual wheelchairs: Skills emerged from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used). The numbers in the table refer to how many participants assigned a specific rank to each of the skills.

	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5
Training and instruction on use	2	2	7	4	1
Functional assessment	3	6	1	2	0
Assess environment	2	4	1	1	1
Assessment of needs	7	0	0	0	1
Funding and ordering	1	3	0	1	2
Fitting	0	2	4	1	0
Follow-up and monitoring	1	0	0	1	5
Product preparation	2	0	2	2	1
Measurement	3	1	2	0	0
Selecting the product	2	3	1	0	0
Trying products	1	2	1	0	1
Transfers training	1	2	0	2	0
Team work	1	1	0	0	2
Positioning	2	1	0	1	0
Repairing	1	0	1	0	2
Assessing need for additional product	1	0	1	0	1
Referral	0	2	0	1	0
Cognitive and psychological assessment	1	0	1	0	0
Instruction on maintenance	1	1	0	0	0
Caregiver training	0	0	1	1	0
ADL assessment	1	0	0	0	0
Environment adaptations	1	0	0	0	0
Supervising modifications	1	0	0	0	0
Problem solving	0	0	0	1	0

Table 6. Commode chairs: Skills emerged from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used). The numbers in the table refer to how many participants assigned a specific rank to each of the skills.

	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5
Funding and ordering	1	3	3	3	2
Assess environment	5	6	0	0	0
Functional assessment	4	3	1	1	0
Training and instruction for use	3	2	3	1	0
Product preparation	1	1	3	0	2
Selecting the product	2	2	0	2	0
Trying products	1	1	3	0	0
Transfers training	2	1	1	1	0
Follow-up and monitoring	0	0	0	1	3
Assessment of needs	2	1	0	0	0
Caregiver training	0	1	1	1	0
Environment adaptations	1	1	0	0	0
Referral	1	1	0	0	0
Fitting	1	0	0	1	0
Personal hygiene	1	1	0	0	0
Repairing	0	0	1	1	0
Measurement	0	1	0	0	0
Team work	0	0	0	1	0
Instruction on maintenance	1	0	0	0	0
Problem solving	0	0	0	1	0

Table 7. Prostheses: Skills emerged from the survey and how they were ranked by respondents in a scale from 1 to 5 (1= skills ranked higher/most frequently used). The numbers in the table refer to how many participants assigned a specific rank to each of the skills.

	Rank 1	Rank 2	Rank 3	Rank 4	Rank 5
Training and instruction for use	2	5	2	1	0
Walking and stairs	0	0	5	3	1
Product preparation	1	1	1	1	1
Measurement	2	1	0	1	0
Fitting	2	1	1	0	0
Funding and ordering	0	1	2	0	0
Instruction on maintenance	2	1	0	0	0
Balance and transfers	0	2	0	0	1
Repairing	0	0	0	1	2
Team work	0	1	0	0	1
Rehabilitation	1	0	0	1	0
ADL assessment	1	0	0	0	0
Stump assessment	1	0	0	0	0
Selecting the product	1	0	0	0	0
Follow-up and monitoring	0	0	0	0	1

The value of vocabulary standards towards improving access to assistive technology

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Abstract

Assistive technology (AT) can be practically defined as products and services used by people, particularly persons with disabilities, to optimize participation in their life situations. Access to AT has been confirmed as critical to attaining the goals established by the Convention on the Rights of Persons with Disabilities (1), Universal Health Coverage (2), and the Sustainable Development Goals (3). Current inconsistencies in terminology act as barriers to research and development on the good practices required for effective provision of AT. Information exchange between all stakeholders in the AT value chain can only become interoperable when terminology standards for concepts, terms, and definitions are established and utilized. These stakeholders include product users, product providers (e.g. designers, manufacturers, distributors, and suppliers), service providers (e.g. clinicians, counsellors, educators, engineers, specialists, & technologists), systems administrators, policymakers, researchers, and academics. Terminology standards underlie the development of scientific tools with which to describe, gather, and analyze internationally comparable data required for coordinated global actions to increase access to AT. International terminology standards are the foundation for effective communication between key stakeholders, capacity building, and good practices across international contexts. This chapter proposes the development of a vocabulary standard to be published through the International Organization for Standardization (ISO) addressing services for assistive products. The proposed ISO standard will be based on international normative references, published literature, and other work by recognized experts and stakeholders in the field of AT.

Keywords

Infrastructure, normative vocabulary, services, standards, terminology

Introduction

The value chain for the provision of high-quality and affordable AT includes process and activities optimized for use by AT stakeholders. Critical to this optimization is the capacity for effective and efficient communication between all stakeholders.

While the rapid evolution of assistive products, and emergence of ad hoc solutions to address immediacy of need, are encouraging, there is a need now to develop robust, evidence-based infrastructure for wider dissemination and scaling. As the AT industry matures, efforts must now seek to generate evidence on which to build and disseminate educational curriculum, design and implement information management systems, and to make informed policy decisions. New practices that comprise disruptive innovation must be paired with effective strategies to diffuse these innovations into education, practice, and other outcomes of the process are critical to assure access to AT. Development of an evidence-based vocabulary standard for assistive products will unify and harmonize international concepts, concept system, terms and definitions. A normative vocabulary in which only one term corresponds to one concept and only one concept corresponds to one term will support the work of other committees by providing the terminology to draft linguistically and conceptually consistent standards and documents.

Objective

The GREAT Summit 2017 Report states “building global research infrastructure is a priority to progress the research agenda and must include users, industry and services”. with options to take this forward including “a commitment to open access publishing to increase information-sharing and collaboration between countries” (4).

Effective information exchange between all stakeholders in the AT value chain representing users, providers of products and services, systems administrators, policymakers, researchers, and academics can only become interoperable when resources are available to identify and clarify concepts, terms, and definitions. Terminology standards could offer scientific tools for consistent, internationally comparable data, description, and analysis for coordinated global actions increasing access to AT.

International terminology standards are the foundation for effective communication between key stakeholders, capacity building, and good practices across international contexts. Development of an initial standard vocabulary for services for assistive products is rapidly achievable through the aggregation of existing knowledge and international consensus.

The objective of the proposed international vocabulary standard is to ensure communication in the domain of services for assistive products is effective and difficulties in understanding are minimized. It is essential that the various participants, both individuals and organizations, use the same concepts and concept representations.

Approach

The following sections present a discussion on the findings, opportunities, and challenges by representative stakeholders on the value of a standard vocabulary to ensure greater access to quality, affordable AT for all.

Clinician

Linda-Jeanne Elsaesser Physical Therapist and Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) certified Assistive Technology Professional

Key concepts: provider capacity, common language and framework, translation of research to practice, process standard, international collaboration

International initiatives highlight the importance of AT to empower all people. Increasing access to AT will require changes in societal attitudes, provider behaviors, system capacity, and public policy. Key issues and challenges to transforming the AT sector include the need for individual and organizational performance measures, improved efficiency of service delivery, and a process standard to facilitate interdisciplinary communication.

As a physical therapist in the United States providing services for re/habilitation and mobility-related AT since 1982, I have witnessed the evolution of services for assistive products. In the 1980s clinicians were focused on educating themselves on the new technologies rapidly flooding the market and how to incorporate their use into practice. As a rapidly emerging field there was no recognition of the need for service or terminology standards. By the 1990s, an increased focus on accountability and productivity mandated clinicians learn a new skill set with a focus on evidence-based management that considered fiscal viability for provision of services, least costly alternatives with comparable impact when recommending assistive products, and determination of socially responsible outcomes with no evidence to support decision making. By the 2000's we began witnessing decreased access to assistive products and services due to denial of funding based on lack of evidence to justify clinical recommendations.

The need for a common language and framework to document the impact of AT on health and well-being becomes obvious when participating in the interdisciplinary decision-making process seen as most effective. The medical Latin-based terminology I had been educated on had little value when attempting to discuss the connection between a person's needs and the characteristics of assistive products with stakeholders of diverse backgrounds and discipline-specific vocabularies. The 2001 common language and framework of the International Classification of Functioning, Disability and Health (ICF) was immediately recognized for its value and became the standard for my evaluations and assessments, the means to match and connect the person to technology, and objectively document the impact of assistive products and services (5).

Continued commitment to the translation of research into practice and evidence-based management resulted in the development of the Assistive Technology Service Method

(ATSM) as an interdisciplinary language and conceptual framework for cross-disability and trans-contextual evaluation, assessment and objective documentation of AT service outcomes (6). An ICF based tool, the Assistive Technology Device Classification (ATDC) was subsequently developed to connect functional needs to AT solutions (7). Adoption of standardized tools to transform current practice will require diffusion of innovation strategies.

Expanding my focus to international settings revealed the need for a global terminology standard for AT services in order to collaborate, share best practices, and coordinate actions improving access to AT (8). Terminology sources included the World Health Organization and United Nations documents, journal publications, international standards, and national nomenclature. Further analysis of international terms used to describe services for assistive products revealed that development of a normative vocabulary standard based on global expert opinion would be required before methodology could be discussed.

Terminology standards are specifically intended to ensure that communication is effective and that difficulties in understanding are minimized. Standardized terminology must be appropriate and usable in all contexts from simple to complex, adequate in scope to include all appropriate elements of the topic at hand, and facilitate wide application. The ISO has established prerequisites for the development of vocabulary reference standards that include identification of concepts and relations, the designation of terms, and descriptive definitions (9).

There is a wealth of international knowledge to be found. What remains needed is the development of a vocabulary standard coupled with diffusion of innovation strategies to assure stakeholders are aware of, recognize the value, and implement the standard as a critical component for effective provision of services that increases access to AT. Increased access to AT mandates use of standards and guidelines for socially responsible organizational performance measures that consider the balance between economics, the welfare of society and the environment to assure sustainability (10).

Administrator

Stephen Bauer, PhD. National Institute on Disability, Independent Living, and Rehabilitation Research

Key concepts: *knowledge transaction spaces, knowledge transfer, diffusion of innovation, public policy administration*

This section addresses the need for and use of terminology standards in the administration of national research and development policy. The definitions for public policy and policy administration are diverse but broadly consistent in concept. For the purpose of this paper, public *policy* will be considered as “a system of laws, regulatory measures, courses of action, and funding priorities *concerning a given topic* promulgated by a governmental entity or its representatives” (italics added) (11) and *policy administration* as “the execution of public affairs as distinguished from policy-making” (Merriam-Webster) (12). Claire Naden of the

International Organization of Standardization states that “International Standards help governments and regulators achieve public policy goals, and the key is *effective dialogue*” (13). What then is “the given topic” and what comprises “effective dialogue” on this topic?

Concerning dialogue, in the normal state of affairs communication within or between government and non-government actors around a shared interest is via “transaction spaces” contrived ad hoc to facilitate “knowledge exchange”. Transaction spaces are “good” if they facilitate efficient and effective bi- or multi-directional knowledge exchange. Measures of efficiency might include communication and error correction rates, while measures of effectiveness might include communication resolution, specificity, fidelity, and accuracy. There is a cost associated with the time and effort to create, refine, and maintain any transaction space. In turn, transaction spaces facilitate diverse shared interests, in full or partial measure, to be satisfied. Here we have described communication for “local scale” policy administration (11, 13).

Knowledge exchanged or produced by government actors sharing any particular transaction space must also be diffused to other government and non-government actors. Actors sharing a common transaction space achieve common understanding via active, bi- or multi-directional negotiation over an indefinite span of time. In contrast, diffusion largely involves the spread of produced knowledge via passive one-directional communication channels. Government and non-government actors who consume diffused knowledge may be regarded as members of distinct social systems. Each actor employs their system’s language and conceptual framework as the basis to understand and act upon consumed knowledge. To the extent that the language and conceptual framework of a social system diverges from the negotiated language and conceptual framework of the producing actor there is a loss of fidelity for both understanding of and actions upon which is exacerbated by imposed time constraints. Here we have described communication for “global scale” policy administration (14).

Two broad approaches might be employed to help ensure that consumer knowledge actors in “social systems” understand and act upon diffused knowledge as intended by an administrative knowledge producer. The first approach to be considered is knowledge translation which requires that administrative knowledge be “translated” from the language and conceptual framework of each “knowledge producer” into the language and conceptual framework of each “knowledge consumer”. The time and effort required to translate each knowledge construct being diffused to a distinct social system is non-trivial, and any inexactitude of translation reduces the fidelity of understanding and actions carried out by knowledge consumers. It is easy to show that the number of knowledge translations that must be carried for each knowledge construct grows geometrically with the number of targeted social systems. As government administration involves multitudinous knowledge diffusions to equally multitudinous social systems, knowledge translation is not scalable and is therefore not a feasible approach (15).

Alternatively, well-defined and comprehensive terminology standards can be constructed to span critical knowledge domains and adopted by social systems. Knowledge producers and knowledge consumers are encouraged to employ these standards to so as to assure a common understanding of and actions upon diffused knowledge with high fidelity. While there is a high initial cost to construct, diffuse, and facilitate adoption of terminology standards, this approach is clearly scalable and feasible.

How might terminology standards “improve dialogue”? As stated in ISO 10241-1:2011 (E) the development and use of terminology standards “[...] ensure[s] that communication in a particular domain is effective and that difficulties in understanding are minimized, it is essential that the various participants use the same concepts and concept representations.” Application of such standards “facilitate[s] communication in science and technology, cross-cultural communication, the exchange of goods and services, as well as the formulation of policies and strategies at national, regional and international levels” and development of terminology standards must be “multi-lingual in its approach” (16).

Returning to the concept of knowledge transaction spaces, the “global common interest” is expressed by the GREAT Summit 2017 Report as “building global research infrastructure is a priority to progress the research agenda and must include users, industry and services” (4 p1). The optimal formulation and administration of national research and development policy requires communication with and across diverse social communities. Communication is essential to understanding and prioritizing disability related needs at a local and national scale, characterizing assistive product requirements, making decisions whether to develop assistive products solutions nationally or to acquire such solutions internationally, and understanding the characteristics of physical, service, and supply chain infrastructures as barriers or facilitators. Literally all of the required communication is most efficient and effective when diverse social communities employ terminology standards.

Manufacturer

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Key concepts: International trade, device lifecycle, medical device regulation, regulatory compliance, specification & adjustment.

The role of standards in international trade is well established. The World Trade Organization (WTO)’s *Agreement on Technical Barriers to Trade* (TBT) recognizes that international standards contribute to improvements in the efficiency of production, and the facilitation of trade internationally (Annex 3) (WTO, as cited in 17).

For AT products, *ISO/TC 173 Assistive products* and its various Sub Committees (SCs) and Working Groups (WGs) are responsible for over 90 standards covering assistive products for walking (WG 1), personal hygiene (WG 9), cognitive disabilities (WG 10), tissue integrity (WG

11), hoists (WG 13), wheelchairs and accessories for wheelchairs (SC 1), ostomy and incontinence (SC 3), and for persons with impaired sensory functions (SC 7) (18, 19). Additional standards reflecting product needs in varying environmental, resource, and user conditions e.g. less resourced environments (LREs) are in development (20, 21). In addition, ISO/TC173 publishes Technical Reports on application and use of its standards (18).

Creation and adoption of AT service standards is a natural and logical extension of standards development for AT systems. Developing a foundational vocabulary standard is a crucial initial step toward this goal. While manufacturers may have an “inherent conflict” in development of product standards (22 p93), AT markets are relatively small, with substantial obstacles to sustainable business growth for businesses in all parts of the supply chain (23).

Various stakeholders in the supply chain (e.g. manufacturers, suppliers, distributors, importers, and authorized representatives) may be responsible for medical device and import-related regulatory compliance in multiple international markets, in addition to the expected responsibilities associated with new product development, manufacture, distribution, maintenance, repairs, and disposal (23-25).

Unlike other consumer products, AT systems may require involvement of stakeholders in addition to the ultimate consumer (user), e.g. AT provision personnel and funders, adding both complexity and potential for delays compared with other consumer markets (23). In a review of Australian AT markets, Summers and Verikios (26) noted that “[u]nlike mass-marketed retail products, much AT is complex and requires significant complementary services by suppliers to ensure products are well matched to individual users” (p101). These services can extend from initial product development activities as described by Smith et al. (25), through all stages of product launch and distribution, ongoing supply (including provision of information, training and education of AT personnel and users, product selection assistance, and AT product delivery), ongoing maintenance and repairs, and eventual disposal. Compliance with medical device regulations may also require manufacturer involvement at all stages of the device lifecycle, including post-market surveillance. Further, existing and emerging evidence suggest stakeholders associated with product development and supply may, at times, assume responsibilities assumed within the GREAT framework as *AT personnel*, such as therapists and health practitioners (27).

Studies by Sprigle and colleagues uncovered a range of activities undertaken by rehabilitation technology suppliers and technicians at all stages of wheelchair service delivery (28, 29). These included pre-sales activities (e.g. assembly of an AT device / product to a single user’s specifications for trial); delivery activities (e.g. AT device / product set up, adjustment and training); and after-sales activities (e.g. maintenance, repair, and adjustment for individual users) (28, 29). Summers and Verikios (26) cited examples provided by Assistive Technology Suppliers Australasia (ATSA) – a peak body representing AT manufacturers, distributors, importers, suppliers, and retailers – of AT suppliers providing services that “would routinely be done by therapists in other countries”, such as

determining specifications and adjustments of complex wheelchair and associated seating (ATSA, 2014, as cited in (26 p103). Regulatory frameworks governing design, manufacture, sale, and ongoing surveillance and vigilance of Class 1 medical devices may also necessitate the manufacturer (or local supplier) to assume responsibility for these, and other activities, associated with *AT personnel*.

Engineers Australia *National Committee on Rehabilitation Engineering* describes AT provision where professional biomedical / rehabilitation engineers and technicians provide all services in an AT system: initial assessment, design, specification, fabrication, trial, fitting, follow up, long term maintenance and repair of custom-made assistive products (seating), and eventual disposal and replacement (30). Emerging manufacturing techniques such as 3-D printing, which could have a positive “disruptive impact” on AT availability (25 p481), may also result in manufacturers undertaking assessment, specification, fitting, and follow-up activities (31). In LREs, it could be argued that overlap between clinical and technical manufacturing roles for wheelchair services personnel already occurs. Both the WHO’s *Guidelines on the provision of manual wheelchairs in less resourced settings* (21), and the *Wheelchair Service Training Packages* (32), describe service delivery models where activities associated with personnel and activities associated with product manufacture occur in close proximity.

Given the examples presented here, it appears paramount that a proposed international AT services and provision standards (8) capture these real-world scenarios, and ensure terms currently defined within the *personnel* domain do not exclude these existing and emerging roles (27, 33). Including manufacturers’ representatives within international standards development committees is a way to achieve this. Indeed, from the manufacturers’ perspective, participation in development of AT services standards offers opportunities to engage directly with stakeholders across AT systems. Manufacturers may learn directly from expert users, researchers, policy makers, and clinicians, while at the same time bringing their expertise in areas such as product development, manufacturing practices, supply chain logistics, business development, regulatory compliance, and direct-to-user service provision across international markets (23).

Academic

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Key concepts: *policy, systems, interpretation, interprofessional education*

States parties to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) and member states of the World Health Assembly (WHA) have made commitments to improving access to quality AT. How they do that, and whether they achieve their intended outcomes depends on national and local policy.

Policy, as defined above, represents a system of laws and regulations determining and responsibilities and priorities for action and funding delivered by a variety of entities.

Policymakers make strategic decisions to use resources within or around health systems to deliver the greatest impact and positive outcomes for a population. This is done in different contexts, including countries with developed and well-resourced systems as well as countries in the process of developing new systems or scaling up programs to expand population coverage. From a systems perspective, access to quality AT is dependent on coherent policies that can be implemented locally by health services in co-production with the communities they serve. Relationships between policymakers, health services personnel, service users and communities are critical to effective health systems (34).

At the macro context, policy defines and interprets concepts that determine access to resources. Policies are then interpreted at the micro context of practice, where practitioners and administrators are responsible for taking action on the priorities and funding in line with the intent of policy. The result of these actions should then be demonstrated as outcomes, but research suggests that AT outcomes have never been consistently reported or linked to legislated mandates or policy goals (6, 35). Arguably this is because AT is a complex phenomenon involving both goods and services that are difficult to commodify (36). Policies intending to address complex social and economic problems are often not realized because of different understandings that create problems in implementation (37). Consistent terminology is necessary to bridge academic research in AT with policy formulation, and its implementation in practice.

The term 'assistive technology' is understood in different ways by people who develop and implement policy, and affected citizens including service providers and consumers. The ascribed meanings shape the actions and funding involved in implementing policies concerning or including AT. Different interpretations of concepts related to AT affect the design and delivery of policies, such as whether AT is part of mainstream health services or specialized disability services (36).

A standardized vocabulary for AT will also facilitate interprofessional education and practice. Interprofessional education aims to enhance client-centered care through effective team communication and collaborative practice. It is being advocated as an innovative approach to addressing increasingly complex health issues in the context of a global shortage of health workers that was estimated to be 4.3 million in 2010 (38). The development of interprofessional curricula is challenging, and involves staff from different disciplines, work settings and locations working toward a shared vision and understanding of each other's roles, responsibilities and expertise. Analysis of interprofessional education (IPE) competency frameworks has identified varying definitions for similar constructs, resulting in greater confusion and highlighting the need for a common language (39). AT is an interprofessional field of practice that could be enhanced by curricula that promote team communication and client-centered practice, and a shared terminology may reveal further opportunities for collaboration within health services personnel working across diverse settings and locations.

Without terminology standards, assumptions about AT will continue to be implicit in policy, education and practice, remaining unchallenged despite their inconsistencies. A common language is necessary to support the relationships between policymakers, health services personnel, service users and communities that are critical in addressing the global inequities in access to quality AT.

Engineer

Takenobu Inoue, PhD. Director of Department of Assistive Technology, Research Institute of National Rehabilitation Center for Persons with Disabilities; Chair of ISO/TC173/SC2: Classification and Terminology of Assistive Products.

Key concepts: AT development and innovation, co-creation, field-based innovation, classification and terminology

Innovative assistive product solutions are needed to address critical needs of people with disability and people who are older across diverse international contexts.

Reported national disability rates range from less than 1% to more than 30% nationally (40).

Eighty nations are projected to have 20% or more of their citizens aged 65 or older with Japan leading the way with 27% in 2017 (41, 42). It is accepted that these populations have additional needs and challenges which might be addressed by assistive products.

Irrespective of the underlying technology, assistive products are only effective if they account for the user's needs, abilities, and environments of use. In this section, the use and importance of terminology standards in the design, development, and commercialization of assistive products is discussed. While this discussion is placed in a first world context, analogous considerations would apply in any international context .

Designing assistive products for persons with disability and elders is more difficult than the design of mainstream products. Inoue et al. (43) presented a five step process that comprised: *setting the goal, concept design, prototyping, commercialization, and use*. Stakeholders critical to the product development process include persons representing the target market and commercialization partner(s). As best practice, critical stakeholders participate throughout.

In *setting the goal*, one identifies user characteristics and needs, market size and diversity, constraints of service provision, competing and related products, practical technology, and societal factors. In *concept design*, requirements are established for the features, functions, and performance characteristics of the proposed product so as to meet established goal(s). Evaluation of competing and related products provides valuable insights. Products must always be usable and effective. In *product prototyping*, proof of concept activities establish product feasibility by validating key product elements, concepts, components, or subsystems. Proof of product activities then establish product realizability by demonstrating that the fully-integrated product prototype substantially meets design requirements. Iterative testing, redesign, and redevelopment is typical. In *commercialization*, intellectual

property for the product prototype is transferred via licensing or other mechanisms to the commercial partner. Subsequent to transfer, the prototype is refined for manufacture, marketing, distribution, and sale. Training and technical assistance may be offered to users and providers. In the use step, product adoption, use and retention, and user satisfaction are assessed, along with a re-evaluation of the user needs identified in the *setting the goal* step. Barriers and facilitators to adoption are identified. Findings from these assessments feed continuous quality improvement for next generation products.

Best practices for assistive product design, development, and commercialization processes include co-creation, field-based innovation, and co-development of assistive services and assistive products. Co-creation requires the involvement of key stakeholders at all stages of the process. For example persons with disability identify needs, establish design requirements, evaluate prototype usability, efficacy and effectiveness, and identify barriers and facilitators to product adoption. Commercial partners provide market information, identify competing products, contribute design and manufacturing requirements, and produce, market, distribute, and support the final product (44).

Field-based innovation is an extension of *participatory design* and emphasizes user and provider evaluation of prototypes in their natural context of use. Such contexts (drawing on ICF Environmental Factors) place prototypes into interactions with other products and technologies, natural and man-altered environments, social-supports and relationships, cultural attitudes, services, systems and policies (45).

Co-development of assistive products and services helps to ensure that product design is optimized with respect to AT services spanning clinical assessment of client capacity/performance/functioning, needs and environmental factors, product identification, selection, acquisition and fitting, and outcomes assessment. Tools supporting product identification, selection, and acquisition by users and providers are considered (6, 44).

Subsequent to product commercialization, well-known online tools are used by persons with disabilities and service providers to identify and select assistive products. These tools include general use search engines such as *Google* or *Bing*, and dedicated searchable assistive product databases such as *AbleData* in the USA (<https://abledata.acl.gov/>) and *EASTIN* in the European Union (<http://www.eastin.eu/en/searches/Products/Index>). In all cases, key word-based searches are used to identify and select assistive products. To the extent that searches employ ad hoc key words or that the description and classification of assistive products employs ad hoc terminology, the identification and selection of optimal assistive products will be degraded. With one exception, ad hoc and unfamiliar terminology is employed in user and provider searches and in assistive product classification and description. The exception is the *EASTIN Global Assistive Technology Network* which classifies assistive products (in part) using *ISO 9999: 2016 standard Assistive products for persons with disabilities—Classification and terminology* (46). The *ISO 9999* was first published in 1992 and has been revised five times, most recently in 2016. The *ISO/TC173/SC2/WG12* is now working to harmonize the next *ISO9999* revision with the

standard terminology and conceptual framework of the WHO International Classification of Functioning, Disability, and Health (5). Overall, the design, development, transfer, commercialization, and adoption of assistive products involves local and remote communication between stakeholders. In all cases, employment of standard terminology improves the efficiency and effectiveness of required communication.

Summary

This manuscript discusses the need for the development of an international vocabulary standard from the perspectives of stakeholders in the AT provision chain. The proposed standard would be published through the International Organization for Standardization (ISO). ISO has established prerequisites for the development of reference standards that include identification of theoretical background, target groups, and purpose. The vocabulary standards work would incorporate international normative references, published literature, and other work by recognized experts and stakeholders in the field of AT.

Numerous ISO standards are available in support of terminology work to include principles and methods, harmonization of concepts and terms, vocabulary theory and application, and requirements for presentation. The proposed ISO standard will integrate existing data for the harmonization of concepts, concept systems, terms and definitions to obtain a normative vocabulary in which only one term corresponds to one concept and only one concept corresponds to one term, thus reducing ambiguities.

Standardized terminology must be appropriate and usable in all contexts from simple to complex, adequate in scope to include all appropriate elements of the topic at hand and facilitate wide application. The standard and its underlying development approach must have the flexibility to address and incorporate updated or new definitions as needed. The terms cannot be open to more than one interpretation, and they must be consistent for accuracy in reporting relationships and outcomes.

Drawing directly from the scope identified in ISO 26000:2010 - Guidance on social responsibility (10), the proposed standard would define:

- a) concepts, terms and definitions related to services for assistive products;
- b) the background, trends and characteristics of services for assistive products;
- c) principles and practices relating to services for assistive products;
- d) the core subjects and issues of services for assistive products;
- e) integrating, implementing and promoting socially responsible behavior throughout services for assistive products and, through its policies and practices, within its sphere of influence;
- f) identifying and engaging with stakeholders; and
- g) communicating commitments, performance and other information related to services for assistive products (8).

The recommended vocabulary standard for services for assistive products is expected to support the work of other ISO committees by providing the terminology to publish linguistically and conceptually consistent standards and documents that can be effectively communicated and readily understood.

Adoption of the proposed vocabulary standard to support AT systems will require diffusion of innovation strategies promoting awareness of this resource. Communication on the value of adopting and implementing standard vocabularies along with establishing a commitment to the continued development of evidence-based, internationally relevant standards will be critical to advance the progress of AT provision.

Effective information exchange between all stakeholders in to educate and support practice the AT value chain can only be realized when interoperable concepts, terms, and definitions are available. Developing linkages between global indexing and retrieval of information on good practices for AT will enable the gathering and dissemination of data to support the global goal of improved AT access for all. The GRéAT Consultation in 2019 represents a tremendous opportunity to support the development and adoption of concept vocabularies with standard terminology as part of the infrastructure critical to capacity building.

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Towards a global quality framework for assistive technology service delivery

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Abstract

Assistive technology supports maintenance or improvement of an individual's functioning and independence, though for people in need the access to assistive products is not always guaranteed. This paper presents a generic quality framework for assistive technology service delivery that can be used independent of the setting, context, legislative framework, or type of technology. Based on available literature and a series of discussions among the authors, a framework was developed. It consists of 7 general quality criteria and four indicators for each of these criteria. The criteria are: accessibility; competence; coordination; efficiency; flexibility; user centeredness, and infrastructure. This framework can be used at a micro level (processes around individual users), meso level (the service delivery scheme or programme) or at a macro level (the whole country). It aims to help identify in an easy way the main strengths and weaknesses of a system or process, and thus guide possible improvements. As a next step in the development of this quality framework the authors propose to organise a global consultancy process to obtain responses from stakeholders across the world and to plan a number of case studies in which the framework is applied to different service delivery systems and processes in different countries.

Keywords

AT service delivery; quality; standards

Introduction

Assistive Technology (AT) has a huge potential to support people with disabilities to live an independent and fulfilling life and to participate optimally in society. Realising this potential, however, is not easy and obvious. Many requirements must be met: the right technology,

training in its use, an environment that enables the technology to be used, services for maintenance and repairs, financial support, etc. And, first of all, people need to be aware that AT might be a solution for them and they must have access to it. As clearly demonstrated by the WHO in the GATE initiative there are great challenges worldwide to ensure that people have access, assistive products are available at an affordable price, training and support is available, and legislation and policies are in place to shoulder all this.

From a user perspective, all the above elements come together in the assistive technology service delivery process. That is the process through which an individual goes to obtain an AT solution that meets his or her needs and fits within the context in which it will be used. The service delivery process is embedded in a service delivery system, involving a whole set of legislation and policy, professionals and organisations. Many countries have public AT service delivery systems in place, and many others are in the process of developing such systems. However, these systems are very different, not only between countries but also within countries for different types of assistive devices, different age groups or for different living settings. This creates a very diverse landscape of AT service delivery systems and processes.

There is not a clear design of a 'perfect' system or process. This is logical because AT is just one of the elements of a country's healthcare and social support policy, which in turn relates to its geographical, historical, political and legislative context. Given this diversity, several authors have proposed to develop AT provision standards that would allow to compare services and to assess their impact in a systematic way, and that could support or guide countries, organisations and individual professionals to improve their systems and processes accordingly. This paper aims to contribute to this ambition by presenting a generic quality framework for assistive technology service delivery that is independent of the setting, context, legislative framework, type of technology or any other aspect. The aim is to present a truly generic framework with quality criteria and indicators that apply to all assistive technology service delivery systems and processes, whether looked at in a micro level (processes around the individual e.g. the practice of a rehabilitation centre of a community district), meso level (e.g. the service delivery scheme of a region or of an insurance company) or at a macro level (the whole country). It is intended to pinpoint at a glance the main strengths and weaknesses of the system or process, as well as the gaps that are worth a more detailed analysis for possible improvements.

Method

The quality framework was developed in three steps. First, a review of the literature on assistive technology service delivery quality was performed (1-13), in order to identify current or suggested best practices and ideas from previous research and theoretical perspectives. On the basis of this review, an initial set of quality criteria and indicators was produced. In the second step, this set was discussed in a series of meetings of the authors. Each author consulted colleagues and experts in his/her own country/region to get wider

input between the subsequent meetings. After three meetings the authors reached agreement on the completeness and relevance of the framework. In the third step the draft framework was sent to five experts in Brazil, Australia and India who had not previously been involved in the process. They were asked to comment on the framework and indicate whether they missed relevant aspects and whether the criteria and indicators would be applicable in their setting. Their comments were incorporated in a final version of the framework that is presented in this paper.

Findings

The resulting framework is presented below. It consists of seven criteria, each of which holds four indicators, formulated as questions. These criteria and indicators apply to the whole process that leads from the user's need identification to the provision and usage of the assistive solution.

This process usually consists of seven steps that can be recognised in most existing service delivery systems: 1) initiative; 2) assessment; 3) solution; 4) products; 5) authorization; 6) implementation; 7) management.

The term 'assistive solution' is used in a broad sense to indicate any assistive products, environmental adaptation and technological set up that – alone or in combination – provide a solution to the user's needs.

The term 'user' indicates the person who actually uses the assistive solution, e.g. the person with disabilities or the older person needing assistive technology to carry out activities of daily living tasks or to participate in education, work or social life (i.e. end-users). This also extends also to the broader sense of user, including family members and other informal or formal caregivers when they are involved in usage of the assistive solution.

The indicators for each criterion are formulated as questions, each to be answered in qualitative terms and on a 4-point rating scale: 1=adequate; 2=requiring improvement; 3=good; 4=outstanding. This relatively simple way of scoring was chosen because the intention is not to provide a detailed assessment or judgement of a system or process but to provide a framework to discuss strengths and weaknesses in a structured and systematic but also open way, allowing any professional or organisation, irrespective of the stage of development they are in, to identify points that might be improved. Thus, it can also become a framework for benchmarking and comparison and driving continuous improvement.

Criterion 1: Accessibility

To what extent is the system, scheme or process ...

- a) [Awareness] ... known, communicated and clearly understood by the people who need AT?
- b) [Eligibility] ... accessible for anyone who needs AT?

- c) [Reachability] ... provided in locations that are easily reachable, physically accessible and at reasonable times available to the people who need AT ?
- d) [Affordability] ... financially affordable by the people who need AT ?

Criterion 2: Competence

To what extent is the system, scheme or process ...

- a) [Knowledge] ... operated at each step by people who have adequate competencies and skills in relation to their duties or responsibilities?
- b) [Transparency] ... applied using clear procedures or evidence-based standards where all steps are tracked, objectives are declared, and meaningful outcomes are measured?
- c) [Safety] ... operated while ensuring that risks and safety issues are properly addressed and managed?
- d) [Information] ... making comprehensive and updated information on the available assistive solutions available to all actors involved?

Criterion 3: Coordination

To what extent does the system, scheme or process ensure that ...

- a) [Consistency] ...all steps of the individual AT intervention are well coordinated with each other?
- b) [Case managing] ... the AT intervention is well coordinated with all other individual health, care, wellbeing, education and social interventions?
- c) [Benefits] ... immediate and wider benefits of AT provision are captured, such as e.g. access to education or employment or other life opportunities?
- d) [Ethics] ... the intervention is conducted in an ethical manner, in accordance with commonly accepted ethical principles of health, care and social interventions?

Criterion 4: Efficiency

To what extent is the system, scheme or process able to ...

- a) [Timeliness] ... provide solutions to each individual's needs within reasonable time?
- b) [Effectiveness] ... make sure that the provided solution is effective in relation to the intended goals, and satisfactory from the user's viewpoint?
- c) [Accountability] ... keep track of the costs and the outcomes of each AT intervention?
- d) [Optimization] ... use costs and outcomes information to continuously improve the system (including products, processes, services) so as to maximize the outcome return on investment?

Criterion 5: Flexibility

To what extent does the system, scheme or process ...

- a) [Products range] ... provide a range of assistive products which is wide enough to meet the varied individual needs of the served population, at an appropriate quality level?

- b) [Customization] ... ensure that the provided products are appropriately installed, fitted and customized to cater for each individual need?
- c) [Responsiveness] ... enable to quickly re-adjust the assistive solution to difficulties that may arise during usage, such as changes in clinical condition, in the person's life or in the lived environment?
- d) [Innovation] ... take advantage of new products or technologies appearing on the market that can meet the users' needs in a more satisfactory and cost-effective manner?

Criterion 6: User centeredness

To what extent does the system, scheme or process ...

- a) [Partnership] ... ask for the user's view and takes it into account at each stage of the intervention?
- b) [Empowerment] ... provide users with all information and knowledge needed to actively participate and take responsibility for the choices, in an informed and responsible manner?
- c) [Trials] ... give users the possibility to try out the proposed solutions before the final choice?
- d) [Freedom] ... give users the possibility to appeal against decisions that don't meet their agreement, or to make different choices?

Criterion 7: Infrastructure

To what extent does the system, scheme or process ...

- a) [Data] ... avail reliable figures and information on numbers and types of people to use services?
- b) [Scoping] ... ensure that the right structure, systems, processes and skills are in place to meet needs?
- c) [Sustainability]... allocate adequate resources and adapt for growth in demand?
- d) [Involvement] ... involve user representatives in service planning, monitoring and assessment?

Discussion and Conclusion

The aim of this paper was to present a generic quality framework for AT service delivery that can be used to support or guide countries, organisations and individual professionals to improve their systems and processes accordingly, as well as to compare services and to assess their impact in a systematic way. The proposed framework covers all aspects mentioned in the literature about service delivery quality and aspects that were considered relevant by the authors. In a (limited) consultation of colleagues in Brazil, Australia and India no missing aspects were identified, which suggests the framework is rather complete. The authors believe that this framework is a good starting point for more systematic analysis and development of the quality of services delivery systems and processes.

A limitation of the procedure followed when developing this framework is that the main contributions as well as most of the publications used came from developed countries. This may have led to a bias in the resulting framework, although good input from colleagues working in a rural area in India was received. Another possible bias is caused by the fact that most of the authors are associated to the AAATE (Association for the Advancement of Assistive Technology in Europe) and thus likely share similar values. In a next phase it would be important to validate this framework for use in more low resource settings. It should be noted that the framework has not been tested in 'real life' to see whether it is indeed generic and applies to different settings. Considering these points, the proposed framework is not final. As a next step in the development of this quality framework we propose to organise a global consultancy process to obtain responses from stakeholders across the world, including users, and to plan a number of case studies in which the framework is applied to different service delivery systems and processes in different countries. On the basis of the result of such next steps a final version of the framework can be developed. Ideally that would be published by the WHO as a tool for countries, organisations and individual professionals to be used in developing and improving AT service delivery systems and processes.

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Technical Education and Skills Development Authority's Assistive Rehabilitation Technology Services: Wheeling towards a nationally recognized training and certification of wheelchair service personnel

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Abstract

Background: There is currently no national policy on training and certification of wheelchair service personnel in the Philippines despite the implementation of the Philippine Health Insurance Corporation (PhilHealth) reimbursement package for wheelchair provision. The Department of Health, academic institutions, and non-government organizations conduct wheelchair trainings independently, guided by the World Health Organization's Wheelchair Service Training Packages. However, access to wheelchairs remains limited due to the absence of a government-sanctioned certification of trained wheelchair service personnel. Moreover, PhilHealth & local government units' financial assistance for wheelchair-users and salaried positions in government facilities for wheelchair providers require proof of national certification of wheelchair training to ensure quality control. The United Nations Standard Rules and the Convention on the Rights of Persons with Disabilities stipulate that governments should create national policies that ensure not only affordable but also appropriate and accessible wheelchair service provision. **Objectives:** This project envisioned a national policy on training of wheelchair service personnel and certification by a government office. **Method:** Physicians for Peace Philippines (PFPP), through the assistance of Latter-day Saints Charities, assembled a health policy team to support the development of a training and certification program for wheelchair service personnel. Exploratory meetings were held with the Department of Health, National Council on Disability Affairs, Technical Education and Skills Development Authority (TESDA), wheelchair-users, wheelchair practitioners, and relevant stakeholders. The team conducted literature review of international, national, and local policy anchors to support the endeavor. Key informant interviews were conducted to ease navigation through the policy environment. A comparative desk review of training manuals used by local organizations involved in wheelchair training was conducted in preparation for a unified set of competencies to be recommended by the national government. Outputs of the evidence synthesis were presented to government agencies to support the development of a training and certification program for wheelchair service personnel. **Results:** The project led to the

approval of TESDA ARTS (Assistive Rehabilitation Technology Services) through TESDA Board Resolution No. 2019-35: “Prioritization of Public Employment Services and Assistive Rehabilitation Technology Services for Training Regulations (TR) Development”. The development of a nationally recognized and government-sponsored training and certification of wheelchair service personnel will be lodged under TESDA. A core group of wheelchair experts from the academe, personnel in active field practice, trainers, and wheelchair users will be assigned to guide development of competencies for training and certification. **Summary and Recommendations:** The Philippines is on its way to having nationally sponsored training regulations and certification of wheelchair service personnel. A dedicated health policy team is instrumental in this project. A good understanding of context, content, process, and actors involved in the policy environment contributes to fostering a consultative and inclusive approach. Policy anchors complemented by scientific evidence helped convince policymakers to prioritize support for the endeavor.

Keywords

Wheelchair, policy, training, certification, wheelchair service personnel.

Introduction

Background

It is estimated that 15% of the world’s population has some form of disability, with at least 70 million needing wheelchairs as an assistive device to enhance mobility, improve participation, and improve overall health and quality of life. However, less than 5% of demand is met in low-resourced areas. This may be due to absence of manufacturing services, lack of wheelchair service providers, and a non-existent referral system for proper wheelchair provision. For many persons with impaired mobility, a wheelchair is a first move towards his/her integration into society. Wheelchair service personnel ensure that wheelchairs are appropriate and meet the needs of the user in his/her environment. They are responsible for the wide variety of services ranging from assessment, prescription, measurement, assembly, fitting, user training, and repair and maintenance (1).

The United Nations Convention on the Rights of Persons with Disabilities, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and World Health Assembly resolution WHA58.23 all identify the need for proper wheelchair service in the developing world (2-4). In 2008, WHO published several guidelines for wheelchair service provision (1). These have served as the guiding principles for proper wheelchair service provision. Health workers and community-based personnel can now be empowered to render proper wheelchair service provision.

The Philippine Health Sector aims to achieve universal health coverage (UHC) for the population. An essential component of UHC is Rehabilitation Services. This requires the availability of practitioners in rehabilitation including wheelchair service personnel.

Significance

There is currently no national policy on training and certification of wheelchair service personnel in the Philippines despite the roll-out of the national health insurance (Philippine Health Insurance Corporation or PhilHealth) reimbursement package which includes wheelchair provision. The Department of Health, academic institutions, and non-government organizations conduct independent wheelchair training, guided by the World Health Organization's Wheelchair Service Training Packages (5-7). However, access to wheelchairs remain limited partly due to the absence of a government-sanctioned certification of trained wheelchair service personnel. Moreover, PhilHealth and other government agencies require proof of certification of wheelchair training to ensure quality control. The United Nations Standard Rules and the Convention on the Rights of Persons with Disabilities stipulate that governments should create national policies that ensure not only affordable but also appropriate and accessible wheelchair service provision (2).

Like all medical interventions, an improperly prescribed wheelchair may cause harm. Joint contractures, pressure sores, and scoliosis are examples of secondary complications. An improperly prescribed wheelchair can also predispose the wheelchair user to accidents especially that the topography of the country varies drastically.

The importance of certification cannot be undervalued. Certification of healthcare workers ensures that standards for education or training are of quality. It allows verifying that the knowledge learned in the training are translated into actual practice. Lastly, it also benefits wheelchair users and their families, lessening the risk of potential harm caused by inappropriate wheelchairs (11-12).

Objective

This project aimed to develop a national policy for training and certification of wheelchair service personnel.

Overview of the Policy Development

Context

In the Philippines, access to appropriate wheelchairs is limited. While wheelchairs can be easily purchased in urban centers, the concept of proper wheelchair prescription is still not well known. Even among health workers, the difference between a transport wheelchair and a fully customized wheelchair is not common knowledge. Referral systems for proper wheelchair services are still in its infancy.

More than 300,000 wheelchairs are donated annually to low-middle income countries by international donors and charitable organizations; this includes an estimated 4000 per year in the Philippines. Often this process is outside the formal health care system (10).

Filipinos gain access to wheelchairs through several means. While some Local Government Units (LGU) provide their constituents with wheelchairs, most patients acquire their

wheelchairs through personal expenses. International organizations or charitable institutions also donate wheelchairs during medical missions. However, the appropriateness of the wheelchairs provided is not guaranteed.

Despite existing policies and programs, wheelchair provision in the Philippines face numerous barriers such as the lack of information, limited priority, limited regulatory standards, and the scarce support mechanism environment, which is detrimental in meeting the needs of those who need this mobility device.

In 2016, the PhilHealth package for Children with Disabilities was approved. The provision of appropriate basic and intermediate wheelchairs can now be financed by the national health insurance system. The Department of Social Welfare and Development (DSWD) and DOH also have their respective programs for wheelchair provision. This provision entails hiring qualified wheelchair service personnel in hospitals before PhilHealth can contract these healthcare facilities (11-12). With increasing government support for wheelchair service provision, it is tantamount that a national regulation system for wheelchair service personnel be initiated to ensure quality.

Brief History of Wheelchair Service Provision and Training in the Philippines

As early as 2008, the World Health Organization (WHO) published the policy document on Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings. The goal of the initial document was to “assist WHO Member States to create and develop a local wheelchair provision system” (1). In 2012, WHO published the Wheelchair Service Training Package – Basic Level (WSTP-Basic) (5). This was followed by the Wheelchair Service Training Package – Intermediate Level (WSTP-Intermediate) in 2013 (6). The training manuals for Managers and Stakeholders were published in 2015 (7). In 2017, WHO published a series of Training of Trainer’s packages for basic level, intermediate level, and for managers and stakeholders. These training manuals were developed in collaboration with the United States Agency for International Development (USAID). The process required extensive expert consultations, field trials and an expert review.

The training packages contained the “minimum skills and knowledge required by personnel involved in wheelchair service delivery.” WHO made the package available for use by training institutes and wheelchair service providers. One goal of the project was to integrate the training into the existing programs for professions in the field of rehabilitation.

Wheelchair Service Training is the terminology adopted by WHO to refer to the process of training personnel for wheelchair service provision. This must not be confused with the training given to wheelchair users and their families in the use and maintenance of wheelchairs.

In the Philippines, Latter-day Saints Charities have been conducting wheelchair service provision throughout the country even before WHO published the wheelchair service training package. The first group of wheelchair service personnel with direct links to the International Society of Wheelchair Professionals (ISWP) was formed in 2015 as the

Philippine Society of Wheelchair Professionals (PSWP). The group has worked on the expansion of wheelchair training across the country. These two groups have been working with various NGOs and government agencies in the provision of wheelchairs and training of wheelchair service personnel. Other groups who have conducted wheelchair service training in the country include the College of Rehabilitation Services of De La Salle Health Sciences Institute and representatives from USAID and World Health Organization. Despite the rising number of wheelchair service providers in the country, there is still no unified national policy for certification of wheelchair service personnel.

Over the past few years, there have been several wheelchair service training (WST) programs held in the country. These have been sponsored by various NGOs, the academe, Department of Health, and several local government units (LGUs). These WST programs followed two main training curricula: the WHO-USAID WSTP manuals and that of the Latter-day Saints Charities.

Despite being a generic training manual, which can easily be revised to suit local context, WHO also published a Wheelchair Service Training Package trainer's manual with structured instructions to guide delivery of the training both for the basic and intermediate level WSTP. WHO also provided open access to videos and presentations for use by interested parties. Most training programs conducted by the Philippine Society of Wheelchair Service Professionals adopted these materials from WHO (13).

On the other hand, LDSC also held several training programs with its partner organizations. In most of these trainings, the LDSC manuals and materials were used. LDSC also played a key role as supplier of wheelchairs and related materials even for WST where the WHO WSTP manuals were utilized.

Process: Wheelchair Provision Overview

There are two classifications of wheelchairs: basic/standard and supportive. There are three levels of training for wheelchair service personnel: basic, intermediate, and advanced. Basic or standard wheelchairs can be provided by personnel who have undergone basic level training. Supportive Wheelchairs on the other hand should only be provided by those who have undergone intermediate or advanced training. The WHO publications currently cover basic and intermediate training.

The World Health Organization developed an eight-step wheelchair provision model with the goal of improving the quality of services in any setting, including low-resourced areas. The eight-step process include the following: (i) referral and appointment; (ii) assessment; (iii) prescription; (iv) funding and ordering; (v) product preparation; (vi) fitting; (vii) user training; and (viii) maintenance, repair and follow-up.

Content

Policy Anchors

There are a number of international, national, and local policy anchors which support the move for governments to create a certification process for wheelchair service personnel. International mandates are echoed by national-level policies. Policies developed at the local government level support these national policies further.

International Policy Anchors

UN Convention on the Rights of Persons with Disabilities (CRPD): The Convention aims to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities and to promote respect for their inherent dignity. Article 20 stipulates that state parties shall ensure personal mobility with the greatest possible independence for persons with disabilities by providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities. Moreover, Article 26 on Habilitation and Rehabilitation urges State Parties to promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services; and to promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation (2).

United Nations' Standard Rules on the Equalization of Opportunities for Persons with Disabilities: The Standard Rules was adopted by the General Assembly on 20 December 1993 and represent strong political commitment of Governments to take action in achieving equalization of opportunities for persons with disabilities. Furthermore, it serves as a policy making instrument, and as a basis for technical and economic cooperation. Rule 14 on Policymaking and planning urges governments to facilitate the development by local communities of programs and measures for persons with disabilities. One way of doing this could be to develop manuals or checklists and provide training programs for local staff. Relevant to the wheelchair profession development in the country, this urges adoption of the developed standards and manuals set by the World Health Organization on wheelchair training (3).

World Health Assembly (WHA) Resolution 58.23: The WHA 58.23 discusses disability, including prevention, management and rehabilitation. This Resolution urges members states to strengthen national programs, policies and strategies for the implementation of the United Nations' Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Furthermore, the member states are prompted to facilitate access to appropriate assistive technology and to promote its development and other means that encourage the inclusion of persons with disabilities in society (Sec. 1.7). Pertaining to providing appropriate assistive technology is the capacity development of wheelchair service provision by adoption of the standards and training manuals for wheelchair service. This is further supported by the statement (Sec. 1.14) on ensuring provision of adequate and effective medical care to people

with special needs and to facilitate their access to such care including to prostheses, wheelchairs, driving aids and other devices (4).

WHO Global Disability Action Plan (2014-2021): The Objective 2 of the WHO Global Disability Action Plan for 2014-2021 aims to strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and community-based rehabilitation. This includes developing and maintaining a sustainable workforce for rehabilitation and habilitation as part of a broader health strategy. The human resources for assistive technologies, this action plan encourages formulation and implementation of national health, rehabilitation and habilitation plans to increase numbers and human resources capacity for rehabilitation. Moreover, it recommends proving working conditions, remuneration and career opportunities in order to attract and retain rehabilitation and habilitation personnel. This is further supported by production of national standards in training for different types and levels of rehabilitation and habilitation personnel that can enable career development and continuing education across levels. Lastly, it urges governments to train health personnel for early identification, assessment and referral of people that can benefit from rehabilitation, habilitation, support and assistance services (14).

United Nations Sustainable Development Goals: The United Nations Sustainable Development Goals (SDGs) has recognized that it would not achieve its full vision of leaving no one behind, without the full inclusion and participation of persons with disabilities (15). Assistive technologies and rehabilitation services are recognized to lessen the barriers in order for persons with disabilities to have independent living or having a full participation in society through school and work. Inequalities and inequities are more prevalent in persons with disabilities, as they can be more prone in the cycle of poverty. It is recommended that States should create policies or laws that will aid in the increase of supplies of assistive technologies. Further, States should be able to make sure that these devices are available and affordable. These can be done through improving health coverage, grant provision and other compensatory schemes. Lastly, investments should be added to enhance the accessible environment for persons with disabilities who are using their assistive products (15, 16).

Philippine Policy Anchors

Magna Carta on Persons with Disabilities: This law signed as Republic Act No. 7277 and cited as the Magna Carta for Disabled Persons aims to provide for the rehabilitation, self-development and self-reliance of disabled persons and their integration. This act stipulates provisions for employment, education, health, telecommunications, accessibility, and political and civil rights for disabled persons. Pertinent to wheelchair practice in the country, this act states that The Department of Health (DOH) is mandated to train its field health personnel in the provision of medical attention to disabled persons (17).

Expanded Senior Citizens Act of 2010: The Republic Act 7437, or the Expanded Senior Citizens Act of 2010 aims to provide access to adequate health services, essential goods and other social services for the elderly. This law stipulates that senior citizens will have a 20% discount

and value added tax (VAT) exemption in the purchase of prescribed medications, supplements and vaccines. This also extends in availing assistive technology devices such as spectacles, hearing aids, and mobility devices. The list of mobility devices includes prosthetics, steel bone replacements, walkers, crutches, canes and manual or electric operated wheelchairs (17).

Philippine Local Financing Mechanisms for Wheelchairs

Healthcare financing of persons with disabilities may be compromised in low-middle income countries, like the Philippines. There is an interplay of disability and other factors that leads to exclusion from employment opportunities and healthcare access (19). Most are unable to purchase assistive devices like wheelchairs on their own, encouraging dependence on donors. It is estimated that 300,000 wheelchairs per year are donated by charities and donors worldwide, and 4000 of which are granted in the Philippines (10).

Apart from these, families and households cover most of the cost for wheelchairs and other assistive devices. This may be due to limited access to government or public funding. However, the Philippines government has initiated several financing schemes for wheelchair provision as described below.

Philippine Health Insurance Corporation (PhilHealth)

In line with the Republic Act 7277 also known as the Magna Carta for Disabled Persons, the Philippine Health Insurance Corporation (PhilHealth) began covering specific needs of persons with disabilities through the Z benefits for mobility, orthosis, rehabilitation, prosthesis help (Z MORPH) and the Z Benefits for Children with Disabilities. This benefit package provides comprehensive social health insurance coverage during assessment, provision of appropriate devices, and rehabilitation towards safe and functional mobility. For the Children with Disabilities Z Benefits Package, the amount of coverage for basic or intermediate wheelchair can be as high as Php 29,450.00 (around 570 USD); and yearly services and the replacement of the devices will support the patient at Php 13,690.00 (around 270 USD) at the maximum (11, 12).

Department of Labor and Employment (DOLE): The Labor Code of the Philippines stipulated the development of the Employees' Compensation and State Insurance Fund, effective January 1, 1975. The Employees' Compensation Commission, now an attached agency of the Department of Labor and Employment, implements the Employee's Compensation Program (ECP) that provides benefits and compensation for employees and their families in the event of illness, injury, disability or death. An employee is entitled to medical services, appliances and supplies, as well as rehabilitation services. The ECP's Katulong at Gabay sa Manggagawang May Kapansanan (KaGabay) Program can provide persons with work related disabilities who have been deemed qualified to have physical or occupational therapy, as well as assistive devices. However, the guidelines did not include the minimum and maximum price range for these services (20).

Philippine Charity Sweepstakes Office: The Philippine Charity Sweepstakes Office (PSCO), under its Individual Medical Assistance Program, provides financial assistance to individuals with health-related concerns (21). A guarantee letter will be given and addressed to the health facility in order to provide proof that PSCO will shoulder the costs of the services rendered. The list of assistive devices covered include hearing aids, wheelchairs, and prostheses.

For wheelchair provision, an application form must be filled out, together with an original medical abstract or certificate from the individual's attending physician must be given, with the reasons why the individual would need a wheelchair, as well as its specifications (21).

Actors

The Department of Health (DOH) has the mandate to ensure access to health services across the country. This includes ensuring availability of services for rehabilitation and disabilities. Furthermore, DOH has the mandate to govern the planning, distribution and design of government hospitals in all regions and provinces. The DOH also provides guidelines and requirements for public and private hospitals. Because the country aims to achieve universal health coverage and improve rehabilitation services, it is essential to ensure that all needed practitioners and professionals are available.

Two government offices hold the mandate for certification of health professionals. Health personnel which require a college-level education are certified by the Professional Regulatory Commission (PRC). Other health personnel trained through technical and vocational courses are certified by the Technical Education and Skills Development Authority (TESDA). As of present, TESDA holds courses and certifying examinations for massage therapist and dental technicians (22, 23).

The National Council on Disability Affairs is the national government agency mandated to formulate policies and coordinate the activities of all agencies, whether public or private, concerning disability issues and concerns (24). The NCDA also has the mandate to monitor the implementation of legislations ensuring the protection of civil and political rights of persons with disabilities. The NCDA represented the concerns of end-users for this policy endeavor.

The Philippine Society of Wheelchair Professionals was established in 2015. The organization has been involved in activities concerning wheelchair service provision, training, policy work, awareness, and advocacy. The society has partnered with the Department of Health in several wheelchair service training events across the country.

There are also several non-government organizations in the Philippines which conduct wheelchair service provision trainings. The Latter-day Saints Charities started wheelchair provision services in the country in 2010. The University of the Philippines College of Allied Medical Professions, the De La Salle Health Sciences Institute (DLSHSI), and the University of the East – Ramon Magsaysay Philippine School of Prosthetics and Orthotics (UERM-PSPO) also conduct wheelchair training.

The list above only includes some of the major actors in the policy environment concerning training and certification. Other valuable actors are more involved in the aspects of supply, service delivery, and utilization. These include local wheelchair manufacturers, importers, distributors, non-government organizations, and persons with disabilities support groups. The roles these additional actors play were considered in situational analysis of the bigger picture of wheelchair service delivery.

Methodology

Physicians for Peace Philippines (PFPP), through the assistance of Latter-day Saints Charities, assembled a health policy team to support the development of a training and certification program for wheelchair service personnel. The team consisted of public health physicians, health policy experts, and rehabilitation medicine professionals. This ensured that different aspects surrounding wheelchair practice is considered during the process.

The team conducted literature review of international, national, and local policy anchors to support the endeavor. International policy anchors included publications from the United Nations, the World Health Organization, and the International Society of Wheelchair Professionals. National level policies included legislation enacted by the Philippine government such as the Magna Carta for Persons with Disabilities and policies governing national institutions such as the Philippine Health Insurance Corporation (PhilHealth), Department of Labor and Employment (DOLE), and Philippine Charity Sweepstakes Office (PCSO). Local policy anchors included regional, provincial, and city ordinances enacted in support of persons with disabilities. Published studies on the role of wheelchairs in medical care were also reviewed. These documents were compiled and used as references during meetings with policymakers and stakeholders.

Key informant interviews were conducted to ease navigation through the policy environment. A comparative desk review of training manuals used by local organizations involved in wheelchair training was conducted in preparation for a unified set of competencies to be recommended by the national government.

Exploratory meetings were held with the Department of Health (DOH), National Council on Disability Affairs (NCDA), Technical Education and Skills Development Authority (TESDA), wheelchair-users, wheelchair practitioners, and other relevant stakeholders. The team initially coordinated with the DOH-Health Regulation Office and identified possible avenues for policy development. Several stakeholder consultations were initiated by the Health Regulation Office. Attendees included relevant DOH offices, TESDA, NCDA, and representatives from other healthcare providers.

The Department of Health has the mandate to ensure access to health services across the country. This includes ensuring availability of services for rehabilitation. However, other government offices hold the mandate for certification of health professionals. Health personnel which require a college-level education are certified by the Professional Regulatory Commission (PRC). Other health personnel trained through technical and

vocational courses are certified by the Technical Education and Skills Development Authority (TESDA). As of present, TESDA holds courses and certifying examinations for massage therapist and dental technicians (22, 23).

The recommendation stemming from the DOH stakeholder consultations was to work with TESDA in the developing a national wheelchair service training and certification program. A series of talks with TESDA personnel were held in preparation for TESDA Board presentation. Further information regarding the labor market and projected employment opportunities were gathered.

During the 30th Direction Setting Committee TESDA Board-TESDA Secretariat Consultation meeting last May 15, 2019, the Physicians for Peace Philippines policy team presented the proposal. TESDA later released Resolution No. 2019-35 on June 11, 2019 entitled “Prioritization of Public Employment Services and Assistive Rehabilitation Technology Services for Training Regulations (TR) Development” (25).

Results

The efforts of the health policy team and their partners have led to a well-defined path for developing a national certification for wheelchair service personnel. After consulting policymakers and stakeholders in determining the legitimate avenue for development of a national certification, TESDA was identified as the most feasible track. The project led to the approval of TESDA ARTS (Assistive Rehabilitation Technology Services) through TESDA Board Resolution No. 2019-35: “Prioritization of Public Employment Services and Assistive Rehabilitation Technology Services for Training Regulations (TR) Development”. This resolution stipulates the condition that the ladderization requirements are 1) in conjunction with industry requirements; and 2) that the qualifications would undergo consultation with relevant stakeholders in determining appropriate qualification titles and levels to be developed. Adoption into the TESDA process also ensured that a unified standard for training will be developed as well.

The wheelchair service personnel training regulations is only part of TESDA Assistive Rehabilitation Technology Services. This is envisioned to be a set of training regulations for rehabilitation personnel. Training programs can cater to non-professionals who wish to become part of the rehabilitation workforce without the need for a college degree. Rehabilitation professionals who wish to learn additional skills may also avail of TESDA ARTS programs. The current endeavor involves development of training programs for Basic Level Wheelchair Service Personnel and Prosthetics-Orthotics Technicians.

Students who are unable to complete their training program but comply with the minimum requirements will be given a Certificate of Competency. National Certificates are issued to students who complete the training programs and successfully pass the examinations.

The development of a TESDA program can be divided into two main parts. The first is the development of competency standards and program standards. This entails developing the

contents of the curriculum. The second stage is the development of assessment standards and assessment instruments. This product of this stage is a set of examinations administered to the students before they are given their National Certificates. A core group of wheelchair experts from the academe, personnel in active field practice, trainers, and wheelchair users will be assigned to guide development of competencies for training and certification. At the current stage, technical experts have been gathered to join the technical working group for the first part of the process.

Practitioners who received their wheelchair service provision training prior to the TESDA program will not be left behind. Recognition of prior learning is a key concept of the TESDA programs. These practitioners need not take the training again. Rather, they can take the certification examinations directly. Those who pass will receive their certification. Those who are found wanting in training can take the TESDA trainings prior to retaking the examinations.

Discussion: Moving forward

The policy anchors discussed above and scientific studies on the impact of appropriate wheelchairs were used as supporting arguments to push for training and certification of wheelchair service personnel by the Philippine government. Existing financing mechanisms for wheelchair provision also added impetus to this endeavor. State-sponsorship of training and certification of wheelchair service personnel will lead to an increase the workforce, creating a robust market for wheelchair products. This can stimulate more interest and investment on the wheelchair production, distributorship, and repair within the country.

Majority of the wheelchair supply in the Philippines is imported from China. Other wheelchair sources are USA, Japan and Spain. According to dealers of medical supplies, wheelchairs frequently bought are the transport/hospital type chairs with size 18” since this carries the cheapest price. However, none of the suppliers have a staff trained in wheelchair service provision.

One of the gaps identified by the PSWP in their 2017 Needs Assessment Report is the lack of local industry. There are several limitations in the local industry of wheelchair, such as limited products and spare parts that are not readily available (26). Hence, there is a need to place related products such as cushions in available wheelchairs.

Once national regulations on training and certification of wheelchair service personnel are in place, the next challenge will be to support the practice of the certified personnel. This will entail fixing the supply chain of wheelchairs. There are already several mechanisms identified which can fund the provision of wheelchairs. However, wheelchair service personnel must have access to a steady supply of wheelchair products. Access will also involve sustainable delivery mechanisms by tapping local couriers and cargo companies.

Conclusion and recommendations

The Philippines is on its way to having nationally sponsored training regulations and certification of wheelchair service personnel. A dedicated health policy team is instrumental in this project. A good understanding of context, content, process, and actors involved in the policy environment contributes to fostering a consultative and inclusive approach. Policy anchors complemented by scientific evidence helped convince policymakers to prioritize support for the endeavor.

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Innovation

The PELE Center: Making tailored solutions for children with disabilities

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Abstract

More than ninety million children around the world suffer from a moderate or severe physical disability¹. In developed countries technology has been a major contributor to enabling children with disabilities the opportunity to grow up and participate in a meaningful manner in society. Whereas in developing countries, less than 15% of the same children have access to the technology they need². In January 2018, ALYN Hospital in Jerusalem, Israel opened a new service to address this exact problem. The PELE Center focuses on finding customized, personalized solutions for children who face physical challenges to act independently in their day-to-day activities. PELE brings together ALYN staff and volunteer experts from various fields to collaborate in developing technologies and solutions that increase the independence of children with physical disabilities. PELE provides consulting services, guidance, and the design and manufacturing of assistive technologies by volunteer makers to produce adaptable, adjustable, accessible and affordable innovative assistive technology solutions. Solutions developed are available open-source for the benefit of children worldwide. To date 420 challenges have been submitted to the PELE team and 230 solutions have been developed. Out of the 420 challenges, 17 have been recognized as having potential commercial value and have been referred to the ALYNnovation Center to realize their potential.

Keywords

Assistive Technology, children with disabilities, tailored solutions

Introduction

Ninety-three million children worldwide (five percent of all children under 15 years of age) have a moderate or severe physical disability (1). In Israel alone, more than 200,000 children have been identified as having a physical disability sufficiently severe as to impact on their daily functioning (2).

Specialized technologies can significantly help these children overcome their limitations and participate fully and meaningfully in society. However, many children remain limited by a physical disability because devices that could help them either do not exist or are only partially successful for them. Although the actual number of children is not known, the

World Health Organization has reported that, at least in developing countries, less than 15% of those in need of assistive technologies actually have such assistance (3).

The WHO in their report (4) state that assistive technologies reduce care costs. Access to assistive technology enables children with disabilities to attend school, attain employment and be productive adults. This effects entire families and communities (family members of people with disabilities are unable to participate in school/employment due to caregiving responsibilities) (4). People with disabilities are more likely to be unemployed and earn less even when employed (4). Less than 20% of working-age people with disabilities dependent upon mobility devices are employed. It has been shown that more than \$150 billion have been lost in USA tax revenue annually due to limited utilization of people with disabilities in workforce.

There are several reasons for the lack of appropriate rehabilitative devices for children with disabilities. When developing technologies, market size and financial profitability are a key factor. Commercial companies focus on the larger and more lucrative adult market than on the smaller pediatric market. Although technologies developed for adults are often used for similar pediatric applications - due to lack of an alternative - these adult solutions are often unsuited to children because children are not simply "small adults", but have their own, unique, reality. To be successful, a rehabilitative technology needs to address the child's limitation holistically, offering a solution for the child not only as an individual, but also as part of a family, part of an educational system and part of a social group. Commercial companies, in contrast, tend to focus only on "the physical problem". Children with physical disabilities (like all children) constantly grow and develop, requiring their technological solutions to change in parallel. Pediatric devices therefore require "flexibility" and "adjustability" as design features more often than do adult devices.

For the product to be relevant for a child the design process has to be more rapid than that for adults, to ensure that the eventual product is still appropriate for the child that it was initially designed for.

As off-the-shelf solutions are often unavailable for specific individual challenges, creative thinking and novel solutions are often required for each individual child. There is therefore a need to encourage the development of novel rehabilitative technologies that are designed specifically for the pediatric population, based on a holistic understanding of the dynamic needs of disabled children, and in a manner that is rapid and flexible.

ALYN Hospital's objective was to develop an innovative service where all children could come and solve everyday challenges that inhibit their independent function, their ability to participate in childhood activities/play and limit their ability to become contributing adults in society. Moreover, our objective was to help children globally with similar challenges and to facilitate and expedite the development process of open source, affordable solutions by providing instructions on how to develop the solutions.

ALYN Hospital in Jerusalem, Israel is a renowned pediatric and adolescent rehabilitation center. ALYN has been treating children from birth to young adulthood with a broad range of congenital and acquired conditions since 1932. Children from Israel and abroad are treated with a holistic approach to help each child according to his/her specific needs.

ALYN Hospital collaborated with the National Insurance Social Funds to build the PELE Center as part of ALYN's Innovation Space. The center opened in January 2018. PELE is a Hebrew acronym for "solutions for children by ALYN" and it literally means, "wonder".

PELE focuses on finding customized, personalized solutions for children who face physical challenges to act independently in their day-to-day activities. PELE brings together ALYN staff and volunteer experts from various fields to collaborate in developing technologies and solutions that increase the independence of children with physical disabilities. PELE provides consulting services, guidance, and the design and manufacturing of assistive technologies by volunteer "makers" to produce adaptable, adjustable, accessible and affordable innovative assistive technology solutions.

PELE is focused on individual tailored solutions, but therapists and children also identify general challenges or barriers in their environment that limit their ability to function and these challenges are also addressed by the PELE team.

Methods

The PELE Model

The concept behind having PELE within ALYN Hospital is to enable a "One- Stop-Shop" for parents, children, therapists, volunteers, entrepreneurs, designers and academia. The One-Stop-Shop includes the physical space, the therapists and their vast expertise, the technical staff/volunteers, children and their families and entrepreneurs.

The physical space is a newly renovated state-of-the-art laboratory (500 square meters). The center uses a well-equipped workshop which has carpentry, welding, electronics and sewing capabilities as well as 3-D printing, laser cutting and more to manufacture and develop prototypes to try out with the children.

The therapists include the multidisciplinary staff members- physicians, nurses, physical therapists, occupational therapists, speech and language pathologists, psychologists, social workers, educators and IT specialists. The staff is encouraged to be creative and is dedicated to the wellbeing and independency of each child. The staff members are leaders in their fields and are very knowledgeable about the children's diagnosis and the effect on function and also about the available technology to enhance the child's function. The therapists work with each child and when a challenge is identified that cannot be solved with existing or attainable solutions, they turn to PELE.

The technical staff and volunteers (3 full time employees and 16 volunteers) include mechanical, electrical and material engineers, a seamstress, carpenters, product designers,

3-D specialists, a robotic specialist and fashion designers. Each staff member is matched with a team developing specific solutions according to their expertise. In addition to the technical staff who develop the solutions, digital, marketing and new -media specialists document and publish the solutions.

The children and their families turn to PELE when they recognize a challenge that is impeding their child's development, ability to participate in childhood activities or to perform activities of daily living.

The Referral Process

A child/ family or therapist submits a challenge to the PELE team. When possible, the team meets with the child to assess the challenge. In other cases, videos are submitted to visualize the challenge. Having the child involved in the process is an added benefit both to the development of an appropriate solution and to the child's own development. Being a part of the process teaches the child how to define their needs, give feedback, how to participate in team work, and perhaps most beneficial to the child is the realization that his/her opinion matters and that even the most incredible challenge can be tackled.

The PELE team confers and seeks additional information to see if an affordable solution is available. If one is not found the challenge is accepted to PELE.

A "challenge champion" is appointed from within staff or volunteers according to expertise. In some cases, the solution is straightforward, and the champion can develop the solution on their own or with minimal help. In other cases, a team is assembled to brainstorm. Therapists from ALYN are called to join the team and help formulate a solution.

Once a solution is decided upon, the parents are given a price quote (parents pay only for materials) and work is commenced once payment is received.

The children try out solutions and if needed, adjustments are made. The full process is documented in order to provide an open source solution for the benefit of children locally and globally. The open source file is supplemented with videos of the child or family using the solution. See Appendix for four examples of solutions made by PELE.

PELE Hackathons: PELETHONS

To kickstart a cascade of solutions and to generate public interest in PELE, we periodically hold an event we named "Peleton". A PELETHON is an intensive full day event where makers, therapists, engineers and creative people join forces to build solutions for children's requests. Each such event has yielded 6-10 practical solutions most of which could be presented to the children within a short time of the event. PELE has hosted four events and participated in six events organized by other organizations. ALYN's children benefit from being able to participate in the events, some with their own requests and others as makers to help their friends. We have experimented with adding social-educational impact to these events by including teams of typically developed and challenged children who help solve the challenges for their peers.

PELE's collaborations

In addition to internal collaboration, PELE is approached by universities (The Hebrew University, Holon Institute for Technology (HIT), Bezalel, Hadassah College and others), commercial companies and other industries offering to help develop solutions for the children. The universities send their students to work with PELE and develop solutions according to their studies plan. For example, Product Design majors from HIT worked on developing six solutions for children in ALYN Hospital's kindergarten (a solution for independent gardening for a child without hands, a solution for independent drawing for a child too weak to hold a crayon). When a challenge is an environmental barrier, or time is less of essence, or when specific talents are needed, we try and enlist engineers through their firms' corporate social initiatives. Most hi-tech industries are very helpful and are eager to collaborate in an opportunity to help a child be more independent. See Appendix for examples made in conjunction with partners.

Individual entrepreneurs also approach PELE with ideas or prototypes that they have developed. In some cases, the PELE team works together with them to further develop the solution. Other times, ALYN can offer its services as a beta site to try out the solution with ALYN's children.

Young entrepreneurs from local high schools enrolled in an Innovation track program spend a semester working with the children with disabilities in PELE to formulate and build a prototype to solve a specific problem they face. In the past two years, solutions developed for the children of ALYN have won local and international prizes. Having teenagers as part of the team teaches them to accept others and to realize that the children with disabilities are not very different than themselves.

Students applying for internships from local and international universities are also part of the PELE team and contribute to the development process.

The majority of the solutions developed in PELE are personalized solutions suited for specific children. When a solution has the potential to benefit a larger population, it is referred to our ALYNnovation Center for further development. PELE and ALYNnovation then collaborate to develop the product.

Findings

PELE officially opened its door in January of 2018, but it served children with disabilities for many years. Starting from 2018 PELE has received 420 challenges. It has developed 230 solutions for the benefit of 300 children in Israel and abroad. PELE has received submissions from a number of countries besides Israel.

In four PELETHON events, 400 participants joined forces to solve 35 challenges.

PELE collaborates with 6 universities and 8 business companies to benefit the children of ALYN. Parents and therapists are contacted after initial use of the product to see if it is beneficial or if changes are needed.

Discussion

Assistive technology enables children with disabilities to be more independent and productive. The technology is not always available and when it is, it is not always affordable. As a society, we believe that we have a duty to decrease barriers for children with disabilities. In some cases, technology is the solution.

Developing solutions for children is more of a challenge than working on a problem for an adult. The solutions need to be developed quickly or the child's need, interest or ability might change before the solution is provided. The result must be modular and flexible enough to be compatible with a child's ever-changing needs and size.

Children developing solutions for children with disabilities is a model that we found to be beneficial for all involved. The children that were working on the solutions could identify with the children's needs and wants. They also had a fresh outlook on the challenge and were not limited by previous preconceptions.

Working with big commercial companies such as Intel, Microsoft, Rafael, Medtronic, Orcam, J&J and others provided us with an extensive support team.

The challenges our kids in Israel face probably reflect the needs of children everywhere. Today, the world has become an online-connected market. It is important to document the challenges and solutions so that people with disabilities world-wide can benefit from the work done in a specific country.

PELE calls for the WHO to formulate an online library to upload solutions for the benefit of people with disabilities globally.

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Appendix

Challenges and their solutions

Figure 1a. Elkana, 19 years old with Duchenne

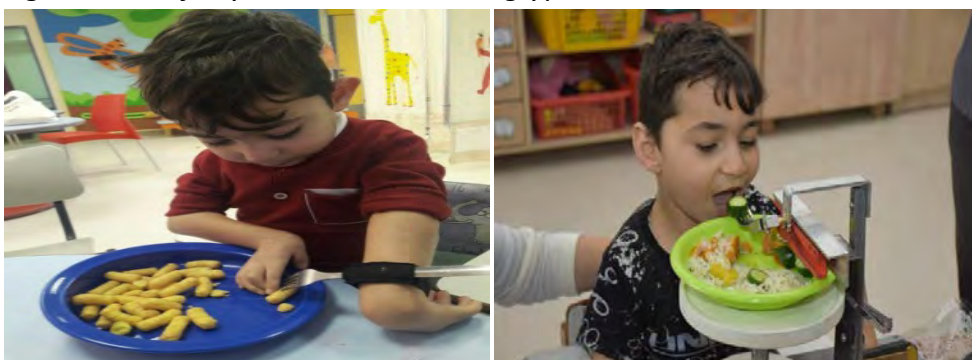


Figure 1b. Elkana, 19 years old with Duchenne



Elkana lives in the Independent Living Neighborhood in ALYN Hospital. Elkana wanted to water the plants independently. The team built a hose mounted on his powered wheelchair that was switch activated.

Figure 2. Yosef, 5 years old with Arthrogryposis



Yosef is not able to bend his elbows to feed himself. He wanted to be independent like his friends. The team tried a number of solutions, including modified commercial solutions, like an universal cuff. After many trials a rotating platform was built that Yosef could turn independently with a lever that collected the food from the plate and lifted it to his mouth (<https://www.youtube.com/watch?v=GWIqob1ZAaw>).

Figure 3. Chaiya, 5 years old with multiple disabilities



Chaiya loves to draw. She is not able to take the lid off the color pens. The team made a rotating pallet with holes that she could put her color pens in and pull. The pallet was printed on a 3-D printer.

Figure 4. Talla, 12 years old with amputations and significant burns



Talla was in a car accident and suffered numerous burns. She lost her hands and has burns all over her body. Talla loves gardening. She couldn't plant seeds or water the plants. A set of tools were made for her (<https://www.youtube.com/watch?v=Xy0LXaYuA6o>).

Mobile phones as assistive technologies: Gaps and opportunities

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Abstract

In the last decade, mobile phones have become invaluable allays in the everyday lives of people with disabilities. Even in low and middle-income countries mobile phones are highly popular and the penetration rate of mobile technology is almost three times higher than for desktop computers and broadband lines. Despite their diffusion and their importance, large datasets on how people with disabilities in lower resourced settings use mobile phones, the services they access and the barriers they encounter when interacting with mobile technology, are scarce. This article presents data from a survey with 1000 participants that explored how people with disabilities use mobile phones and the impact that mobile technology has on their daily lives. Findings highlight the presence of a mobile gap with many people with disability struggling to acquire and operate mobile phones independently. Most respondents had only access to basic or feature phones that lacked appropriate accessibility features and offered limited functionality. However, participants still described mobile phones as invaluable tools that could increase access to basic services and offer support in many important activities in their daily lives.

Keywords

Mobile phones, Applications, Accessibility, Mobile data, Smartphones

Introduction

Assistive products are generally defined as products whose “primary” purpose is to support the independence and promote the wellbeing of people with disabilities (1). However, it is important to remember that there are also other products which are equally important to the everyday independence and wellbeing of people with disabilities. These technologies might not have specifically been designed with that purpose in mind but add benefit none the less. Mobile phones are an interesting and potentially unique case as they simultaneously belong to both categories of products. A mobile phone can effectively work as an assistive technology (AT) in one of two ways. Firstly, a mobile phone can offer important support to a person with disabilities through built-in features or applications that

were not specifically designed with that purpose in mind (2). For example, a mobile phone can easily be used by a person with memory loss to receive text messages with reminders about which medication needs to be taken when. Alternatively, a mobile phone can work as an AT due to external applications or accessibility features that were explicitly designed for people with disabilities (2). For example, a person with a visual impairment can use an application such as BlindSquare to receive relevant information about their surroundings in order to locate shops or other points of interest and navigate to these. Due to their versatile nature, mobile phones have the potential to become incredibly powerful, bespoke and cost-effective tools for people with disabilities, essentially clustering together multiple ATs in a single device (3).

Arguably, laptop and desktop computers can offer similar capabilities. However, the penetration rate of laptops and desktop computers is significantly lower than for mobile phones. In many low and middle-income countries (LMICs), the diffusion rate of these technologies rarely goes above 25% of the total population (4). On the other hand, mobile phones have become nearly ubiquitous in most countries around the world with over 5.1 billion users recorded at the end of 2018 (5). In contrast with more expensive and infrastructurally complex technologies such as landlines or laptop computers, mobile phones are intrinsically portable and more likely to be accessible even to the poorer segments of the population, which unfortunately include most people with disabilities (6). Yet, although mobile phones are getting more widespread and sophisticated, many people with disabilities in LMICs still encounter significant difficulties in leveraging them effectively to eliminate or reduce the impact of their disability (7).

For example, many built-in features and applications that can be used as ATs are only available on smartphones, whereas many people with disabilities only have access to basic or feature phones (8, 9). Furthermore, many applications rely on the use of mobile data which could represent an additional barrier for people with limited incomes. Finally, to take full advantage of certain applications or accessibility features a person needs to have a sufficient level of digital literacy that many people with disabilities might not possess due to a lack of training and adequate support (10).

Most of the current research on the availability and use of mobile technologies by people with disabilities is, as expected, largely focused on high income countries (11,12). Geographical and cultural context can radically change how people access and use mobile technologies due to the availability of different devices and services, the state of physical and legal infrastructures, the implementation of specific policies by various mobile operators and the personal preferences and concerns of individuals who might live in very different situations. Developing international or even global policies and interventions based on data gathered mainly in high income countries could lead to the formulation of solutions that exacerbate the digital divide rather than lessening it.

Especially in domains such as Human Computer Interaction and Computing in general, recent efforts from researchers and developers on improving the functionality of mobile

phones for people with disabilities, have mainly focused towards the development of novel smartphone applications to facilitate access to education (13), healthcare (14), public transport (15) or leisure opportunities (16). Although these efforts are laudable and could generate a positive impact on the everyday lives of people with disabilities, many mainstream mobile-based services and applications still remain largely inaccessible (17). Interestingly, the development of new AT mobile applications seems to be targeting some groups of people with disabilities more than others. In particular, in recent years a significant amount of effort from the mobile technology community has been invested on the development of new applications to support people with visual impairment, especially within the context of independent navigation (18). In contrast, significantly fewer applications seem to be specifically targeted towards individuals with a hearing impairment. However, previous studies have suggested that people who are deaf are more likely to own and use a smartphone or a tablet compared to blind people (19). This discrepancy suggests that there is a disconnect between baseline research and development of specific applications which needs to be addressed in order to formulate clear and cross-cutting recommendations that could enable a more coordinated effort from the various actors within the mobile technology ecosystem.

Generally, the research on mobile phone ownership and the benefits and barriers associated with its usage among people with disabilities who live in LMICs has used small datasets (20) and is focused on very specific groups (21) making it difficult to create more generalised recommendations. Gathering larger and more comprehensive datasets will allow researchers, developers, governments and mobile providers to formulate comprehensive guidelines, promote country-level and international policies, implement better services and develop new functionalities where appropriate. However, it is important to ensure that new datasets collected can also be easily disaggregated into relevant subcategories to facilitate the development of a more detailed understanding of the needs of different mobile phone users with disabilities.

The aim of the study was to capture a comprehensive picture of how people with disabilities in Kenya leverage the potential of mobile phones to overcome difficulties they encounter in their everyday lives. Data is collected and analysed as part of a survey on mobile phone usage among people with disabilities in Kenya to present an overview of how people with disabilities in a LMIC access and use mobile phones and services, and the resulting benefits or barriers encountered in their lives. Based on the results presented, we will provide a series of recommendations for researchers, mobile operators, developers and government agencies on how mobile products and services could drive inclusion of persons with disabilities in LMICs. The study was funded by the United Kingdom's Department for International Development as part of the larger AT2030 programme which aims to increase access to ATs for people with disabilities who live in LMICs.

Approach

To quantify access and usage of mobile phones and services, a survey with 1000 participants has been carried out in Kenya between May and June 2019.

Survey data were collected in collaboration with local agencies that employ interviewers with experience gathering survey data. Interviewers received appropriate training before the start of data collection to ensure that data were collected in a systematic manner and that participants' rights were respected at all times. Participants were identified and recruited through a variety of methods. Survey sessions were held in community spaces on predefined days and local Disabled People's Organisations (DPOs) shared within their networks a series of calls for participants with the details about location and date for each session. Other participants were recruited directly by the interviewers at specific events for people with disabilities such as sport events or community gathering. Some participants were recruited via word of mouth or directly via phone by the volunteers at DPOs who had their contact details. All participants were briefly screened by the interviewer who also explained the research and enquired about their willingness to participate. Before the start of the survey, each participant was given an explanation of the purpose of the research, the structure of the survey, data handling procedures and their rights as participants. Interviewers read each question aloud to the participants in order to enable individuals who were unable to read, due to visual impairment or illiteracy to take part in the research. The questionnaire was administered in English, Kiswahili or Kenya Sign Language depending on the preferences of the participant and the responses were digitally captured by the interviewers.

As we wanted the dataset to be as inclusive as possible, participants with different functional impairments were recruited for the study. An approximate quota of 200 individuals for each of four categories (vision, hearing, mobility, speech/memory) of functional impairment was established to guarantee equal statistical representation to each subgroup. To enable for comparison between people with disabilities and nondisabled people, a group of 200 nondisabled respondents was also included in the survey. Nondisabled respondents were mainly recruited by random selection by volunteers on the streets in the same communities in which people with disabilities had been recruited. Furthermore, to ensure sufficient variability in the dataset, people of different gender, educational level, socio-economic status and geographical location were included in each subgroup. This was achieved by setting sub-quotas for gender, age, environment (urban/rural) and income level which were weighted on the latest census data to guarantee the representativeness of the sample. Disability status and categorization were determined based on the recommendations and reports made by the different DPO's that identified participants.

Individuals under the age of 18 were excluded from the study as only participants who were old enough to provide legal consent were allowed to take part in the study. Individuals who, based on recommendations from local DPOs or their caregivers were unable to understand

what participating in the survey meant and who were not able to provide informed consent independently were excluded due to ethical concerns.

The survey was structured across six different parts: Classification of impairment, Mobile phone access and ownership, Mobile phone usage, Access to basic services and participation in society, Difficulties with mobile phone usage, Socio-demographic characteristics.

- **Classification of impairment:** This section of the survey featured six questions directly extracted from the Washington Group short set questionnaire on disability and focused on identifying the type of impairment that the respondent was affected by.
- **Mobile Phone Access and Ownership:** This part of the survey revolved on determining if the respondents directly owned mobile phones and SIM cards or if they were able to access them through family members, friends or local organizations. Reasons for lack of ownership or reduced access to a mobile phone were also explored.
- **Mobile phone usage:** This section of the survey explored the usage of different mobile services (such as voice calls, text messaging, mobile internet, mobile money and other applications), the frequency of use for different types of services and the reasons determining frequency of use.
- **Access to basic services and participation in society:** This section of the survey investigated the level of access that respondents had to various basic services such as healthcare, education, employment, transportation and financial services. The impact of mobile phone usage on people's ability to access various services was also analysed.
- **Difficulties with mobile phone usage:** This section of the survey looked at the different barriers encountered by respondents when using mobile phones in general and when accessing specific applications or mobile services. The use of additional ATs in combination with the mobile phone (such as braille keyboards, magnifiers, text-to-speech technology) was also explored.
- **Socio demographic characteristics:** This section of the survey aimed to capture general characteristics of the respondents (such as gender, education level, age group).

Statistical analysis was carried out on the data collected to identify relevant groups of respondents and to present an overall map of how people with disabilities access mobile phones, the services they use, the barriers they encounter and the impact that the use of mobile phones have on their everyday lives. Written informed consent was recorded before the start of the survey for all participants. Participants who were unable to sign the informed consent sheet due to illiteracy or visual impairment were asked to sign their consent using their thumbprint. Procedures for ethics approval and data protection compliance as stated by the UCL ethics committee were appropriately followed.

Findings

A total of 1005 completed surveys were collected. Impairment quotas were respected as responses were categorized as follows: 201 from participants with visual impairment, 220

from participants with hearing impairments, 206 from participants with mobility impairments, 182 from participants with impairments affecting speech/memory/cognition/self-care (common causes reported for such impairments were stroke, dwarfism, depression, cerebral palsy) and 196 from participants who reported no impairments. When comparing responses to the WG questions with the categorizations based on the recommendations made by DPOs we found the a priori classification to be mostly correct, however, few discrepancies were found. For example, 15.9% of people who declared to have severe or insurmountable difficulty seeing even when wearing glasses were not directly assigned to the visual impairment subgroup. Although of these 8.8% were participants with multiple disabilities who had a visual impairment associated with difficulties in mobility or hearing, the remaining 7.1% were classified as nondisabled people. Despite these discrepancies that the total percentage of people with disabilities among respondents according to the WG questionnaire and according to DPOs recommendations were found to be mostly similar and were respectively 81.2% and 80.5%. Ultimately, we relied on the assessment that identified the most people with disabilities. For example, some people with difficulties remembering and concentrating were identified as people with disabilities by relevant DPOs despite only stating that they encountered “Some difficulties” in the WG questionnaires. On the other hand, people who reported “A lot of difficulty” in one of the WG questions were reassigned to the relevant impairment category regardless of the DPO assessment.

Across both people with disabilities and non-disabled people, the distribution of survey respondents was found to be mostly homogeneous across different demographic and social characteristics. Forty six percent of the respondents were female and 52.3% reported living in an urban environment. Younger age groups were in general better represented with 50.6% of participants between the age of 18 and 34. Participants between 35 and 44 years of age and between 45 and 54 years were respectively 22.6% and 12.5%, whereas only 14.2% reported to be above 55 years old. Educational levels were generally high with 34.8% of participants stating that they completed higher education and 30.8% had completed at least secondary school, 26.3% had completed only primary school and 8.1% had received no formal education. Despite the high level of education, only 42.3% of respondents reported to be regularly employed, either self-employed or employed in the private or public sector.

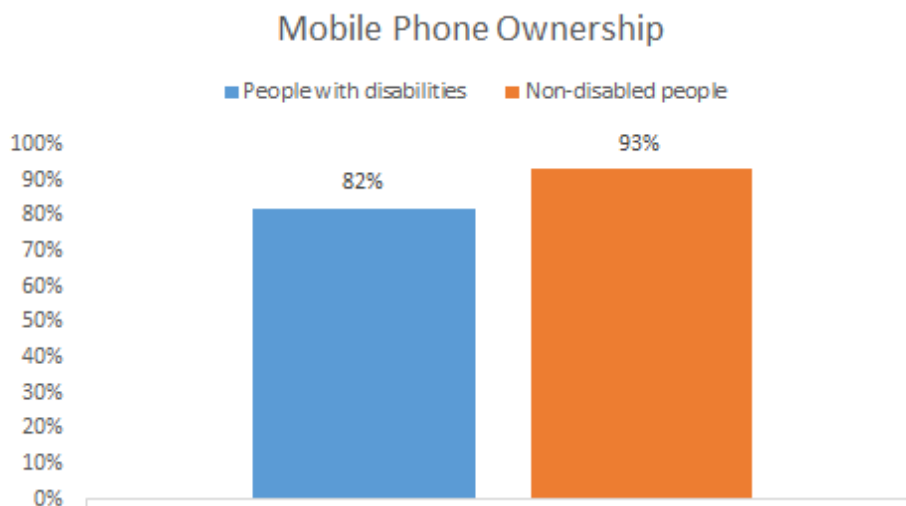
Mobile phone ownership was found to be significantly lower for people with disabilities compared to nondisabled people. As shown in Figure 1 below, only 82% of people with disabilities reported the ownership of a mobile phone compared to 93% of non-disabled people, establishing a mobile gap of 12%¹. Over one third of people (36.4%) who did not own a mobile phone did own a mobile SIM and more than two thirds of people (71.6%) who did not own a mobile phone were able to access one occasionally through friends, or family

¹ The disability gap in mobile phone ownership tells by how much people with disability are less likely to own a phone compared to non-disabled persons. It is defined as follows:
(% non-disabled owners - % owners with disabilities) ÷ (% non-disabled owners)

members. However, when people with disabilities accessed a mobile phone via a third party they often encountered restrictions regarding cost, frequency or duration of use and the level of autonomy they were allowed to have during use.

Among people with disabilities, mobile phone ownership levels did not seem to be affected by their living environment, but it was moderately influenced by type of impairment and highly influenced by level of education and age. Almost 90% of people with vision, hearing, mobility or communication impairments owned a mobile phone, compared to approximately 80% of people with cognitive impairment or people who encountered significant difficulties with self-care tasks. Education was found to be the biggest differentiator with 99% of people who obtained higher education reporting possessing a mobile phone compared to 77% of people who had received no formal education.

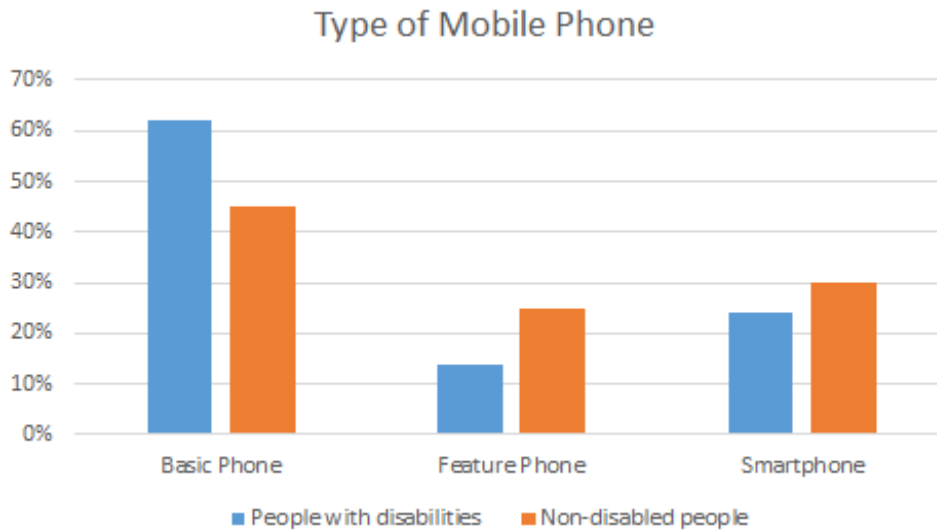
Figure 1. Bar Chart showing the rate of mobile phone ownership among people with disabilities and non-disabled people



When looking at the reasons for not owning a mobile phone, cost was found to be the main one. Over 50% of the people who did not own a mobile phone thought that the device was simply too expensive to buy and another 10% found that the cost of airtime was too high. Perceived physical or cognitive limitation associated with personal impairments prevented 15.9% of respondents from owning a mobile phone and lack of confidence due to no digital skills training was a deciding factor for 9.1% of participants.

When looking at the type of phone accessed, people with disabilities were significantly more likely to have access to basic mobile phones. On the other hand, as shown in Figure 2, over half of non-disabled people had access to either a smartphone or a feature phone.

Figure 2. Bar Chart showing the type of phone owned by people with disabilities and non-disabled people



People with disabilities are not only less likely to own a mobile phone, but they are also less likely to be able to use various services independently once they have access to a mobile phone. Only 54% of people with disabilities were able to make or receive calls autonomously compared to 91% of non-disabled people. Similarly, only 47% of people with disabilities were able to send and receive SMS without help, compared to 74% of non-disabled people. Mobile internet and applications for messaging, entertainment and social media were only fully accessible for 24-29% of people with disabilities compared to 33-40% for non-disabled people. Finally, specific apps for transport, maps and other services were only accessible to 18% of people with disabilities compared to 29% of non-disabled people. Thanks to the M-Pesa service, mobile money has become increasingly widespread and more accessible to both people with and without disabilities in Kenya (23). This was shown by the fact that over half of respondents with disabilities reported being able to access mobile money services independently and the rate increased to 78% among non-disabled people.

Amongst various groups of people with disabilities, people with visual impairments appeared to be the most disadvantaged when it came to be able to use mobile phone independently, regardless of the application considered. The most accessible mobile service to people who were visually impaired was making and receiving calls, which only 34% of respondents were able to do independently. SMS and Mobile money were only accessible to respectively 16% and 18% and all other services and applications were accessible to less than 10% of visually impaired users. As expected, 94% of hearing impaired participants and 82% of speech impaired participants were unable to make voice calls independently. However, most of them were able to use SMS services (76% hearing impaired and 69% speech impaired) autonomously.

Only 22.6% of participants with disabilities reported using accessibility features such as text-to-speech, voice commands and magnifiers, in order to be more independent when using the mobile phone. The use of accessibility features was found to be more common amongst speech impaired (24%) and hearing impaired (20.1%) respondents compared to other impairment sub-groups (16.6%). The impairment group who reported the lowest use of accessibility features was visually impaired with only 12%. The lack of accessibility features was also one of the most often cited barriers to mobile phone usage, although many respondents frame this as a limitation caused by their impairments. Other significant barriers to mobile phone use were cost (of mobile phones themselves, airtime and accessibility features such as apps or external products), illiteracy and lack of knowledge on how to effectively use the mobile phone.

Despite the difficulties encountered when attempting to use various mobile services, most people with disabilities reported using their phones on a daily basis. Figure 3 and 4 show the frequency of use for SMS and voice services for both people with and without disabilities. Although in general mobile phone usage was less frequent among people with disabilities, the frequency of use for specific services was affected by the type of impairment of the individual. For example, respondents who had a hearing or speech impairment, were more likely to use SMS texts and mobile money than their non-disabled counterparts. On the other hand, only 6% of respondents with a hearing impairment and 14% of respondents with communication difficulties were able to make and receive voice calls independently. Finally, although only a few people with disabilities had access to mobile internet through their phones, the ones who did were as likely to access it on a daily basis as respondents who were non-disabled.

Figure 3. Bar Chart showing the frequency of voice call use among people with disabilities and non-disabled people

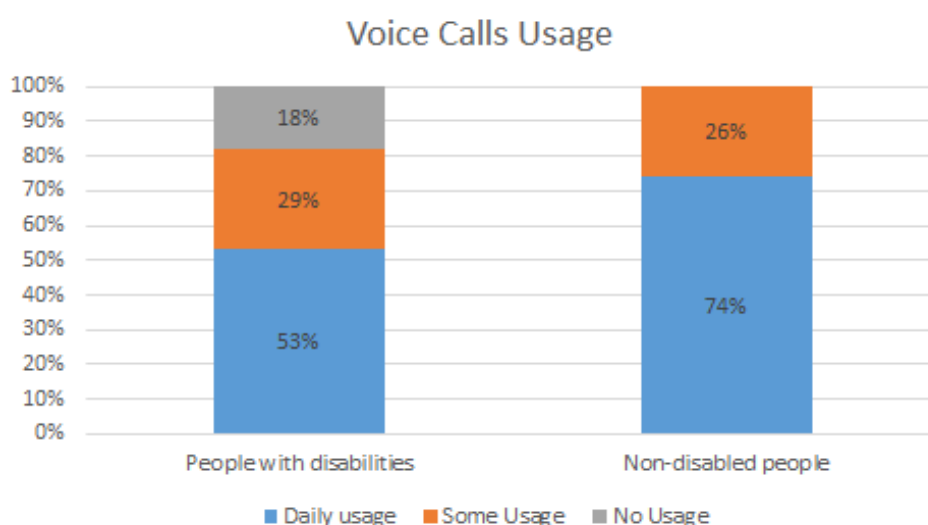
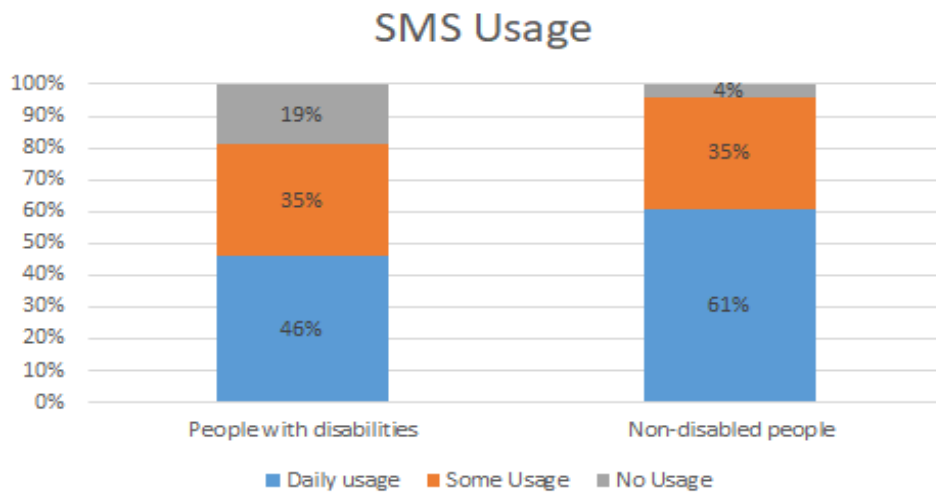


Figure 4. Bar Chart showing the rate frequency of SMS texting use among people with disabilities and non-disabled people



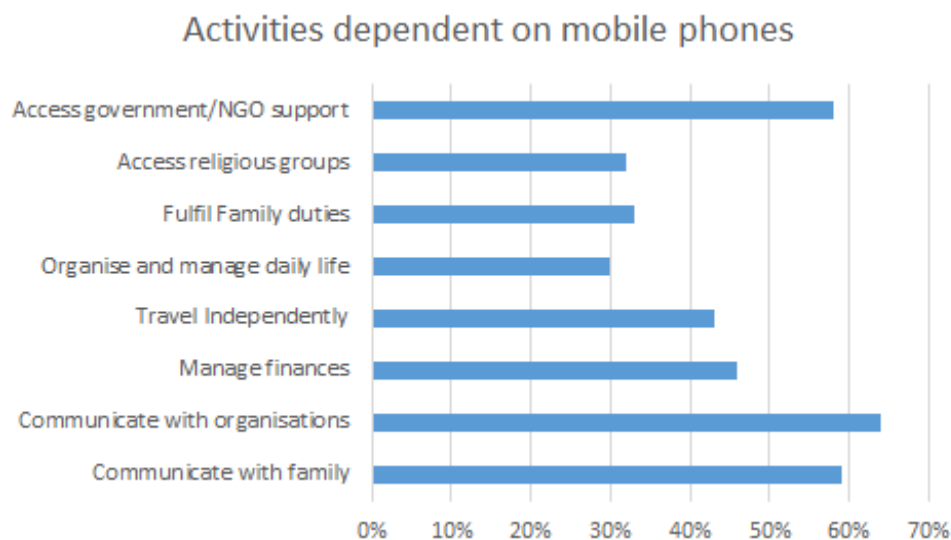
As expected, most respondents who had a disability reported limited access to basic services such as healthcare, education, employment and transportation. However, it was surprising to see that the level of access to different services were often similar for people with no disabilities. For example, 57% of participants with disabilities stated that they had no access to employment, which was also reported by 52% of non-disabled respondents, creating a gap of “only” 5%. A larger gap between people with and without disabilities was recorded for education (9%), whereas people with disabilities were found to be more likely to have full access to healthcare services when compared to non-disabled people (respectively 25% and 19%).

Most respondents stated that mobile phones had been a crucial enabler for their ability to access different basic services. Across all types of impairments, approximately one third of participants found that mobile phones had provided significant help in accessing healthcare (33%), education (33%) and employment (36%) services. Higher rates were reported for transport (43%) and financial services (62%). However, these findings varied considerably depending on the type of impairment. For example, only 26% of people with hearing impairment stated that mobile phone use had a significant impact on their ability to access transportation. However, the rate increased to 45% for people with reduced mobility and to 72% for people who had difficulties remembering and concentrating. Furthermore, great differences were also observed among participants who had similar impairments but had access to different types of mobile phones. Among people with visual impairments, only 36% reported that their mobile phone facilitates them in gaining access to education, but the rate almost doubled (71%) when looking only at visually impaired users who had access to a smartphone.

Owning a mobile phone was found to be not only important to access basic services, but also in support to many daily activities that are crucial for the personal and social wellbeing

of the individual. Figure 5 shows the rate of participants with disabilities who declared that they would be unable to complete certain activities without their mobile phones.

Figure 5. Bar chart showing the percentage of people with disabilities who described their mobile phone as "essential" for carrying out different activities



Discussion

Results from this large-scale survey present a complex and detailed picture of mobile phone ownership and usage among people with disabilities in Kenya, their role as activity enablers, and the difficulties encountered in their daily lives when using mobile phones or accessing mobile services.

When recruiting participants to take part in the survey, we relied on recommendations made by local DPOs to identify a sufficient number of participants to reach our quotas for different types of impairment. It is worth noticing that, as mentioned in the findings, when analyzing the responses to the WG questions collected as part of the survey we found a few discrepancies between the perceived severity of the impairment and the classification provided by DPOs on the ground. These discrepancies were only minor if, for the purpose of our stratification, we assigned participants to a particular impairment group if their response to the related WG question was at least “Yes - a lot of difficulty”. Nonetheless, we found that a lot of participants who were not registered as people with disabilities with their local authorities, nor had been identified as people with disabilities by relevant DPOs, responded to at least one of the WG questions with “Yes - some difficulty”. This underreporting of functional impairments, despite experiencing quite significant difficulties in everyday lives is in line with what shown in both Kenya and Cameroon when subjective estimation and objective assessment of impairment were compared (22). Findings from this survey corroborate previous evidence that highlights how both government and DPOs services often underestimate the number of people with disabilities in the country.

Overall, most people with disabilities in Kenya reported owning a mobile phone. Such a high diffusion rate points to the importance of leveraging mobile technology when developing new AT products or service delivery models in order to reach the largest possible number of people with disabilities. Over two thirds of people who declared that they did not own a mobile phone stated that they were able to access one when needed through family members, friends or local organizations. However, mobile access through third parties was often sporadic and subject to heavy restrictions, which severely limited the independence of the person and the potential positive impact of the mobile phone. Although individuals with intellectual challenges or particularly severe functional impairments might not have been able to take part in the survey, they are likely to also experience these barriers and not enjoy full access to a mobile phone.

Mobile phone ownership was less common among people with cognitive and self-care impairment, which were also the most likely to have multiple impairments. This trend is particularly problematic as people with more severe and multifaceted disabilities are more likely to experience social exclusion (23), hence they are the ones who would benefit the most from the ability to use a mobile phone without restrictions. Mobile phone access was also influenced by the level of education of the person. People who had generally received little or no education are less likely to be confident to use mobile phones. Moreover, someone with had no knowledge of mobile technology is unlikely to be able to foresee the potential benefits that a mobile phone could offer, and consequently is less likely to be willing to invest money in purchasing one. Although the decision to not own a mobile phone is not necessarily a negative one, people with disabilities should be empowered to make that decision in an informed manner to ensure that they understand the potential impact that mobile technology could have on their everyday lives.

Survey respondents confirmed results from previous research (8,9) showing that only a relatively small percentage of people with disabilities had access to smartphones, whereas the majority was only able to access basic phones. This finding is particularly relevant as researchers, developers and mobile phones operators continue to develop new products and services for people with disabilities that are only available to smartphone users. Although basic and feature phones have significantly less capabilities, they are almost twice as popular amongst people with disabilities living in LAMICs and they are often the only choice available to people with lower incomes.

As expected, the high cost associated with mobile phones was found to be not only one of the main entry barriers to acquiring and operating a mobile phone, but also one of the main difficulties encountered when attempting to access mobile services and accessibility features. This highlights the need to develop cross cutting strategies between, governments, DPOs, open-source developers and mobile operators that aim to reduce the various costs associated with mobile phones ownership and usage. Lack of training and knowledge of how to effectively use the mobile phone was also a significant barrier for many respondents with disabilities. Currently, some people with disabilities in LMICs might be able to receive a

mobile phone for free from a family member or friend, or through donation schemes run by NGOs. However, they rarely receive appropriate training that would enable them to become more competent users and to take full advantage of the possibilities offered by the technology. Within this context mobile phones represent a perfect example of how ATs cannot be simply considered as a standalone device but they need to be incorporated the wider ecosystem that encompass the various elements that determine the success, or failure of AT interventions. Individual elements of the system, from cost of devices, to education of users and operators will constantly influence each other, creating a complex system that needs to be considered in its entirety (24).

Finally, regardless of the difficulties and barriers encountered when using mobile phones, the large majority of the respondents considered them essential to their daily lives. Mobile phones were described as a precious tool in accessing services such as education, healthcare and transportation, but also to stay in touch with family and take part in religious and social life. Smartphones in particular were found to be extremely impactful enablers for many basic services and crucial everyday activities. Although this is largely due to the increased possibilities offered by a more advanced technological means, the development of new products and services for basic and feature phones could allow us to increase the impact of more affordable technologies to a wider range of people with disabilities. Putting disability at the forefront of the development of new products and services could revolutionise the mobile technology domain. Leveraging participatory and disruptive approaches as advocated by the new Disability Interaction (DIX) manifesto will enable the creation of innovative and inclusive solutions that would benefit not only people with disabilities but mobile users around the world (25).

Overall, mobile phones might not precisely fit the definition of AT, yet they represent one of the most powerful, ubiquitous and versatile technologies to support people with different disabilities in their everyday lives.

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Introduction of 3D printing technology for orthotic manufacturing in West Africa

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Abstract

Additive technologies intend to address a major barrier to access to rehabilitation services by combining 3 of the 6 main measures identified in the 2011 WHO World Report on Disability: 1) expanding and decentralizing delivery; 2) increasing the use and affordability of technology and technical aids; 3) increasing human resources for rehabilitation, in this case by compensating for the necessary but long training times, thus bringing existing resources closer to the huge needs of communities furthest from the services. The specific aim of this project was to strengthen the capacities of the OADCPH, a network based in Lomé (Togo) that brings together 68 rehabilitation centers in 22 African countries. A 3D manufacturing laboratory has been set up at the OADCPH to produce and supply "3D orthotics" to 4 rehabilitation centers in Togo, Mali and Niger. 4 professionals (2 P&O, 2 physiotherapists) per center have been trained in 3D printing technology and have practiced Telerehabilitation, i.e. fitting patients with the help of an expert P&O via videoconferencing. The Belgian partner, the Collège Universitaire Thomas More, supervised the research process, guaranteeing its scientific validity. By introducing 3D printing technology into the field of physical rehabilitation in West Africa, this operational research aimed to meet the challenge of increasing the productivity of current orthopedic technicians to reach more children and adults with disabilities, by inventing an intervention method to address the isolation of many patients living in dangerous areas, in conflict situations or with limited access. Basically, the chosen methodology was a crossover design study aiming to administer the 2 treatments consecutively to the same group of subjects. We conducted clinical and technological trials to evaluate the performance of orthotics printed in 3D by matching 100 patients successively with a "conventional orthosis" and then with a "3D orthosis" or vice versa. In addition to this clinical part, a qualitative study on the social impact and economic sustainability of this new method of intervention was carried out. The first results clearly demonstrated that, over the entire process, orthoses produced by additive technology offered a quality of service at least equivalent to the conventional production. These results were particularly encouraging considering the level of maturity of this technology and if we consider that the perspectives of progress are still largely to come. The first elements of cost and efficiency were also encouraging. To date, production costs

using the two processes are of an equivalent order of magnitude. In addition, an important positive point was highlighted: Initially professionals were reluctant to use these new technologies for fear of seeing their jobs disappear. Perception has changed, and this now seems to be a natural evolution for professionals. Improving skills is an important motivating factor. The future of additive technologies and tele-rehabilitation in the field of rehabilitation is certainly not to replace conventional approaches but rather to open up new perspectives and promising alternatives to extend and strengthen services to users. This first phase of the project must now be refined and looking for efficiency gains at each stage of the orthotics production chain.

Keywords

Additive technologies, tele-rehabilitation, orthotics manufacturing

Introduction

The IMP&ACTE 3D Project (3D Printing & Access to Telerehabilitation) examined whether 3D printing of orthoses (night splints, referred to as postural orthoses, and AFOs/KAFOs for walking, further referred to as dynamic AFOs/KAFOs) for the lower limbs can help to improve access to orthopedic devices in developing countries. It investigated whether the 3D printed orthoses were equally effective and evaluated the costs and feasibility of implementation. Remote support was provided via videoconferencing. The project was implemented between November 2017 and April 2019 in three countries in West Africa to explore how innovation can improve access to physical rehabilitation services for the most vulnerable and isolated people in low-income countries and in fragile humanitarian contexts.

Context of the study

Regarding clinical aspects

The use of additive manufacturing or so-called 3D printing has seen a strong development in recent years, due to the increase in various new materials and techniques that are becoming available, and also due to the ever-decreasing cost price. There have also been developments in orthopedics for many years concerning the application of digital measurements, digital corrections and 3D printing.

The study was conducted in Togo, Niger and Mali. A total of four orthopedic centers were involved, where a proportionate number of patients were recruited.

Recent scientific studies show that the functional clinical parameters in patients with lower-knee orthoses are similar in traditional and 3D-printed orthoses (*e.g.*, 1). These studies have been carried out with the production techniques that are available in Western countries.

There is a potential for the use of 3D scanning and 3D printing in developing countries. However, there are few large-scale studies on the use of 3D printing for lower leg orthoses in developing countries. This study hopes to contribute to filling this gap.

Regarding technical aspects

A majority of people with disabilities live in developing countries, meanwhile almost all major prosthetic / orthotic manufacturers are located in western countries and most of their products are aimed at the western market. As a result, the majority of people with disabilities do not benefit from technological developments in the production of orthopedic appliances. According to the World Health Organization (WHO), more than 30 million people in low-income countries need an artificial limb or an orthopedic device but only 5% to 15% of them can access to this service. The production is too low, often of poor quality, while the manufacturing time remains too long and therefore too expensive for patients, especially for those who have to travel long distances for their treatment. In addition, there is a shortage of trained personnel to manage the manufacturing of such equipment, particularly at the provincial and district levels.

During recent years we see an increasing interest from the orthopedic sector worldwide to use additive manufacturing (3D printing) for production of orthopedic devices. 3D printing is extremely suitable for producing complex anatomically shaped objects such as orthoses and prostheses. The use of this digital method of production brings a number of advantages such as a reduced waste production, improved accuracy and repeatability of produced orthoses, simple digital storage of 3D shape of the patient's limb and the orthopedic device. Moreover, a digital workflow that uses 3D scanning and 3D printing also offers the advantage that you can easily perform a 3D scan measurement at a remote location, and then send the 3D scan to a central Fab lab where the orthopedic device is designed, and 3D printed. Finally, the orthopedic device is sent back to the remote location where it is further finished before it is delivered to the patient.

In this way, the need for a fully equipped workplace at remote locations can be eliminated, making it easier and cheaper to help people with disabilities in remote areas.

Regarding social impact of the project

In 2016, Handicap International (Humanity & Inclusion) conducted a pilot project to test the added value of 3D printing technology for the fabrication of above knee prostheses in low-income countries (Togo and Madagascar) and in a war context (Syria) (1). This experiment highlighted the need to develop other operational research to scientifically validate the relevance of 3D printing coupled with tele-rehabilitation, to include other intervention contexts, and to test this technology on other types of orthopedic appliances, in particular, posture and walking orthoses which constitute a real need for children suffering from cerebral palsy and club foot, pathologies that remain neglected, and for adults with hemiplegia and other deformities.

It is in this context that the IMP&ACTE 3D project was developed and obtained funding from the *Direction générale de Coopération au développement (DGD)*, which seeks to encourage innovation in the humanitarian field by investing in new approaches to reach more vulnerable people and achieve greater impact and efficiency.

Goals and objectives

Regarding clinical aspects

The research part of this study had 3 goals:

1. to check whether the clinical impact of 3D printed lower leg orthoses is similar to traditional orthoses,
2. to evaluate patient satisfaction with traditional and 3D printed lower leg orthoses, and
3. to investigate the cost of 3D printed lower leg orthoses and evaluate the impact of the implementation of the new measurement and production workflow.

Regarding technical aspects

Within the Imp&Acte3D project we wanted to investigate the technical feasibility of the use of such a digital workflow in a West African context. Furthermore, we wanted to compare the clinical effects of orthosis produced with 3D printing with traditionally manufactured orthosis. The general technical objective of the project was the implementation of a complete digital workflow for the production of all orthopedic devices within the project. To achieve this general objective several specific objectives had to be reached.

Specific Objectives:

- Identify suitable 3D printing technique and 3D printers for use in this context.
- Test and identify 3D printing materials for the production of orthopedic devices.
- Determine a good set of print settings and print strategies to be used for the production of orthosis.
- Identify suitable 3D scanner and 3D scanning software + computer hardware.
- Train personnel from OADCPH to prepare 3D models for printing and operate and maintain the 3Dprinters.
- Set up a Fab lab facility with all necessary computer hardware, a controlled environment (temperature, humidity) and a stable power supply (back-up generator, solar panels, UPS, etc.) to ensure the proper operation of the 3D printers.
- Train clinical staff in the different orthopedic centers to use the 3D scanner and 3D scan software instead of plaster casting for measurement of the patient.
- Implement a digital rectification process using CAD software for O&P

Regarding social impact of the project

The study on the social impact of the IMP&ACTE 3D project was a complementary component of Mobilab's operational research on technological and clinical dimensions. If the Mobilab team focused on the feasibility, effectiveness, efficiency and quality of the new service offer offered by the IMP&ACTE 3D project based on 3D printing technology coupled with tele-rehabilitation, our study looked at the question of its social impact. More specifically, the objective was to collect qualitative data in order to demonstrate the added value of the new mode of intervention proposed by the IMP&ACTE 3D project compared to the existing one by:

- analyzing the perception and reception of the duo 3D printing / tele-rehabilitation to beneficiaries and professionals;
- identifying the social value created;
- describing the social and economic changes;
- identifying the organizational changes produced with stakeholders; and
- identifying the challenges related to the implementation of the duo 3D printing & tele-rehabilitation in order to propose possible solutions to perpetuate this new mode of intervention.

Approach

Regarding clinical aspects

There were two groups of patients; those who needed an (knee) ankle foot orthosis to walk (dynamic AFO / KAFO) and those who needed a night splint to correct the ankle or knee position. Adult patients (>18 years) with ankle instability (e.g. due to drop foot) or knee instability (e.g. as a result of polio) were recruited and fitted with a dynamic AFO and KAFO, respectively. Children (between 2 and 8 years) with a deformity of the ankle joint or genu varum /valgum were recruited and fitted with a postural AFO and KAFO, respectively.

The national ethical committees in Togo, Mali and Niger approved the studies. Adult patients and parents of children were informed about the research and signed a consent form.

All patients in the study received a treatment program in which a new traditional orthosis was fitted and where a new 3D printed orthosis was fitted. After they were equipped with an orthosis, they went back home and wore the device at home for two weeks (dynamic orthosis) or 25 days (night splint). When returning to the center, they were clinically tested, and interviewed. The order of application of both treatments was randomized in a crossover design. The patient was measured at the start of the trajectory (baseline), after the first treatment and after the second treatment period.

The primary outcome measures were different for both groups of patients: the walking time when performing the 10 meters walk test in the patients wearing the dynamic AFO / KAFO, and the measured angle (knee or ankle) in patients with a postural orthosis.

From a clinical perspective, the 10 meters walk test was performed by patients fitted with a dynamic orthosis, and the ankle or knee angles were measured by patients fitted with a postural orthosis. All patients filled in the OPUS Satisfaction with Devices questionnaire to evaluate the patient satisfaction. All different production steps were timed, and the costs of the material and components were registered to be able to compare the production process of the conventional and 3D printed orthoses. Lastly, the implementation process of the study was evaluated.

A repeated measures analysis of variance was performed to test for significant differences in measurements at different time points. To compare paired data, which did not include

different time points, paired t-tests or Wilcoxon signed rank tests were performed, depending on the type of data.

Regarding technical aspects

In order to determine the most suitable 3D printing technique and 3D printer to be used within the project, different printing techniques and printers were evaluated on different criteria such as price, accuracy, complexity of the print process, printer specifications, printer reparability, sensitivity to environmental factors, available printing materials and availability and price of these materials. In a next step, several 3D printer producers and resellers were asked to print sample orthosis to get a better idea of the accuracy, print speeds and capabilities of the different 3D printers. The FDM (Fused Deposition Modeling) technique was chosen over other techniques, such as, laser sintering, multi jet fusion or SLA (Stereolithography Apparatus). The main reasons for this choice were the lower complexity of the FDM print process compared to the other processes, the reparability, the price of the available printers, and the sensitivity of the print process to environmental factors. In the end, two Stacke FDM printers (Stacker S2 and Stacker S4) were bought. Numerous other FDM printer brands were compared, such as German reprop, WASP and aon3D. The printer specifications of the WASP 3D printers were similar to the specs of the Stacker printers, but these printers were not chosen due to poor accessibility of the distributor.

The same exercise was done for the 3D printing materials. Different materials were evaluated taking into account printability (low warping), price/kg, impact resistance, strength, hygroscopic nature, adaptability after printing (grinding, drilling holes, attachment of straps, etc.). Once it was decided which 3D printers would be used within the project, a series of lab tests was conducted to determine the influence of print strategies and print settings on the 3D printed orthosis. The printability of different materials was assessed and a number of dogbone samples was printed. Tensile tests were conducted on these samples in order to get a better insight into the influence of print settings on the material properties of the end product. Furthermore, this allowed us to compare the mechanical properties of different 3D printing materials in a more quantified way. Based on these tests the XT polyester filament (PETG) was initially chosen for the production of the orthosis. At that time this filament promised to be a good combination of price, material properties, and printability.

Another important choice we had to make at the beginning of the project was the type of 3D scanner we would use. Keeping in mind that the digital workflow should be as economically viable as possible, a good tradeoff between price and accuracy of the scanner was an important factor. The sense scanner (3D systems) was chosen, partly because this scanner was already used during the previous 3D printing project in Syria.

The personnel of OADCPH that run the Fab lab were trained on several topics such as: preparation of 3D models for printing, the use of slicer software, the use of different free software packages to fix defects in 3D models, 3Dprinter operation and maintenance.

Furthermore, we used teleconferencing and remote desktop software to resolve printer related problems together.

Regarding social impact of the project

A qualitative approach was used:

- Tour of the four rehabilitation centers in Togo, Mali and Niger to observe the casting, rectification and fitting sessions with professionals participating in the project, but also tele-rehabilitation sessions with the centers (in July and October-November 2018);
- In-depth individual interviews with patients who completed the process (32patients);
- Individual and collective interviews with project partners and professionals;
- Interviews with key actors on issues and challenges of ICT integration in the field of health in the 3 countries.

Findings

Regarding clinical aspects

When comparing the walking times between walking with a conventional and 3D printed orthosis of the 40 patients who completed all evaluations, we observed a statistically significant walking improvement when wearing a conventional orthosis compared to all three evaluations when walking without orthosis (baseline, first evaluation, second evaluation), see figure 1. Similarly, we observed a statistically significant improvement while wearing a 3D printed orthosis versus the three evaluations when walking without orthosis. Furthermore, there was no significant difference between walking with a conventional or 3D printed orthosis.

Figure 1. Overview of participants and results

THOMAS
MORE

Kris Cuppens, Tom Saey, Veerle Creyelman









Research on clinical and production aspects

Within the Imp&Acte3D project we wanted to investigate the technical feasibility of the use of a digital workflow for the production of orthosis in a West African context.

Furthermore we wanted to compare the clinical effects of orthosis produced with 3D printing with traditionally manufactured orthosis.

WHICH PATIENTS PARTICIPATED

Patient timeline



# 90	Night splints 	Dynamic orthoses 
Ankle foot orthosis (AFO) 	Deformity in ankle joint	Ankle instability e.g. drop foot
Knee ankle foot orthosis (KAFO) 	Genu varum/valgum	Knee instability e.g. due to polio

CLINICAL RESULTS

Dynamic orthoses



10 meter walk test

Statistically significant improved walking speed for conventional and 3D printed



5 conditions compared using repeated measures ANOVA

Night splints



Angle measured (knee / ankle)

Statistically significant improved knee angle for conventional and 3D printed

Non-significant improved ankle angle for conventional and 3D printed



PATIENT SATISFACTION

Conventional	3D printed
<ul style="list-style-type: none"> Weight better manageable More durable Preferred by patients with dynamic orthosis 	<ul style="list-style-type: none"> Patients prefer 3D scanning Better looking Preferred by patients with night splint

Preference night splint



Preference dynamic orthosis



Preference taking measures



PRODUCTION OF DEVICES

Conventional	3D printed
<ul style="list-style-type: none"> Rectification faster Lower cost components Total cost dynamic orthosis similar 	<ul style="list-style-type: none"> Shorter manufacturing time Overall working time is shorter (but long printing time) Cost filament lower than conventional materials Total cost night splints lower



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The improvement of the angles of the 44 patients equipped with a postural orthosis was statistically significant. When investigating the patients fitted with an AFO and KAFO separately, we observed that patients treated for genu varum/valgum (KAFO) showed a statistically significant improvement of the angle after the first evaluation and second evaluation. The improvement when wearing a conventional or 3D printed was also significant. There was no difference between the conventional and 3D printed orthosis. The improvement of patients treated for a deformity of the ankle joint was not significant.

Regarding patient satisfaction, there was a significant difference on the satisfaction of the durability and managing the weight between the two types of orthoses in favor of the conventional device. Patients found the 3D printed orthosis significantly better looking. The cost and time of production were in favor of the 3D printed orthosis, mainly due to the longer manual manufacturing of the conventional device, and the lower cost for the filament compared to the material to produce the conventional orthosis. But for the dynamic orthoses, the difference in time was less pronounced and the costs were similar. When patients had to express a preference for one of both devices, the patients equipped with a postural device were more in favor of the 3D printed one, whereas the patients equipped with a dynamic orthosis had a preference for the conventional one. Furthermore, a large majority (82%) of the patients preferred the 3D scanning over plaster casting as measurement technique.

Regarding technical aspects

During the course of the project problems occurred with orthoses printed with the selected filament as they showed fractures over time. These failures occurred more often in the dynamic orthosis compared to the postural orthosis. It turned out that this material was very susceptible to high impact forces which caused brittle fractures of the orthosis. Because of these strength issues, additional tests were carried out to improve the printability of PP and nylon filaments. These materials are more ductile and should therefore be able to withstand the forces typically acting on such orthosis in a better way.

Even though the initial material tests at the beginning of the project showed that these materials are very difficult to print, we were able to come up with a method to significantly improve the printability of these filaments. In the end, PP was identified as the most suitable material, since it is not susceptible to humidity unlike nylon. By using an additional PP print plate, we were able to resolve a lot of the printability issues we noticed during our initial tests.

Even though all clinicians were trained to use the 3D scanners at the start of the project, we noticed that it remained difficult for some of them to produce 3D scans with a consistent quality.

Another factor, which was at the root of many of the 3D printer and material related problems we encountered during the project, was the environment in which the printer needed to work. More specifically, the high humidity must be considered when choosing

both the 3D printer and printing materials. A lot of thermoplastic materials (such as nylon, but to a lesser extent PETG) have the tendency to absorb moisture. This has a negative influence on the printability of the material and the mechanical properties of the printed orthosis. In order to avoid this problem, non-hygroscopic materials (such as PP) are preferred. In addition, the humidity can also have a direct influence on the lifespan of the 3D printer. Near the end of the project, some mechanical and electronic components of our 3D printers already started to rust. This phenomenon may be exacerbated by the proximity of the sea and the salty sea air.

Finally, we encountered a lot of 3D printer electronic component failures. To date, the exact causes of these failures remain unclear. Possible causes include the high ambient temperature that prevents the electronics from efficiently dissipating its heat, power surges, and quality of electrical power delivered by the electrical grid.

Regarding social impact of the project

From the point of view of beneficiaries and professionals, this research showed that the process of digitization and 3D printing to make orthoses was effective and qualitative. Tele-rehabilitation was feasible and provided added value in terms of improvement of quality of service, if good ICT infrastructure is available for ensuring a quality and fruitful video conference. The main social value the IMP&ACTE 3D project was hoping to create was more social justice in terms of health of people with disabilities, a population generally left behind.

The foundation is laid to offer a service that will reach geographically isolated populations across tele-rehabilitation and democratize access to equipment for people with disabilities thanks to reduced costs and production time facilitated by 3D printing technology. In terms of observed changes, there is a positive reception on the part of patients, who have full confidence in new technologies, and an appropriation of the technique by professionals.

This research shows that initial fears about the destruction of employment because "the machine would replace the man" were dissipated to the extent that it became clear that the role of the professionals was central in all stages of this new process. Indeed, the professional is placed in the center of the device production process and the quality of the intervention depends on its formation.

Discussion

Regarding clinical aspects

The 3D printed orthoses seem clinically equivalent to the conventional orthoses. The weight and durability are points for improvement of the printed devices. Especially patients fitted with a dynamic 3D printed orthosis indicated that the weight is high. Several fractures of the 3D printed dynamic orthoses were the cause of the lower perceived durability of the 3D printed devices.

Some steps are already taken to improve these two issues, by changing the type of filament (to polypropylene). If these issues are solved, the way for a broader implementation of 3D printing of orthoses is open, as some other advantages are clear. There seemed to be a certain reduction in cost and time for production, patients like the 3D scanning better than the plaster casting, and the fact that measuring the patient with a scanner is possible, can enable treating patients that live on a remote location, far away from an orthopedic center.

Regarding technical aspects

After completion of this project we can conclude that it is indeed possible to implement a digital workflow for the production of orthopedic devices in a West African context. We were able to successfully 3D print a large number of orthosis throughout the duration of the project in spite of the many failures of the printers. The experience and insights gained within this project can be a good starting point for future projects to build on. Given the rapid pace of evolution of the current 3D printing landscape, future projects should keep exploring new 3D print technologies, 3D printers and materials that could potentially offer better material properties, higher print speeds, etc. The same goes for the 3D scanning technology.

The difficulty for some of the clinicians to produce 3D scans with a consistent quality, underlines the importance of the user friendliness of both 3D scanner and 3D scanner software. In future projects this problem could be partly resolved by choosing a 3D scanner with a build in screen. Experience shows that such a scanner is perceived as more user friendly because the operator does not need to look at the screen of an additional laptop and can focus on the object that's being scanned. Apart from that, the clinicians should receive a more in-depth training, so they have a better understanding of the influence of the 3D scan software parameters on the resolution and accuracy of the final 3D scan. Furthermore, they should be aware of the fact that the quality of the 3D printed orthosis largely depends on the accuracy and quality of the 3D scan used as a starting point of the digital workflow.

Regarding social impact of the project

The positive conclusion of this research is that 3D printing / tele-rehabilitation is a possible solution to the shortage of professionals by opening up the medical deserts which mainly concern sub-Saharan Africa, improving the productivity and skills of health professionals.

Togo, Mali and Niger will face many challenges, including better Internet connectivity and infrastructure in rural areas, as well as the training of the health / rehab workers to new technology to assure the transition to health. The prospects of developing tele-rehabilitation in these countries will depend closely on their ability to coordinate and organize dialog between multi-stakeholder, researchers, the private sector, start-ups, international donors, NGOs, maker communities from FabLabs, and the patients themselves.

To make this solution sustainable and equitable, the use of ICT in the service of health has to be planned together with caregivers and patients. It must respond to the priorities of national health policies, to be developed, planned and financed in a long-term approach. Sustainable economic models taking into account the economic situation of more vulnerable people remain to be found and tested.

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Controlling costs and improving satisfaction in wheelchair provision in resource limited environments

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Abstract

The objective of this project is to develop advice for wheelchair manufacturers, governments, distributors, and providers in resource limited environments (RLE) on how to improve product designs and supply chain towards the goals of increasing user outcomes and satisfaction and decreasing costs. The local provision systems of wealthy environments (WE) differ from RLE, and this raises product design considerations. The paper will look at sample products of one product type, supportive pediatric wheelchairs, to understand best practices for cost control. The authors have observed that wheelchair provision systems frequently have several unnecessarily severe cost drivers that are related to the supply chain and product design: initial product cost, provision cost, repair cost, and supply chain cost. The question of interest is, "Can product manufacturers, in collaboration with other stakeholders, control product costs and minimize downstream costs by designing wheelchairs which are easy to provide and maintain?" Seeking an answer to our question, we gathered product specific data on supportive pediatric wheelchairs by use of a questionnaire to expert providers who have extensive provision experience in WE and/or RLE. The wheelchair attributes being compared are: setup and fitting time, initial cost, number of tools needed for adjustment and maintenance, difficulty and costs of replacement rear tires and bearings, and growth range of the seating system. Experts also commented on the cost savings opportunities across the supply chain. Multiple experts noted that design is very important to user outcomes and should not be deprioritized. Design can increase or decrease the service or maintenance cost. Also, a design with more parts requires more replacement parts in the supply chain and more complexity. Experts noted that every supply chain layer and company involved must add 10% - 40% to survive financially. Experts noted that a possible approach is supply chain streamlining. There are notable differences between wealthy and resource limited environments regarding price expectations, the availability of providers, the use cases, and the local competitive landscape. Design of wheelchairs for RLE needs to include considerations related to systems that deliver wheelchairs that may face different designing constraints compared to those in WE. Designers can improve user satisfaction outcomes by prioritizing speed and simplicity of

provision of wheelchairs, easy self-service maintenance by the user, and a simplified product ordering and delivery system.

Keywords

Assistive products, resource limited environments, cost control, product design, wheelchairs, supply chain

Introduction and Objectives

The objective of this project is to develop advice for wheelchair manufacturers, governments, distributors, and providers in resource limited environments (RLE) on how to improve product designs and supply chain towards the goals of increasing user outcomes and satisfaction and decreasing costs.

From the authors' observations, the major layers of the wheelchair supply chain are typically as follows: Manufacturers, National Distributors, and Local Vendors. Manufacturers are responsible for product design, production, testing, and typically take the lead on marketing strategy. National Distributors are responsible for registration of the product with the national regulatory and import body, maintaining supply, selecting products fit to the market, and building local awareness. Local Vendors provide retail environments for viewing of products by users, product orientation for clinicians, and relations with clinicians, hospitals, and users. In some WE, local vendors may be responsible for initial setup, repair, and providing a consultative service to clinicians on complex products.

The paper will look at sample products of one product type, supportive pediatric wheelchairs, to understand best practices for cost control. Future work on this project will be to develop case studies that describe the market structure in detail for Russia, Turkey, and Colombia. These case studies will be compared to the USA and Canada to better understand where WE approaches to the problem are a good fit.

From the authors' observations, the local provision systems of wealthy environments (WE) differ from resource limited environments (RLE) in price expectations, the availability of service providers, the use cases, and the local competitive landscape; and, these differences raise product design considerations. The authors observe that price expectations for supportive pediatric wheelchairs are quite different in RLE versus WE. The government reimbursement rate in many RLE markets is \$500 or less and in many WE markets it exceeds \$4000 for a complete product, not including service provision or repairs. The use environment of the products, by the authors' observation, differs with regards to terrain, environmental stresses such as higher impacts in RLE, and regular use in small spaces such as small cars and small homes. In RLE there is frequently a shortage of qualified service providers who are capable to work with these products and users. Notably, the knowledge and experience level required to setup and adjust some products, such as the Quickie Iris, is a technical specialty. Market development in many RLE locations is at an early stage. The authors observe that the first competitors are dealers which offer very basic style products

to pharmacies and high-end manufacturers who exclusively target private insurance and wealthy individuals who can afford to pay cash. With regards to the author's objectives, neither of these competitor types is well suited to serve the majority of the population in need. Their operational activities, operating margins, and existing suppliers are mismatched to the problem and adaptation is observed to be difficult for both types.

From our experience over the last ten years, the authors have observed, in both RLE and WE settings, that wheelchair provision systems frequently have several unnecessarily severe cost drivers that are related to the supply chain and product design: initial product cost, provision cost, repair cost, and supply chain cost. The question of interest is, "Can product manufacturers, in collaboration with other stakeholders, control product costs and minimize downstream costs by designing wheelchairs which are easy to provide and maintain?"

Approach to the Question

Seeking an answer to our question, we gathered product specific data on supportive pediatric wheelchairs by use of a questionnaire to expert providers who have extensive provision experience in WE and/or RLE. The experts were selected: 1) because of their experience in both provision and business aspects of wheelchair service provision, and 2) because of their direct experience in both RLE and WE settings. Between the experts, many thousands of wheelchairs have been directly provided. Several experts had experience with the Quickie Iris and the Sunrise KidKart Xpress; and 7 other models were mentioned by only one or two experts. The wheelchair attributes being compared are: setup and fitting time, initial cost, number of tools needed for adjustment and maintenance, difficulty and cost of replacement rear tires and bearings, and growth range of the seating system.

Experts also commented on the cost savings opportunities across the supply chain.

Data collected from Professionals in the Industry

Six experts were consulted who had provided supportive pediatric wheelchairs as part of their regular professional activities in both WE and RLE settings. The experts are two women and four men, one wheelchair user, two born in RLE and four in WE, all have advanced degrees in relevant fields, and have between ten and forty years of experience in the industry. Table 1 shows which products the experts have evaluated and their advertised retail price.

Tables 2-6 present the responses to the following questions:

- How many different tools and how much time are required to do setup and fittings for each chair? (Table 2)
- How many tools and how much time is required to replace a caster wheel? (Table 3)
- In your area how many days are required for delivery if the user pays cash or uses the government system to replace a rear tire or caster swivel bearings? (Table 4)

- What percentage of the final cost is contributed by each major layer of the supply chain? (Table 5)
- Where in the supply chain is the best opportunity for cost reductions? Rank 1-5 where 1 is the best opportunity. (Table 6)

Table 1. Wheelchair products evaluated by responding experts

Wheelchair Product	Respondents	Advertised Retail Price
Quickie Iris	4	\$4,360
Sunrise KidKart Xpress	4	\$2,156
UCP Liberty	2	\$268
Leggero Dyno	1	\$1,790
ROC Wheels ROCKIT	2	unknown
Motivation Motigo	2	\$345
Modified Whirlwind RoughRider	1	\$216
Participant Product1	2	\$325
Convaid Trekker	1	\$2,920
Other supportive chairs	3	n/a

*Table 2. Tools and time required for setup and fitting**

Wheelchair Product	Number of Tools Required **	Time Required for Fitting (minutes) **
Quickie Iris ***	6	93
Sunrise KidKart Xpress	2	40
UCP Liberty	2	90
Leggero Dyno	6	30
ROC Wheels ROCKIT	4	30
Motivation Motigo	3	120
Modified RoughRider	8	120
Convaid Trekker	3	20
Participant Product1	2	15

*Notes: * To normalize responses, experts used a standard user case with measurements, tilt, and recline; ** Where experts gave different data, a simple average was used; *** Experts were asked to consider only the original equipment manufacturer parts that are offered and not aftermarket modifications which, though widely used, can increase the time required.*

Table 3. Tools and time required for repairs

Wheelchair Product	Tools Required to Replace a Caster Wheel	Time Required to Replace a Caster Wheel (minutes)
Quickie Iris	3	20
Sunrise KidKart Xpress	2	15
UCP Liberty	2	20
Leggero Dyno	2	10
ROC Wheels ROCKIT	1	10
Modified RoughRider	2	20
Convaid Trekker	2	25
Participant Product1	2	10

Table 4. Delay days for simple replacement parts

Wheelchair Product	Days Needed for Cash Payment	Days Needed for Government System
Quickie Iris (special tire)	12	75
Sunrise KidKart Xpress (special tire)	7	75
UCP Liberty (common tire)	7	53
Leggero Dyno (special tire)	4	90
ROCKIT (special tire)	2	30
Motigo (common tire)	2	60
Modified RoughRider	2	30
Convaid Trekker	2	45
Participant Product1 (common tire)	2	30

Table 5. Expert opinion on supply chain layer costs. The percentages are the mean of the experts' opinions

Supply Chain Layer	Experts' Opinion
Manufacturer	47%
National/ Regional Distributor	19%
Local Vendors	34%

Experts noted that in WE, manufacturers and vendors often gain significant revenue by creating special parts that require a specialist technician and a special service center.

Table 6. Ranking of cost reduction opportunity in the supply chain. The ranking is the mean of each expert's ranking opinion

Supply Chain Layer	Cost Reduction Opportunity Rank
Manufacturer	1
Local Vendors	2
National/ Regional Distributor	3
Import taxes	4
Design	5

Multiple experts noted that design is very important to users' outcomes and should not be deprioritized. Design influences the manufacturer's price and any import taxes. Design can increase or decrease the service or maintenance cost, which is a component of the Local Vendor's cost. Also, a design with more parts requires more replacement parts in the supply chain and more complexity.

Experts noted that every supply chain layer and company involved must add 10% - 40% to survive financially and that a less complicated supply chain may be more cost efficient. Experts noted that a possible approach is supply chain streamlining, which can require intensive effort, governmental support, and investment.

General Questions to the Experts

Statement: Supportive pediatric wheelchair price is primarily a function of the payment ceiling set by the government as opposed to R&D cost, material cost, or liability costs. Agree or disagree?

Response: Five of the six experts agreed. Multiple experts mentioned that because of profit seeking, a ceiling price set by the government encourages vendors and distributors to market the cheapest sellable products so that they can maximize their margins. Experts noted that because product categories have set "required feature lists" (for example HCPCS codes in the USA), innovation is discouraged. A truly new product would require an acceptance process and a new HCPCS code, resulting in longer time to market, higher risk, and generally less incentive to innovate. In WE, genuine user-centered design appears to be unusual and code-centered design may make better business sense.

Statement: As opposed to "What is best for users?", the business decision a distributor faces with adding a new supportive pediatric wheelchair is related to profit per unit (price - landed cost - related operations cost), forecast of units sold, and opportunity for profit on repair activities. Agree or disagree?

Response: Four of the six experts agreed.

“Since a profit needs to be present for business continuation. The problem is the business model which increases price and often lowers value by having too many parties collecting money. The best way to ensure financial sustainability is to provide innovative, simple & highly versatile designs, to reduce the number of parties collecting money, and to localize the service providers as much as possible.” - Respondent A

“Importers/Distributors need to have a suitable profit margin in order for the business to survive and to continue to provide the service offered. While most Importers/Distributors will try to balance their profit needs with their customers’ needs, there are circumstances where the best suited product would not be considered simply due to high cost/low margin. There are products that are just not viable in RLE due to complexity, availability of parts and compromised margins, in particular when many layers of businesses are involved.” - Respondent B

Experts expressed concerns regarding the ultimate effectiveness of designing an affordable, high-quality, wheelchair product line and noted that local vendors have other motives. A sellable product at a lower cost may simply be an appealing way for local vendors to increase their margins if a competitive business environment is not maintained by the government.

Conclusions

The data gathered provided some useful insights on the realities and challenges of providing reliable, low cost, easy to use and repair wheelchairs in RLE. While some well-known wheelchairs provide extensive adjustability and customization, delivery times can be and are long, while the final cost to the consumer is high, making the product inaccessible to a large portion of the RLE population. In addition, the time required and cost to do initial fitting and, later, basic repairs can be high and prohibitive in RLE. In contrast, a well-designed chair, with innovative design features and easy to adjust components, combined with low manufacturing costs, can be delivered to the end user in a timely manner and a reduced cost to the end user.

The *speed and simplicity of provision* can be improved by simplifying adjustments and decreasing the variety of fasteners used in constructing the wheelchair. These improvements decrease tool switching time, problems with tool availability, and adjustment is eased during the moments when users are exhausted and waiting for their final adjustments. There is a relationship between the number of tools needed and the time required. However, product design and other factors are also at play as some products with few tools required also required extensive time.

Wheelchairs have consumable parts, such as casters, rear tires, and bearings, which are a concern for reducing product downtime and cost. For example, special narrow, high-pressure, and colored tires have aesthetic and measurable performance benefits. However, these desirable attributes may not justify the additional complexity and stock-outs which

results in downtime and increased costs, especially in RLE. Of the evaluated products, those using common, locally available parts, as opposed to specialized parts, show a significant decrease in wait time for repairs.

Wheelchair service and maintenance schemes for RLE can be improved by designing for *easy self-service maintenance by the user*: 1) educating, equipping and empowering users to do regular maintenance, 2) providing easy e-commerce systems for users to directly order and reclaim costs for consumable parts and warranty parts, 3) providing online videos for common repairs for use by users and caregivers, and 4) designing intuitive mechanisms which require only common tools.

Layers in the supply chain can add valuable services, such as customization and repair services; but, these must be evaluated against the additional costs. Designing the supply chain so that fewer parties are involved and fewer complicated procedures are required, such as filing a clinical justification for a product or a stringent application process for local product registration, may result in overall savings and less wait time. E-commerce approaches may allow significant streamlining, especially in cooperation with government to setup a fitting reimbursement system. By keeping the lifetime cost and system cost in mind, product designers can play a role in cost control.

Design of wheelchairs for RLE needs to include considerations related to systems that deliver wheelchairs that may face different designing constraints compared to those in WE. Designers can improve user satisfaction outcomes by prioritizing *speed and simplicity of provision of wheelchairs, easy self-service maintenance by the user, and a simplified product ordering and delivery system*.

Disclosure statement

Keoke King and Dave Calver are designers of Participant Product1 and beneficial owners of Participant Assistive Products.

Multi-disciplinary and lean innovation for assistive technology

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Abstract

Upper limbs are not suitable to provide mobility for a long time. Pushing a manual wheelchair is inefficient and might cause serious upper body overloading. Long-term wheelchair pushing almost inevitably leads to steadily deteriorating physical capabilities for the user. The World Health Organization (WHO) estimated that at least 1% of the world's population uses a wheelchair. Novel multidisciplinary teams and processes, working with lean innovation and validated learning approaches are the key to design, develop and provide new categories of assistive technologies that can further improve the health, quality of life, and autonomy of this large number of people by addressing important unmet needs.

Keywords

Wheelchair, self-balancing, rehabilitation, quality-of-life, innovation management, lean innovation, design thinking, shoulder pain, customer-centered, rehabilitation, APW

Introduction and objectives

The "Active Powered Wheelchair" (APW) could represent a new category of assistive technology that provides an improved level of mobility and independence for people with disabilities and might serve as a physical rehabilitative medical device that indicatively can contribute to protect, maintain, and improve bodily function. It is not propelled forward or backward by the use of a person's hands or arms, but rather by an electrical motor that responds to shifting weight on the seat through subtle upper torso movements that may provide training in the form of additional physical therapy. It is designed to remove the negative health impacts affecting active wheelchair users caused by the wear and tear on fingers, hands, wrists, arms, and shoulders necessary for manual wheelchair pushing. The APW requires the ability to self-balance the wheelchair through control and coordination of movements of the upper body and the head. The subtle movements back and forth of the upper body allow mobility without the use of the upper limbs, leaving hands free to steer

the wheelchair or to perform tasks or work activities while in motion that were previously not possible with an active or power wheelchair.

The APW's use of the innovative technology of "Self-Balancing Advanced Mobility Systems" opens the door to a "fourth industrial revolution" in the design and production process of wheelchairs as we know them today, and the technology is cited as an example for such progress in this manuscript.

Background

The wheelchair was conceived as a mobility device to enhance the ability of people with limited walking abilities to be able to be more independent, attend school, work, and participate in social activities. Over the centuries, R&D, design improvements, and more efficient manufacturing techniques, have led to lighter products, construction with carbon fiber instead of iron or wood, models that were easier to push or self-propel, the ability to lift, fold or disassemble a wheelchair with one hand, among others.

The limits of active wheelchairs: Pushing is not natural or efficient, and can cause health deterioration

While the manual (active) wheelchair has allowed people with disabilities greater mobility, it still uses the same basic technology invented almost 90 years ago by Harry Jennings and Herbert Everest that requires the use of the human body as a propulsion system. Time has shown that its long-term use could undermine people's health, which would be counter-productive to the reason for its existence. In fact, the WHO's Global Cooperation on Assistive Technology (GATE) definition of an assistive product is a device "... whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their wellbeing" (1).

Homo sapiens upper limbs are not suitable to provide mobility for a long time (2). Pushing a manual wheelchair is inefficient and it might cause serious upper body overloading (2). Long-term wheelchair pushing almost inevitably leads to steadily deteriorating physical capabilities for the user (2). Rotator cuff tears were present in 49%, unilateral in 20% and bilateral in 29% (3). Additionally, about half of the people who use an active wheelchair eventually develop carpal tunnel syndrome (4). Moreover, the most common posture acquired while using an active wheelchair, thoracic hyperkyphosis, was associated with a markedly high rate of rotator cuff tears (5). The repetitive strain imposed on the upper body - hands, fingers, wrists, elbows, and shoulders - by pushrim propulsion leads to a very high prevalence of additional medical care in active wheelchair users (2).

Avoiding the damage from long-term use of an active wheelchair can require a shift to a power wheelchair, even for people without severe medullary lesions. Compared to an active wheelchair, a power wheelchair is less physically demanding, and can lead to a more sedentary lifestyle and lack of use of active muscles that can result in additional secondary health problems and an increased need for medical care. Moreover, because the power

wheelchair was developed for people with tetraplegia, and people with injuries that severely restrict bodily movements, patients with less severe injuries such as paraplegia often do not feel comfortable using it because psychologically the transition to a power wheelchair sometimes creates a deep downgrade in self-esteem (6). For some people a power wheelchair may not be feasible due to financial constraints or difficulty transferring or transporting it.

Usually, rehabilitative and preventive measures to mitigate the effect of using an active wheelchair are performed together with injury-specific clinical practices. Occupational and physical therapists teach users which specific muscles need to be stretched and strengthened to protect the structures of upper limbs, provide stability, improve transfer and wheelchair propulsion skills, and prevent other secondary health conditions (SHCs). Neuropathic pain (83.7–92.1%), musculoskeletal pain (62.3–87.1%) and urinary tract infection (56.5–58.9%) were the most frequently reported SHCs (7). Additionally, active wheelchair-related accidents can occur during transfers, propelling over uneven terrain, reaching for objects, and maneuvering curbs or stairs. Tipping and falling are the most common form of incidents (8).

Therefore, despite the positive innovation in conceiving, designing, and producing active wheelchairs, their long-term use is, still today, a critical health issue (9). The objective of the active power wheelchair is to address these shortcomings and fulfill unmet needs by providing a practical and effective assistive technology that improves not only a person's autonomy, but also serves as a physical rehabilitation medical device to improve their health and wellbeing, which is in line with a "WHO Factsheet on Wheelchairs"(10) that says that "wheelchairs should be designed to enable users to lead a more active life and to participate in as many activities as possible without affecting their health and safety.."

Methodology for a multidisciplinary assistive technology innovation process

With the goal of identifying the main critical issues for long-term active wheelchair users, and to propose both a process and technologies for addressing them, we performed grey literature searches within Google Scholar, WHO, UN and other sources, in addition to specific academic searches on PubMed, Disability and Rehabilitation: Assistive Technology Journal, Disability and Rehabilitation Journal, and the Journal of Product Innovation Management. We used as a timeframe, the last 16 years of publications in English, and we included reviews, pilot studies, cross-sectional studies, case studies, factsheets. We used the following keywords: postural abnormalities, wheelchair, active wheelchair, rotator cuff tears, long-term, secondary health conditions, shoulder surgery, SCI rehabilitation, lean innovation, product innovation, innovation management.

Active Powered Wheelchairs and the positive health effects of self-balancing motion schemes

The recent emergence of active powered wheelchairs based on self-balancing technology is particularly interesting because it reproduces the same motion as walking but the

propulsion comes from an electric motor stimulated by subtle movements of a person's upper body, shifting weight on the seat. That means that with Self-Balancing Advanced Mobility Systems the human body generates the motion in a different way. Moving the APW forward requires tilting the torso forward, and stopping the wheelchair requires moving the torso backward. The active power wheelchair has only two wheels, eliminating the front casters, and is both active (uses the body) and power (uses the electric motor) at the same time.

A self-balancing APW is not suitable for all forms of motion disability. Medical guidelines must be developed and required to assess and define each case individually. People need to satisfy several clinical prerequisites. They need to have good control and functioning of the upper limbs; good control and coordination of movements of the head and of the torso in forward and backward positions, even with a non-stabilized spine. They must be able to transfer (on and off) the wheelchair independently and maintain their balance in the sitting position. In a broader sense, the self-balancing wheelchair can be used, for example, by anyone with paraplegia, incomplete tetraplegia that meets specific requirements, people with neurodegenerative diseases in the initial stage, people with lower-limb amputations, and those with illnesses such as poliomyelitis, cardiovascular diseases, or other fatiguing conditions.

To operate the active power wheelchair requires movements equivalent to physical exercise that have a wide range of positive effects on the user's health. Sitting in the right position to properly activate the mobility response allows users to avoid posterior pelvic tilt, kyphotic spine, and any other incorrect posture-related conditions. The joints of the fingers, wrist, elbow, and shoulders are hence protected, as they are not used to propel the wheelchair. Moreover, using self-balancing technology brings added value to the neurorehabilitation of the person's equilibrium because it requires continuous control over the body, activation of the location senses, movement back and forth, and self-balancing while remaining stationary. Propelling the wheelchair forward and backward requires exercising postural control. The presence of an electric motor enables long-distance autonomy and the possibility to travel uphill and on uneven outdoor paths impossible to access with an active wheelchair. This expanded freedom creates a positive impact on a person's self-esteem through the psychological perception of a more friendly and accessible social environment in which the person can finally be more autonomous.

Figure 1. Posture and equilibrium control on active vs active powered wheelchair



For the first time, the active power wheelchair demonstrates how mobility and rehabilitation features can coexist in the same assistive technology product. Physical rehabilitation protocols could now include exercising that occurs naturally by using the active power wheelchair for daily mobility activities. This can reduce the cost and number of physical rehabilitation visits, as well as produce savings due to the avoidance of damage to fingers, hands, wrists, elbows, and shoulders, as well as secondary health conditions such as neuropathic pain.

The Self-Balancing Advanced Mobility Systems constitutes a new propulsion system for active wheelchairs. Currently, self-balancing wheelchairs are under ISO 9999:2016 in 12 class, 23 subclass, and 06 division, so that as powered wheelchairs if we only consider the propulsion system. Taking into consideration the role of the human body, this could create the need for refining the AP classification category as "Active Power Wheelchairs (APW)".

Figure 2a. Active wheelchair



Figure 2b. Power Wheelchair (PW)



Figure 2c. Active Power Wheelchair (APW)



An "Active Powered Wheelchair" (APW) as a new category of 21st century assistive technology that is both mobility and rehabilitative medical device

An innovative APW goes beyond the concept of mobility and integrates elements of physical rehabilitation into its design and function. Although an APW may initially be manufactured in high-end user countries, through technology transfer it can become available to people living in low-resource settings. To achieve this there must be international standards and regulatory frameworks for this new technology that ensure its effectiveness, high-quality and safety. Currently, there are companies manufacturing active power wheelchairs in the absence of such regulations and this could result in wheelchairs that are dangerous and unsafe. This paper invites manufacturers worldwide to come together and work in synergy to leverage the full potential of this innovative process for the benefit of people with disabilities around the world, 85% of which live in developing countries. In several Southeast Asian countries, scooters and e-scooters are more prevalent than in high-income countries because they are inexpensive to own and easy to use. Therefore, it may be possible with government or international financial assistance to expand existing infrastructures to produce APWs. Since adopting new innovative technologies takes time, in the interim there are projects like FreeWheel¹, funded by the European Commission, that are developing a low-cost self-balancing electrical module that can be attached to a manual wheelchair to propel it forward and relieve people across the globe from the health damages and fatigue caused by manual wheelchair pushing.

Preliminary results from two pilot studies on the APW

In addition to regulatory standards, medical guidelines and patient assessment criteria for APWs, there also need to be more clinical trials to provide scientific evidence of the health benefits they can provide. There are very early preliminary results from two pilot university studies on APWs. The first study is entitled "Occupational therapy in the assessment of the self-balancing wheelchair rehabilitation value in the post-acute phase of people with medullary lesion: pilot study"⁽¹¹⁾ done by the Università Cattolica del Sacro Cuore - Faculty of Medicine and Surgery "A. Gemelli" in Rome and experiences within the Unipolar Spinal Unit "Niguarda Ca 'Granda Hospital" in Milan. The study collected the data of the 8 patients with spinal cord injury who own an APW, to verify for the first time whether it also has a

¹ The FreeWheel project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement N° 768908

valid rehabilitative value in terms of the balance of the trunk, influence on spasticity, influence on the pain of the limbs, upper limbs and spine, influence on performance in the "activities of daily living" (ADL). The evaluation protocols used in the study are: Shoulder Pain and Disability Index (SPADI); Wheelchair User's Shoulder Pain Index (WUSPI); Visual Analogic Scale (VAS); Modified Ashworth Scale (MAS); Penn Spasm Frequency Scale (PSFS); Spinal Cord Assessment Tool for Spastic Reflexes (SCATS); Sitting Balance Scale (SBS); Spinal Cord Independence Measure (SCIM); and SF-36 (VI) standard health questionnaire. The main results suggest that the APW reduces shoulder pain due to its special ability to move without the person using their arms to push. The patients recorded reduced pain between 4% and 35%. Using the SBS scale, which measures the balancing ability of the trunk of the body, the study recorded that all patients had an appreciable improvement on average of 12.4%. The conclusion of the study is that the APW, due to its self-balancing property, greatly stimulates the body's ability to balance itself due to the constant exercise derived from daily movements using the wheelchair.

The second pilot study is "Use of The International Classification of Functioning, Disability and Health (ICF) in the assessment of a self-balancing advanced mobility system"⁽¹²⁾ within Alma Mater Studiorum, University of Bologna. This study employed a method of assessing the general health of an individual, using an advanced self-balancing mobility system such as an APW. To achieve the study goal, it was necessary to select the most relevant ICF checklist items related to physical rehabilitation and social inclusion, which are the areas in which mobility assistive technologies are used. The results of the customized checklist show significant improvements in the performance of activities and social inclusion, mainly related to the relationship with others, such as relatives and friends, as well as leisure activities.

Through the pilot studies, it was possible to obtain an early evaluation of both health and economic benefits deriving from the daily use of an APW, which lays the foundation for the continuation of more specific and in-depth studies on these issues.

Multidisciplinary, lean innovation, and validated learning processes for APWs

Developing the Active Powered Wheelchair implies a change in the perspective of building an assistive technology with a focus not only on maximizing mobility and autonomy and avoiding secondary health conditions but also on incorporating effective physical rehabilitation into the everyday use of the wheelchair. The innovation process requires new skills that were previously not conceived of, or included as critical, in the product design and innovation process of an active wheelchair. For example, physiotherapists and occupational therapists should now play an important role during the "discovery of needs" and the "evaluation process", to catalyze the rehabilitative data analysis.

To be successful, a multidisciplinary innovation process must deliver three things: superior solutions, lower risks, and change-related costs, and employee buy-in. The entire multidisciplinary process is governed by a balanced mix of what are called "Scrum" and

"Lean" approaches. While "Scrum" provides the iterative structure to the team, "Lean" innovation principles require human empathy, as well as end-user experiments and evidence that reduce waste in the design phase - technically combining three essential methodologies: design thinking, and the ability to remain lean as well as agile.

A "lean innovation process" uses "validated learning" as the main practice to assess and develop the right assistive technology, in this case, an APW. The "validated learning process" includes a multidisciplinary team composed of electrical, mechatronics and software engineers; product designers; physiotherapists and occupational therapists; user researchers; public policy and legal regulations specialists. It brings together all stakeholders who have a shared interest in the success of the APW's final outcome. "Validated learning" employs a process in which the team translates an assumption into a hypothesis, which it then tests with a series of studies, usually engaging real-world end-users of the assistive technology they are developing. The design and production teams then process the data collected from the studies and learns from it so that it feeds into the product design and development phases. Practices and experiences that focus on the end-user of assistive technology should allow the team to quickly adapt to new information and prioritize features important to the end-user, as well as make decisions based on market-based evidence. For example, preserving shoulder joints from wear, rehabilitating and improving bodily balance while in motion, adapting to changing health and muscle capabilities of the end-user, and providing increased autonomy and additional health and social benefits for the person using the wheelchair, are all challenges that new technologies must overcome.

Striking the right balance between all of the above-mentioned processes can be found in a modern and innovative approach named "Agile Customer Thinking", which can be described as a continuous cycle of user response and action, a method of relentless technology improvement and customer co-creation (13). For organizations and teams exploring brand new categories of assistive products, that is, devices that the customers or end-users have not yet "seen", it is necessary not only to explore the feasibility of the technology or the business viability but also to co-create the technology with the end-users. The end-users often do not know what they want until they see it (14), and one of the purposes of the "lean method" is to continuously learn from the feedback provided in the studies with them, to be able to adapt the APW to the needs of the individual user almost in real-time. Working towards solutions that the end-users both discover themselves and co-design provides true value (15). It also establishes value metrics and ensures the design team has direct contact with the end-users who understand how their efforts and feedback are producing value (16). This scenario creates an environment where the end-user becomes a partner in the product design process and where delivering valuable outcomes to them becomes the main focus for the team developing the product and its related services. "Agile Customer Thinking" offers the design and production teams - and the entire organization - a lean, agile design framework for operating in co-creation with end-users to develop, with low risk and high confidence, new assistive technologies that solve the users' unmet needs and promote

technological progress (17). In fact, the most effective modern organizations have re-engineered themselves as a network of autonomous, responsive small teams (18) with substantial innovative freedom and accountability (19).

Summarising, the advantages of using Agile Customer Thinking approach are related with (a) using data all the time so it's not a linear process with data at the beginning, (b) testing and measuring with real-time connected behavior, making an instant feedback loop that gives the organization needed insight before it becomes outdated; (c) using digital platforms that can allow teams to test and collect behavioral data at scale - at close to no additional cost; (d) continuous data collection through automated software; (e) sharing anonymized data openly with anyone on the team or in the organization, so that everyone is enabled to translate the insights into a solution through a democratic, inclusive model; (f) the need for continuous input that small teams are dependent upon to learn, evaluate and improve.

The traditional wheelchair provision with a linear flow, usually including the design, production, supply and delivery of wheelchair services, finally has an iterative circular flow with a closed feedback loop that includes the end-user.

Public policies, regulations, education, and training for a new category of assistive technology, the APW

International and national public policies and regulations play a key role in product design for assistive technologies, especially new ones.

APWs are assistive technologies that do not yet have a proper commercial market or medical and industry regulations. Only some APWs are Class I medical devices and have self-declared medical guidelines. This lack of regulation is a matter of grave concern. To correct this situation, it is imperative that product innovation teams interact with policymakers in order to facilitate the development of new rules and regulations on APWs for the quality, design, safety, testing, and service delivery processes. Suppliers of assistive technologies should be required to officially register as such. The provision of APWs requires a medical prescription and the fulfillment of specific medical criteria, including the successful completion of a certified education and training course.

The WHO's GRaT Summit 2017 Report notes a balance that needs to be maintained between international or national product standards that can be experienced as a barrier to innovation and affordable production, and the need for a set of minimum standards to which assistive technologies are fit-for-purpose, of high quality, and safe. The report calls for "internationally-applicable, simple guidelines; minimum requirements; legal frameworks for provision; and AT information systems" (1). The report proposes that "strategies could include building stakeholder networks based on existing models and the development of private and public partnerships" (1).

Therefore, it is essential that public policy and legal regulation specialists are included in the multi-disciplinary team, lean innovation, and validated learning processes for APWs, as well

as the Agile Customer Thinking cycle of feedback and action. They must also ensure adequate research funding, clinical trials to provide evidence of effectiveness and safety, and the dissemination of knowledge about new and innovative assistive technologies.

Affordable active powered wheelchairs for low-resources settings

Advanced prototypes for APWs as Class I medical devices currently exist (20). Because APWs are highly technological assistive devices, that have not yet reached the stage of mass production and economies of scale, they are expensive. Therefore, both technological innovation efforts and business models need to push towards cost reduction for the public health system and the end-users. Additional research is required as to the extent of time and cost savings APWs provide to national healthcare systems by enabling some physical rehabilitation to be done independently by the APW user, and by avoiding or eliminating secondary health conditions requiring medical care – savings which can offset APW production costs.

Luckily, the market already offers plug-in solutions for adding power mobility for active wheelchairs. There is a wide number of power motor add-ons to help solve the autonomy issue and partially relieve the physical fatigue and strain on the upper limbs. Pushing and pulling add-ons are equally efficient compared to manual propulsion, but they have negative aspects as well. For example, front casters risk getting stuck while the back motor is still pushing, causing injuries, and the front extra pulling motor reduces maneuverability, limiting the use of the wheelchair indoors. Additionally, what is lacking are the advantages of the self-balancing techniques that support physical rehabilitation, such as those provided with the APW. The average cost of an add-on is about US\$ 4,000 and is still high for low-resource settings. The future aim of technological research should be to develop lighter and cost-effective self-balancing add-on components to transform any active wheelchair into an APW, thereby bringing their positive advantages to the end-users across the globe.

As the 2019 UN High-Level Meeting on Universal Health Coverage approaches on 23 September governments need to be prepared to implement its Political Declaration whose text (21) on disability states that countries will “Increase access to health services for all persons with disabilities, remove physical, attitudinal, social, structural, and financial barriers, provide quality standard of care and scale up efforts for their empowerment and inclusion, noting that persons with disabilities, representing 15% of the global population, continue to experience unmet health needs”.

If the world is to live up to the promise of universal health coverage by 2030, which is one of the main goals of the 2015 United Nations Sustainable Development Goals (SDG) (22), it must prioritize the provision of assistive technologies that best meet the needs of people with disabilities, and allows them the highest attainable standard of health and full inclusion in society which is their basic human right (21).

Conclusions and future developments for active powered wheelchairs

A new paradigm exists for the evolution of the active wheelchair into an active powered wheelchair. Promising preliminary results from studies in Italy provide evidence that APWs can help avoid some long-term health issues associated with active wheelchair use. Larger clinical studies with APWs are necessary to collect bigger and wider datasets, particularly to understand in-depth the clinical effects of the self-balancing technology on the human body. In that way, it will be possible to develop rehabilitation guidelines and practices that continue producing positive health effects seamlessly outside the hospital setting. An important goal is to harness current technological capabilities to allow the design of APWs to be adaptable to changing the health and muscles capabilities of the APW end-user.

Innovative multidisciplinary teams and processes, working with lean innovation and validated learning approaches, within the framework of Agile Customer Thinking, are key to developing APWs and other related digital and mechatronic technologies that can further improve the quality of life and autonomy of a large number of people with disabilities by addressing their most important unmet needs. This manuscript is a call-to-action for all stakeholders to work together to develop innovative assistive technologies and processes to help make universal access to essential assistive technologies a reality, because the time to act is now, and no person with a disability should be left behind.

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Appropriate assistive technology co-design: From problem identification through to device commercialisation

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Abstract

The role of assistive technology (AT) in the lives of people living with an impairment cannot be understated. Defined as commercially available or customised devices to maintain or improve functioning, independence and thereby well-being (1), assistive products are part of the assistive technology ecosystem that includes skilled personnel, effective policy, and coordinated product provision (2). Product innovation is one key strategy for a vibrant marketplace that enables AT users to participate and flourish. Innovation and the development of new products and services is an essential ingredient for any sector or organisation, particularly the disability sector. Innovation within the disability sector often benefits mainstream users, for example telephony itself, vibrating alerts, speech recognition and speech output devices. The objective of this paper is to illustrate the applicability of innovation and design thinking at every stage, from need identification through to commercialisation. Two case studies within the field of AT are presented to exemplify design processes and examine how methods such as co-design and design thinking tools can be used to nurture user-centred innovation within design teams.

Keywords

Co-design, design/creative thinking, innovation, end user, products

Approach

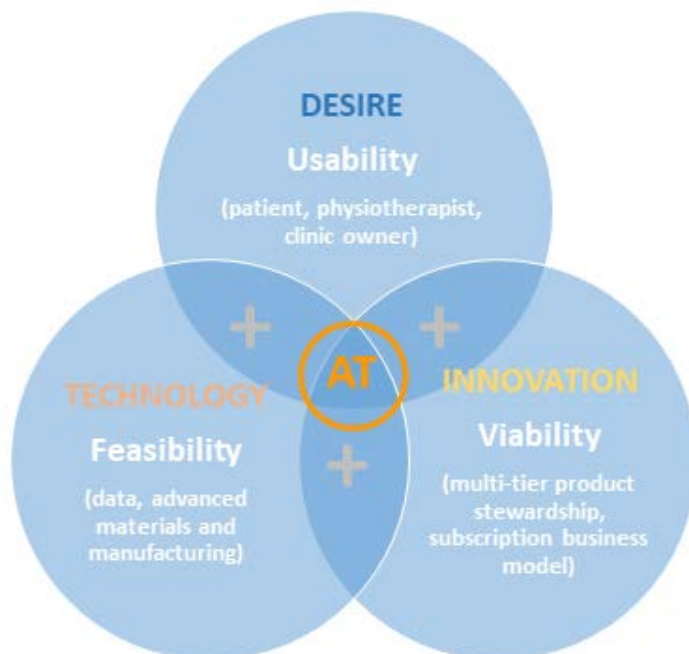
This paper distils the perspectives of a rehabilitation engineer, a product designer, and an occupational therapist all of whom are teaching and researching in the area of AT design. After introducing design thinking and co-design, we present two case studies showcasing user-centred, design thinking processes. The first case study examines the design and development of a clip-on device that communicates rehabilitation exercise data in real-time to both the client and practitioner, addressing exercise quantity (resistance and exercise volume) and exercise quality (type of contraction and control). The device provides a user-centric data capture platform for intelligent rehabilitation and healthcare. The case study process for this device is presented in detail to explain and highlight the design stages. The

second case study provides an overview of the processes that led to the development of a novel computer gaming system for rehabilitation of the upper limb (3), which was shown to have a positive therapeutic effect for children with cerebral palsy and adults recovering from stroke during pilot trials (4). We conclude with recommendations for the AT sector regarding design thinking and the potentials offered by co-design.

Design Thinking

The application of design thinking within an AT context, can be thought of as a structure composed of three intersecting domains: usability, viability, and feasibility (5). Usability relates to end user performance, viability relates to business model innovation, and feasibility relates to the application of appropriate technologies to solving human-centred problems. AT innovation is optimised where all three perspectives coincide, as shown in Figure 1.

Figure 1. The intersection of usability, feasibility and viability

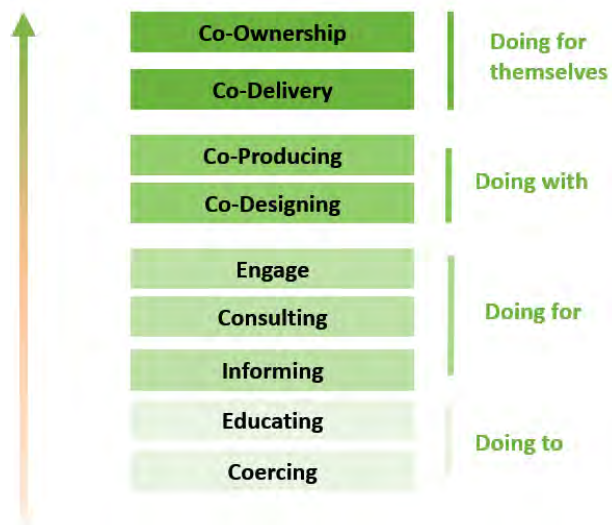


Co-design

“Nothing about us, without us” is a fundamental message from people living with functional diversity (including disability) (6). The inclusion of recipients in the design and evaluation of services and supports demonstrably improves outcomes of, and satisfaction with, services and products, yet medical, rehabilitation and social care fields are still on a journey towards full co-production (7). The term ‘co-design’ can have multiple meanings and lacks consistency within the literature (8). The ‘ladder of participation’ (Figure 2) is a useful way to conceptualise the extent of involvement being offered to service users (9). Efforts to engage AT users as researchers, product designers, and commissioners of design work will

enable full 'co-production' to be realised. The consultant roles proffered by both case studies within this paper sit at the 'doing for / doing with' levels of the participation ladder.

Figure 2: Ladder of Participation, acknowledging the New Economics Foundation



Design fields have long understood the value of user-led design, and design thinking therefore has valuable methods to offer the disability and rehabilitation sectors (10).

Key process ingredients include adopting authentic co-design principles during the design journey and assembling a collaborative multi- and trans-disciplinary team. Understanding how innovation within teams can be supported by processes such as design thinking methods and tools, delivers benefits not only to the end user, but is of considerable interest from a business perspective.

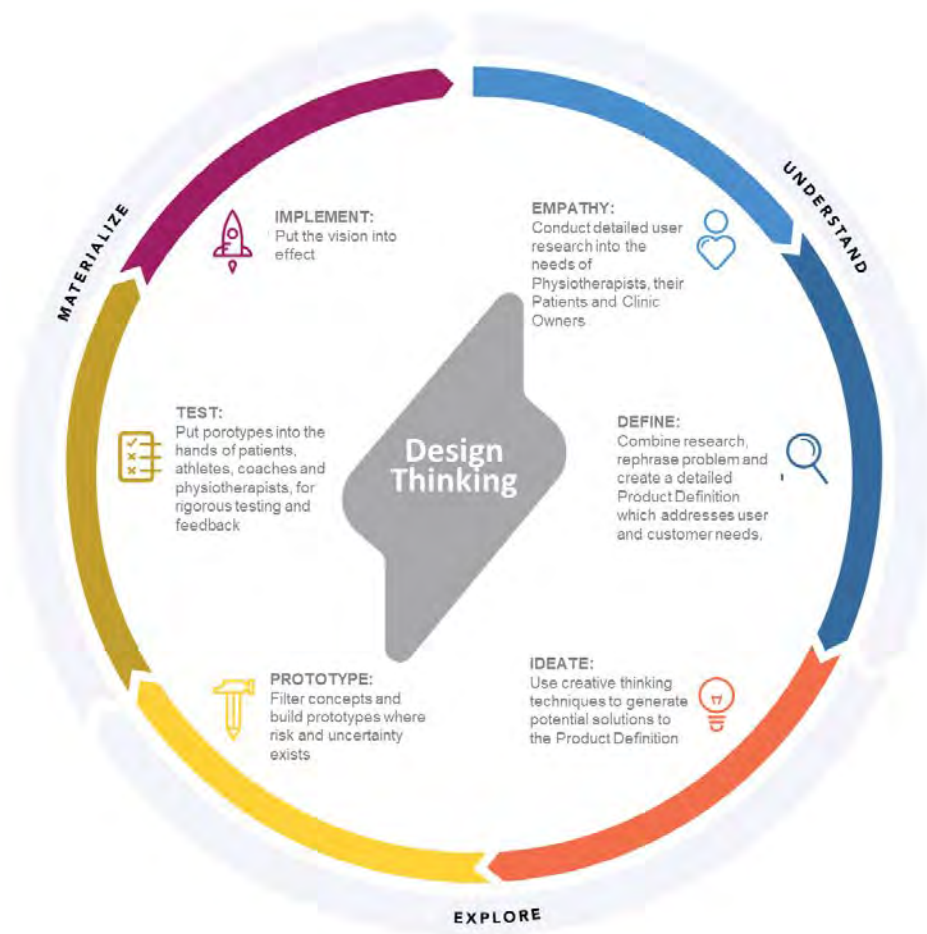
Case Study 1: The Prohab Device

Prohab, the name of both a startup company and a new portable strain gauge rehabilitation device, undertook a 'Design Thinking' exercise with Flinders University, culminating in the device's launch at the 2018 Commonwealth Games. This case study describes the design thinking process executed by Flinders University and Prohab, in response to multiple user needs for usable human performance data, and the subsequent use of design thinking as a creative approach in the development of the company's new products and services.

Prohab Design Approach

Once a user problem and associated business opportunity has been identified, design thinking and user centred design processes have the common themes of creating **Empathy** for the user (observing and engaging with people) and **Defining** a desirable future scenario, exploring solutions through **Ideation** (using creative thinking techniques to generate ideas), **Prototyping** solutions (using additive manufacture and digital technologies to create rapid prototypes), materialising solutions through **Testing** (observe, engage and test with people) and finally **Implementing** the optimal solution, as outlined in Figure 3.

Figure 3: The Design Thinking Process used for the Prohab project



Problem and Opportunity Identification

The design process commenced when a problem and potential opportunity was identified, which was the creation of a rehabilitation device that could measure, and record exercise performance data generated by resistance-band equipment. This issue was initially recognised by the inventor when a relative was recovering from a falling injury, resulting in considerable pain, mobility issues, slow recovery progress and the individual requiring many months of rehabilitation. The inventor realised that if resistance band data were available, it could then be used to inform better recovery planning and improved rehabilitation management. Resistance band data could be captured and transferred to a software application, where it could be viewed and understood immediately, as well as recorded and tracked over time.

Whist the device would initially be developed for the rehabilitation market, it could also have applications within the training programs of professional athletes across various sports. The portable force gauge device could allow athletes and coaching staff to monitor improvements in strength testing or rehabilitation training over time. Coaches could then prescribe set training programs for the athletes. As the system would be directly compatible

with existing resistance band or cable-based equipment, it would present an efficient and effective method of monitoring the impact of training program changes.

Design Thinking Steps

Good design starts with the design team trying to understand what the real issues are prior to imagining solutions. That is, remaining 'solution neutral' and not jumping to a solution too quickly, before the real problem is understood.

The Understand Phase

Research and understand the real problem that needs to be solved. Problems do not come fully defined and problems, beyond the problem 'symptom', must be uncovered. Observe users' activities in their natural environment of use, and understand their interests, motives and true needs.

Empathy: Empathy for the user helps the design team select the most appropriate features and benefits that are required. A strategy to clearly define the target group is the use of a clearly articulated series of user profiles and 'personas'. These clearly define the person that the team is designing for in a way that the entire design team can understand and relate to.

User Persona: A persona, as used in user-centered design, is an imaginary personality that has been created by the design team to represent a user-type that might use a product in a particular way. Even where end users are part of the design team, a wide lens on user diversity is valuable, thus qualitative personas are constructed in order to be representative of specific user types. Personas are useful when considering the users goals, desires, and the limitations of users, in order to help to guide the design team's decisions when evaluating the required features and benefits that a service or product may require. A user persona is a representation of the goals and behaviors of a theoretical group of users. In most cases personas are synthesised from data collected from observations and interviews with users, captured in descriptions that include behaviour patterns, goals, skills and attitudes, with imagined personal details to make the persona more realistic in character. Multiple personas may be required as alternative needs of persona types may need to be satisfied. Figure 4 illustrates the two 'end user' personas for the Prohab case study – that of the allied health professional (in this case, a physiotherapist) and of the assistive technology user (otherwise termed client or patient).

Figure 4: Prohab physiotherapist and patient personas



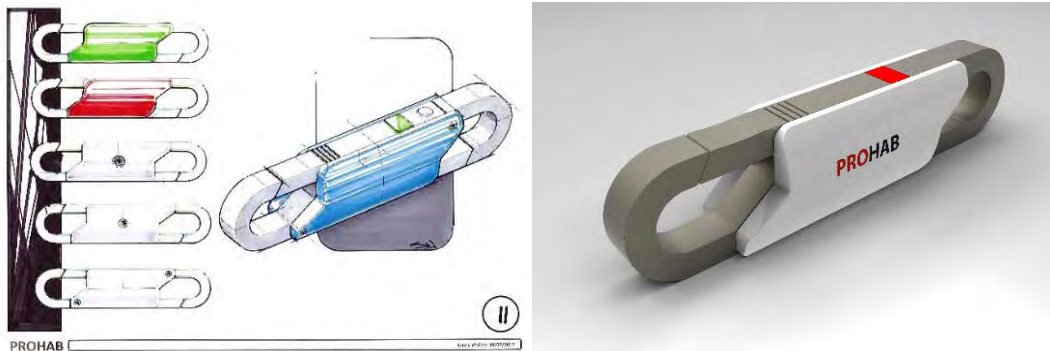
Customer Journey Map: A customer journey helps the team to look outside-in from the user's perspective, instead of an inside-out organisational perspective. Journey maps facilitate the exploration of cultural and behavioural phenomena, where the product design team observes the user's behaviours in their natural context. Journey(s) are visual representations of the customer's experience as they interact with a product, service or organisation, to capture what the customer or user thinks, feels, needs, wants, says, shows and tells. The tool can be used to depict the user's actual or ideal journey. Plotting the journey stages focusses the design team on the customer experiences by capturing the emotional highs and lows and the meaning that the experience holds for the user. For example, the design team will observe an end user when they interact with a product or service to see if they become confused, over exert themselves, experience an annoying or unpleasant feature, skip a step in a process or appropriate the product for a new and different purpose.

Define: Product definition provides a link between the language of the customer and the language of the design team, providing precise, measurable and unambiguous detail about what the product must achieve, without providing unnecessary constraints and without suggesting possible solutions (that is, remaining solution neutral). The definition should be based primarily on "what users need". To support this, it is useful to think both in terms of "must have", "need" and "want" as a simple way of classifying and prioritising product requirements. The product definition is a promise of value that should be delivered by the future product. It is also a positioning of value, where $\text{Value} = \text{Benefits} - \text{Cost}$. As value is a measure of the benefits or gains provided to a customer by a product or service, the design team must quantify what the maximum price or cost a customer is willing and able to pay, for a particular product and/or service. This is a fundamental question that must be answered, as it will affect the commercial viability of the product and the associated business case.

The Explore Phase

Ideate: Ideation is the creative process of generating, developing, and communicating new ideas and can be either visual, physical, convergent or divergent. Ideation comprises all stages of a thought cycle, from innovation, to development, to actualisation, and as such, ideation is an essential part of the design process. For the Prohab device, ideation was used to generate conceptual solutions to criteria identified in the Product Definition, through ideation sketching and 3D modelling visualisation, as shown in Figure 5.

Figure 5: Prohab ideation sketch and 3D visualisation, investigating design for manufacture methods



Creativity and Innovation: Creativity is described as “*the ability to make or otherwise bring into existence, something new, whether a new solution to a problem, a new method or device, or a new artistic object or form*” (11). Creativity is a mental process that involves the generation of new ideas or concepts, or new associations between existing ideas to solve a defined problem. Creativity is seen as a collaborative, purposeful activity in a range of disciplines from science to business. In a product design context, creativity is concerned with finding solutions to problems bounded by criteria constraints, typically with a human focus. Innovation on the other hand can be described as “*the successful exploitation of new ideas*” (12). Exploitation indicates that the idea must be implementable and ideally value generating, where Innovation = Invention + Exploitation, and successful implies that the idea is adopted and embraced by the target user. Product innovation can be viewed as the complete business process of introducing new or improved products and/or services to the market. It spans the entire product life-cycle from initial identification of a problem and market opportunity, through to commercialisation and eventual retirement or rebirth.

Creative Thinking Techniques and Methods: Creative or divergent thinking is a way of looking at problems from alternative perspectives. Convergent thinking involves aiming for a single, correct solution to a problem, whereas divergent thinking involves the creative generation of multiple answers to a set problem. Project design teams regularly use creative thinking techniques such as lateral thinking, mind mapping, morphological analysis, brainstorming and visualisation. Brainstorming was used extensively during the ‘Explore’ phase of the Prohab project.

Brainstorming is a creative thinking process of problem-solving that exploits the collective experience and creativity of all members of the group. Prototyping and simulation are additional strategies to (i) reducing market and commercial risk, (ii) reducing technical risk and (iii) building design team confidence and support. Market and commercial risk can be reduced by testing the market's response to novel features and concepts, comparing design alternatives with users and key stakeholders, and gaining early feedback on 'soft' aspects of the design mix, including usability and appearance. Technical risk can be reduced by permitting early testing of novel technical solutions, allowing evaluation of critical

performance characteristics of a new product, and resolving manufacturing issues. Design team confidence and support can be achieved through the team's participation in brainstorming and creative exercises where prototypes can demonstrate and communicate the viability of new principles, concepts and alternatives within the team. Prototypes can take many forms, from very simple mock-ups or visualisations through to sophisticated pre-production products and detailed analytical simulations. The value of a prototype can be defined as how accurately the prototype represents either functionality, performance, appearance, producibility or usability. During the development of the Prohab device, well in excess of 100 physical and virtual prototypes were designed and constructed, exploring new customer features, user benefits and functional characteristics, some of which are shown in Figure 6.

Figure 6: Various stages of the Prohab prototyping and testing process



The Materialise Phase

Different types of testing can be applied at different stages in the product development process. These distinctions assist in the consideration of the purpose of each test, the required value of the prototype and the deliberation of how the test data is recorded. Exploratory, assessment, validation or comparison test methods have different objectives, approaches and types of modelling (13). Prototypes should be tested and iterated with a diverse range of subjects for feedback, but especially people who correspond closely with the target user(s), by having them use prototypes in the actual context of use. Discussion should be encouraged with users, implementing improvements through iteration and refinement, until an optimal solution can be decided on and implemented.

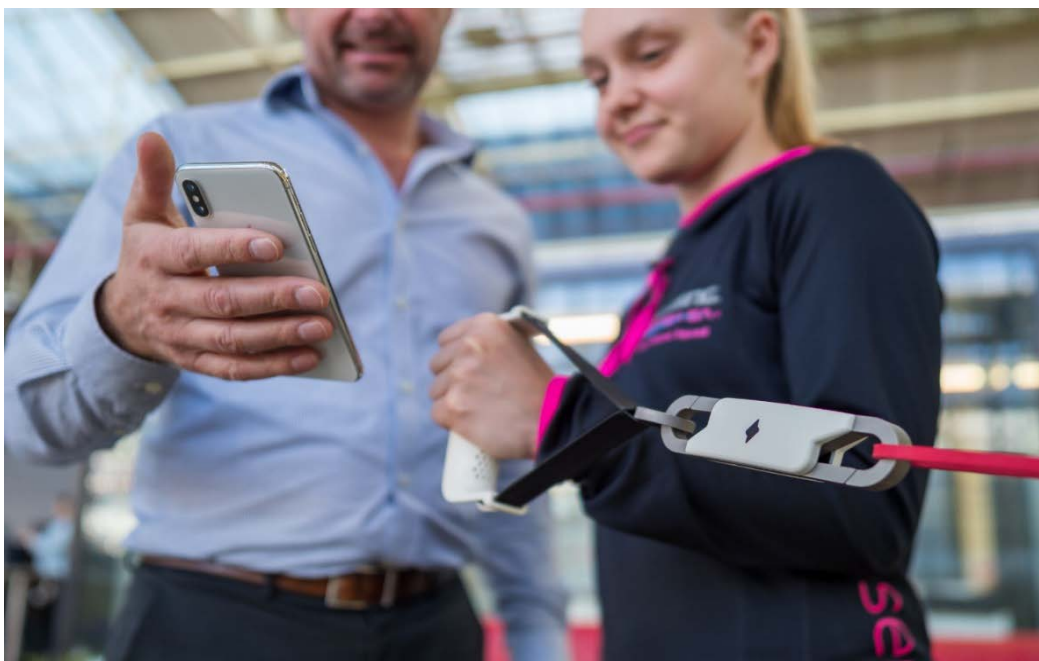
Manufacture: A system of flexible manufacture can facilitate early-stage production, providing a workflow translation directly from digital representations of major components, through to the final product and components being manufactured without the use of more traditional manufacturing processes. Additive manufacturing technologies represents a range of technologies and processes that can be used to quickly fabricate digital representations of physical parts or assemblies using digital-twin data. Reduced tooling

dependency has resulted in many parts being created directly from digital models, resulting in:

- Adaptive/flexible manufacturing operations, where the production mix can be changed at short notice;
- Reduced time to market, where a flow from low to high volume manufacture can be achieved;
- Reduced inventory, where components can be produced “just-in-time” and “on-demand”;
- Decentralised manufacture, resulting in reduced logistics costs as parts can be made where and when they are required;
- Part consolidation and design freedom to minimise the component count;
- Part weight and material content reduction opportunities being exploited, resulting in an optimised design with fewer process restrictions; and
- Intellectual Property (IP) protection has been achieved by keep the device’s embedded IP in-house and therefore safe.

Implementation: The Prohab device connects to standard resistance bands and cable equipment, which are widely used in physiotherapy and sport, to precisely measure forces. The data is captured and sent to the user's mobile device, where it can be visualised instantaneously, as well as tracked over time, as shown in Figure 7. This helps users create more engaging, accurate, and tailored programs for rehabilitation from injury or surgery. The Prohab device also enables professional athletes and their coaching staff to monitor improvements in strength through testing or rehabilitation training. The Prohab rehabilitation device was recently launched at the Gold Coast 2018 Commonwealth Games.

Figure 7: The final commercialised Prohab device being used on a resistance band, while the end user can view the output shown on their mobile device



Case Study 2: The OrbIT Gaming System

The *OrbIT* Gaming System is a standalone, home-based, accessible and haptic computer gaming system that resulted from a 'Design Thinking' exercise in response to a need to motivate children with cerebral palsy (CP) to engage in an upper limb rehabilitation activity. This exercise followed the same design approach as the Prohab strain gauge rehabilitation device (Figure 3), by creating **Empathy** with the user group, developing and **Defining** a desirable future scenario, exploring different solutions through multiple rounds of **Ideation**, the **Prototyping** of different promising solutions, **Testing** with end users, and finally the **Implementing** of an optimal solution. This particular case study was conducted within a tertiary (University) educational framework was used, where students worked their way through each design thinking stage, guided by supervisors, as they progressed towards a solution. Ethics approval was gained for every phase of the research process.

The Understanding Phase

Cerebral palsy (CP) is the most common cause of physical disability in childhood (14). Affecting approximately two per 1,000 live births (15), CP is also accompanied by "disturbances of sensation" (16). Our sense of touch has been described as "our first language", the first system that functions in-utero, the system that connects and bonds us to others (17), and the most mature sensory system at birth (18). Intact upper limb sensation is crucial for processing, interpreting and understanding sensory information and interacting with the world through touch (grasping/holding and touching objects, etc.) and avoid potentially hazardous situations (such as pain receptors to warn of extreme hot/cold surfaces, etc.). Moreover, the literature reports that for cases of severe sensory dysfunction, limb neglect may lead to a non-use phenomenon resulting in limb function deterioration (19). Within the WHO International Classification of Functioning, Disability and Health (ICF) context, a sensory deficit is considered an impairment that potentially leads to limitations in the activity domain and restrictions in participation.

While the current consensus definition for CP makes specific reference to sensory disturbances, historically this was a neglected area of clinical investigation and understanding until the pioneering work of Tizard and Crothers last century (20). Upper limb somatosensory deficits are now acknowledged and appreciated for this population (21-23); however, interventions that focus on sensory training for children with CP are less common. This is in contrast to the field of post-stroke rehabilitation, where since the late 1980's studies have focussed solely on sensory retraining (24-26), recognising the capacity of the nervous system to modify its organisation and adapt to new experiences – a process known as neuroplasticity. While the evidence for upper limb sensory impairments has been established for children with CP, what is not well established is the area of sensory training to improve upper limb function.

Engaging children with CP in meaningful therapy or exercise can be difficult, despite the merits of the intervention and the best intentions of family and rehabilitation specialists to

motivate and encourage the child. Therapy can be difficult because the aim of most interventions is to improve the function of what is known as the non-dominant (or more impaired) limb. Children avoid using this limb because it does not function as well as their dominant limb. Play-based learning that involves computer games is referred to as therapy ‘gamification’, ‘health gaming’, ‘active video gaming’ (AVG) or by the industry term ‘Serious Games’ (SGs). The aim of SG interventions is to use a child’s natural curiosity and interest in computer games to motivate them to engage in their therapy. As noted by Golomb *et al.* “...rehabilitation that incorporates play also aids in motivation” (27), with a 2014 review reporting that SGs have been trialled with children with CP since 1998 (28).

Hand function is known to depend on more than just physical functioning – it also depends on behavioural (concentration, attention), social-emotional (motivation), cognitive, and perceptual (somatosensory integration) components (19). The specific aim of this particular project and case study was to design, develop and trial an accessible and independently operable system that motivated and encouraged children with CP to use both their hands, whilst also providing a haptic experience that was enjoyable and cognitively engaging. The intent was to turn therapy into ‘play’, making it a fun, engaging and motivating activity and not something that was seen as ‘work’. Being a haptic system meant that the hands of the person using the system would be exposed to a range of mechanical vibrations and feedback, providing a cutaneous sensory experience. The unique aspect of this project was that the intended system was an upper limb intervention that focused on sensory and not motor training, which had not been attempted before according to recent reviews of the SG and AVG literature (29-31).

An additional requirement was for the system to be home-based. Home-based interventions have the advantage of eliminating the cost and inconvenience of travel and car parking to attend a hospital or clinic, coupled with the ability for the participant to use the intervention whilst at home, without the need for a health professional.

The Explore Phase

An appropriately designed SG system was identified during the ‘Explore’ phase as one option that satisfied the project requirements, capitalising on the merits of play-based learning and a child’s natural curiosity and interest with respect to computer games. Accessibility and a Universal Design (32) philosophy were an essential element of the design fabric from the outset, alongside a co-design process that embraced the “*nothing about us, without us*” philosophy of participation (6) – viewing the intended end users (children with CP) as co-designers in the process. Within the context of this project, children with CP were involved in the co-design process by critiquing, testing, suggesting options, evaluating and trialling prototype hardware and software aspects of the project, through focus group sessions and home-based trials that lasted multiple weeks (33, 34). Additionally, typically developing children of the same age were also part of the co-design process, critiquing and evaluating the custom games as they were developed and being iteratively refined (3).

From a design thinking perspective and given the tertiary (University) education setting that was the basis for this student project, the design thinking process (Figure 3) was followed to steer and supervise different project elements to completion, utilising generative and exploratory research to define the problem, combined with lived experience (co-design) and professional expertise to identify and direct the outcome.

An example of one such phase is the iterative prototyping phase that was used to develop the controller for the gaming system, which took the most promising designs from the ideation phase and generated fully operational controllers that could be tested with end users (Figure 8). The professional expertise represented a multi- and trans-disciplinary team, where rehabilitation medicine, allied health and rehabilitation engineering experience guided the clinical and rehabilitation project goals; computer science, Information Technology, digital media and software engineering was applied to design, develop and deliver a range of accessible games for the system; and biomedical engineering and industrial design expertise was used to ideate, conceptualise, design, prototype and manufacture the accessible controller, where the focus was on accessibility, the form of the device, and intuitive use (3).

Figure 8: Different prototype gaming controllers that were manufactured during the project, from first concept (left) to final controller design (right)



The Materialise Phase

Over a two-and-a-half-year period, the iterative co-design, design thinking process produced a home-based, intuitive and accessible haptic assistive technology product named 'OrbIT' (Figure 9). The system is standalone, integrated and self-logging, featuring 15 different interactive games that randomise game events to increase player engagement. *OrbIT* was successfully piloted with children with CP (n=18) and adults in the acute phase of stroke recovery (n=10), recording statistically significant improvements in upper limb motor function (both trials) and sensation (stroke trial only)(4). Additionally, the trial with children with CP highlighted the ability for *OrbIT* to foster enhanced socialisation and competitive gameplay amongst siblings. While the results from both trials demonstrated early promise,

larger and appropriately powered trials need to be conducted to validate the pilot trial results.

Figure 9: The final trial version of the OrbIT Gaming System, showing the novel 'orb' shaped controller in the foreground and the laptop that supports the gaming system in the background (left), and a child being introduced to the OrbIT Gaming System (right)



Throughout both trials, *OrbIT* proved to be an acceptable, feasible, and robust technology that was appropriate for people with upper limb sensory and motor impairments, which was rated highly and demonstrated high utility. The novel intervention has been patented in Australia, Singapore and the United States, and following significant end user, professional and commercial interest, the technology has successfully transferred to a local disability organisation for commercialisation. The next generation of the technology, referred to as *i-boll*, is due for release in late 2019/early 2020.

Discussion and Recommendations

Understanding how design thinking tools and user centered design approaches can be used to foster innovation in problem solving in the application of assistive technology is an area of increasing importance that has received little attention in existing research. This paper has showcased examples of 'best practice' with respect to innovative AT development. Both case studies applied design thinking methods and approaches, a strong co-design focus, a multi-disciplinary team, and resulted in commercial outcomes. The findings of both case studies support the use of a systematic design thinking approach and co-design principles, as a way of incubating novel ideas to create innovative solutions.

Design thinking makes AT usable, by appropriately connecting people with technology and has been central in the development of both Prohab and *OrbIT* products. It represents the creative application of science, engineering and technology while addressing real human needs. Desirability and pleasure are also integral components of design thinking, which when partnered with business and technology, result in effective product development strategies.

The best practices recommended are:

- The combination of co-design and design thinking, where the end user is an integral part of the multi-disciplinary team, and
- The process of translating a clinical need or opportunity into an innovative commercial product.

We propose design thinking is highly applicable to the growing need for AT products in low to middle income countries, where challenges for equitable AT centre on *Access*, *Appropriateness*, and *Affordability* (35, 36). Design thinking is included within the regenerative recommended by the World Economic Forum (37). Circular business models, combined with robust, durable, and re-manufacturable product architectures allow products to undergo multiple product-use-cycles (38), greatly increasing device affordability and environmental sustainability.

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The development of innovation sharing platforms for low cost and do-it-yourself assistive technology in low and middle-income countries

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Abstract

Assistive Technology supply and provision has traditionally been seen as the preserve of professionals in the healthcare or education sectors or those working in specialist assistive technology companies. In order to scale up AT service delivery globally to address the needs of almost 90% of disabled persons around the globe who have little or no access to Assistive Technology, this prevailing view necessitates the expansion of manufacturing, supply chains, service infrastructures and professional expertise at a minimum five-fold to help cope with this growing global demand. Given the length of time it takes to train professionals in this area, such a goal would take decades to achieve, if at all economically feasible given all the other pieces of the jigsaw needed to successfully establish such services. Furthermore, simply exporting technology from one part of the planet to another can often result in completely inappropriate provision for local needs and leads to unnecessary cost increase. There is a need for greater localized capacity building to enable technologies to be designed and built that are truly fit for context, from the personal, clinical, cultural, social and economic perspectives, while at the same time benefiting from the decades of experience in AT design, manufacture and service delivery mechanisms in the industrialized nations. There is certainly a strong case to be made for greater expertise to be available in a number of areas e.g complex mobility needs and AAC provision. However, in parallel, there are also numerous and growing examples of highly successfully DIY initiatives, for example the open prosthetics community e-Nable, which now boasts thousands of children using adaptable prostheses designed uniquely for each individual's needs. Increasing connectivity and a democratization of design and fabrication tools such as 3D printers or DIY electronics have the potential to enable individuals across the world to develop prototypes and solutions that address their own localized unmet needs. Furthermore, these individuals are able to share such solutions online and even co-create new solutions with collaborators in other parts of the world, using emerging online design sharing platforms. However, these tools are still relatively inaccessible for many with disabilities, require considerable digital literacy and are predominantly used in the higher income countries reflecting a global digital divide.

This chapter will provide a brief survey of existing design & innovation sharing platforms, featuring examples of locally produced and low-cost assistive technologies that have been created using local resources and then shared online on a variety of design sharing platforms, sometimes by end users themselves or caregivers. We will also discuss how useable these platforms are to enable localized design, fabrication and knowledge sharing for persons with disabilities and assistive technology providers globally.

Keywords

User Innovation, Frugal Innovation, Assistive, Technology, Maker, DIY, Design, Platform

Introduction

User innovation, a term coined by MIT professor Eric Von Hippel, is used to describe the notion that many innovations in products or services around the world have their roots in a consumer having invented that solution to address their own unmet need (1). Eventually resulting in a mass market product when other users identify with same need and entrepreneurs (who may be from the user community or established companies) start to see market potential. Some popular examples of this “ground up” approach to innovation include the ice cream cone, the mountain bike and the AirBnB website.

Frugal innovation is the concept that many unmet needs can be addressed by developing products by focusing only on the core essential features needed, reducing both cost and complexity in their development (2). Low- and middle-income countries like Pakistan and India are replete with examples of both user and frugal innovation in numerous domains (3). The hindi term “*jugaad*” (loosely meaning “a hack” in Hindi) is increasingly used across South Asia to describe such innovations, which in many cases this includes solutions created for disability needs (4). The Jaipur foot (5), for instance, is often hailed as a prime example but many other “hidden” examples exist in numerous streets across many villages, towns and cities across low- and middle-income countries but these solutions are very rarely documented or shared.

As is often the case with user innovation, the impetus for the creation of these “*jugaad*” solutions frequently comes from an enterprising individual with an unmet need due to a lack of availability of assistive technology appropriate to the local context. There are numerous dimensions to this local context, which can include issues around affordability, localization, robustness to the local climate and inadequate local technical support or training for those assistive technologies that are commercially available. However, another major factor is a lack of awareness of available solutions developed elsewhere which could possibly result in a “re-invention of the wheel”.

We are interested in exploring how user innovations in Assistive Technology are developed and, more importantly, shared in an open-source fashion. In the authors’ opinion, with regards to AT innovation, one of the most valuable aspects of increasing social connectivity through the proliferation of platforms on the world wide web is the emergence of design

and innovation sharing platforms. These platforms enable innovators to research, develop, share and even co-create solutions to a whole host of problems, collaborating in ways that were completely unprecedented before the emergence of the web. With technology design, development and fabrication becoming more democratized (though currently, mainly) in the higher income countries and increasingly in the low- & middle-income countries, opportunities are ripe to be able to leapfrog innovation in assistive technology by leveraging learnings from the maker-movement as well as through these innovation-sharing platforms. However, considerable work is required to help build the appropriate infrastructure, digital tools and to adapt the resources required for such tools to truly empower people with a disability as well as assistive technology services across the globe.

The main objectives of this study are to explore the prevalence of user innovation in assistive technology and how these innovations are increasingly disseminated through innovation sharing platforms. This study forms part of a longer-term research initiative to identify the barriers and enablers to developing and sharing both user and frugal innovation in this domain, especially in low- and middle-income countries.

Methods

The approach taken for this report consists of a mixture of literature review and a survey of current design or “hack” sharing platforms. Case studies were gleaned from the following platforms, all of which include examples of assistive technology:

1. Thingiverse (www.thingiverse.com)
2. Pinshape (www.pinshape.com)
3. Instructables (www.instructables.com)
4. Hackaday (www.hackaday.io)
5. Hackster.io (www.hackster.io)
6. Github (www.github.com)
7. Sourceforge (www.sourceforge.net)
8. Patient Innovation (www.patient-innovation.com)
9. Makers Making Change (www.makersmakingchange.com)
10. Careables (www.careables.org)
11. Open Assistive (www.openassistive.org)

Some of the above platforms tend to focus on sharing designs for physical devices (e.g. Thingiverse for 3D printing), others focus on software (e.g. Sourceforge) and a few that bring all of the above together (e.g. Instructables or Hackaday). Of the bottom four, Patient Innovation and Careables are dedicated to curating healthcare related innovations by users or carers, while Makers Making Change and Open Assistive are exclusively for assistive technology.

For each of the above platforms we searched for AT solutions using the following terms - “disability”, “assistive”, “prosthetic” and “braille”. These are some of the same terms that yielded a relatively larger number of assistive technology solutions compared with a host of

other search terms used to search for AT solutions on the Thingiverse platform in a detailed study of that platform alone conducted by Beuhler et al in 2015 (6).

We also conducted a formal survey with over 60 assistive technology hackathon participants to better understand from their perspective how they found these platforms usable while researching specific designs for their own challenges. The survey took place during a two-hour workshop session at a university, where eight disability challenges were presented to the participants, of mostly engineering or science students. Every participant took one challenge each and conducted a search for possibly relevant solutions within each of these platforms and then against each of them listed any found solutions within a (Google) survey form. In addition to free text field allowing the participants to give general feedback on the usability of each platform, the participants were asked to score platforms on the basis of:

1. **Ease of finding a solution** relevant to their particular disability challenge (Score of 1 = Very Difficult and Score of 5 = Very Easy to find a relevant solution)
2. The **quality of information**, which was judged by how much information was provided on the platform in order to recreate the solution. (Score of 1 = Unable to recreate solution from available information and Score of 5 = All information available to recreate solution).

Due to the diversity of challenges and the varied type of solutions searched (e.g. software vs hardware) a more scientifically valid comparison of these platforms will necessitate a much larger cohort of participants. However, due to the nature of hackathons, there is a limit to how many people can be engaged at any one time. Therefore, in this paper we do not report any conclusions from the survey as this is the first stage of a longer-term study that will evolve as we gather more data over several hackathons and international consultations. For the purposes of this report, we provide a review of the state of the art and recommendations relevant to the GREAT consultation.

Findings

This section describes some of our findings relating to the prevalence of DIY and low-cost assistive technologies on each of the above listed platforms.

Apart from Makers Making Change, Open Assistive and to some degree Patient Innovation and Careables, the vast majority of solutions on the above platforms are for mainstream needs with Assistive Technology solutions forming a small minority of projects on these sites. Furthermore, none of these platforms have been specifically designed with the needs of countries with resource constraints in mind. To our knowledge, currently no such platform exists. Almost all mainstream platforms are primarily English language based and only two (Thingiverse and Pinshape) offer mobile app versions of their platform. Table 1 below lists results for disability related solutions using a small number of search terms.

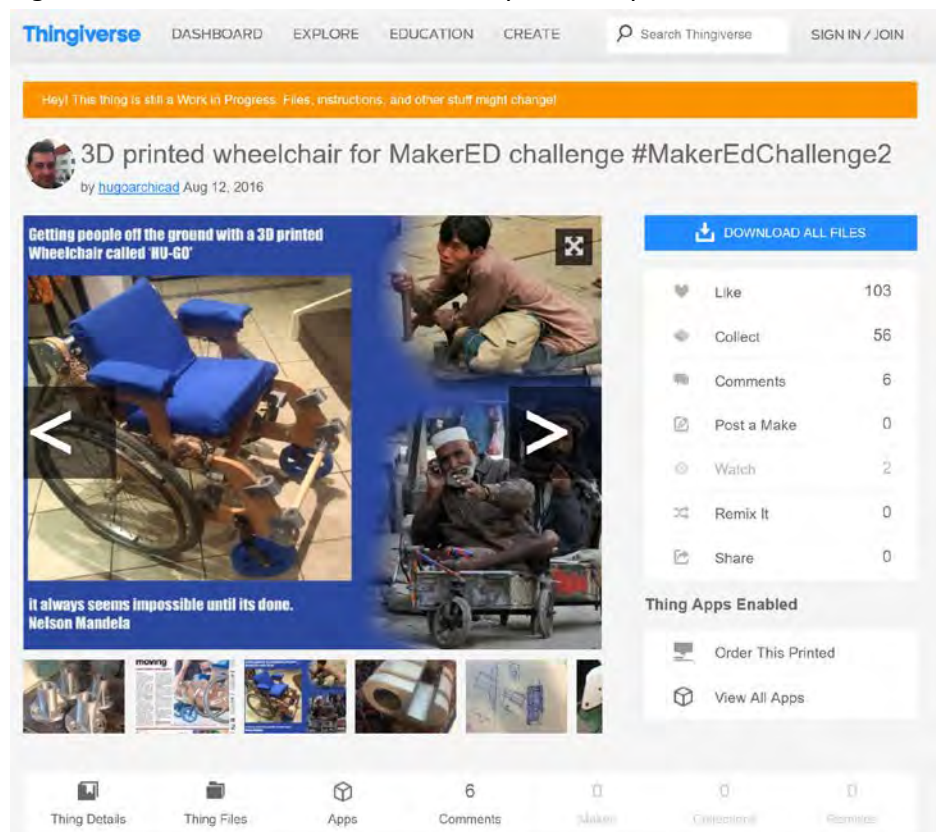
Table 1. Mainstream Design Sharing Platforms Search Results for AT Solutions (July 2019)

	Thingiverse	Pinshape	Instructables	Hackaday	Hackster	Github	Sourceforge
“Disability”	300	33	201	32	72	776	89
“Disabled”	626	9	201	65	197	2017	4
“Assistive”	273	47	1034	113	49	10951	21
“Prosthetic”	217	42	147	55	16	400	4
“Braille”	399	85	40	38	11	1,297	65

Thingiverse (US - owned by Makerbot)

Thingiverse was launched in 2008 to share designs of physical objects created using 3D printers, laser cutters, CNC machines etc. The number of solutions on this platform is growing exponentially and in 2018 on its 10th anniversary, well over a Million 3D printable projects were recorded on the site, with over 3 Million people accessing the site on a monthly basis to share or download solutions.

Figure 1. Low cost wheelchair with 3D printable parts



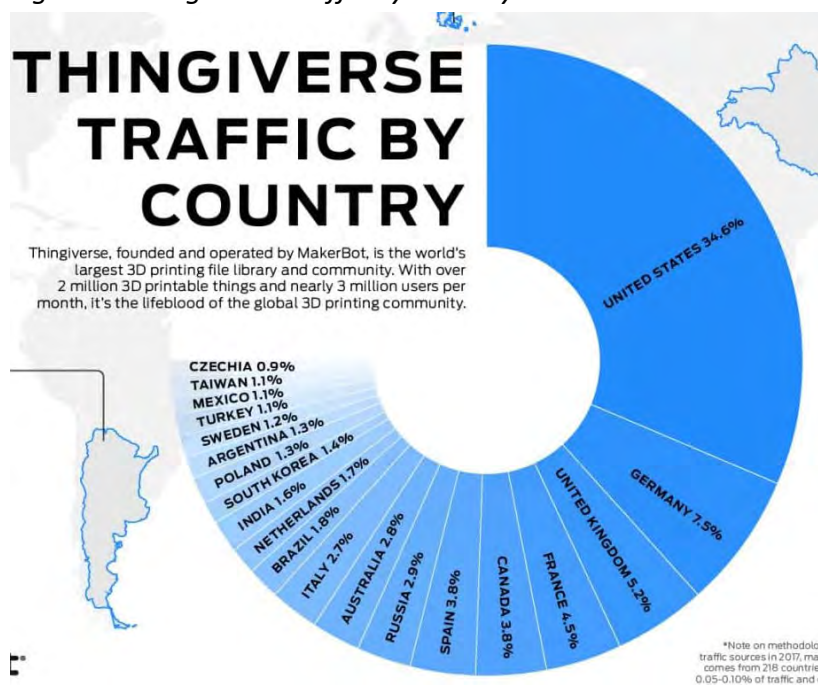
Source: Thingiverse.com

In 2015, Buehler et al studied the prevalence of assistive devices found on this platform and discovered over 383 unique designs by 273 contributors that could be described as assistive technology (6). At the time, the research team reported considerable challenges in

searching for these assistive solutions from within a much larger pool of over 100,000 mainstream designs. Using search terms such as “disabled” (14 items), “disability” (12 items), “assistive” (9 items), “braille” (18 item) and many more, the team would discover hundreds of projects being filtered that still included items that would fall outside their inclusion criteria for classifying as assistive technology. Since 2015, the total number of contributions to the site has grown exponentially and we ran a selected number of the same search terms used by Buehler et al to explore the current number of disability related solutions and although the number of items found has increased considerably (“disabled” - 626, “disability” - 300, “assistive” - 273, “braille” - 399, “prosthesis” - 217), nonetheless finding appropriate assistive technology solutions for a particular unmet need is still very much like finding a needle in a haystack, given over 1.4 million designs to search from.

Looking at the internet traffic data for the site, the vast majority of traffic associated with the platform does not originate from low and middle-income countries. Indicating that the vast majority of solutions are still very much designed for a western context.

Figure 2. Thingiverse Traffic by Country

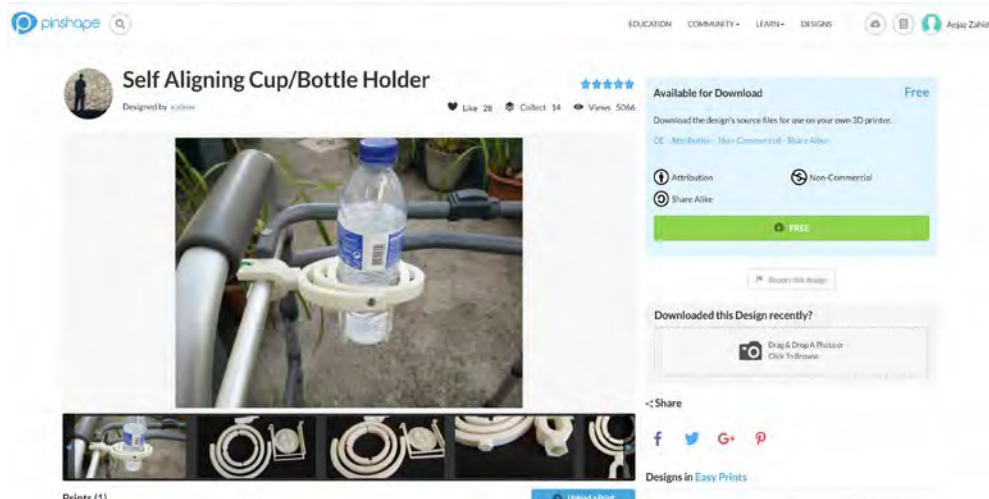


Source: MakerBot

Pinshape

Pinshape is a platform similar to Thingiverse and is dedicated to supporting 3D print design sharing. A relative new-comer (launching in 2013) amongst these platforms that, in addition to open source sharing, also allows for commercial transactions between site users.

Figure 3. Cup & Bottle holder attachment for wheelchairs & frames



Source: Pinshape.com

The site holds an increasing number of assistive technology solutions, although far fewer than Thingiverse. Our search under the selected tags “disability”, “assistive”, “prosthetic” and “braille” revealed 33, 47, 42 and 85 projects respectively.

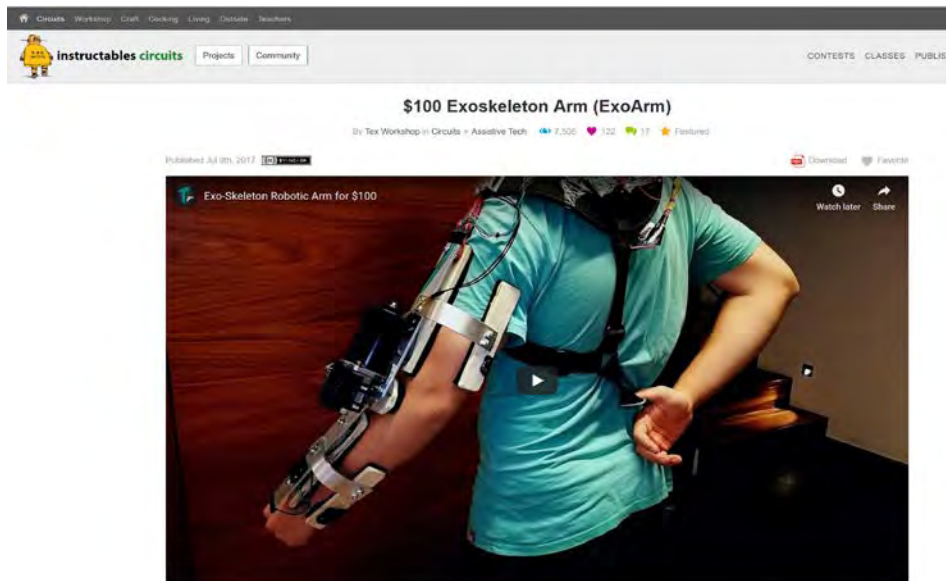
Instructables (US - owned by Autodesk)

Instructables is a platform launched in 2005 that is popularly used to share step by step instructions for making (including 3D prints, electronics, software code etc), DIY hacks and even food recipes. In 2015, Autodesk, the company that owns Instructables, stated that there were over 30 Million active users of the site and there are currently hundreds of thousands of “instructables” on the site, from cake recipes to instructions on how to fabricate components for and build fully functional drones or robots (8).

The site aims to categorise by seven broad themes - “Circuits”, “Workshop”, “Craft”, “Cooking”, “Living”, “Outside” and “Teachers”. Although there is some overlap between these over-arching themes, each of these themes also includes a number of sub-categories. For example, the “Workshop” theme has 25 categories which includes varied themes such as “3D Printing”, “Electric Vehicles”, “Hydroponics” and “Home Improvement”.

Within all of these themes and sub-categories there exists a large and diverse range of DIY assistive technology solutions that span physical devices, electronics, software and a combination of the above to cover a range of disability needs. In fact, very recently within the “Circuits” theme, the Instructables site now includes a dedicated sub-category of “Assistive Tech”. The total number of projects within this sub-category as of July 2019 stands at just over 700. However, when we searched for items using the same selected terms as above, we found just over 1000 projects that were tagged with the keyword “Assistive”, over 200 tagged under “Disability” or “Disabled”, 147 tagged under “Prosthetics” and 40 under the keyword “Braille”

Figure 4. \$100 Exoskeleton to Support Upper Limb Weakness

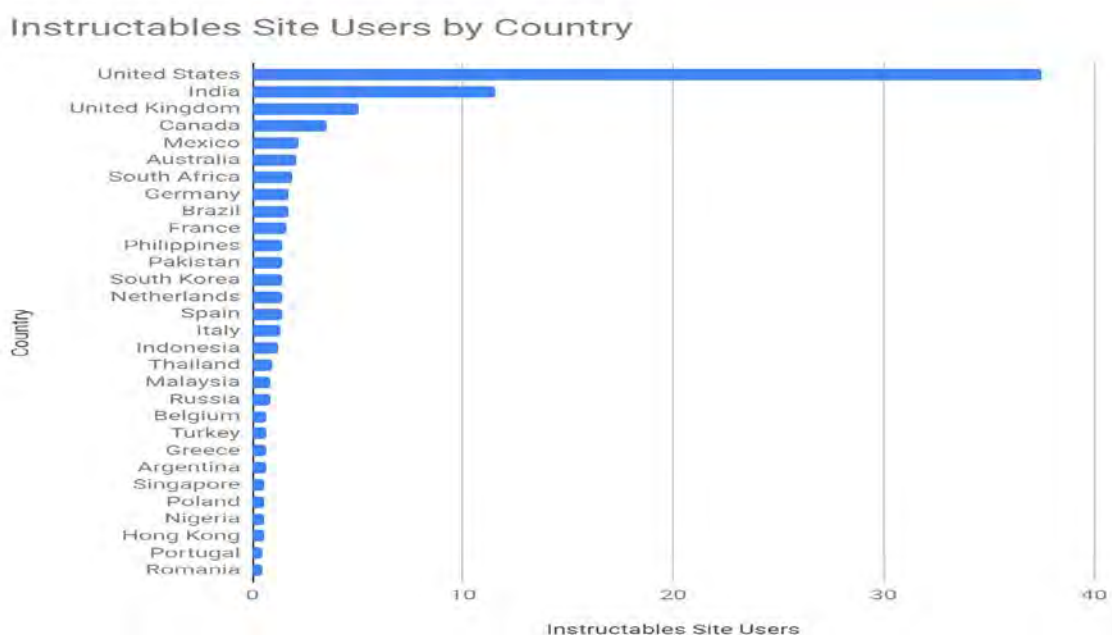


Source: *Instructables.com*

Examples are as diverse as simple mechanical devices to help an individual with dexterity issues hold cutlery to an eye gaze-controlled wheelchair system.

In terms of site traffic, as with Thingiverse, the USA and European countries represent the bulk of users of the site. However, in recent years, we have steadily seen the growth of traffic from countries such as India and Pakistan. Although India, with four times the population of the USA, now represents second place in the use of the site, the traffic it represents is still only a third that of the USA.

Figure 5. *Instructables Site Traffic by Country (as a percentage of total)*



Hackaday.io (US)

Hackaday is a very popular blog and web magazine (in the English language) established in 2004 that promotes DIY hacks that cover the full range of physical, electronic and software projects. In 2014, the site started hosting projects and has evolved into another design sharing platform similar to Instructables in its diversity and now boasts over 350,000 members.

Figure 6. Affordable Assistive Home Automation App & Electronics



Source: Hackaday.io

A major highlight of this platform is that it regularly hosts competitions around particular themes, including having had some popular assistive technology competitions in the past. This kind of activity, along with engaging articles, has resulted in increasing popularity of the site. Upon searching for assistive technology solutions using our selected search terms we found over 100 projects tagged with the “assistive”, over 30 projects tagged with the term “disability”, 55 for “prosthetic” and 38 for “braille”.

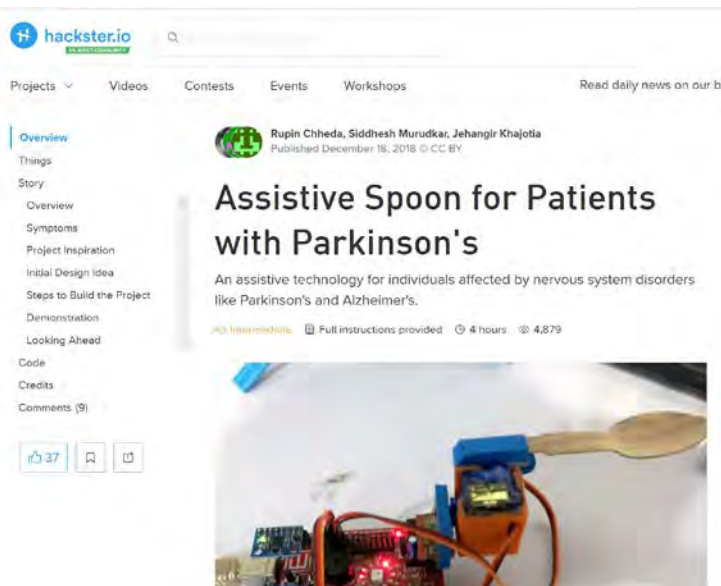
Website traffic statistics for Hackaday indicate that this site is most popular in the USA (35% of traffic) and the remaining countries in the top five are all from Europe (9).

Hackster.io (US - owned by Formlabs)

Hackster.io is a platform that brings together a diverse set of engineering projects and is very popular amongst developers specializing in particular tools (e.g. Arduino, Microsoft Azure etc) to help form communities around a specific development toolkit. The site now boasts over 1 Million members and over 18,000 projects.

One of the strengths of the site and what makes it popular with developers is that it has some very useful categorization features under a number of technology schemes. Categorizing by type of tools and technologies used to build the projects, as well as curating projects under specific topics (currently these number at 51 topics). For example, “Internet of Things”, “Home Automation”, “Health & Medicine” etc. From amongst these (18,000+) projects our selected search terms revealed over 72 projects tagged under the term “disability”, 49 under “assistive”, 16 under “prosthetic” and 11 under “braille”.

Figure 7. Tremor Reducing Spoon



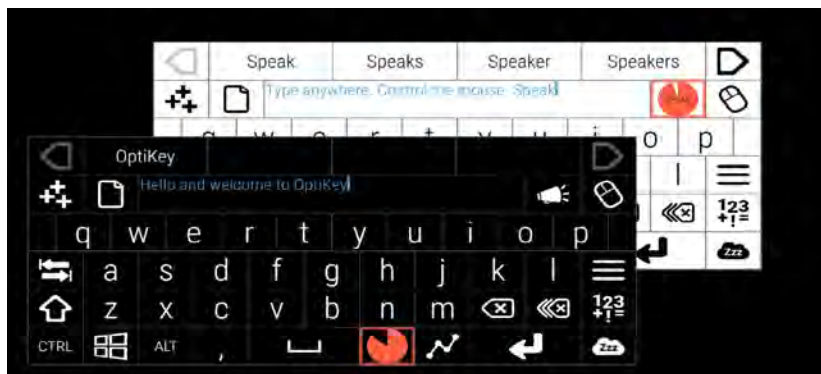
Source: Hackster.io

Interestingly, Hackster.io is gaining rapid popularity in India, particularly amongst students, making the country the highest contributor of traffic (22.2%) almost at par with the USA (21.9%) (10).

Sourceforge (US)

Sourceforge has been a popular site for sharing open source software since the late 90s. Mainly directed at software developers, it has maintained a number of features designed for sharing source code and for collaboration. The number of developers registered on the site is currently over 3.7 Million and the site relies on this large user base to help over 450,000 software projects remain active. The number of assistive technology related software projects on this platform is relatively small in comparison, with our selected search terms revealing only 89 projects tagged under the term "disability", 21 for "assistive", 4 for "prosthetic" (mainly code to control the hardware in prostheses) and 65 for braille.

Figure 8. Free Onscreen Keyboard for Eye Gaze/Head-tracking



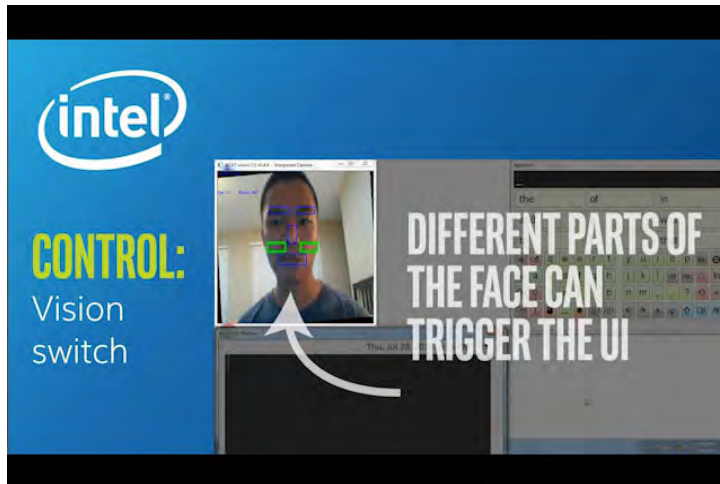
Source: forge.net

An analysis of the traffic to this site revealed that Brazil (2nd), India (3rd) and China (4th) are within the top 5 countries representing traffic to this site (11).

GitHub (US - owned by Microsoft)

GitHub, like Sourceforge, is also a platform that serves as a repository for sharing and collaboration on software code, both open source as well as closed collaborative projects. Although much younger than Sourceforge, the platform has become far more popular since its launch in 2008, with over 37 Million users and over 28 Million open source projects (12).

Figure 9. Facial Gesture Controlled Switch to Control ACAT Keyboard



Source: Github.com

Within this vast range of software projects our selected search terms revealed a 776 projects tagged under the term “disability”, almost 11000 displayed upon searching the term “assistive” (however, we discovered that many items tagged under the word “assist” were also appearing under this search hence highlighted in red in Table 1), over 400 under the term “prosthetic” and 1,297 under “braille”. Site traffic statistics again revealed China (2nd), India (3rd) and Brazil (4th) in the top five countries using this site (13).

Specialized Design Sharing Platforms

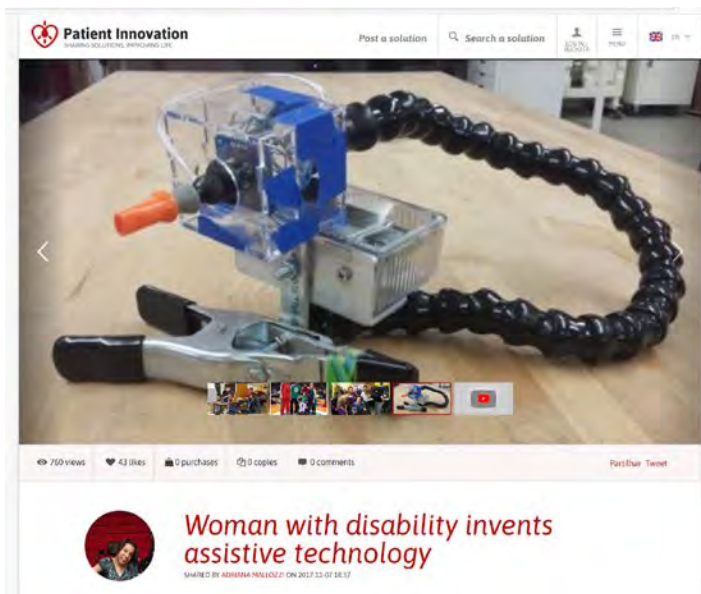
A relatively recent phenomenon has been the emergence of more specialized platforms that allow for more accurate and relevant search of DIY assistive technology solutions shared by the technology users themselves or people close to them.

We focused on four of the most relevant platforms amongst these in terms of ‘solutions’ for people with disability. The majority of these platforms are very new in comparison to some of the mainstream ones described above, the speed of growth is far slower and none of these platforms currently offer a mobile app to complement the site.

Patient Innovation (Portugal)

The patient innovation platform launched in 2014, is designed to curate and share user innovation in healthcare. Unlike some of the mainstream platforms described above, there is a filtering and validation process that contributions have to pass through, which entails a review by a panel of healthcare experts before the contribution is uploaded for public view. This is to reduce the risk of harm, particularly with projects relating to medical devices. The current list of healthcare solutions on the site have recently exceeded over a thousand and approximately a third of these related to assistive technology.

Figure 10. Sip/Puff Joystick for Android Phone Control



Source: Patient-Innovation.com

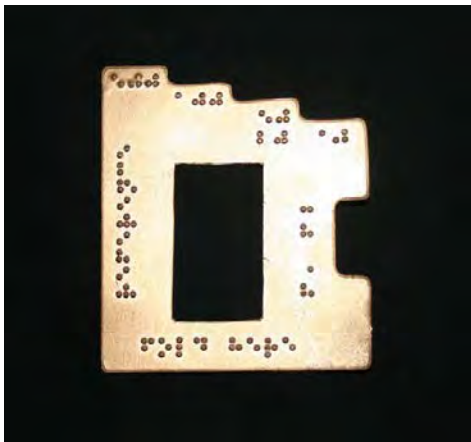
The site allows for solutions to be tagged by areas of functional need. Therefore, allowing users to pinpoint solutions very close to their area of need.

Although the majority of contributions do not provide enough detail for reproduction of the same solutions, some projects are linked to other platforms such as Instructables, where the site user can then download instructions on how to build it for their own needs.

Furthermore, the site is currently not designed for collaboration but is more of a tool for curation. If an individual requires access to the same solution, they would need to contact the original contributor via the Patient Innovation team.

We used the same search terms as above to reveal almost 300 innovations tagged under the term “disability”, 59 items tagged under the term “assistive”, 126 under “prosthetic” and 57 under “braille”. Of these solutions, the vast majority again originated from the USA and Europe and with a number of interesting low-cost solutions from India but still representing less than 5% of the total. For example, the Tiffy Template shown in Figure 11 below is designed to support individuals with visual impairments to ascertain the monetary value of a note by folding the note over this assistive tool.

Figure 11. Tiffy Braille Template for reading Indian Notes

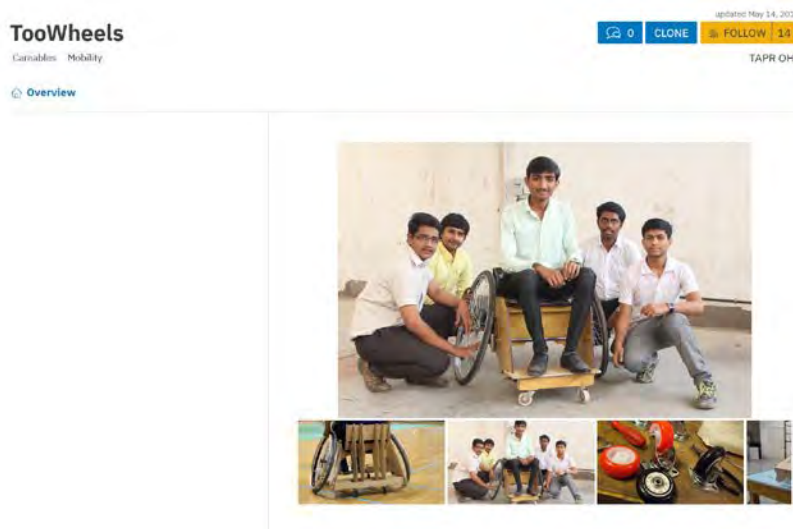


Source: Patient-Innovation.com

Careables (Germany)

Careables is a relatively new platform similar to Patient Innovation that is designed for health care design sharing but with an additional element of co-creation. The site also allows for solutions to be listed under themes and currently curates under nine categories such as Communication, Mobility, Self-Care and Therapy.

Figure 12. Open Source Wheelchair Design



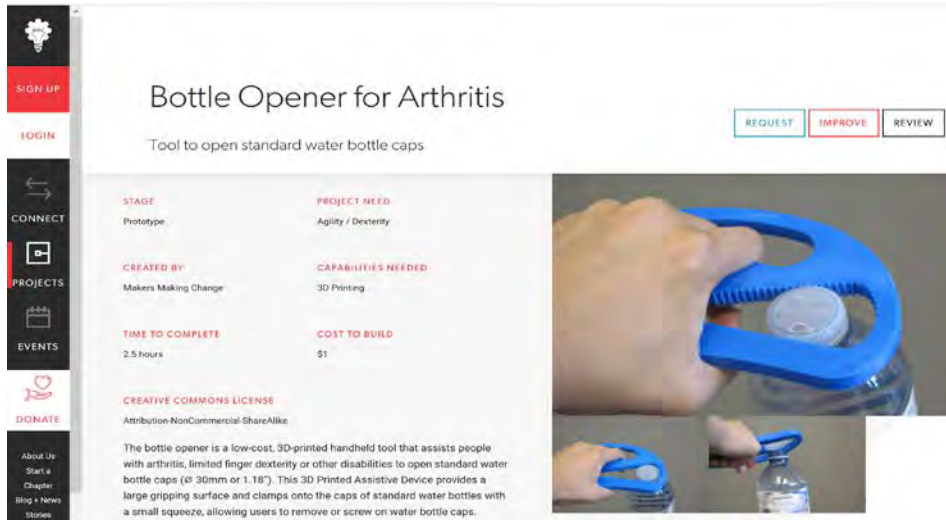
Source: Careables.org

As this is a very new platform, we found relatively fewer solutions currently on the site and many of these were curated from or linked to submissions on sites like Instructables (as in the case with many submissions to the Patient Innovation platform). As of July 2019, the site lists around 51 projects relating to assistive technology.

Maker Making Change (Canada)

Makers Making Change is a design sharing platform that has been specifically created for assistive technology solutions. The portal is designed to support curation, sharing and collaboration on DIY assistive technology projects. As of July 2019, the site hosts about 70 unique projects.

Figure 13. Affordable 3D Printed Bottle Opener



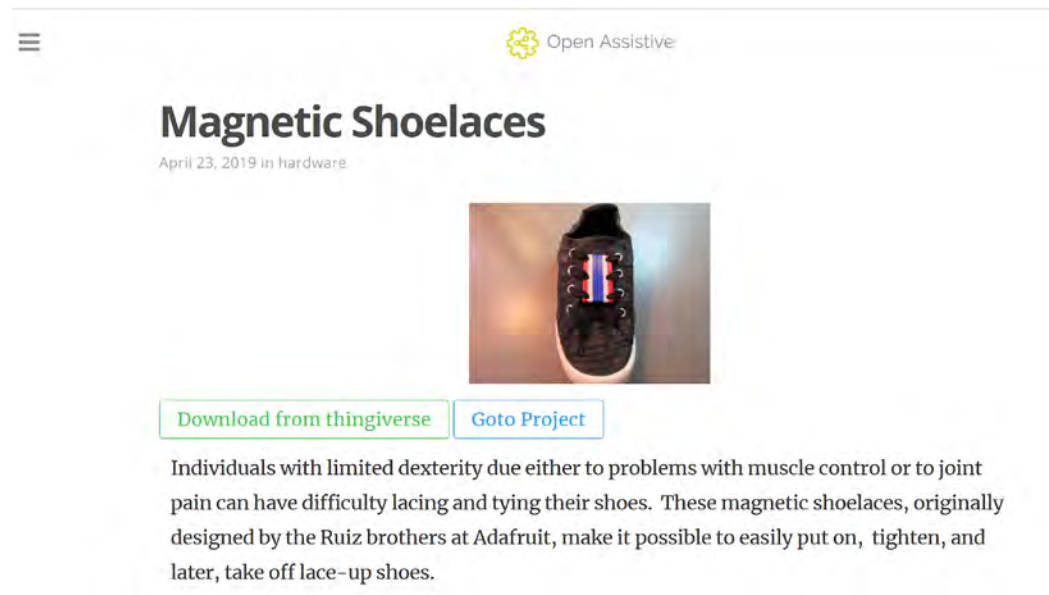
Source: MakersMakingChange.org

The site is designed to bring makers and persons with disabilities and professionals working in the AT field to collaborate and co-create solutions for an unmet need submitted to the site. An individual with an unmet need can post a challenge on the site, logged as a “request” and then makers (in any part of the world) can attempt to solve the challenge. Posting a solution (in the form of 3D print files, fabrication instructions etc.) back on the site for others to download, use and adapt.

Open Assistive (UK)

Open Assistive is a platform designed to crowd-source the *curation process* of finding assistive technology solutions discovered on other platforms such as Thingiverse or Instructables. The site allows contributors to separate solutions into predominantly hardware or software-based solutions and currently shows around 80 hardware solutions and half as many software solutions.

Figure 14. Magnetic Shoelace for Motor Control Challenges



The screenshot shows a webpage from Open Assistive. At the top left is a hamburger menu icon. At the top center is the Open Assistive logo, which consists of a green gear icon with a person silhouette inside, followed by the text 'Open Assistive'. Below the logo is the article title 'Magnetic Shoelaces' in a large, bold, black font. Underneath the title is the date 'April 23, 2019 in hardware'. In the center of the article is a photograph of a black shoe with red and white magnetic laces. Below the photo are two buttons: 'Download from thingiverse' with a green border and 'Goto Project' with a blue border. Below the buttons is a paragraph of text: 'Individuals with limited dexterity due either to problems with muscle control or to joint pain can have difficulty lacing and tying their shoes. These magnetic shoelaces, originally designed by the Ruiz brothers at Adafruit, make it possible to easily put on, tighten, and later, take off lace-up shoes.'

Source: *OpenAssistive.org*

This approach effectively allows site users to filter results from other platforms and is predominantly used by United Kingdom-based assistive technology professionals. With a large enough cohort of AT expertise contributing to the site, this methodology for curation has the potential to rapidly identify solutions for a vast range of needs and bring an element of quality control to curating DIY AT solutions found on mainstream platforms. However, to date, the platform has yet to build enough of a critical mass of contributors to grow its content significantly.

Discussion

It is clear that innovation sharing platforms have tremendous potential to help support and empower individuals with disabilities and can be a valuable resource for nascent assistive technology services globally and small-scale manufacturers in low and middle-income countries. The flexibility offered by DIY solutions to adapt these assistive technologies for individualized needs can enable more customised and localised solutions to be created that can arguably be better fit for purpose and draw on locally available resources (7,14,15).

However, studying the above platforms, we can immediately see major challenges that affect the adoption of these platforms in the populations we wish to serve and as we have seen consistently throughout our studies, the majority of internet traffic to these platforms is predominantly from the wealthier nations. This reflects a considerable gap in access to online information between the wealthier nations and low & middle-income countries, which can be due to:

- A lack of traditional telecommunication infrastructure - particularly in rural areas. According to the International Telecoms Union, the uptake of fixed broadband

subscriptions in low and middle countries ranges between 2% and 10% of inhabitants having access (16).

- Language barriers due to existing platforms and instructions mainly written in the lingua franca of the wealthier nations
- Education and literacy differences that impact on meaningful engagement with these platforms (17,18).
- Gaps in digital literacy (17,18).
- Expense of digital equipment to access information (18).
- Lack of access to electricity to run the digital devices that would run such platforms (18)

At the same time, we are seeing numerous ways in which many low and middle-income countries are now able to leap-frog through some of the infrastructural challenges. For example:

- For access to online and digital resources, many parts of the world are going directly to a wireless telecommunications infrastructure, which opens up online access for rural areas (16).
- More sustainable and deployable forms of electricity generation are becoming increasingly more accessible and affordable (due to innovative business models) across the lower and middle-income countries and in particular, rural areas (19).
- There is rapid growth in mobile adoption, with mobile broadband rapidly becoming the main form of access to online information (16).
- Digital devices such as internet enabled phones (dubbed “smart-feature” phones costing well under \$50) or tablets are becoming both cheaper and more powerful (20).

With improving mobile infrastructure, there are opportunities for better designed interfaces that take into account the digital device features, the platform, the language, accessibility, cultural and literacy challenges. There are numerous examples within popular media platforms such as Youtube (which is predominantly video based) gaining wide traction across the globe despite language and literacy challenges. There is an opportunity to develop a strategy and incentives to share localized knowledge & innovative practices globally that can lead to tremendous economies of scale.

Parallel to the digital infrastructure, we are also witnessing fabrication tools such as 3D printers and electronics prototyping kits (e.g. Micro:bit, Arduino etc) becoming more accessible and affordable. This has led to a proliferation of makerspaces such as FabLabs setting up local makerspaces (at least in major cities and slowly in more remote locations) all across the globe (21). In recent years, some of these makerspaces are increasingly being designed with accessibility in mind (22) and some have started hosting popular hack-a-thons (sometimes called make-a-thons) such as Hackcessible (23) specifically created to address disability related challenges. Many teams at such make-a-thons are increasingly referring to some of the platforms we described above as they ideate solutions for their own challenges and then in turn, are utilising these platforms to share the solutions they create in an open

source manner. Unfortunately, our research shows that inspite of this information being widely available online there are still major challenges for AT users and professionals in low and middle-income countries to retrieve appropriate solutions for their needs. Conversely, the data shows that sharing solutions that these individuals may have developed in these countries are even less likely to end up on these platforms.

Our primary recommendation is to co-create a new mobile based platform for design sharing by collaborating with persons with disabilities and professionals working in nascent AT services in low- and middle-income countries that draws on the strengths of some of the above platforms but also takes into account the digital devices and services available locally. This platform could be developed in partnership with one or more of the existing platforms described above and in the early stages could be populated with a select number of existing solutions relevant to the local context.

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The role of the Industry Advisory Group of the International Society for Prosthetics and Orthotics as a vehicle for enabling appropriate innovation

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Abstract

The submission is made by the Industry Advisory Group (IAG) of the International Society for Prosthetics & Orthotics, the Vision of which is “A world where all people have equal opportunity for full participation in society”. ISPO’s purpose is enhance the quality of life for everyone who may benefit from prosthetic, orthotic, mobility and assistive devices. Membership of ISPO is open to all individuals, associations, organizations, and institutions with a bona fide interest in prosthetics, orthotics, wheelchairs, assistive devices, rehabilitation engineering and related subjects who support the its vision and purpose. Composed of senior representatives from companies operating in the P&O industry the Industry Advisory Group (IAG) provides a forum for on-going dialogue, information sharing, joint exploration of shared challenges and solutions in the P&O fields and a platform to support collaboration with industry partners worldwide. The Group is open to industry partners active in the P&O field or related disciplines including manufacturing P&O devices and/or providing P&O and rehabilitation services. Members represent different lines of business and regions to promote rich dialogue. The objectives would be to build a joint understanding amongst the IAG members of: - How innovation in the prosthetics and orthotics industry is defined and measured; - Which factors are vital to foster an enabling environment, and; - How ISPO’s Industry Advisory Group (IAG) successfully contributes to enabling appropriate innovation for improving accessibility and affordability of high quality AT. The aim would also be to illustrate that: - Through its activities the Industry Advisory Group (IAG) is a good example of how a group of companies in the P&O industry can work together to Enable Appropriate Innovation, with benefit for end-users; - The functioning of the IAG is a benchmark for “Good practices and processes for innovations in assistive technology”. The approach would be to develop a case report reflecting industry views and experiences about opportunities and barriers for innovation, as well as showcasing the approaches and best practices related to addressing challenges through the working groups of the IAG. In the second half of 2018 the IAG members agreed to initiate two important

initiatives, both of which are expected to contribute to ISPO's vision. These are: - Outcome Measures (OM); - Core Data Set (CDS). The case report would describe the objectives and processes of these two important initiatives, highlighting the results achieved, and best practices developed. Medical and technological advancements in prosthetics and orthotics have led to a more patient-centred fitting approach resulting in increased mobility and quality of life of its users. However the term innovation should not be limited to the technical product perspective, but also include manufacturing, treatment and delivery processes. Innovation may be also achieved by improving ease of process, as well as accessibility and affordability in terms of higher quality at a better price through higher effectivity or productivity. A heterogeneous understanding of the meaning of innovation and the use of inconsistent measures and methods to assess related outcomes at national as well as global level result in diverse legislative and regulatory environments, thus building a barrier for innovation. Furthermore an insufficient data base hinders evaluating and monitoring where innovation can have the most impact. The IAG Working groups in collaboration with ISPO contribute to creating a better information base for demand planning, and for the development of harmonized standards on how to measure treatment outcomes, This will promote an enabling environment for innovation. The harmonization of the legislative and regulatory environment at international level will promote an enabling environment for innovation and improves the accessibility and affordability for prosthetics and orthotics products and services. A multi-stakeholder approach such as the creation of the IAG Working groups in collaboration with ISPO, illustrates a best practice example of how to overcome barriers for innovation through harmonized standards. Modular technology approaches adopted as a modern industry "standard" for manufacturing and fitting has led to increased productivity. Through prefabricated components as well as enhanced individualization of treatment this has resulted in higher mobility and quality of life for the user. Today this standard is still not available to all users with need of assistive technology, leading to a huge technological gap in fitting standards across the world. In many countries there is currently insufficient infrastructure for care and education, in terms of number, facilities and distribution of facilities, equipment and know-how. Therefore WHO and national governments call for lower margins, innovation and higher volumes, enabling high quality AT to be accessible and affordable for all. However this requires planning visibility for the industry players. Missing data for demand planning and lacking or inadequate social security and reimbursement systems hinder the achievement of high volumes needed to decrease investment cost. At the same time industry is facing increasing regulatory requirements for market entry at national level as well as a growing requirement of clinical evidence. The requirements vary between different countries and this decelerates or acts as a barrier to entry of innovative assistive technology. Progress and innovation in digital technologies represent the potential to transform manufacturing and delivery modes. Specialized service centres using CAD/CAM technologies and additive manufacturing may increase productivity by bundling equipment and expertise. To address these challenges, and set targets, we first need to know the current situation. This involves building of core

data, and a solid information base. Based on transparent knowledge about the needs, and health systems industry will be able to allocate and invest resources to drive the necessary improvements in infrastructure, and outcomes for those in need. Therefore IAG calls to initiate a multi-stakeholder approach where governments, international organizations, NGOs, user groups and industry collaborate to create an innovation friendly environment. This should not only consider manufacturing cost on the industry side, but also reliable demand planning, strengthened health care and reimbursement systems including prosthetic and orthotic services and a harmonized regulatory environment to make innovation accessible and affordable to the benefit of persons in need.

The private health sector is a relevant stakeholder in achieving greater access to health services

In the light of aging societies and the increase of non-communicable diseases and chronic conditions such as diabetes, stroke and cancer, the demand for mobility devices and assistive technology is rising globally (1). Increasing trauma rates from road traffic accidents, natural disasters and conflicts further contribute to the numbers of person's in need (2).

An estimated 0.5 percent of the world's population needs an orthosis or prosthesis and related services (3) and about 1 percent a wheelchair (4). Mobility devices and related rehabilitation are critical to lead a healthy, independent and dignified life and being able to participate in education, the labor market and social life, the lack of which disproportionately affects those in less resourced settings.

In many developing countries less than 10 percent of the persons in need have access to products and services for successful rehabilitation and even in countries with higher coverage of basic services, the range of rehabilitation solutions are often not appropriate to regain mobility and lead an independent life.

Improving access to quality assistive technology (AT) and rehabilitation services not only allows member states to fulfill their obligations under the Convention of Rights for Persons with Disabilities (CRPD), but also in meeting the Sustainable Development Goals (SDGs). Beyond goal 3 "Enabling healthy live and well-being for all at all ages" it impacts further SDGs such as reduction of poverty (1), access to education (4), access to labor and economic growth (8), innovation and infrastructure (9) and reduces inequality (10). Goal 17 underlines the role of multisectoral partnerships to cope with the current challenges.

Whereas in the past many initiatives especially focused on humanitarian aid for vulnerable persons there is an increasing awareness of the interdependence of economic growth and health resulting into a systemic approach.

OECD Studies confirm that economic growth and development depend on a healthy population. Around one quarter of economic growth between 2000 and 2011 in low- and middle-income countries is estimated to result from the value of improvements to health (5). In recent years it became evident and widely accepted that the private sector needs to

be involved in creating systemic and sustainable solutions fostering socioeconomic development.

The private health sector has played a vital role in working towards greater access to essential medical services (6). The connection between public and private health care systems will be essentially important (7). One of the key enablers for industry to contribute to increased health access is that governments provide a supportive regulatory framework and set the right incentives.

When it comes to improving of access and quality of care it is often referred to innovation. Governments and policymakers often restrict innovation in health exclusively to new technologies. However, innovation includes many facets. Beyond technological advancements further aspects such as supply structures and processes, services, financing models and workforce skills also need to be considered. Health care innovation is thus a topic that needs to involve all related stakeholders, such as policymakers, academics, professionals, civil society organisations and the private sector.

ISPO builds expertise through bringing together multisectoral and multidisciplinary partners

The International Society of Prosthetic and Orthotic (ISPO) is a multidisciplinary organisation that promotes access to appropriate and equitable rehabilitation, mobility devices, and other assistive technology to improve the quality of life for people with reduced mobility. Membership of ISPO is open to all individuals, associations, organizations, and institutions with a bona fide interest in prosthetics, orthotics, wheelchairs, assistive devices, rehabilitation engineering and related subjects who support its vision and purpose.

ISPO has a strong history of bringing together partners from different sectors and building cooperation. Since its founding in 1970 ISPO has involved international organisations such as the United Nations (UN), the World Health Organization (WHO), and Rehabilitation International (RI), non-governmental organizations and other international societies involved in its work. A special focus has been improving access and quality of services in low- and middle-income countries.

Over the years the network has continuously enlarged and resulted in establishing the Open Board, recently renamed as the Global Partnership Exchange of ISPO (ISPO-GPEX) to more correctly reflect the breadth of the partners. Serving as a connection between ISPO, international organisations and non-governmental organisations, members of the ISPO-GPEX come from different regions of the world. Membership is open to institutions and organisations active in rehabilitation, assistive products and mobility devices, disability or related fields, either providing or supporting services, training of professionals, or representing professionals and/or user groups. Current members include professional organisations, international NGOs involved in prosthetic, orthotic and assistive technology service provision and education in these fields.

ISPO's purpose is to enhance the quality of life for everyone who may benefit from prosthetic, orthotic, mobility and assistive devices, by:

- *Serving as an international impartial and non-political coordinating, correlating and advisory body on prosthetics, orthotics, wheelchairs, rehabilitation engineering and other matters related to the neuromuscular and skeletal system in close collaboration with other national and international bodies, offering appropriate guidance and advice to these bodies to avoid unwitting duplication of effort and to encourage maximum use of resources*
- *Fostering scientific exchange among its members and others by collecting and disseminating information through publications, correspondence, exhibits, regional or international courses, seminars, symposia, conferences, contributions to Cochrane Rehabilitation, staff efforts or otherwise.*
- *Promoting and when requested, assisting in efforts to co-ordinate or guide research, development, and evaluation activities related to prostheses, orthoses, wheelchairs and rehabilitation engineering around the world.*
- *Guiding, and supporting the efforts of all those responsible for the education and training of the professions involved and correlating these activities around the world as required.*
- *Encouraging, guiding, and supporting the efforts of all those responsible for care of patients involving these important fields and, correlating these activities around the world as required.*
- *Undertaking, when requested, appropriate projects to encourage and facilitate high-level uniform practice by development of standards for nomenclature, curricula, design of devices, techniques and processes, testing, and by involvement in all appropriate aspects of patient care, research and development, evaluations, and education and training.*

In 2014 ISPO has launched a regular exchange platform for the industry bringing together the major players in the field leading innovation. Reporting to the Executive Board of ISPO the ISPO Industry Advisory group is composed of senior representatives from companies operating in the prosthetics and orthotics industry. The Industry Advisory Group (IAG) provides a forum for on-going dialogue, information sharing, joint exploration of shared challenges and solutions in the P&O fields and a platform to support collaboration with industry partners worldwide. The members support the objective to benefit prosthetics and orthotics users across the world. The President of ISPO and other representatives of the ISPO Executive board are an essential part of the group.

The Group is open to industry partners active in the prosthetics and orthotics field or related disciplines including manufacturing devices and/or providing rehabilitation services. Members represent a diverse mix of sectors and regions to enrich the dialogue.

The IAG currently has senior representatives from companies comprising:

- Chas. A. Blatchford & Sons Ltd
- Fillauer LLL
- Össur hf
- Ottobock SE and Co. KgaA
- ProsFit Technologies JSC
- Proteor

This breadth of experience brought together in the different groups by ISPO, reflecting the views, perspectives and experiences of multisectoral and multidisciplinary partners, allows for a broad-based consultation, development, buy in and ownership. ISPO brings in a long-standing experience in balancing conflicts of interests that may arise within and among these different stakeholder groups. This is essential for enabling appropriate innovation for mobility related assistive technology and rehabilitation, and for driving the global research agenda.

The IAG adopts challenges to enable greater access to quality, affordable AT for all

Modular technology approaches adopted as a modern industry “standard” for manufacturing and fitting has led to increased productivity and functionality. Through prefabricated components as well as enhanced individualization of treatment this has resulted in higher mobility and quality of life for the user.

Today this standard is still not available to all users in need of AT, leading to a huge technological gap in fitting standards across the world. In many countries there is currently insufficient infrastructure for care and education, in terms of number, facilities and distribution of facilities, equipment and know-how. Therefore, WHO and national governments call for lower margins, innovation and higher volumes, enabling high quality AT to be accessible and affordable for all.

However, this requires planning and visibility for the industry players. Missing data for demand planning and lacking or inadequate social security and reimbursement systems hinder the achievement of high volumes needed to decrease investment cost.

At the same time industry is facing increasing regulatory requirements as well as clinical evidence in support of products and technology for market entry at national level. The requirements vary between different countries and this decelerates or acts as a barrier to entry of innovative assistive technology.

Progress and innovation in digital technologies represent the potential to transform design, manufacturing and delivery modes. Specialized service centres using CAD/CAM technologies and additive manufacturing may further increase productivity by bundling equipment and expertise.

To address these challenges and set targets, we must first appraise the current situation. This involves the building of core data and a solid information base. Based on transparent knowledge about the needs and effectiveness of interventions, health systems will be able to allocate resources more efficiently for those in need. The cooperation of health care provider organisations and Industry can thrive where criteria for outcome-based investments are defined within the context of a consistent regulatory environment.

Therefore, the IAG proposes a multi-stakeholder approach where governments, international organizations, NGOs, user groups and industry players collaborate to create an innovation friendly environment. This collaboration should prioritise reliable demand planning, strengthened health care and reimbursement systems, including prosthetic and orthotic services, and a harmonized regulatory environment. Equally it should consider the input costs (manufacturing, research and development) on the industry side, but also to make innovation accessible and affordable to the benefit of persons in need.

The IAG working groups

The identification and further development of appropriate clinical instruments for outcome measures to demonstrate benefit to patients, and the health economic impacts, is a vital factor enabling healthcare systems to allow innovation to reach the patient. While a significant range of outcome measures is available for physical rehabilitation in general, the determination of the appropriate biometric properties related to prosthetics and orthotics remains challenging. The identification of a clinical core data set may enhance outcome research and enable international health economic evaluations.

Currently information regarding epidemiology and efficacy of amputee rehabilitation outcomes is often limited by the size of studies and generally follows a fragmented scientific approach (e.g. most studies are small and focused on a specific question). A global approach is needed to broaden the database and allow an exchange of data through harmonized data collection.

The IAG members therefore agreed in the second half of 2018 to launch two important initiatives, both of which are expected to contribute to ISPO's vision.

These are:

- Outcome Measures (OM)
- Core Data Set (CDS)

The IAG working groups can build on expertise and experiences of their members with different national initiatives.

The Working Groups will draw upon the experience of various existing initiatives, including AMPROM in the United Kingdom, SwedeAmp in Sweden, and a USA National Limb Loss & Prevention Registry.

A National Registry for Amputee Reported Outcome Measure (AMPROM)

A vision established by University of Southampton FortisNet, an interdisciplinary network of clinical, academic and industrial partners, for the United Kingdom NHS through ISPO United Kingdom was for a web based “open source” “big data” depository and registry of amputee outcome data called Amputee Reported Outcome Measure (AMPROM). The data repository at national and then international levels can be used to promote the science of prosthetics and further amputee rehabilitation. The logical expansion of this vision is into other areas of prosthetics and orthotics and is a natural extension into the emerging digital healthcare landscape. The registry already established in Sweden “SwedeAmp” and the work started in the United States will naturally complement this vision at a truly global level.

AMPROM aims to collect outcome data in an open source registry

The concept of a National Registry like AMPROM is to have the broad strategic goal of linking multidisciplinary teams (MDTs), patient outcomes and scientists.

The specific aim of AMPROM is to establish the digital platform and mechanism to capture data relating to the clinical outcomes of patients. To explore what this might “look like” various paths have been developed and tested for compliance with patient information security. The demo platform can be accessed at www.amprom.uk

Three portals were designed and developed. The project partners envisaged that entry and use of AMPROM should be free if possible and run on a non-profit basis. The data stored may be non-personally identifiable using linked anonymity with general epidemiological identifiers.

A process for data validation, security and management would need to be set up. In one possible example embodiment, clinicians would use a unique code and password for each amputee participant in the PROM survey (who also confirms consent and identity).

Researchers at Universities could, subject to ethical approvals etc., use the data for research purposes with appropriate acknowledgement and reference to the national registry as the data source.

The Swedish amputation register (SwedeAmp)

SwedeAmp is a Swedish national register that collects data and follows the chain of care from amputation to prosthesis supply and rehabilitation. The work on the registry was started by Bengt Söderberg in 2008 and was financed by the Scandinavian Orthopedic Laboratory until it was accepted as a national quality register in 2011 and supported by the government.

SwedeAmp collects data about the chain of care

The SwedeAmp register collects data about the amputation and the prosthetic fitting, as well about the situation before and after the amputation. It consists of totally 184 parameters. SwedeAmp has around 65% coverage of amputations in Sweden increasing every year. At present, there is data on about 8000 amputations. The registry has a clear multidisciplinary focus to load the database and provides opportunities for improvement work both within and between different care teams.

Work is now underway on a regional care program for amputations in Stockholm. The steering committee for SwedeAmp plans to establish a working group in 2019 to develop national guidelines for amputations.

US National Limb Loss & Prevention Registry

In fall 2018 Dr. Kenton Kaufman was awarded a \$5 million five-year contract by the National Centre of Medical Rehabilitation Research to develop and launch the National Limb Loss and Preservation Registry.

The USA National Limb Loss & prevention registry will combine data of hospital records, providers and self-reports

The registry will include the electronic health records of U.S. adults and children, and the goal is to establish the number of Americans who have limb loss and preservation procedures and then improve prevention, treatment and rehabilitation activities for this population.

Registry data will come from three sources - Hospital records when amputations occur, Providers who care for people who have lost a limb, and Self-reports by individuals who have lost a limb.

Data will include cause of amputation, rehabilitative therapies, prosthesis use, mobility, barriers to care, quality of life, and other outcomes.

Between now and 2020 the team will determine the data elements, number of potential participants, security requirements, data entry and storage, data access and permissions, reporting requirements and analytics.

Researchers will use data from the limb loss registry to determine regional and cultural variations in care, the best standards of care, prevention strategies, health policy changes to offer better support, and technology advances needed to provide better devices.

If a consistent approach were used to capture outcome data, a large and evolving dataset would quickly become available for analysis and meta-analysis.

A global data registry should be available as “open access” to the professional and scientific community, for the benefit of all. Such outcome data registries would form a deep and rich database that could then be accessed by the research community, health and other government authorities responsible for provision of orthotic and prosthetic services. The content could be “mined” to generate new understanding and knowledge in the field of amputee rehabilitation. This would further enhance education, evidence based practise for MDT teams, and enable greater pace of innovation and advancement in the field.

The data could be analysed from varying perspectives, ensuring the relevance of the database to all subgroups within the field of amputee rehabilitation, making the database a reference standard for service provision.

The approach proposed is to “cast a wide net” using patient reported outcome measures and other clinical outcome metrics to create the data registry described.

The task requires a high degree of coordination and oversight and management at national and international levels, through independent management and advisory boards. The complexities of compliance with data protection legislations, safeguarding privacy and anonymity of individuals who are included in the data base, and other considerations which need to be accommodated in such a venture, make this project a significant challenge.

It is however an ideal challenge and task for the ISPO IAG to develop a concept and roadmap for such a project. The design and implementation of such a most challenging but invaluable endeavour may require funding.

Conclusion

Medical and technological advances in prosthetics and orthotics have led to a more patient-centred fitting and rehabilitation approach, resulting in increased mobility and quality of life of its users.

However, the term innovation should not be limited to the technical product perspective, but also include design, manufacturing, treatment and delivery/logistics processes. Innovation may be also achieved by improving ease of process, as well as accessibility and affordability in terms of higher quality at a better price through higher efficiency, effectiveness or productivity. Innovative approaches should therefore be considered across all aspects of services including policies, products, personnel and provision of services.

There are a number of factors leading to diverse legislative and regulatory environments, and barriers for innovation. These include a heterogeneous understanding of the meaning of innovation, and the use of inconsistent measures and methods to assess related outcomes at both national and global levels. Furthermore, the lack of a suitable database hinders evaluation and monitoring of where innovation could have the most impact.

The ISPO IAG Working Groups' workplans will include the establishment of an international data registry. Patient reported outcome measure will contribute to creating a better information base for demand planning, and for the development of harmonized standards related to measurement of treatment outcomes.

The harmonization of the legislative and regulatory environment at international level will promote an enabling environment for innovation and improves the accessibility and affordability for prosthetics and orthotics products and services. A multi-stakeholder approach such as the creation of the ISPO IAG Working groups in collaboration with the GPEX of ISPO, illustrates best practice examples of how to overcome the numerous barriers for innovation through harmonized standards.

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A distribution strategy for driving product diversity and demand creation

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Abstract

Background and objectives: This commentary will present the experience of Consolidating Logistics for Assistive Technology Supply and Provision (CLASP) - a USAID-funded project designed by UCP Wheels for Humanity (UCPW) - in incentivizing assistive technology (AT) product innovation, including discussion of challenges and opportunities and the relevance of emerging best practices in establishing global product quality standards. **Approach:** UCPW will present commentary on its experience designing and managing the CLASP project, and in particular its multidisciplinary Product Advisory Council (PAC) and its role in driving innovation in the global AT marketplace. CLASP uses innovation competition and tailored feedback from the PAC to encourage manufacturers, both large and small, to innovate and improve their products, and uses the CLASP platform to reward suppliers of innovative product of high quality and reasonable price with access to new markets. **Expected findings:** CLASP is a supply chain solution that consolidates a diversity of AT products from a range of suppliers at its product distribution center in China. The CLASP catalog offers buyers the ability to make large or small orders of mixed products and sizes, and because CLASP keeps a consistent supply in stock at its distribution center, buyers can receive their products more quickly than if they were to order directly from manufacturers, which typically manufacture to order. CLASP is therefore able to deliver AT products that best suit users' individual needs faster and more efficiently. CLASP has provided more than 40,000 products to 30 countries and has sold products to multiple major donor agencies and governments. After four years of operation, CLASP is realizing its potential as an AT innovation engine and a global platform for LMIC product development and supply. The CLASP experience has shown that this platform is not just a tool for buyers to access a range of product types quickly and easily; the more it is used, the more it can be a tool for encouraging product innovation. CLASP has established the peer-nominated, competitively selected PAC to review and recommend products for inclusion in the CLASP catalog. The PAC was formed under advisement of the International Society of Wheelchair Professionals (ISWP) and is composed of a mix of clinical, technical, and wheelchair-user experts. CLASP uses the WHO's Priority Assistive Products List as guidance when determining product categories and issues an open Invitation to Bid (ITB) on a periodic basis to solicit product submissions. The PAC and CLASP have developed standardized scoring criteria for the AT

product categories, including product specifications, product quality requirements (e.g. ISO-compliant manufacturing processes, ISO durability testing), operations thresholds, price parameters, and product support and promotional materials. Products are screened to meet minimum thresholds for product quality and market viability, and if met, an in-person product review and several rounds of Q&A are conducted by the multidisciplinary PAC team. The products ultimately selected for inclusion in the catalog are marketed to buyers, who are able to test out new products from CLASP—a supplier they can trust to assure quality and appropriateness. Because CLASP itself is market driven, it balances its responsiveness to the demands of the current immature, dislocated market with its anticipation of new market potential for improved products, thereby resulting in selection of the widest variety of quality AT products that the global market will support. **Challenges and opportunities regarding greater access to quality, affordable AT for all:** People with mobility impairments have a right to appropriate wheelchairs and other mobility enhancing AT. However, the appropriateness of an AT product will vary according to the user’s environment, health and lifestyle. When diverse users all receive the same kind of wheelchair regardless of individual needs, the impact can be damaging. Research shows that an inappropriate wheelchair, provided without support services, can result in negative outcomes for the user, including product abandonment or resale, increased risk of life-threatening secondary consequences, and reduced cognitive and physical development as a result of restricted mobility. There is, therefore, an indispensable need for diversity in the global AT marketplace. Governments and organizations procuring assistive products have historically faced complex challenges in sourcing a diverse and appropriate range of AT products in Low- and Middle- Income Countries (LMIC). The AT industry globally is dominated by manufacturers that design products for high-income countries, often operating under a high-margin, low-volume model. In countries where local production does exist, products are often low-quality, do not meet global standards, and are comparatively high cost. The relatively small market in any LMIC for a particular type of AT product makes it difficult for in-country manufacturers to benefit from economies of scale. For LMICs that import AT products, limited financial resources and a small variety of available products mean buyers tend to procure from a single supplier with limited, often low-quality options and long lead times to manufacture and ship. These challenges both inhibit product innovation and inhibit innovative products from reaching LMIC markets. The history of low investment in products designed for LMIC means there is significant opportunity for substantial, disruptive product innovations, in addition to the continuous product improvements needed in any market. Still, for LMIC countries to take advantage of the opportunity, there must be demand for AT, which will require a total market and whole of population approach. Within the context of these challenges, there is opportunity for an innovation competition mechanism to incentivize small and large manufacturers alike to enter the market, while also establishing global benchmarks for product quality. The more such a mechanism is used by global buyers, the more potential it will have in catalyzing product innovation. By stabilizing volume, and by raising product visibility and accessibility for selected suppliers, such a mechanism can offer

an attractive incentive to improve product quality and design. Though this may create short-term barriers for domestic manufacturers that may not be able to meet global standards, this will ultimately generate innovations that best serve user needs and will establish uniform global product criteria that can be contextualized to meet national procurement protocols.

Keywords

Assistive technology product design, innovation, global distribution, demand creation

Introduction

People with mobility impairments have a right to appropriate wheelchairs and mobility-related assistive technology (AT)¹ (1). However, the appropriateness of an assistive product (AP)² (2,3) will vary according to the user's environment, health and lifestyle. Particularly with regard to wheelchairs, when diverse users all receive the same kind of product regardless of individual needs, the impact can be damaging. Research shows that an inappropriate wheelchair, provided without support services, can result in negative outcomes for the user, including increased risk of life-threatening secondary consequences, reduced cognitive and physical development as a result of restricted mobility, and product abandonment or resale (1,3,4). There is, therefore, an indispensable need for diversity in the global AT marketplace.

The Global Cooperation on Assistive Technology (GATE), the WHO's global initiative to improve access to high-quality affordable AP globally, has encouraged national governments to ensure access to a diversity of products and details the 50 most essential assistive devices in its Priority Assistive Products List (APL). As governments commit themselves to global ambitions such as Universal Health Coverage, the Convention on the Rights of Persons with Disabilities and the Sustainable Development Goals, they will need structures that can readily facilitate their uptake of a range of appropriate AP.

Governments and organizations procuring AP have historically faced complex challenges in sourcing a diverse and appropriate range of AP in Low- and Middle-Income Countries (LMIC). The AT industry globally is dominated by manufacturers that design products for high-income countries, often operating under a high-margin, low-volume model (1,3,4). In countries where local production does exist, it is often at insufficient scale, and products may be low-quality and fail to meet global standards (1,3,5). For LMICs that import AP, financial constraints, complex and costly importation requirements, and inadequate expertise on the need for a variety of products mean buyers are led to procure from a single

¹ Assistive technology refers to "assistive products and related systems and services developed for people to maintain or improve functioning and thereby promote well-being," as defined by Holloway et al (1).

² Assistive product refers to any product (including devices, equipment, instruments, and software), either especially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their well-being, as defined by Khasnabis et al (2).

supplier with limited, often low-quality options and long lead times to manufacture and ship. These challenges inhibit availability of product diversity and have the net effect of inhibiting innovative products from reaching LMIC markets.

This paper provides commentary on this topic, derived from the Consolidating Logistics for Assistive Technology Supply and Provision (CLASP) project, which was designed by UCP Wheels for Humanity (UCPW) with funding from the United States Agency for International Development (USAID). CLASP is a global AP distribution mechanism which includes an international competitive bidding process to ensure that the products offered by CLASP provide the greatest value to the consumer. Greatest value is secured by a diversity of products competing within a single category. However, a dearth of designs and manufacturers competing in this space means consumers have historically been availed limited product. Unlike other open competitions with established markets and existing demand for like-product, in the LMIC wheelchair market, competition paired with a global distribution mechanism serves to mitigate start-up risk while simultaneously calibrating towards a global standard for the market. The more the CLASP mechanism is used by global buyers, the more potential it will have in catalyzing product innovation through its demand creation potential. By stabilizing volume, and by raising product visibility and accessibility for selected suppliers, this mechanism can offer an attractive incentive to improve product quality and respond to design gaps.

The need for disruption in the mobility AP market

The history of low investment in assistive products designed for LMIC creates significant opportunity for substantial, disruptive product innovations, in addition to the continuous product improvements needed in any market. Still, for LMICs to take advantage of the opportunity, there must be demand for AP, which will require a total market, population-based approach. Specifically, integration of rehabilitation services and associated AP into health systems, financed through Universal Health Coverage for LMIC consumers, will dramatically increase access to appropriate product and services. Combined with state legislation and policies establishing standards for product and service, state-led procurement will, over time, drive demand for AP.

Meanwhile, as systems in LMICs catch up to consumer AP needs, there is a potential global wheelchair market of up to 75 million people, and a need for a broader range of AP in the hundreds of millions. But the global market is immature and fragmented, and it has been obfuscated for decades by well-meaning charities that have donated large numbers of unregulated products of variable quality that have often been inappropriate for the environments in which they have been donated (1,3-6). Further, the scarcity of personnel trained to provide AT within LMICs results not only in poor, potentially unsafe provision, but also in a lack of local awareness of the need for product diversity and quality (1,3-5).

International non-governmental organizations, with the support of influential donors, have addressed product-related inefficiency in part by shifting from small-scale local workshops

to mass production in countries with industrial manufacturing capacity. While this has led to improved designs, greater quality assurance, and lower costs per wheelchair, there are still few product styles available, limiting the product options for users and service providers.

The PAC: Driving quality and innovation through open competition and product feedback

CLASP selects the products included in its platform based on the recommendations of its multidisciplinary Product Advisory Council (PAC), a peer-nominated, competitively selected group of clinical, technical, and wheelchair-user experts. The PAC—which was formed under advisement of the International Society of Wheelchair Professionals (ISWP) and is composed of volunteers representing broad geographies—is responsible for desk and in-person product evaluation against established criteria, product testing review, and ultimately product recommendation to CLASP. Following PAC’s recommendations, CLASP’s management makes final product selection, places an initial order of the selected products for inclusion in the CLASP system, and utilizes its marketing platform and personnel to market, sell and deliver the new products.

The PAC and CLASP issue an open Invitation to Bid (ITB) on a periodic basis to solicit product submissions for each product category. CLASP uses the WHO’s APL as guidance when determining product categories, though its product categories are more specific than the APL. CLASP breaks product categories down to the level of material or terrain use; for example, an active rough terrain wheelchair is classed differently than an active urban terrain wheelchair. The PAC coordinator and CLASP have developed standardized scoring criteria for the AP categories, including product specifications, product quality requirements (e.g. ISO-compliant manufacturing processes, ISO durability testing), manufacturing capabilities, market-based price parameters, and product support and promotional materials. Products are screened to meet minimum thresholds for product quality and market viability, and if met, an in-person product review and several rounds of Q&A are conducted by the multidisciplinary PAC team.

It is through this open competition and the ensuing feedback process that the PAC influences product quality and design, implicitly. This is done, in part, through establishing minimum thresholds required for inclusion in the CLASP catalogue. As the PAC’s product selection criteria becomes more widely known, it can influence new product development in line with its standards. A positive ISO 7176 test report, for example, is a minimum threshold for inclusion. This in turn improves quality assurance for buyers and users alike. Meeting testing standards is particularly important for AP destined for LMICs where terrain may be rugged and environments unforgiving to products poorly or inappropriately designed for the context.

Further, during the review process itself, product designers receive feedback that can inform product improvements. The PAC provides the bidders with questions, photos and videos indicating product concerns. In some cases, the questions asked, followed by a rejection of the bid, will implicitly inform the bidder of the area of improvement needed. In

other cases, the PAC makes offer for inclusion in the CLASP platform contingent on advised changes to the design. Currently only the bidders whose products have been recommended by the PAC for inclusion in the CLASP catalog have received direct recommendations for design improvement—and even then, it is a limited version of the very detailed product evaluation that is completed by the PAC.

When the PAC was formed, it was intended to standardize the quality of product, and the product selection process, for the CLASP platform, without conflicts of interest. It is an unintended consequence that having this expert committee review products also generates valuable information for bidders on their designs. The role of the PAC in improving product design has evolved organically through the feedback process from the multidisciplinary expert committee to the designers. This could be commodified, though it is not currently part of the PAC's role.

The PAC can also identify product design deficiencies that can inform future ITBs and more directly solicit product innovations. For example, through the ITBs conducted to date, the PAC has determined that there is a need for active manual wheelchairs that are lighter, for wheelchairs with postural support that are lighter, transportable, and more user friendly, and for good quality and affordable high-pressure relief cushions. The PAC can use the data collected through its product reviews from past ITBs to issue subsequent ITBs with even more detailed product criteria to solicit designers to address these product gaps.

CLASP: Encouraging innovation by linking products with new markets

While the PAC serves as a neutral arbiter of quality, implicitly incentivizing product improvements, CLASP uses its marketing platform to reward suppliers of PAC-vetted products with access to new markets.

Market entry for new products is difficult; new products face significant barriers including but not limited to, lack of familiarity among service providers, concern about spare parts availability, lack of product performance data, and lack of brand recognition and brand loyalty. Together these factors contribute to lack of demand for unknown product. CLASP uses its marketing platform and online marketplace to de-risk market entry for suppliers.

CLASP's product catalog provides buyers the ability to make large or small orders of mixed products and sizes, and because CLASP keeps consistent stock levels at its product distribution center in China, buyers can receive their products more quickly than if they were to order directly from suppliers, which typically manufacture to order.

The products selected for inclusion in the CLASP platform are marketed to buyers, who are able to test out new products from CLASP—a distributor they can trust to assure quality and appropriateness. Because CLASP itself is market driven, it balances its responsiveness to the demands of the current immature, dislocated market with its anticipation of new market potential for improved products, tactically resulting in selection of the widest variety of quality AT products that the global market will support.

In a fragmented market with low access to information for buyers and suppliers alike, innovation competitions without direct market linkages won't successfully shepherd new products to market. CLASP's role in engaging buyers thus creates an incentive for suppliers to respond to ITBs. CLASP can incentivize quality and innovation by rewarding suppliers with volume stabilization and market intelligence. By representing the CLASP catalog at trade shows and in direct and online marketing efforts, CLASP is able to leverage its sales and marketing team for the benefit of multiple suppliers, making their initial investments in product research and development more worthwhile.

The more CLASP can become a preferred distribution mechanism, the better it is positioned to consolidate market information that can be used to benefit multiple suppliers to further encourage suppliers' investment into CLASP and to leverage the information that CLASP is able to collect for the betterment of their products, sales, and the industry as a whole. CLASP is able to provide to its Committee of Suppliers (COS) with analysis and data, including sales and product performance data that is disaggregated by manufacturer, product type, SKU and geography, and trend analysis, which includes identification of product gaps, regional trends, and donor preferences. All this dislocated information would be burdensome and near impossible for individual companies to cull and would offer each supplier just a limited view of the market from the vantage point of their own supply chain. This data can further incentivize existing manufacturers, as well as new entrants, to fill design gaps.

CLASP in support of AT market shaping

CLASP is a promising mechanism in an unregulated market; CLASP attempts to harness the market to solve problems of access, but up against a history of charity that has fragmented the market into those who are willing to wait for donated products and those that are willing to pay (1). This has made the market diffused and noisy and has made it difficult to set quality bars for product.

Without market development strategies—catalytic interventions that support the market to become more competitive, accessible and sustainable—the market failures that define the AT sector will continue to inhibit access to appropriate products for marginalized AT users. Market shaping efforts, however, typically presuppose existing market demand, while CLASP operates under the hypothesis that there is some demand—but that demand by and large needs to be *built*. CLASP is working to create demand *and* respond to the demand, to champion high-quality product *and* high-quality service provision within the constraints of the LMIC market.

UCPW's experience designing and managing the CLASP project has enriched our understanding of the global AT marketplace, and the market shaping levers most applicable to the wheelchair sector. In designing the CLASP project, UCPW has drawn from its nearly 25 years of experience with the wheelchair industry—including as a manufacturer and provider of more than 100,000 assistive products, a contributor to the WHO Wheelchair Service

Training Packages, and chair of the ISWP's Wheelchair Advocacy Working Group. This range of experience has allowed UCPW to understand the challenges and potential of today's wheelchair supply chain, as well as stakeholder needs.

The CLASP distribution mechanism is a reasonable approach to building demand for an undervalued, poorly understood commodity. Through CLASP, buyers outsource product vetting to CLASP/PAC, while building their own competency. This can in turn accelerate the establishment of AT procurement processes at the state level. Procurement systems will further contribute to diversifying product design as local manufacturing rises to global standards or competes globally. In both cases, more demand leads to more product diversity.

The establishment of quality standards and the competition for inclusion in the CLASP catalog may create short-term barriers for domestic manufacturers that may not be able to meet global standards. Still, as with other health commodities, regulation will ultimately generate competition, leading to innovations that best serve user needs, and will establish uniform global product criteria that can be contextualized to serve national procurement protocols.

CLASP has the promise of securing larger volumes for its suppliers, potentially reducing prices for consumers and increasing revenue for suppliers which can be invested in new product design. CLASP seeks wholesale pricing from suppliers and offers manufacturer's suggested retail pricing to buyers, wherein suppliers gain the benefits of a global distributor that manages marketing, sales and shipping logistics on their behalf, and buyers benefit from reduced transaction costs through ordering, shipping and import that is simpler, faster and more inclusive of a wider range of products.

It should be noted, however, that CLASP does not have supplier exclusivity, and in some cases to date suppliers have sold directly to buyers at lower rates. This practice dulls CLASP's value proposition, its ability to influence design and the shared interest of greater access. As buyers gain knowledge of the need for a diversity of products, thereby growing demand for a consolidating platform such as CLASP, it is anticipated that CLASP will have more leverage in requiring supplier exclusivity and will be able to offer volume commitments to suppliers, resulting in more competitive pricing for buyers. Further, as governments establish AT regulations that include product and service standards, the donor (and charity) community can reinforce those regulations by coordinating or pooling financial resources directed at product procurement and workforce development to meet the standards. Consolidated donor financing can shift the center of gravity toward appropriate product and thus drive demand.

Conclusion

People with AT needs deserve choice, quality and ease of access to products. AT is integral to personal mobility, function and health, and settling for lowest common denominator products is simply insufficient as well as inefficient.

After four years of operation, CLASP is realizing its distinctive potential as an AP innovation engine and a global platform for LMIC product development and supply. The CLASP experience has shown that this platform is not just a tool for buyers to access a range of product types quickly and easily; the more it is used, the more it can aggregate volume, the more it can be a tool for encouraging product innovation. Because CLASP is a relatively small, nimble platform, it can adjust the products offered within its catalog quickly. By refining the CLASP catalog to reflect the most affordable, high quality products available, and by establishing product quality standards that can then be shared with suppliers and buyers alike, CLASP is able to aggregate and steer demand toward an optimized set of products that are vetted by a multidisciplinary, neutral expert committee.

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Using three dimensional technologies to make high quality assistive products and services available to people who live in remote and regional locations in Australia

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Abstract

A team from three Australian organisations, Northcott Innovation, Northcott and AbilityMade, are currently developing a service model for delivering orthotic services to children who live in remote areas of New South Wales, Australia, a state spanning 809,000 km². The benefits of the application of three-dimensional (3D) technologies are current and realised in the Prosthetics and Orthotics (P&O) industry. One of the numerous benefits of using 3D technology in this industry is applying it in remote and regional areas with limited access to P&O services. The team aims to provide a solution for high quality lower limb orthoses and orthotic services for children with disability who live in remote and regional areas, therefore shaping Assistive Technology (AT) systems around the people who need to use AT products. People with physical disabilities, like cerebral palsy, often need to wear lower limb orthoses to aid mobility and pain management. Currently, it is estimated that globally, 17 million people have cerebral palsy (1). The projection at this stage is that only 1 in 10 people will receive the orthoses they need due to: high cost, reduced availability, limited trained personnel, and constraints within policy and financing (2). During 2017 - 2018, seven organisations took part in an Australian clinical trial to explore the clinical validity of applying 3D technology to the clinical assessment, fabrication and fitting of lower limb orthoses. This trial included the development of a purpose built instantaneous scanner, the use of 3D modelling software and the 3D printing of Ankle Foot Orthoses (AFOs) for Australian children with disability between the ages of 2 and 8 years. Outcomes of the clinical trial indicated that: i) 3D printed AFOs were biomechanically equivalent to traditionally fabricated AFOs; ii) the mechanical properties of Nylon 11 and Nylon 12 are sufficiently robust to act as a clinically viable alternative to Polypropylene plastic; and, iii) children and parents/carers participating in the trial found digital scanning to be significantly less distressing and anxiety-inducing compared to the traditional plaster-casting process. The team comprising of Northcott Innovation, Northcott and AbilityMade therefore has adequate evidence for the clinical application of the 3D technologies as explained above. It is believed that the application of this technology in regional and remote locations can bring

high quality P&O services and products to people where they live. The team will provide literature evidence to support how the proof of concept and proposed service model complies with Australian Disability standards, the Australian National Disability Insurance Agency's (NDIA) Remote and Regional Strategy as well as P&O practice and service standards. The team will further provide a proof of concept explaining the approach followed through the use of data from their service model. It is expected that the service model will provide P&O services to people who live in remote and regional locations. The solution will be people centred, holistic and provide high quality products and experiences for customers in their local environments, hence creating sustainable high-quality systems. There is a further expectation that this service model could hold potential for further/other AT products and services, evolving it fully to an AT system which is centred on the holistic needs of a person. This could mean that a person needing more than one type of AT would not need to consult with numerous clinicians at several different appointments as the current practice demands.

Keywords

People centred, 3D technology, regional, AT systems, holistic, eHealth

Introduction

A team consisting of members from three disability-focussed organisations – Northcott, Northcott Innovation and AbilityMade – came together during a New South Wales (NSW) (Australia) government funded project during which three dimensional (3D) technologies were made available to the orthotic community (May 2018 - June 2020). As part of this project, we have developed an innovative service model that provides high quality lower limb orthoses and orthotic services to children with disability who live in remote and regional areas, therefore shaping the Assistive Technology (AT) systems around the AT user.

The team is in the process of testing the service model in different locations in regional and remote NSW, in order to assess its potential for adoption by orthotic service providers. This paper describes a proof of concept for a service pilot that specifically targets users of AFOs, who live in communities classified as MM5, MM6 and MM7, which are communities 100 - 1,500km away from Sydney, the state's capital city. Within an Australian context, the degree of remoteness of a community is measured using the Modified Monash (MM) Model (3).

This service model has been developed using the orthotic and disability service provision expertise of Northcott, the human-centred design and project management expertise of Northcott Innovation and the instantaneous scanning and central fabrication expertise of AbilityMade.

Terminology:

- *Customer* - describes a child with disability who requires AFOs.
- *AFOs* - describes both a single AFO and a pair of AFOs.

- *Local support person* – describes an individual in the same regional or remote location as the customer, and may include: early intervention specialist, therapist, disability support worker, teacher, General Practitioner, community health nurse, early childhood educator.
- *Personal support person* – describes an individual the customer may need or want to be present during the consultations, and may include: a parent, relative, paid carer or unpaid carer.
- *eHealth* – describes the use of the internet for providing healthcare including allied health. The terms telemedicine, telehealth and telerehabilitation are also widely used and accepted terms.

Current models of orthotics service provision for regional/remote communities are not sustainable under Australia’s National Disability Insurance Scheme (NDIS). These models include:

1. **Mobile Clinician:** where the orthotist delivers comprehensive orthotic services in the region from a privately-owned mobile van equipped with all required equipment;
2. **Shared Fly in Fly Out:** where the orthotist travels with the Australian Royal Flying Doctors to the region;
3. **Fly-in-Fly-Out or Regional Clinic:** where the orthotist provides intermittent services, travelling in and out of the region, while manufacturing the orthoses in their primary (metropolitan) clinic.

All of these models are financially unsustainable under NDIS pricing guidelines and all experience high AT abandonment rates due to reduced follow-up care. The Mobile Clinician model also has high set-up and maintenance costs alongside significant Workplace Health & Safety risk factors.

This paper describes a proposed service model for delivery of orthotic services in regional and remote areas and the testing of this model in a proof-of-concept across four trials.

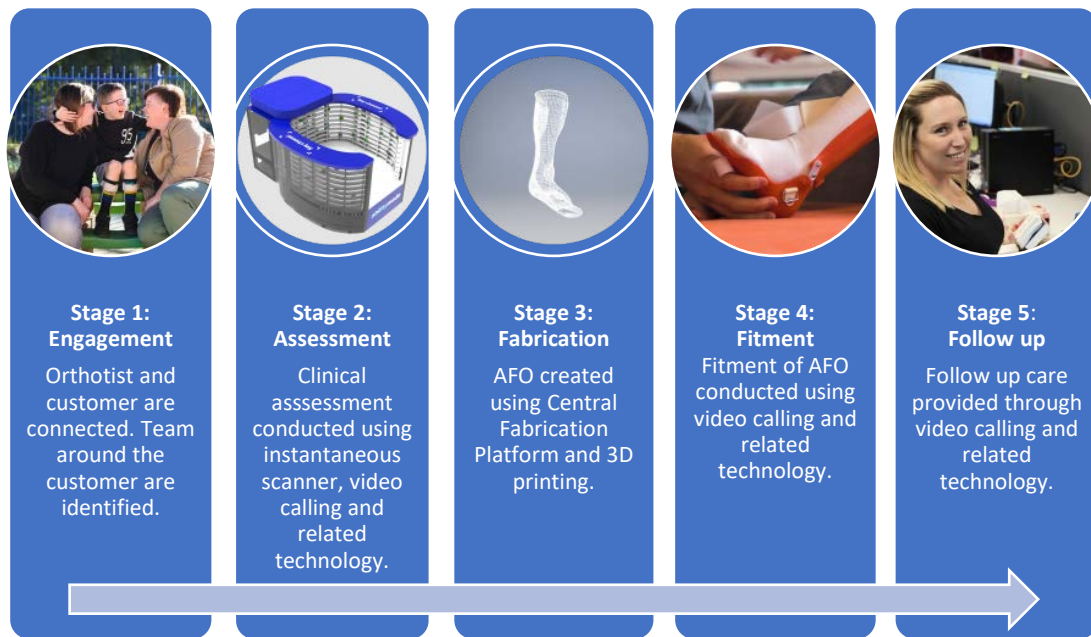
Methods

The proposed service delivery model

When developing the model, the team considered collaborations alongside local non-orthotic allied health providers; community nursing services; public health services; early childhood intervention services and Aboriginal medical services. The team also considered the development of a local therapy assistant model.

The developed service model (Figure 1) consists of five stages: Engagement, Assessment, Fabrication, Fitment and Follow Up.

Figure 1. Regional and Remote Service Delivery Model



Stage 1: Engagement

The orthotist and customer are connected via existing referral pathways and discuss: customer's orthotic need, remote service delivery model, where the customer would like the service to take place (home, school, doctors office), the role of local support person and personal support person (referred to as supports) and the person-centred goals for orthotic service provision.

Stage 2: Assessment

The orthotist arranges for the instantaneous scanner and related technology to be sent to the region, in addition to distributing required training materials to supports. Orthotist, customer and supports connect via video call, with the orthotist conducting clinical assessment, providing live feedback/guidance as required. Instantaneous scanner, mainstream technologies (video calling, video recording) and supports are utilised to capture clinical information regarding the customer's anatomy, posture, range of motion, movement, strength and orthotic requirements.

Stage 3: Fabrication

The orthotist reviews images and content captured by scanner and related technology using the Central Fabrication Platform and prescribes the AFOs. Central fabrication team create virtual model of AFOs and sends to orthotist for approval. AFOs are approved by the Orthotist, 3D printed and sent back to orthotist for finishing (straps, padding) before being sent to customer.

Stage 4: Fitment

Orthotist, customer and supports connect via video call, with the orthotist conducting fitment appointment, providing live feedback and guidance as required. Customer and

supports adjust the AFOs as required and/or AFOs are sent back to orthotist for reprint or adjustment. Orthotist provides instructions to customer and supports on use and care of AFOs. Person-centred goals for orthotic service provision are reviewed.

Stage 5: Follow Up

Orthotist, customer and supports connect via video call. Customer and supports provide update on use of AFOs, and person-centred goals for orthotic service provision are reviewed.

Required Standards and Strategies

The model proposed takes into consideration a range of national and international standards and strategies. This ensures that orthotic service providers can continue to meet their responsibilities with regard to these standards and strategies. This includes:

The Australian Disability Standards

In Australia, there are six National Standards (4) that disability service providers are expected to adhere to as part of providing appropriate services to people with disability.

Australian National Disability Insurance Agency (NDIA) Remote and Regional Strategy

The Australian NDIA's Remote and Regional Strategy (5) ensures:

1. Effective, appropriate supports are available wherever people live;
2. Creative approaches are utilised for individuals within their communities;
3. Collaborative partnerships are harnessed to achieve results; and
4. Local capacity of rural and remote communities is supported and strengthened.

To ensure orthotic service providers are able to align their practice to the NDIA's Remote and Regional Strategy, the developed model is focused on:

1. Finding ways for customers to receive orthotic services where they live, instead of having to travel to metropolitan areas;
2. Identifying previously unexplored service models;
3. Improving service provision by building relationships with existing service providers in rural and remote communities;
4. Utilising a strengths-based community capacity building approach which leverages off the local communities' existing knowledge, skills and capacity.

World Health Organisation (WHO) Standards for Prosthetics and Orthotics (6); International Society for Prosthetics and Orthotics/ WHO Guidelines for Training Personnel for Prosthetic and Orthotic Services (7); and International Organisation for Standardization Technical Committee (ISO/TC) 168 Standards, Prosthetics and Orthotics (8)

The proposed service model does not propose any significant changes to orthotic practices, thus maintains alignment to the WHO Standards. The model also addresses ISO/TC Standard

24 - affordable prosthetic and orthotic products that are cost-effective, of good quality and context-appropriate should be developed and made widely available.

eHealth in the Orthotics Industry

Lemaire and Jeffreys (9) considered eHealth in the orthotic industry over twenty years ago and found it to be a plausible service delivery option, however there has been limited research in the specific area of orthotics (10-16). eHealth is accepted as an emerging and appropriately developing service delivery option worldwide, with encouraging research (12,13,16) about eHealth in other allied health fields. Recent research (14) finds that eHealth needs to be researched further in terms of providing practical strategies and evidence in allied health fields in order to encourage service providers and stakeholders to participate in and provide eHealth services with confidence.

Findings

Proof of Concept - Procedure

Four customers took part in muscle strength and Range of Motion (ROM) assessments. Assessment activities were firstly conducted by a local support person with the orthotist providing guidance and instruction via video call. Assessment activities were then completed a second time with the orthotist in person to enable comparative data.

It is noted that coaching via telehealth – as happens when the orthotist guides the local support person over video phone call – frequently takes longer, regardless of prior knowledge, experience or training.

Trial 1

Customer: person with physical disability including bilateral high muscle tone, who is non-ambulant.

Local support person: An allied health professional (speech pathologist) with no prior experience with muscle strength or range of motion assessments.

Results:

Assessment: When completing ankle ROM and strength tests the local support person measured 10-15 degrees less range than the orthotist. It is hypothesised this is due to unfamiliarity with how to manipulate the limbs and unfamiliarity with the person's body and movements.

Assessment time: The local support person took 11 minutes longer than the orthotist.

Customer feedback: The customer reported that she was able to relax her muscles more during the orthotist assessment due to the orthotist's verbal prompts and the way in which the orthotist touched and moved her limbs (with firm but gentle pressure).

Local support person feedback: The local support person reported difficulties with: knowing how to move the customer's limbs; how far to range the joints on instruction

from the orthotist; finding bony prominences like hip bones and ankle bones and handling the goniometer and measuring tape while holding and manipulating limbs.

Trial 2

Customer: person with physical disability including bilateral high muscle tone, who is ambulant.

Local support person: An allied health professional (speech pathologist) with some prior experience with muscle strength or range of motion assessments, having completed the Trial with Customer 1.

Results:

Assessment: The local support person got the same results as the orthotist.

Assessment time: The local support person took 11 minutes longer than the orthotist.

Customer feedback: The customer didn't indicate a difference between the experience with the orthotist and the local support person.

Local support person feedback: The local support person reported difficulties with knowing how to move the customer's limbs; how far to range the joints on instruction from the orthotist; handling the goniometer and measuring tape while holding and manipulating limbs.

Trial 3

Customer: person with physical disability including bilateral high muscle tone, who is non-ambulant.

Local support person: An allied health professional (occupational therapist) with prior experience with muscle strength and range of motion assessments.

Results:

Assessment: The local support person got the same results as the orthotist.

Assessment time: The local support person took 11 minutes longer than the orthotist.

Customer feedback: The customer didn't indicate a difference between the experience with the orthotist and the local support person.

Local support person feedback: The local support person reported difficulties with: identifying bony prominences; handling the goniometer and measuring tape while holding and manipulating limbs; knowing how far to range the joints on instruction from the orthotist.

Trial 4

Customer: person with physical disability including high muscle tone in one lower limb only, who is ambulant.

Local support person: The parent, and primary carer, of the customer (referred to as the personal support person previously).

Results:

Assessment: The personal support person was unable to obtain measurements using the goniometer or measuring tape. When the goniometer and measuring tape were removed the personal support person was able to complete the activities with the same degree of accuracy as the orthotist. The video calling and related technology enabled the accurate measurement of the activities.

Assessment time: The personal support person took 15 minutes longer than the orthotist when using the goniometer and measuring tape. When not using the goniometer and measuring tape, the personal support person took 5 minutes longer than the orthotist.

Customer feedback: The customer didn't indicate a difference between the experience with the orthotist and the local support person.

Personal support person feedback: Moving and manipulating the customer's limbs was a natural task. Handling the goniometer and measuring tape was difficult.

Proof of Concept - Findings

Clinical assessment

After completing the trials, the team has divided the clinical assessment process into four parts:

1. Range of Motion (ROM)
2. Muscle strength assessment
3. Gait assessment
4. Scan with the instantaneous scanner

Parts 1, 3 and 4 of the clinical assessment can be consistently captured and evaluated through the use of technology, which reduces inter-rater inconsistencies. Part 2 of the clinical assessment is accurately delivered through targeting training to the local supports in advance of the assessment. This approach increases the accuracy of the assessment and therefore the accuracy of the prescription of the AFOs.

Personnel and Physical Resourcing Requirements

In order to be successful, the model requires the following personnel:

Local support person, personal support person, orthotist (who also acts as the service coordinator) and the central fabrication team.

Early iterations of the service model saw the local support person completing the required assessment activities with the customer under the guidance of the orthotist during the

video call. Four trials (as discussed above) with customers have led the team to believe that the personal support person could provide more appropriate services and accurate results under the guidance of the orthotist, than the local support person. Recent research (13) have found that parents or carers could be successfully trained and/or supported during telehealth practice, to participate in therapy or assessment activities.

These findings lead the team to believe that there are potentially 3 groups of people that could be assisting the orthotist on the customer's side, according to previous experience with limb related assessments and familiarity with the customer's body and movement. They are people with:

1. A background in working with customers, but no lower limb related assessment experience,
2. A background in working with customers and with lower limb related assessment experience, and
3. No prior experience in lower limb related assessments, but who are familiar with the particular customer's body and movements.

These three groups of people would need different levels of prior training, would attract different levels of costs to the assessment and services and would potentially be less or more accurate in assessment results.

Table 1 shows a summary of the assumptions related to each group, drawn from the team's trials.

Should a customer choose to make use of a local support person's services, it should be taken into account that involving an individual from a local service provider or organisation may attract additional costs as per the NDIS Guidelines.

In order to be successful, the model requires the equipment presented in Table 2.

Table 1. Assumptions related to each group according to the team's trials

Groups	Examples of Typical Professions	Estimated Assessment Accuracy - Without prior training	Estimated Assessment Accuracy - With prior training	Time and cost requirements
Workers in human sciences with no prior experience in lower limb assessments	Speech Pathologists, Social workers, Psychologists, Teachers, Early Educators	Not accurate enough for orthotic prescription	Accurate enough for orthotic prescription, providing no goniometer and measuring tape usage	2 hours prior training 1-hour attendance during assessment
Workers in human sciences with some prior experience in lower limb assessments	Occupational Therapists, Physiotherapists, Therapy assistants with relevant experience, Community nurses, Doctors	Accurate enough for orthotic prescription	Accurate enough for orthotic prescription	1-hour attendance during assessment
Individuals Known to Customers	Parents, Guardians, Carers, Support workers	Accurate enough for orthotic prescription, providing no goniometer and measuring tape usage	Accurate enough for orthotic prescription providing no goniometer and measuring tape usage	1-hour attendance during assessment

Table 2. Necessary equipment for successful application of the model

Customer side (Regional Location)	Orthotist side (Metropolitan Location)
Internet Access	Internet Access
Smart phone with video capacity and internet	Tablet for video calling with internet
Instantaneous Scanner and associated foot platform, heel wedge and socks	Tablet with Central Fabrication Platform Software
Physical room with space for 3-5 people	Central Fabrication Service
Flat, firm, stable, surface appropriate for the customer to sit/lay on 10-15 meters space for walking activities Tape measure* Goniometer*	3D Printing Service

*Note: * A mainstream, freely available app is being trialled during the gait analysis and muscle strength / range of motion assessments. If successful, the app may replace the use of these tools.*

Benefits to Customers

The service model provides an opportunity for customers who live in regional and remote locations who need AFOs to:

- Receive an innovative orthotic service close to their home (or potentially in their home);
- Reduce the time and costs associated with travelling to Orthotic specialists in metropolitan areas, or reduce the fees associated with the Orthotist charging to travel to the customer in a regional location;
- Receive orthotic services which are more user/child centric;
- Be part of an innovative service delivery model for providing assistive technology to people who live in regional and remote locations.

Benefits to the P&O Industry

The service model provides potential opportunities for Orthotists to:

- Decrease time spent travelling to regional and remote communities, increasing their capacity to provide orthotic services to other customers;
- Decrease costs associated with travelling to regional and remote communities;
- See increased numbers of customers from regional and remote communities increasing the reach and impact of their services;
- Decrease their workplace health and safety risks due to the decrease in health risks related to the manual labour involved with plaster and plaster casts, as well as handling hot polypropylene plastic, e.g. respiratory risks, cutting/sawing risks, burn risks;
- Decrease the time spent on manual labour during traditional manufacturing practices due to the use of 3D technology;
- Potential to increase face-to-face time with customers which can be used for measurements of outcomes due to decrease in manufacturing time (or time spent as Orthotist sees best fitted to customer service, business success/development, professional development, etc.)
- Increase the longevity of their careers due to benefits to work-life balance, health and business-related pressures.

Discussion

Video Calling Technology

Standard videoconferencing technology (large monitor with mounted camera at top of screen) and standard mobile phone technology were trialed to determine the most appropriate video calling technology for this service model. The team found the following:

- A mobile phone available on the 'side' of the customer was most appropriate as its handheld nature enabled the camera to be dynamically positioned inline with the orthotists requests;
- A stationary camera mounted on top of videoconferencing equipment could not be moved or zoomed into appropriate positions that would provide adequate visual information necessary for the orthotist to make clinical decisions;
- The local support person on the customer 'side' was necessary to hold the mobile phone camera in position, while the personal support person performed muscle strength and range of motion assessments;
- During the video call a tablet sized screen was necessary for the orthotist to clearly see the customer's limbs, anatomy and movements, with a mobile phone sized screen not providing enough coverage.

Service Model Travel Cost Comparisons with Shipment Costs

Under the Australian NDIS, a small portion of the costs associated with regional service delivery can be covered. In order to have a clearer understanding of the financial benefits to the proposed service model a comparison has been conducted between the *travel* costs associated with the orthotist travelling to the region, the customer travelling to a metropolitan area and the shipment costs associated with the proposed model. Please note: The comparison does not include the cost of actual orthotic service delivery (assessment, fitment and follow-up).

Estimated Savings

Table 3 outlines the costs and associated savings in relation to the above comparison.

This service model clearly offers potential benefits to customers, families/carers, orthotists as well as the NDIA. The team believes that this proof of concept validates further investigation and testing of this service model. Barnett et al (10) implore Australian eHealth researchers to use cost comparisons and focus on savings the eHealth service models provide to service providers, when applying for funding to research the implementation of eHealth service models, particularly in allied health fields. The team agrees that providing this crucial information regarding costs savings related to travel illuminates the sustainability of this service model.

Disruption to the Orthotic Industry

eHealth in Orthotics is not a new concept, as stated previously (9). What marks this service model as innovative and disruptive to the P&O industry, is the use of instantaneous scanning technology, accessed remotely by the orthotist, and the use of digital fabrication instead of manual fabrication.

Table 3. Costs and savings association with service model travel costs and shipment costs

Area	Region (NSW Specific)	Travel	Total Travel Costs (\$AUD)	Shipping Costs (\$AUD)	Total Savings (\$AUD)
Metropolitan	Inner	Orthotist to Customer	19.32	26.2	-7.28
		Customer to Orthotist	72.17	26.2	45.57
	Middle	Orthotist to Customer	249.19	26.2	222.59
		Customer to Orthotist	160.9	26.6	134.3
	Outer	Orthotist to Customer	747.57	156.6	590.97
		Customer to Orthotist	377	156.6	220.4
MM 4-5	New England	Orthotist to Customer	7,382.54	156.6	7,225.94
		Customer to Orthotist	3818.6	156.6	3662
	Murrumbidgee	Orthotist to Customer	5,527.02	156.6	5,370.42
		Customer to Orthotist	3,092.20	156.6	2,935.60
	Far West	Orthotist to Customer	5,391.44	156.6	5,234.84
		Customer to Orthotist	2,674.34	156.6	2,517.74
MM 6	New England	Orthotist to Customer	9,943.32	156.6	9,786.72
		Customer to Orthotist	4,558.50	156.6	4,401.90
	Murrumbidgee	Orthotist to Customer	10,881.18	156.6	10,724.58
		Customer to Orthotist	5,101.16	156.6	4,944.56
	Far West	Orthotist to Customer	7,322.67	156.6	7,166.07
		Customer to Orthotist	3,321.05	156.6	3,164.45
MM 7	New England	Orthotist to Customer	12,248.56	156.6	12,091.96
		Customer to Orthotist	5,632.40	156.6	5,475.80
	Murrumbidgee	Orthotist to Customer	12,056.20	156.6	11,899.60
		Customer to Orthotist	5,440.04	156.6	5,283.44
	Far West	Orthotist to Customer	14,804.37	156.6	14,647.77
		Customer to Orthotist	6,706.24	156.6	6,549.64

Challenges

1. Slow rates of technology utilisation and uptake by P&O professionals. Reduced rates of uptake may be reflective of: hesitancy of P&O clinicians to alter their current practice; reduced personal and business capacity of the P&O professional to learn and integrate a new approach; fear of the impact the technology may have on the sustainability of their profession and therefore livelihood.
2. Retaining quality of orthotic service provision, if components of the new orthotic process utilise unqualified / less qualified individuals.
3. Creating a landscape where professionals from various sectors across metropolitan and regional locations can collaborate in order to provide quality orthotic services to people with disability. For example: The state Department of Health funds the regional community health nurses' time, whilst the federally funded (Australian National Disability Insurance Scheme) funds the metropolitan orthotists' time.
4. Financial sustainability: Identifying which entity is responsible for paying for the orthotic services; exploring the affordability and financial sustainability of the orthotic services.
5. The safety and quality of digitally fabricated orthoses, with orthotic products requiring rigorous laboratory testing over thousands of cycles to demonstrate safety and reliability.
6. Access to reliable, high speed internet / other connectivity to allow successful implementation in remote / regional locations.
7. Reliability of the peripheral technologies used for example: does connectivity in local area support seamless transmission between the instantaneous scanner and the central fabrication platform; is there a 3D printing service locally which meets the required standards.
8. Potential problems with software programme and programme interactions along with limited remote access from service providers could cause challenges for the successful implementation of this technology.
9. Minimum requirements for mobile phone and tablet technology need to be determined and noted.
10. Ensuring data security of confidential customer information recorded.
11. Logistic problems in delivering the orthoses, e.g. access to postal services and cost of postal services to remote locations.
12. Workplace health and safety requirements for the local support person have not been addressed or determined.

Opportunities

1. Widespread application of the broader remote service delivery model to provide a more holistic service and better end product experience for people who utilise AT. For example: an individual in a remote location who requires AFOs in addition to hearing aids, could be supported by a local community health practitioner, to dial into a telehealth session with the metropolitan orthotist and audiologist, resulting in the

individual receiving the best available technology, and a holistic person-centred care model.

2. Design a holistic and people centred AT system for the future of providing AT to end users.
3. Central Fabrication Platform utilises a user-friendly interface which enables simple prescription of lower limb orthoses with the potential to be used for other orthotic and prosthetic products.
4. Purpose built scanner and other supporting technology is transportable to most parts of the world.
5. Open source technology for the purpose-built scanner could be used anywhere in the world.
6. Scalability.
7. Potential market disruptor and model for other orthotic devices.
8. Potential use of application software that could negate the need for a local support person or personal support person to use a goniometer during the assessment appointment.
9. Further development and design of the robust scanner to suit regional and remote specific needs.

Recommendations

This paper provides a proof of concept for a sustainable service model to provide AT systems to people who live in regional and remote locations in Australia, with evidence to support the further testing of this service model in true regional and remote assessment, fitting and follow-up situations. It is recommended that the team continue to develop, test and refine the service model in true conditions and keep sharing results with the P&O industry to prove its application in real world situations.

The comparison of costs between travelling involved in regional and remote service provision and the shipment of the instantaneous scanner to regional and remote locations in NSW, provides evidence for further financial modelling of all inclusive, start to finish, services. It is recommended that the team completes a full financial model with regards to this service model and then does a comparison with existing service models' costs. This information should be shared with government, funding bodies and the P&O industry.

The team should continue to share their findings with the P&O industry to ensure early awareness, buy-in and eventually implementation of this service model or similar methods of providing services to people who live in regional and remote locations around the world.

The challenges and opportunities this proof of concepts brings should be taken into account during the further testing and reporting of this service model.

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Prosthetics services in Uganda: A series of studies to inform the design of a low cost, but fit-for-purpose, body-powered prosthesis.

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Abstract

The majority of people with upper limb absence (PWULA) live in lower, or middle-income countries (LMICs). However, efforts to develop improved prostheses have largely focused on electrically powered devices, sustainable deployment of which, in LMICs, is difficult. In the 'Fit-for-purpose, affordable body-powered prostheses' project, teams from the United Kingdom, Uganda and Jordan are developing mechanically-operated prostheses, optimised for LMICs, and establishing local methods for fabrication, fitting and evaluation. Here we first report on preliminary studies aimed at grounding the project in the reality of current prosthetics services and the experiences of people with limb absence in Uganda. Finally, we outline our ongoing work in the context of our findings.

In our first two studies we reviewed current prosthetics and associated repair services. An issue which came up repeatedly was the difficulty faced by orthopaedic technologists in accessing componentry/materials. All specialised prosthetics components and materials are imported, often at a high cost. Purchasing does not appear to be well coordinated between centres, meaning potential economies of scale are not being fully exploited. Although there is supposed to be government funding for prosthetics, in practice budgets are often inadequate and a reliance on donations is common. The resource limitations mean Orthopaedic Technologists often resort to ad-hoc solutions; unsurprisingly perhaps, failures in prostheses were reported. In particular, lamination-based socket manufacture is very difficult, given the complexity (and cost) of the processes involved. Repair services are also limited, in part also due to problems accessing materials/components. Despite (or in part, as a result of) these challenges, the orthopaedic technologists are generally an extremely

resourceful and multi-skilled group and there is genuine enthusiasm to see services improve. Further, there is a growth in interest and capabilities in the area of medical device innovation.

In the third of our studies, we interviewed 17 PWULA and present preliminary results from the analysis of a subset of five participants. Firstly, we found that only 2 of the participants reported experience with using an upper limb prosthesis, again supporting the picture which emerged from the other studies. The findings illustrate the emergence of four key themes: a) attitude towards disability; b) barriers to prosthesis use; c) coping without a prosthesis; and d) communication with other PWULA. Although attitudes to those with limb loss varied, participants reported impacts in terms of social isolation and a mixed experience of emotions that appeared predominantly negative; barriers to prosthesis use were broader than just cost and functionality, and included a lack of training and psychological support; given that it is difficult to access an upper limb prosthesis, PWULA have found ways to perform daily life activities without relying on one; finally, most PWULA find the suggestion of communicating with other people with the same experience appealing.

In our project we are addressing some of the issues found in the preliminary studies. To make socket manufacture less dependent on access to imported materials and specialised equipment, we are investigating the development of lattice-style, adjustable sockets, made from locally available materials. We are also investigating alternatives to the traditional harness-controlled, body-powered prosthetic hands. Given that clinicians have no objective means of evaluating the value of the prosthesis to their clients, we are testing the use of low-cost digital monitoring tools. We are also exploring the potential value of using mobile-phones to reduce the isolation of PWULA. Finally, we are exploring how these innovations may be translated into the Ugandan health setting.

Keywords

Prosthetics; upper limb; low cost; fit-for-purpose; body powered; Uganda; manufacturing; fitting; repair; user needs; user experiences; monitoring real-world use of prostheses.

Introduction

The majority of PWULA live in lower, or middle-income countries (LMICs), likely due to factors such as road traffic accidents, armed conflict and industrial accidents. By contrast, most of the studies into the consequent impacts have been carried out in high income countries. From these, it is clear functional abilities are significantly reduced, even when using a prosthesis (1), mental health may be affected (2), and quality of life may be reduced (3). In unilateral users (of myoelectric prostheses), a heavy reliance on the intact limb appears to be common (4), which may contribute to overuse injuries (5).

In wealthy countries PWULA can typically access high quality prostheses, which may be passive, electrically powered, or mechanically-operated (sometimes referred to as body-powered) (6). Despite the clear constraints on the deployment of electrically powered

prostheses in LMICs, such as the need for reliable charging points and potential difficulties with maintenance, most research in upper limb prostheses has focused on these devices. In part as a result of the dominant focus for both industry and academia on electrically powered devices, there remains significant scope for improvement to commercially available, mechanically-operated prostheses (7).

Mechanically operated devices offer a potentially appropriate alternative to electrically powered prostheses, particularly for those living and working in rural areas. Our team were awarded £1.4 million from the United Kingdom Global Challenges Research Fund to design and test a low-cost mechanically operated prosthesis, optimised for LMICs, and establish local methods for fabrication, fitting and evaluation. The project, entitled 'Fit-for-purpose, affordable body-powered prostheses' (abbreviated to F4P in this paper) is led by the University of Salford, in collaboration with the University of Jordan, Makerere University, the universities of Portsmouth and Southampton, and University College London. In order to better understand the context for the work, and to ensure that any new developments are 'fit for purpose', we have carried out a series of scoping and exploratory studies on prosthetics services in both Jordan and Uganda. In this paper we report on the findings from the studies carried out in Uganda and outline how the ongoing work may help to address some of the identified challenges.

Uganda's population is approximately 41 million, with a gross national income/capita of ~USD1300 (<https://www.who.int/countries/uga/en/>). Health expenditure is low, both in absolute terms (~USD130 per person, per year) and as a proportion of GDP (~7%). However, significant improvements in a number of key health indicators, including life expectancy and infant mortality rates have been seen over recent decades. Nevertheless, the prevalence of disability appears high (8).

However, in common with many other LMICs, data on the demand for prosthetics and the extent to which it is being met are poorly understood. There is no limb loss or absence registry in Uganda, nor a legally recognized association or society of prosthetic users, although an informal community group of people with limb absence exists in the Busoga region and there are associations of people with disabilities. A recent retrospective study of clinical notes from hospitals in the Acholi region (9) highlighted the lack of national limb loss/absence prevalence data and provided an interesting insight into some of the challenges faced by clients and clinicians. For example, in a region with poor transport infrastructure, the average distance from a client's home to the referral hospital where they were seen was 91km. Further, less than 1% of clients were formally referred to rehabilitation services.

Objectives

The objectives of the studies presented here were to better understand the current state of prosthetic services in Uganda, from both the clinician and client perspective, with a view to informing and underpinning the F4P project.

Methods

We adopted a Patient and Public Involvement (PPI) framework to understand the context and inform the development of methods for subsequent studies, in collaboration with our partners and involving PWULA. This flexible approach enabled us to engage the users and wider stakeholders to help focus our efforts on technological developments likely to meet the user's needs. In the first section we present the findings of two studies on Ugandan prosthetics manufacturing and fitting services. The second section summarises a study on the state of prosthesis repair services. Finally, we report preliminary data from a series of interviews with PWULA on their needs and experiences regarding prosthetics.

Findings

Section 1: reviews of prosthetics manufacturing and fitting services

This section summarises findings from two PPI exploratory and scoping studies that investigated prosthetics manufacturing and fitting services in Uganda. In the first study, members of the F4P team visited: The Mulago National Referral Hospital and the partner orthopaedic workshop and training school (referred to as Mulago in this paper); two non-governmental organisation-run facilities; and a private workshop. The team also met with PWULA and visited the Ugandan Industrial Research Institute. In the second visit, two students studying Prosthetics and Orthotics spent 1 month in Uganda, visiting Mulago, Makerere University, Katalemwa Cheshire Home for Rehabilitation Services (referred to in this paper as Katalemwa), Orthotech & Physical Rehabilitation International and Fort Portal Regional Referral Hospital (referred to in this paper as Fort Portal). The findings have been discussed in detail with co-authors who work at two of the clinical centres.

The clinical facilities visited varied considerably in their ability to provide services, from rather poorly resourced public facilities to better-resourced private/NGO-funded facilities. Due to space limitations in this paper we will focus on one example of a public hospital (Mulago) and one NGO-run clinic (Katalemwa)

The Mulago workshop has 13 staff (orthopaedic technologists) and was founded in the 90's with the help of the International Committee of the Red Cross (ICRC). From 1989 to 1996, both the workshops and associated supply of materials were managed through the British Red Cross. However, support for the Mulago workshop from the ICRC and British Red Cross was withdrawn in the 1990s and the responsibility was passed to the Ugandan government.

The Orthopaedic Technologists are multi-skilled clinicians and technicians who essentially fulfil, what in the United Kingdom would be multiple roles (Prosthetist, Orthotist, Technician and, to some degree, Occupational Therapist). They are also responsible for the sourcing and obtaining of materials and componentry and, in many cases, negotiating costs with clients. Most of the workshop machines are quite old and some are faulty (the parts to repair them are not easily available). While the facilities for manufacturing of metal-based and wooden products are quite functional, the prosthetics workshop is less so. For instance,

much of the equipment needed for the fabrication of laminated sockets is in a poor state of repair. While Mulago has a rehabilitation service, it was reported to be under-staffed and under-used and few-referrals are made from the prosthetics team to the occupational therapists.

In terms of materials, thermoplastics are locally sourced; however, polypropylene is in constant low supply and difficult to acquire. Indeed, during one of the visits, the team were told there was no polypropylene available in the whole of Uganda. However, leather, wood and common metals, such as mild steel, can be readily acquired locally. Lamination materials are generally available (lay-up material, resin – mainly sourced from India) however they have a specific difficulty in acquiring PVA bags. Mulago is also heavily dependent on donations of components, which come at irregular, unpredictable intervals, making scheduling of appointments and planning of services very difficult.

Mulago see approximately 30 people with lower limb absence a month, and around 10 with upper limb absence and the main cause is trauma (primarily road traffic accidents, followed by tumours). Previously the staff at Mulago undertook outpatient clinics in villages but they no longer do so as funding and transport are both a problem.

A typical client journey through Mulago is described here. When a client (primary or pre-existing) requires a new prosthesis they move from amputation surgery (in the case of primary patients) through to in-patient recovery and referral to the Orthopaedic Workshop for prosthetic fitting. However, a critical part of the fitting process is the negotiation between client and orthopaedic technologists over both the availability of materials and components, and the cost. Typically, an attempt is made to acquire the required components via their, or colleagues' donated stock. When/if the components can be acquired the client will be contacted and the cost discussed before the components are ordered. When componentry is acquired, it is not often compatible with other components and hence ad-hoc mechanical adaptations may be needed. Although there is supposed to be government funding for prosthetics, in practice budgets are often inadequate and so, if the client cannot afford to pay for the materials/components which are both suitable and available, they go onto a waiting list until alternatives can be found. Although costs vary, upper limb prostheses (cosmetic or basic mechanical devices) are of the order of USD400-USD945 (lower limb prostheses may cost up to around USD400). To put this figure in context, the average monthly income per household in Uganda in 2016/17 was reported to be under 0.5 million Ugandan shillings (<USD133) (10).

By contrast to the Government run Mulago centre, some NGO facilities have better access to working machinery and appear to be somewhat better positioned to meet the needs of clients. Below we present a brief review of the Katalamwa Cheshire home.

Katalamwa is a non-profit organisation founded in 1970, providing comprehensive rehabilitation services to children with disability. Katalamwa's orthopaedic workshop was started in 1999 under the support of the Christoffel Blinden Mission (CBM). The workshop

has 12 staff (4 orthopaedic technologists, 2 leather technicians, 2 carpenters and 4 welders/metal technicians). It fabricates assistive devices including wheelchairs, special chairs, orthoses and prostheses.

With the support from the CBM and other donors, in terms of machinery, tools, and resources, the workshop is functional, with the ability to provide services to the children with disabilities at a relatively low cost. For example, a lower limb prosthesis fabricated out of local materials, such as mild steel joints and a Solid Ankle Cushioned Heel (SACH) foot made of rubber, may cost around USD130. Fabricating a similar device out of imported components costs on average USD360. However, the Katalamwa team recognise that the robustness of a prosthesis made in a small workshop, from local materials may be somewhat less than an equivalent imported device. Upper limb prostheses are all made from imported components, making them expensive.

Katalamwa sees approximately 130 people with limb absence a year using its community-based and centre-based approaches (20% of these have upper limb absence). The main cause of amputation is trauma, followed by congenital anomalies and vascular diseases. Most of the prostheses fitted at Katalamwa are paid for by a donor, such as Mobility Equipment for the Needs of the Disabled New Zealand, banks and well-wishers; this is a less than fully sustainable solution, particularly when repairs are required (see next section), or in cases where the donor withdraws their support. Out of the 130 clients seen each year, around 95 get prostheses. Cost is one main reason why a client may not receive a prosthesis after being referred.

Section 2: prosthetics repairs

This section reports on a study investigating how people in Uganda get their prostheses repaired. To understand the technical perspective three workshops were visited: Mulago, Katalamwa, and Fort Portal. According to the technologists, the biggest issue facing all 3 workshops was access to components and materials. Basic adjustments and repairs can be completed for free, however clients are required to cover the costs of any new materials or components which are needed. The challenges with sourcing components in Uganda translate into high costs which are often unaffordable to clients. In these cases, the prosthesis is not repaired, or an improvised repair is completed to allow use of the prosthesis while the client saves money or finds a sponsor to cover the cost. During the study it was observed that the technologists were very resourceful with materials, such as repurposing plastic from Jerry cans to reinforce failed socket-pylon interfaces, and the technologists re-use materials and components as much as possible.

To understand the client perspective on repairs, semi-structured interviews were conducted with prosthesis users from Mulago and Fort Portal hospitals. 13 people were interviewed (7 female, age: 22-48 years), of which 11 had a lower limb loss (5 below knee and 6 above knee) and 3 had upper limb loss (all above elbow) (note: 1 interviewee had both upper and lower limb loss). All clients were experienced prosthesis users, and on average they had

their prosthesis for 11 years at the time of interview (range 4-29 years); 2 out of the 3 PWULA had a cosmetic upper limb prosthesis; the third did not have a prosthesis, reportedly because his stump was too short.

11 out of 13 interviewees had experienced at least one failure of their prosthesis (4 had experienced 3 or more failures). Clients get their prosthesis repaired in one of four ways: 1) returning to the original workshop where their prosthesis was provisioned, 2) going to a local trades-people, such as a mechanic, 3) completing the repair themselves or 4) not getting the prosthesis repaired. All but 2 of the clients had returned to the original workshop at least once for a repair. However, this may not be representative, because, for practical reasons all those interviewed lived near the workshop. Their average travel time to the workshop was 63 minutes (range 5 minutes - 2 hours), very different to the average distance of 91km reported in the Acholi region (9). It is suspected that clients who live further away are more likely to try to repair the prosthesis themselves or go to local trades people.

Clients typically initiate the repair process by contacting the orthopaedic technologists who fitted the prosthesis to be assessed. Clients reported inconsistent costs for repairs; some reported that maintenance was usually done for free, while others had been charged. This contributed towards client's reluctance to attempt to get their prosthesis repaired, as they reported they were hesitant to pay for travel if they were not sure it would result in getting their prosthesis repaired. The payment negotiation process takes time and may not result in a successful outcome, due to availability of materials and/or components and what the client can afford. More than one visit to the workshop is often needed, to allow the technologists to source the relevant materials. Clearly, travel to/from the clinical centres for repairs may be particularly challenging. Perhaps partly as a result of these challenges, two of the interviewees had completed their own repairs on their prostheses.

In summary, from the technologists' perspective, almost all the technologists interviewed said their biggest challenge was poor access to resources. From the client's perspective, their biggest concern was cost, with many of them struggling to pay for transport to the workshop, even if the repair itself would be free. These are both systemic problems which will be difficult to overcome, but they will need to be considered in the design of any new prosthesis if it is to be introduced in a successful and sustainable way.

Section 3: User needs and experiences regarding prosthetics

This section summarizes the preliminary findings of a study aiming to gain an in-depth understanding of the user's perspective that will underpin each of the work packages, as well as linking and synthesising other stakeholder perspectives throughout the duration of the study. As 'many technologies and scientific interventions continue to fail due to a lack of understanding of their social and cultural and historical context and the likely reception by the people and societies that are intended to benefit', user engagement throughout will focus our work on developments which are fit-for-purpose from the user's perspective (11).

We used a flexible qualitative approach that involved the use of semi-structured interviews. Working in partnership across countries and institutions, we constructed a semi-structured interview schedule that focused on daily experiences with or without a prosthesis, perceptions and expectations of prostheses, challenges in relation to the amputation and access to prosthetic services, social inclusion and design characteristics of prostheses. Reflecting the importance of understanding the social and cultural issues the interview schedule was translated into various languages spoken in Uganda. The interviews were carried out by four members of the Ugandan team (biomedical engineers, prosthetics and orthotics technicians and community rehabilitation experts). They were new to the field of qualitative research and therefore undertook training run by members of the United Kingdom team within a co-researcher and co-production framework.

We interviewed 17 PWULA, 11 of whom were amputated above the elbow. The main reason for amputation was road traffic accidents followed by violence, fire accidents, illness and occupational accidents. The time since the amputation ranged from 20 years to five months and only two people had experience of using a prosthesis, illustrating the issues with access described in the previous sections. We are analysing the data using thematic analysis and here present preliminary findings from a subset of five participants. These findings illustrate the emergence of four key themes:

Theme 1: attitude towards disability

There was a mixture in attitudes towards living with upper limb loss from the individuals themselves and how they viewed their own disability, as well as their views of social perceptions and attitudes towards upper limb loss. For example, participants shared stories and experiences of ableism, which was illustrated in terms of heightened staring, heightened pity, reducing the humanity of people with limb loss, intense and cumbersome curiosity with intense questions, exclusion, discrimination and social pressure to seek a prosthesis as a means of covering up the limb loss as fast as possible.

The impact of ableism is observed in the form of social isolation and a mixed experience of emotions that appeared predominantly negative and damaging to the wellbeing of people with limb loss. Although we found exceptions where close friends and family members were supportive towards people with limb absence, some participants expressed concerns about what they may say about their disability when they are not with them.

Theme 2: barriers to prosthesis use

Barriers to prosthesis use appeared to be multidimensional and not limited to the physical properties, cost and functionality. These barriers are related to inadequate or insufficient: training to use the prosthesis, and psychological and social support to overcome the often-traumatic nature of becoming a PWULA. Prostheses are also considered too expensive and some participants said they would have to sell their land or family home to finance one. Prostheses are perceived as heavy, becoming a key reason to not using one. These factors were also linked to wider frustrations following the physical and psychological

trauma of the amputation, such as feelings of ambitions being shattered and the realisation that a prosthesis will not replace their own arm.

Theme 3: coping without a prosthesis

Given that it is difficult to access an upper limb prosthesis, PWULA have found ways to perform daily life activities without relying on one. Some of them have reached a level of independence and do not consider that they need an upper limb prosthesis. The coping techniques identified were: relying on other parts of their body, relying on other people, relying on other devices that are not a prosthesis. In addition, they have shared strategies that are relevant to communication and management skills. For example, consult an occupational therapist to strengthen muscles of healthy arm and plan activities ahead, since performing tasks with one arm takes longer than with two.

Theme 4: communication with other people with upper limb loss

Most PWULA find the suggestion of communicating with other people with the same experience appealing. However, they report not to have the opportunities to start such communication (cannot afford a prosthesis therefore do not visit an orthopaedic workshop as often). People with limb loss have identified various potential benefits of being able to engage with people with the same experience and one risk. Identified benefits are: obtain information of where other people get their prosthesis, help others to get a prosthesis, share the living experience of limb loss, share advice and listen to other people's struggles and how they have overcome them. The only risk identified in this preliminary analysis is meeting other people using a prosthesis that they cannot afford and the subsequent frustration and sadness.

After we have finished the analysis and identified final themes, in addition to gaining an in-depth understanding of the user views, we will also be able to use this inductive set of results as a framework for more deductive analysis for the related work packages.

Discussion

The findings from this series of studies paint a rather bleak picture of the state of prosthetic services in Uganda. A few key points emerged from the studies and these are discussed below.

An issue which came up repeatedly across all our studies was the difficulty faced by orthopaedic technologists in accessing componentry/materials. All the sites we visited faced resource difficulties and hence often sought donations from well-meaning organisations or individuals. A reliance on donated materials/components makes predictability and sustainability of supply difficult and, in turn, impacts on the scheduling of appointments. Indeed, interactions between orthopaedic technologists and clients due, either directly, or indirectly to uncertainty in supply, places a burden on clients and leads to frustration on the part of the clinicians. Further, the heterogeneous nature of donated componentry presents the orthopaedic technologists with major challenges often requiring bespoke solutions to

assembly of prostheses, which in turn may compromise their robustness. Even when funding is found to purchase materials, accessing high quality plastics, particularly polypropylene, is an ongoing challenge. A continued reliance on charitable donations is at odds with a number of the Sustainable Development Goals (SDGs) (12).

As Uganda has no prosthetics industry, all specialised componentry/equipment is imported. Very recently, a new supplier which has a local distributor in Uganda, has made ordering componentry and materials easier; nevertheless, the budgets particularly in government run facilities are not sufficient to meet demand. Further, as the purchasing process is not centrally managed, centres cannot take advantage of the potential economies of scale which would come with a coordinated approach. Maintenance of machinery is also an ongoing problem.

With regard to repairs, again we found this process to be both time consuming, sometimes requiring multiple visits to clinical centres; and frustrating, with no guarantee of a positive outcome in the end. Clinicians' extremely tight budgets and difficulties in accessing materials and components means they are often forced to attempt ad-hoc repairs using whatever resources are available to them; perhaps as a result, clients sometimes attempt repairs themselves. It was noted that repeated failures appear common.

Despite (or perhaps, as a result of) these challenges, the orthopaedic technologists are generally an extremely resourceful and multi-skilled group and there is genuine enthusiasm to see services improve. Further, the establishment of a degree course in Biomedical Engineering at Makerere University has led to a growth in interest and capabilities in the area of medical device innovation.

In the third of our studies, we interviewed 17 PWULA and present preliminary results from the analysis of a subset of five participants. Firstly, it was notable that of the 17 participants, only 2 had experience of using an upper limb prosthesis. Further, the themes which emerged pointed to the extremely difficult situations that these people face, from a lack of access to prostheses and associated support services to social isolation and negative attitudes from people they encountered. Coping strategies included finding ways of performing activities without the prosthesis. Finally, they expressed interest in being put in touch with people in similar situations as a means of sharing advice, experiences, and coping strategies.

Ongoing work

Below we discuss our ongoing work to develop new designs and methods, which we hope may go some way to addressing the current situation.

Sockets. At present, sockets in Uganda are either fitted and fabricated using a lamination process or draping of plastic sheets. Neither approach is an ideal solution for Uganda; lamination-based socket manufacture requires the unusually encountered situation where skilled personnel have access to multiple different materials, a reliable electricity supply, and (working) specialised equipment. Further, a monocoque design is hot and fails to

accommodate fluctuations in limb volume. We are developing a low-cost, adjustable lattice-style socket, which could be fabricated locally, using locally sourced materials, and which may be amenable to repair (ideally in a typical 'bicycle repair shop', rather than a prosthetic clinic).

Prosthetic hand and wrist. We encountered a small number of instances where people had received harness-controlled, body-powered prostheses. These were generally in a poor state of repair and were reportedly not used functionally. We are exploring alternative approaches to the traditional Bowden cable-controlled device, including semi-passive hands and solutions based on the use of hydraulic transmissions. We are also exploring the potential to develop a low-cost wrist unit.

Mobile phones for social inclusion. Preliminary analysis of our data has indicated that Ugandan PWULA generally do not use mobile phones for peer support, although they would like this to happen. When F4P first started, we devised methods to support PWULA to establish communication with other PWULA to understand how best to use communication technology and how it could impact on their experiences as PWULA. Fortuitously we discovered a small group of PWULA led by one person (holding the contact details of around 50 other PWULA). To capitalise on this, we will carry out a study using ethnographic methods; first we will perform semi-structured interviews with members of the existing group of (50) PWULA and others. We will lend mobile phones to whoever cannot afford one, give them the contact details of others in similar situations, ask them to keep a diary of their experiences and communications. The resulting data will be analysed using thematic analysis and triangulation. This study is expected to start shortly.

Real-world monitoring. Once a client leaves the clinic with their prosthesis, there is no objective means of evaluating whether the prosthesis is of sufficient value to the user for it to be used in their everyday life. As the acid test for any assistive technology is whether, or not the person chooses to use it in their everyday life, we are providing clinicians with the tools to objectively and simply record these data using wrist-worn sensors. The approach builds on our recent work (4), which demonstrated the value of such data.

Translation. One of the challenges faced by aspiring Ugandan medical device manufacturers wanting to commercialise new devices has been an absence of a well-defined regulatory system. However, work by the Ugandan Industrial Research Institute to develop and bring through regulatory approvals, an infusion controller, has shown the potential opportunities for medical device innovation. A PhD student, based in Uganda, is working with the project team and others on the translation of the results towards the market.

Finally, none of our studies attempted to characterise the demand for services, and high-quality data on this is not available. Researchers from the University of Manchester and Gulu University in Uganda are studying the distribution of people with limb absence in the Acholi region of Uganda, through the creation of detailed maps using satellite images and Open Street Map, combined with house-house health surveys

(<http://huckathon.org/about.html>). Clearly, such information will be of value when planning prosthetic services and if this could be extended country-wide and include mapping of clinical and repair facilities, this would be a major step forward.

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Enabling the sector

ATscale: Establishing a cross-sector partnership to increase access to assistive technology

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Abstract

Given existing gaps in access to Assistive Technology (AT) globally, it is important to think broadly and identify innovative approaches to overcome them. After an initial scoping in 2018, involving consultations and landscape analyses, ATscale, the Global Partnership for Assistive Technology was launched at the Global Disability Summit in July 2018 with the aim of reaching 500 million more people with life-changing AT by 2030. Applying lessons-learned from other areas of global health and development, ATscale was established with the recognition that to influence the complex systems for AT access, a broad set of stakeholders is needed to invest in and coordinate a multi-faceted, systematic approach spanning market shaping, capacity development, and political prioritisation. Already, ATscale has demonstrated how a multi-sector group can come together and develop a cohesive strategy. This strategy overview has been released and shared broadly for additional consultation and feedback to further refine ATscale's approach moving forward. ATscale has captured the attention of a diverse set of stakeholders. It now has eleven organisations within the Forming Committee and a broad community willing to inform its development. Now that it has been established, ATscale is working to move from an initial forming phase to a more formal organisation and to refine its operating model by late 2019 or early 2020. While there is significant momentum towards taking new, innovative approaches to address the gaps in access to quality, affordable AT for all, research shows that a wide range of systemic, underlying barriers and cross-cutting factors are contributing to the challenge in matching appropriate supply and demand for AT. While ATscale will address many of these, it is also going to require partnership on multiple levels with a coordinated strategic approach across a variety of stakeholders. This collective effort will enable the global community to have an impact greater than the sum of its individual parts in improving access to affordable, appropriate AT globally.

Key words

Assistive technology, cross-sector partnership, access, prioritisation, investment, markets

Introduction

Today, over 1 billion people need at least one form of assistive technology (AT), such as wheelchairs, eyeglasses, or hearing aids, but over 900 million people (90%) do not have access to the AT they require. The number of people who need AT is expected to grow to more than 2 billion people by 2050 (1).

Access to appropriate AT enables people with loss of function, disabilities, non-communicable diseases, and the aging population to participate in education, work, family, and community life. Without AT, individuals may experience isolation and exclusion from education, the labour market, and civic life. Lack of access to appropriate AT causes poorer health outcomes including premature death, deteriorating mental health, and increased risk of chronic health conditions and secondary complications. Increasing accessibility and affordability of AT unlocks unrealised economic potential and provides socioeconomic benefit for individuals, families, and countries by increasing productivity and participation in the workforce.

Despite the evidence and consensus around the huge unmet need for AT, research shows that there is a wide range of systemic, underlying challenges in the wider AT environment contributing to the challenge of matching and building appropriate supply and demand for AT, including inconsistent political will to prioritise AT, a lack of understanding of the role and function of AT in improving health, social, and economic outcomes, significant gaps in resources and investment in AT, insufficient data on impact to drive investment, a lack of global coordination for activities and investments in AT, and discrimination and stigma, particularly at the community level.

Many of these gaps in the enabling environment are intertwined with market barriers, which impact both supply and demand of AT. Obstacles to clearly articulated global demand include, but are not limited to, limited awareness, inadequate funding, fragmented procurement, and insufficient service delivery capacity. These all contribute to lack of demand across the value chain, including from users, service providers, and/or country governments. On the supply-side, limitations on AT products are related to availability, affordability, appropriate design, and assured quality, and the associated barriers are multi-faceted. As a result of varied challenges, there is insufficient participation by AT manufacturers and suppliers in low-and middle-income (LMIC) markets. Further, where they do participate, prices are usually high, and product and services are only available for more affluent segments of the population. Additional challenges include ineffective investment in innovation, complex and long processes to bring new products to market, and an absence of standards and guidelines. In order to improve upon the current challenges across supply, demand, quality, and price for AT in LMICs, a coordinated approach to overcoming identified barriers is needed to continue to build and shape the market for AT.

Given the nature of the existing gaps in access to AT globally, it is important to think broadly and identify innovative approaches to overcoming these challenges. ATscale¹, the Global Partnership for Assistive Technology, was launched in July 2018 as a multi-sector group to build a cohesive strategy to address the lack of global prioritisation, coordination, and investment in AT, as well as to tackle market challenges.

This paper describes the initiation of the partnership, the current state of the partnership, and the key components of the strategy to be implemented to support ATscale to achieve its global aim of reaching 500 million more people with life-changing AT by 2030. It articulates the ongoing work to move from an initial forming phase to a more formal organisation and discusses some of the challenges the partnership may face moving forward. It closes by highlighting opportunities and the need to build partnership on multiple levels through ongoing engagement with a diverse set of stakeholders to enable ATscale to impact the broad AT ecosystem. Text throughout this paper is pulled from and summarised from the Strategy Overview, which can be found on the website: atscale2030.org/strategy

Initiating the Partnership

Globally, while progress has been made in improving many aspects of AT delivery, the sector has been fragmented and under-resourced for some time. While a few donors have invested in this work in recent years, the required investment, attention, and implementation capacity far surpasses that which a few agencies can provide. Historically, there has been a lack of recognition of the importance of AT in the context of global agendas including Universal Health Coverage (UHC) and the Sustainable Development Goals (SDGs). Within the health sector, an area that should play a critical role in AT delivery, AT has not been prioritised, with limited to no funding allocated for it within health budgets among donors or local governments. There is limited evidence to build an investment case and to articulate the critical importance of improving access to AT to uphold human rights and to achieve related health, economic, and social outcomes.

In early 2018, the United States Agency for International Development (USAID) and the then Office of the United Nations Special Envoy for Health (UNSEO), initiated work with the Boston Consulting Group (BCG) to understand what opportunities exist to address access barriers to AT. BCG looked to consider how the market-oriented approaches that have been utilised within health to increase access and decrease the price of health commodities, known as market shaping, could be applied to the AT sector (2). Over the past decade, the global health community has deployed market shaping approaches for essential health commodities, successfully increasing availability and affordability. Successes include: halving the prices of polio and pentavalent vaccines; increasing market information through demand forecasting to increase reliable supply of antiretrovirals for HIV; and using volume guarantees to decrease time-to-market and lower prices for contraceptive implants (3-6).

¹ Pronounced as "A", "T", "scale"

Through this analysis, a hypothesis emerged that these approaches could be successfully adapted for AT, which has highly unique and fragmented markets.

Leading up to the Global Disability Summit, the Steering Committee for this work was expanded, incorporating the UK's Department for International Development (DFID), with experience in market shaping and a growing interest in AT, as well as a few other partners. It was during this time that DFID initiated further analytical work with the Global Disability Innovation (GDI) Hub and the Clinton Health Access Initiative (CHAI), who each led different components of the scoping process (7). A broad community of organisations and individuals with expertise, experience, and connections across sectors was instrumental in providing critical information around the gaps and shaping early ideas about opportunities. The report that emerged from this specific scoping contributed to the evidence base about challenges and also supported development of a fast start programme known as AT2030 (8), to implement initial activities to further inform the necessary approach.

While the analysis in the early phase focused on exploring the potential for applying market shaping approaches to AT, the work illuminated the fragmented nature of the response necessitating new, innovative approaches. Emerging from this was the need for broad political prioritisation and resource mobilisation. While some progress has been made globally in the context of political commitment, including establishment of the World Health Organization's (WHO) Global Cooperation on Assistive Technology (GATE), as well as the 71st World Health Assembly in 2018 passing a resolution on improving access to AT (9), there is still a long way to go. For example, there remains almost no domestic investment into AT among governments and there are limited international, large-scale commitments against AT from any of the traditional global health donors.

In order to influence the complex systems for access to and provision of AT, and to make sustained impact, it became clear that a broad set of stakeholders across sectors would be needed to invest in and coordinate a multi-faceted, systematic approach spanning market shaping, capacity development, and political prioritisation. Additionally, the consultations highlighted that successes in market-based approaches for other health commodities relied on a comprehensive analysis of the entire value chain followed by a plan to coordinate interventions on the supply and demand side and to address how the market is organised. These analyses and action plans can then provide a framework for the entire community to guide action. Given this, the work of BCG, was amended in the lead up to the Global Disability Summit in July 2018 to also support an effort to better understand how a global partnership could evolve to address the barriers to increasing access to appropriate, affordable AT.

The scoping considered successful partnership models used in other areas of international development. Global partnerships such as Unitaaid, the Global Fund, Gavi, and others have taken leadership roles in transforming their respective sectors. This is both in terms of global commitment, as evidenced by a multitude of diverse stakeholders prioritising and financing their work, as well as in the delivery of innovative, strategic, organised market-

based solutions that have revolutionised access to their respective products and services. Since its inception in 2000, “Gavi support has contributed to immunisation of more than 700 million children”, health systems and immunisation services have been strengthened in more than 60 countries, and they have articulated the case that “for every \$1 USD spent on immunisation, \$18 USD are saved in healthcare costs, lost wages, and lost productivity due to illness” (10). Reflecting on global HIV treatment 20 years ago, there were only 0.7 million people on treatment (3% treatment coverage) and the average cost to treat someone each year was ~\$10,000 (11). It has taken partnership and strategic focus across a variety of areas including service delivery, global technical guidance, and market shaping to increase that treatment coverage to more than 60% in 2018, more than 23 million people on treatment, and an average cost per treatment of less than \$100 per person per year (12). For some reviewed partnerships including Roll-back Malaria and the END Fund, setting an agenda and convening stakeholders are a core proposition. It is critical to learn from the models of those who have come before, as their approach has enabled increased political prioritisation and coordination, a high level of sustained resources, and transformed markets, all of which are paramount for increasing access to AT.

Information gathered throughout the evaluative, consultative process was considered in a series of meetings and workshops to develop the framework for the new partnership model. The rigorous analyses conducted, including initial AT market assessments, key informant interviews, and high-level secondary research, informed ATscale’s strategic priorities, objectives, and proposed focus areas. This work culminated with the launch of ATscale, the Global Partnership for Assistive Technology, at the Global Disability Summit in July 2018 in London by former United Kingdom Prime Minister, Theresa May. This summit, hosted by the United Kingdom Government, the Government of Kenya, and the International Disability Alliance, brought together more than 1000 delegates from governments, donors, private sector organisations, charities and organisations of persons with disabilities. There was an increased focus on AT and an emphasis on making tangible commitments for change in this area (13). ATscale launched as a commitment by key actors to develop a cross-sector partnership for AT that aims to bring greater resources and strategic focus to this significant global challenge with the goal of reaching 500 million more people with life-changing AT by 2030.

Current State of the Partnership

ATscale’s vision is to enable a lifetime of potential where every person can access and afford the life-changing AT they need. To accomplish this, ATscale is guided by a set of core principles underpinning its activities and approach. In short, the work will be user-centric, equitable, catalytic, galvanising, evidence-based, entrepreneurial, and empowering. Further, ATscale’s work will be informed by six interdependent priorities, which constitute critical areas to invest in to drive transformation in availability and access to AT, including: 1) generating data and evidence; 2) sparking innovation and new solutions; 3) driving

affordability and availability; 4) strengthening policy, systems, and implementation; 5) building capacity and participation; and, 6) galvanising investment and political support.

Overall, ATscale's path to its 2030 goal will likely fall into three phases. The initial phase (2019-2021) will involve demonstrating that ATscale, as a global partnership, can accelerate change leading to increased access to AT, as well as establishing a long-term organisational model. In the second phase (2022-2026), ATscale will expand its activities and seek additional investments as programmatic needs accelerate. The third phase (2027-2030) will emphasise taking what works across strategic priorities and geographies to scale.

Current Operational Model

Currently, ATscale is governed by a Forming Committee, comprised of 11 organisations,² which oversees ATscale's development, guided by an internal Statement of Principles collectively developed by the partner organisations. The Forming Committee is advising on strategy, coordinating stakeholders, mobilising resources, identifying and considering potential interventions and investments, and will shepherd ATscale to its permanent structure. ATscale has a small staff facilitating its daily operations including a Director who reports to the Forming Committee. By the end of 2019 or early 2020, ATscale will move to a more formalised structure.

Current Strategy Overview

To facilitate the direction of its initial work, ATscale developed a Strategy Overview. The document was developed by the Forming Committee through a series of consultations and incorporates ATscale's vision and mission, goal, approach, and near-term objectives. The strategic approach proposed by ATscale includes lessons-learned from other areas of global health and development, including market shaping approaches, as well as increasing political prioritisation, galvanising investment, and strengthening critical, cross-cutting systems. The Strategy Overview was released in February 2019 and shared broadly for additional consultation and feedback to further refine ATscale's approach moving forward. ATscale has proactively engaged with interested stakeholders via networks such as WHO's online GATE community and at key global events and forums.

ATscale proposes a twin-track approach that will seek to (1) develop an enabling environment across all AT on global, regional, and national levels and (2) identify targeted, catalytic interventions to address both supply and demand barriers to access for priority products. This twin-track approach will kick-start ATscale's work and inform both its coordinated investment strategy and activities in the long-term. These two tracks, defined by the objectives summarised below, are mutually reinforcing:

²ATscale Forming Committee: China Disabled Persons' Federation, Clinton Health Access Initiative, Global Disability Innovation Hub, Government of Kenya, International Disability Alliance, Norwegian Agency for Development Cooperation, Office of the UN Secretary-General's Special Envoy for Financing the Health Millennium Development Goals and for Malaria, United Kingdom's Department for International Development, UNICEF, United States Agency for International Development, World Health Organization.

Objective I: Develop an enabling environment for increased access to high-quality, affordable AT by growing political will, advocating for and informing policy reform, mobilising investment, and strengthening systems and service delivery at global, regional, and country levels

Political commitment at the global, national, and sub-national levels is critical for translating need into increased, funded demand for AT, and this is true for governments, donors, and civil society across all levels. Further, there are policy, financing, service delivery, and system changes required to create an enabling environment that supports appropriate provision of AT for existing and potential users. This space requires new investment, new incentives for a variety of stakeholders to engage, and the channelling of existing funding into the most catalytic interventions. ATscale will identify and develop interventions to address the enabling environment at all levels, including within specific countries, and will evaluate opportunities across contexts, including emergency settings.

To support this first objective, ATscale will evaluate existing information about challenges and opportunities and conduct select additional analyses to inform the development of targeted activities. The initial work will take shape in the form of raising political will and inspiring action by developing an investment case and advocacy plan, identifying key opportunities for influencing political prioritisation of AT on global and country levels, and mobilising resources from new sources. Further, ATscale will identify investable, targeted, cross-cutting interventions to increase accessibility and affordability of appropriate AT. These analyses and identified subsequent interventions will likely span a variety of focus areas at the global and country levels, particularly for LMICs.

In the context of increasing political prioritisation and galvanising resources, ATscale is already engaging with different stakeholders on a variety of platforms to both understand the need, to begin to increase visibility around the importance of AT, and to advocate for additional partners to come on board. ATscale has had an opportunity to speak at several engagements to share the work and plans for the future, which has opened up discussion about future partnership and has provided a platform for engaging on new ideas. ATscale has presented at international forums including the Global Action on Disability Network Annual Meeting and it will contribute to sessions at conferences including the AAATE 2019 Conference and the International Agency for the Prevention of Blindness Council for Members. Later this year, ATscale will speak on a panel at the World Health Summit in Berlin, Germany and ATscale is co-designing sessions for the Global AT Conference in Beijing, China, bringing together governments, AT users, and private sector. Conversations are occurring across fora including the Global Rehabilitation Alliance, Rehabilitation 2030, the World Hearing Forum, ISPO, and on individual partner organisation levels. ATscale has also been invited to engage with private sector partners involved in AT both to jointly advocate for AT to be included on the global stage, as well as to further inform the work of objective II.

Objective II: Identify interventions required to shape markets and overcome supply and demand-side barriers for priority AT

Building on the market landscape analyses conducted leading up to ATscale's formation, ATscale is conducting more in-depth analyses across five priority product areas. These five product areas and their associated services and systems for focus over the next few years (wheelchairs, hearing aids, prosthetics, eyeglasses, and digital devices with appropriate software) were selected through an analysis and assessment of the WHO Top 50 Priority Assistive Product List (14). The selection considered the level of unmet need and the potential for impact through new market shaping approaches.

The work to assess these product areas identifies key barriers and promising market interventions across the value-chain, stretching from research and development to production and procurement, all the way through to supporting service delivery at the user and healthcare worker levels. The result is the development of *product narratives*, which are comprehensive strategies that define a sustainable approach to increasing access to affordable, appropriate AT. Each product narrative incorporates not only the strategic objectives that will guide progress in building and shaping these markets, but also articulates potential investable opportunities and actions that could have a significant impact. Outputs from this work will inform ATscale's action plan for further programmatic interventions and investments and will also provide data and evidence to inform implementation and investments beyond ATscale. The product narratives will provide the analytical and coordinating framework not just for ATscale, but for other funders, implementers, and the wider community, which is central to guide action and deliver change.

A public-facing product narrative for wheelchairs launches at the GReAT Consultation in August 2019 and will be available on the ATscale website (www.atscale2030.org). ATscale will evaluate the opportunities articulated within this document and develop an investment plan that it can follow in the coming months and years to enable the sector to collaboratively expand and grow the value of the market and unlock potential to reach those most in need. The product narrative for hearing aids is in progress and should be available in October 2019. Further, there is initial consultation commencing for the prosthetics market analysis and this product narrative should be complete in December 2019. Initial efforts are starting in the context of eyeglasses in the coming months. Market analysis for the fifth product, digital devices with appropriate and accessible software, will commence in early 2020. CHAI is delivering these product narratives under the United Kingdom's aid-funded AT2030 programme in support of the ATscale Strategy.

ATscale's activities and investments will focus on LMICs; however, broad engagement will be critical to achieve global impact. While country-specific work will be important in overcoming barriers, leveraging opportunities, and mobilising resources, there will also be an emphasis on establishing strong global markets and growing an overall enabling environment, which will require global engagement. Across both strategic objectives,

ATscale will continue to refine its understanding of the greatest challenges and most critical interventions required and will utilise the collective strength of committed organisations to address these barriers and achieve its overarching goals. Further, as lessons are learned, and evidence is established, new objectives in line with ATscale's strategic priorities will be developed or expanded and interventions will be scaled up.

Continuing to Build the Partnership

Next Steps

Challenges to access to affordable, appropriate AT exist across the entire ecosystem. It is essential that ATscale is strategic about its investments and activities so that it can make a direct impact, but also catalyse impact more broadly to lift the overall sector. ATscale will be ambitious, but will also be focused, and it will require coordination and complementary initiatives so that expertise is harnessed across a variety of areas. ATscale has established a framework for its plans for the coming years and now needs to build out detailed action and investment plans. Building on the existing and ongoing analyses, as well as future planned assessments, ATscale will prioritise interventions, identify the most impactful and effective way to carry these out, and then execute and monitor the resulting investment and action plans.

One of ATscale's priorities now that the Forming Committee has come together and begun to move the initiative forward, is to establish a more formal operating model and governance structure that harnesses the depth and breadth of the technical and operational expertise in the AT community to support effective performance. ATscale is in the process of evaluating the most appropriate legal structure for the partnership to provide a robust, yet flexible backbone for its work going forward; this includes the design of its governance structure. The future structure will likely include a small secretariat responsible for driving the goals of ATscale and implementation of its strategy, as well as a funding mechanism that supports coordinated investment. This work to develop this steady state will not only provide the foundation from which to effectively deliver ATscale's strategy, but it will also more explicitly define how ATscale will effectively engage with stakeholders across sectors. It will be important to consider a variety of platforms and opportunities for strengthening access to AT, including health as well as other sectors such as education. In this stage of development and refinement, ATscale endeavours to build on the experiences and strengths that exist within this space, as well utilise its position to bring partners, resources, and expertise to a space that has been under-resourced and fragmented for a long time.

ATscale anticipates not only being a catalyst for change, but also acting as a body that can amplify existing work and coordinate and mobilise global stakeholders along a unified, focused, strategy to increase the availability of and access to affordable, appropriate, quality AT. While ATscale is already comprised of a diverse set of organisations guiding its development, it will require partnership on multiple levels with an even broader group, including stakeholders who have not been engaged in this space previously. Within the

context of this work, everyone will have a role to play. All stakeholders are going to be required to increase awareness and raise the profile of AT work. Country governments will need to take a leadership role in prioritising AT, carving out space within national plans and budgets, and partnering with ATscale to overcome barriers both nationally and globally. AT users are needed to inform the design and implementation of interventions to ensure they are more user centric. Funders of all types are needed both to join ATscale to invest in the catalytic work and to align AT investments within the overall strategy. All stakeholder voices are needed to share experiences, contribute expertise, and to inform ATscale's strategic approach. Further, there will be room and a need for implementers to align with and accelerate programming to ATscale's strategic objectives.

Challenges

This partnership brings varied perspectives and backgrounds, meaning there is going to be broader reach and the possibility to take the best from other areas and apply it here. That said, varied perspectives also require work to achieve consensus and alignment around what is most critical and how best to implement it. Thus far, this structure has worked effectively to bring different voices to the table to ensure that a broad perspective is incorporated in the focus as well as the approach to addressing the core needs within this space. Strengthening this current engagement will be important. ATscale plans to define a more specific approach to actively and meaningfully engage with partners, including disabled persons organisations and AT user groups, in the coming months.

As highlighted above, while many stakeholders within the AT sector recognise the challenges and required initiatives to achieve ATscale's goals, a significant amount of advocacy and new evidence is necessary to bring new partners and resources to the table to enable this work to take shape. Accessing high quality data and evidence of the impact of investment in this space will require time and it will be critical to prioritise this to ensure sustainable data-driven policies and interventions are adopted and the right groups are investing now.

Further, as highlighted within this paper, as well as ATscale's Strategy Overview, addressing access to affordable, appropriate, high quality AT is complex. This speaks to the scope of what ATscale takes on; it will remain imperative to address the most critical enablers and remain strategic and focused. ATscale will need to identify ways to scope work so that it can be most successful, leveraging expertise across the Partnership and more broadly within the community. ATscale needs to continue to refine its greatest value add and focus on impact. At the same time, action is critical to ensure that the work moves forward.

Finally, while much of what has been illuminated here addresses the global level, solutions will require tailoring to individual country contexts. Even within countries, fragmented approaches often exist. The needs and solutions must be well understood on a national level to enable governments to make decisions and adopt appropriate changes. Additionally, there are pressing and competing priorities for budgets both nationally and

globally; stakeholders will need to continue to identify opportunities for efficiency and integration, including taking opportunities to encourage countries embrace the importance of increased AT coverage as fundamental to realising commitments to the SDGs, UHC, and the UN CRPD.

Conclusion

The launch of ATscale marks a new, coordinated, global response to the challenge of increasing access to AT and already, the formation of the partnership is showing promise. Current Forming Committee organisations have brought together a large network of stakeholders to consult with and learn from and have provided the prospect for potential collaboration moving forward. The members of the Forming Committee themselves have also brought new, fresh perspectives to AT from other areas, including health. As ATscale expands, it will further evolve with contributions from stakeholders who are aligned with its vision, mission, and goal. It is imperative that ATscale learns from what has come before and that it builds on the successes, while also applying a new and innovative, strategic approach. This collective effort will enable the global community to have an enhanced impact, far beyond what any one group could achieve alone. In this moment, there is a unique opportunity to think big and act together in order to reach 500 million individuals with the life-changing AT they need by 2030.

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Overcoming systematic global barriers to assistive technology: A new methodology and quick-start testing through a £20m programme

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Abstract

Between March and June 2018, the Global Disability Innovation Hub (GDI) led a consortium tasked by the United Kingdom's Department for International Development (DfID) with comprehensively scoping the barriers to Assistive Technology (AT) access in order to inform the design of a significant new global programme. This paper summarises the evidence examined in that Scoping Report; presents the methodology it proposed for AT2030; and shares the early findings for the subsequent £20m funded programme, called 'AT2030 – Access to Assistive Technology for All' (www.AT2030.org). The Scoping Report sought to unpick the multi-layered and multi-faceted ways in which economic, social, and political factors interact to create barriers to AT for those who need it the most. The team used a mixed-methods approach which was necessarily flexible and iterative, bringing in expertise from the broad partnership. The data showed that the challenge of AT access represents a complex web of market and system failures, compounded by a lack of participation from AT users, that results in a supply/demand mismatch affecting almost a billion people. This making AT access one of the most pressing global challenges. Because of poor data on use, need and impact this 'wicked problem' is largely hidden from view to all but those facing the daily struggles its absence creates. Yet at an individual, family and community level there is no doubt at all about the implications of lack of access to appropriate AT; isolation, economic and social exclusion, poor physical and mental health, and reduced life expectancy. Our evidence suggests that barriers to AT access are about far more than just cost. Issues such as undeveloped policy frameworks, inefficient or non-existent markets, poorly resourced services, stigma and discrimination all play a role, often with a gender impact. The Scoping Report proposed that the resulting global programme (AT2030) trial strategic interventions based on the principles of: building a global mission-led approach; generating better research and data; piloting market-shaping activity; delivering systems

strengthening interventions; harnessing innovation; and building community participating and capacity. Findings from the first ten months of delivery have reinforced and confirmed the need for a mission-led approach to AT, embedded within a normative framework of social development. ‘Amazing early results’ have resulted in a slightly tightened impact framework (theory of change) along with doubled investment. The programme is still in its early stages, but the working assumption is still that the participation of AT users is a necessary factor in the design of innovative solutions, and moreover that the availability of AT products alone is not sufficient to ‘enable a lifetime of potential’ without a systematic approach to inclusion.

Keywords

Assistive Technology, Disability Innovation, AT2030

Introduction

This paper presents the findings of the Scoping Report on Assistive Technology (AT) (1) ‘*On the road to Universal AT coverage*’ (hereafter, Scoping Report) produced by the Global Disability Innovation Hub (GDI Hub) and partners for the United Kingdom’s Department for International Development (DfID) in the early Summer of 2018. It also presents the initial findings from the first ten months of delivery of the subsequent programme intervention, AT2030.

Globally, WHO estimate that only ten percent of people have access to the AT they need to play an active role in their families or communities; to earn a living, enjoy their older age, or to attend school. This need is set to double by 2050 (2) and achieving AT access has been shown to be a necessary factor in enabling the Sustainable Development Goals (SDGs) to be met (3). Yet despite significant progress across the global policy arena¹ and increasingly strategic development of implementation tools² most interventions in this space have been piecemeal, pilot, poorly conceptualised, or not properly evaluated. Good work has been done, but the global impact has yet to be felt.

In early 2018 the United Kingdom and Kenyan Governments announced they would host a joint Global Disability Summit (GDS) on the Queen Elizabeth Olympic Park, home to the London 2012 Paralympic Games. AT was identified as key theme providing the opportunity - political backing, global platform, focus, deadline and engaged stakeholders – needed to drive momentum around AT access. Reminiscent of the focus on disability inclusion generated by London 2012, the GDS offered the chance to research, design and launch a strategic, global approach to AT like never before. This paper provides an overview of the resulting Scoping Research (1), and subsequent quick start programme, AT2030, launched at the Global Disability Summit and starting in September, 2018.

¹ The UN convention for the Rights of Person’s with Disability is now 10 years old

² See for instance the Assistive Product Priority List produced by WHO GATE and product-specific implementation tools (e.g. Wheelchair standards)

The paper is organised as follows: section 2 summarises the approach taken to the Scoping Research, its methodology, findings and consequent recommendations. Section 3 uncovers key, early stage findings from AT2030. Though it is less than a year since the programme began, significant steps have been taken to augment the methodology and so section 4 provides a discussion of the slightly evolved framework and draws conclusions.

Approach

Scoping Study: Methodology

Between March and June 2018, the GDI Hub led a consortium tasked with comprehensively scoping the barriers to AT access to inform the design of a significant new global programme to address these barriers. The resulting Scoping Report (1) sought to unpick the multi-layered and multi-faceted ways in which economic, social, and political factors interact to create barriers to AT for those who need it the most. Through primary and secondary research, the Scoping Report explored the current landscape and the limitations and current initiatives ultimately answering the question: *“How best could a targeted intervention around AT affect positive change for poor, disabled and older people in the Global South?”*

To understand this question, the research team looked at two specific lines of enquiry:

1. What are the barriers which prevent access to AT for the people that need it, with a focus on those living in low resource settings? (Barriers)
2. How should DFID, in partnership with others, best direct its intervention toward overcoming these barriers? (Methodology and Framework proposal)

The team used a mixed-methods research approach, which was flexible and iterative, bringing in expertise from GDI, University College London (UCL), Clinton Health Access Initiative (CHAI), Global Cooperation on Assistive technology (GATE) at the World Health Organization, Leonard Cheshire (LC), Motivation, and input from local organisations across East Africa and beyond. The team worked in partnership with DFID’s Global Health and Innovation and Research divisions, occasionally drawing in other partners, such as USAID, through a series of co-creation workshops as the thinking progressed.

GDI conducted a literature review and held 23 semi-structured interviews focussing on five themes: priorities; examples of best practice; activities that could scale; ideas on geography; and red flags. This was backed up through 18 group discussions, and 10 workshops of external events organised with partners (including co-creation workshops). This data was further enhanced by a secondary policy study of AT in in East Africa; and primary survey research with 22 key stakeholders conducted by Motivation in Kenya. Finally, the emerging conclusions were triangulated with the findings from the work conducted by the Boston Consulting Group for USAID (2) with a focus on Wheelchairs and Hearing Aids and enhanced by additional rapid ‘deep dives’ on prosthetics and glasses led by CHAI with GDI [unpublished, content to be used in Product Narratives, forthcoming].

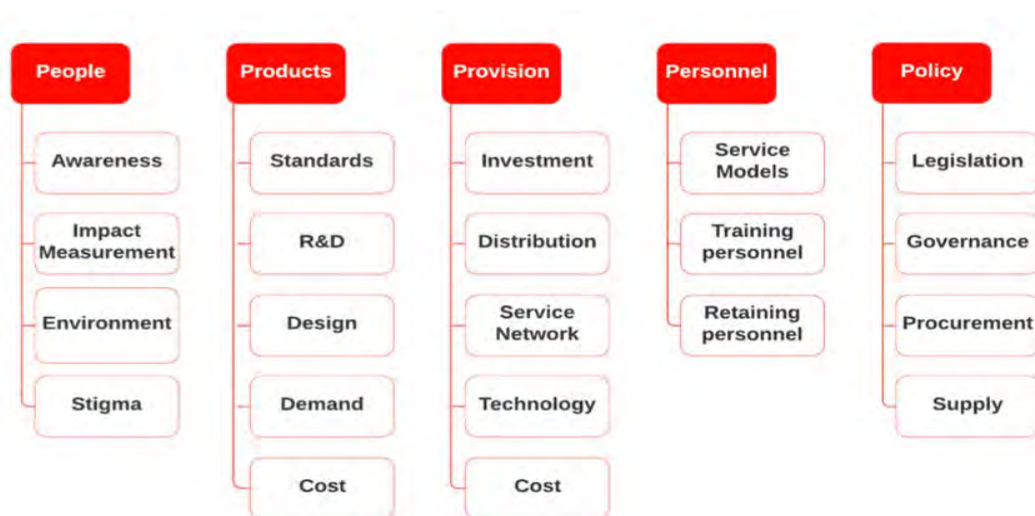
The teams took a participatory and consultative approach designed to enable interactions between stakeholders of different types (sectors, geographies and disciplines) and since GDI was established ‘to build a movement for disability innovation for a fairer world’ (17) we also set clear objectives on inclusion of AT users within the team.

Scoping Study: Findings - Barriers

The Scoping Study found that the challenge of access to, and use of, AT “presents a complex web of market and system failures, compounded by a lack of participation from AT users from design to selection. This results in a supply/demand mismatch affecting almost a billion people, making AT access one of the most pressing problems facing the global health sector, development agencies, governments, communities and families” (1). But, because of poor data on use, need, and impact, this ‘wicked problem’ is largely hidden from view to all but those facing the daily struggles its absence creates. Yet at an individual, family and community level there is no doubt at all about the implications of lack of access to appropriate AT - isolation, economic and social exclusion, poor physical and mental health, and reduced life expectancy.

The principle barriers to AT could naturally be classified under the 5Ps set out by GATE³. These are shown in figure 1.

Figure 1. Barriers to AT as set out in the Scoping Report



The data suggests that lack of resources to purchase AT (at a Government and Individual level) is of course a reality, but barriers to AT are about more than just cost. Issues such as undeveloped policy frameworks, inefficient or non-existent markets, poorly resourced

³ To note – this happened naturally, emerging as themes from the analysis rather than being used as organisational principles, from the start – further evidence for the relevance of the 5Ps

services, stigma and discrimination all play a role often with a gender impact. While levels of AT market development vary across countries, key barriers are often similar.

Scoping Study: The need for a mission-led approach

In designing AT2030, GDI Hub built upon its own foundations – the learning from the 2012 London Games. In the 2012 context the impact and force of a mission ‘to deliver the most accessible Games ever’ (incidentally; the most accessible Olympics as well as the most successful Paralympics), was well rehearsed. From the tone set by Channel 4’s ‘superhumans’ campaign to the beautiful force of Bradley Hemmings and Jenny Sealey’s Opening Ceremony (co-created and performed by disabled artists); London’s 2012 Paralympic Games offered a celebratory revolution in attitudes to disability (see: Iain Dury’s ‘Spasticus Autisticus’ (4)) and used art and performance as an unapologetic, bold and positive presentation of disability and culture. This was empowering, and demonstrably so, not an add on or a tokenistic ‘inclusive’ segment among business-as-usual. It was a fundamental shift in approach. The mission was not to hold a significant sports event, but to ‘inspire a generation’; and largely it did.

Inspired by this, and reflecting on the evidence, the Scoping Report proposed that our mission for AT should be beyond reducing the cost of wheelchairs (as essential as that is) but rather should be to, for instance, enable wheelchair-users to lead their countries, write in their media, teach in the schools their children attend, be innovators and entrepreneurs and leaders in their communities. Our global mission on AT should be to enable a lifetime of potential (we thank David Constantine for coining the phrase) by improving access for all that need it.

Building on the Paralympic Legacy and emerging thinking about ‘mission-led’ approaches to global grand challenges (5) by the UCL Institute of Innovation and Public Purpose (IIPP), the Scoping Report advocated for a global approach to delivering genuinely revolutionary change which was embedded in, and also reached beyond, traditional healthcare systems and approaches, or NGO delivery. This type of mission-led approach would recognise the importance of market-shaping and co-creation, and provide new ways to evaluate dynamic impact and spill-overs of innovations and investments (5). Such evaluative schemes require thinking beyond classic returns on investment (ROI) models, and hence bringing in partners to develop that approach became a key element of the findings (6).

Scoping Study: Methodology (AT2030 initial Programme Framework)

The AT Scoping Report argued unambiguously that an effective approach to AT provision would require an explicit normative framework for intervention. We suggested that DfID’s broad social development lens (as applied to disability inclusion (7)), could provide an impetus for focus on outcomes for AT users, rather than solely addressing the cost of AT products. As later sections of this paper explain, this still requires evolutionary conceptual development as such an approach can be both subjective and political. For this reason, the

Scoping Report advocated for strong, open and diverse leadership of the AT mission, including robust representation of the interests of AT users themselves, ‘unusual suspects’, and Global South nations. Similarly, priorities for intervention – the Report suggested - should be able to be shown to lead to better outcomes for AT users. The Scoping Report concluded by proposing a set of principles (Table 1) on which the resulting programme investment should be established. This investment framework is detailed in Figure 2.

Table 1. AT2030 Principles

A global, mission-led approach with measurable outcomes and clarity of how to ensure a return on investment.
Research and better data are essential to enable countries to understand the return on investment for AT and genuine economic choices before them.
Testing and piloting market shaping accepting there is a way to go before this approach can be scaled. A strong research base will need to be developed, trialled and refined with leaders in the field of market shaping.
Determined work on systemic interventions with national governments. The role of the global community to reduce the cost of AT must be defined in conjunction with national governments, with clear routes for the provision of AT within healthcare, education and other nationally developed systems.
Harnessing innovation and new market entrants – with a focus on leapfrog technology, looking beyond the traditional understanding of products or services and bringing in new players.
Community participation and capacity building – the exclusion of AT users from programme design policy and decision-making leads to poorer outcomes, continued power imbalances and political exclusion – these things are all part of the problem and solutions must be designed to counter this

The AT2030 programme was intentionally designed to be delivered through a partnership of expected (e.g. WHO) and unexpected (e.g. Kota Kita (‘a city for all’, Indonesia) organisations. The programme was not proposed to be geographically specific, though had a focus on DFID priority countries. The intention was explicitly to find ‘the magic in the middle’.

Figure 2. AT2030 investment proposal framework



Implementing the findings of the Scoping Report: AT2030 programme delivery after the first ten months of implementation (September 2018 – July 2019)

The sections below set out what has been done during the first ten months of operation of AT2030; key achievements; what we have learned; and future plans. The programme so far has found confirmation of the broad principles of the initial implementation framework, though has also seen extension of the work into new areas and a redoubled effort on country implementation and innovation. It is a reflection on the hard work of the teams that (then) Minister of State Lord Bates heralded ‘amazing early results’ (8) from AT2030 in March 2019 and announced £9.8m additional resource to triple the impact by 2024.

Research, Evidence and Impact (led by GDI/UCL with ALL Institute and Leonard Cheshire)

GDI with colleagues in UCL’s Institute of Innovation in Public Purpose are leading the work to answer the two main research questions:

1. How can the return on investment for AT be reimaged?
2. What role can a mission-led approaches make in ensuring AT provision globally?

These research questions are intrinsically linked. Findings so far suggest that the mission-oriented approach to AT will reimagine the ROI framework by demonstrating the overall public value that is created by AT, with a view to motivating new investment. In common with many ‘mission-led’ approaches the ROI for AT research is exploring a wider definition of benefit; and is currently scoping case studies. Literature is being searched sourcing from industrial policy, science and technology studies, political economy, methods papers on policy evaluation, narratives from assistive technology users, and case study analyses to understand the impact and potential of the dynamic spill-overs that can be generated by a mission for AT. An initial Working Paper on this topic has been produced by the IIPP and

UCL (6). This sub-programme aids the WHO's World Report on AT through contribution to the Executive Ad Hoc Advisory Board (through Academic Director Dr. Catherine Holloway).

The specific problem of stigma and discrimination faced by AT users has been established as a stand-alone piece of work which focuses on the design and assessment of initiatives to shift people's attitudes towards AT users and thereby increase the demand for AT co-creating a more positive experience for AT users when undertaking their daily activities. This research is led by Leonard Cheshire, working closely with initiatives across AT2030 including the innovation ecosystem in Kenya.

Spark Innovation (led by UCL/GDI with AMREF, OxCATS and the University of Nairobi)

Early Product Trials & initial scoping

AT2030 has now undertaken the first in-person trials of a new lower-limb prosthetic socket (developed by start-up Amparo); and begun planning for a new wheelchair provision model study (led by Motivation) in Kenya; making use of local and digital manufacturing processes. Both innovations included proven product which met user need, however, both needed support with trials to enable the products to be ready for market. Trial designs have been led by the innovators and supported by GDI Hub and Oxford Brookes University new trials unit, OxCATS. The AMPARO trial is underway and will result in 40 amputees receiving lower-limb prostheses. The Motivation study will start this September and conclude this year. These Early Product Trials have helped the AT2030 team to understand what is needed to build the Innovation Ecosystem.

Early Product Trails, combined with additional research with AT innovators have shown that the 'Valley of Death' for AT is much deeper and longer than for non-AT product innovations, partly because of the need for medical trails. This has resulted in a reshaping of the Innovation Hub approach proposed in the Scoping Report, to an Innovation Ecosystem model.

Development of the Innovation Ecosystem 'Innovate Now'

The idea of a single Innovation Hub has evolved into an inclusive innovation ecosystem model which connects into the already thriving innovation ecosystem in Kenya, delivered by AMREF, focuses on three aspects for investment:

1. **Accelerator Programme for AT entrepreneurs:** 4/5 rounds will each support 10-20 innovators providing business and marketing development; supporting the design of experiments; legal and IP support; as well as the provision of domain specific expertise and study design.
2. **Live Labs:** connected to the Accelerator will be spaces where AT users can test and give rapid feedback to innovators on new AT ideas.
3. **Capacity Building of the Innovation Ecosystem in East Africa:** achieved through the creation of an inclusive innovation mission across the ecosystem

'Innovate Now' was launched in June at Nairobi Tech Week and was showcased in July at the Mobile 360 global conference in Kigali. Applications to its first accelerator programme are now open.

Exploring the power of Mobile as AT

GSMA (the Mobile Phone Operators partnership) have led research into mobile access for disabled people supported by GDI Hub and UCL; interviews, diary studies and focus groups are being undertaken in Kenya and Bangladesh to understand the size and effect of the mobile gap on AT users. Initial results are presented in 'Mobile Phones as Assistive Technologies: Gaps and Opportunities' (presented to the GREAT consultation) (9), and will be published in a Disability Gap report for mobile phone operators later this year. It is also intended that a joint approach to innovation between GDI and GSMA will be developed following publication of the findings.

This work has been supplemented by two separate research studies by UCL teams on mobile phone use by people with a visual impairment, and wheelchair users, in the settlement of Kibera, Nairobi, Kenya. Findings are pending but early indications highlight the need for skills training and the importance of social networks when using mobile for AT.

Scale Fund

As part of AT2030 GDI Hub CIC will host an AT Innovation Scale Fund to provide catalytic investment to businesses which have demonstrated a market fit, received initial investment, and have some revenue stream but require further investment to scale. This is forthcoming in 2020 but is being adapted, based on the early findings from this programme.

Drive Availability and Affordability (led by CHAI)

Development of the Product Narratives

To accelerate access to AT, we need to leverage the capabilities and resources of each of the public, private, and non-profit sectors. This element of AT2030 focusses on market shaping, building on what CHAI have learned from market-shaping in other health care commodities such as drugs and vaccines. Market shaping can play a role in enhancing market efficiencies; coordinating and incentivising the number of stakeholders involved in demand and supply-side activities. CHAI has conducted a market and sector analysis on specific priority assistive products (initially wheelchairs, prosthetics and hearing aids, to be followed by glasses and personal digital devices) and are developing strategies to improve the efficiency of how the markets operate in these sectors. The resulting strategy – or Product Narratives (see Wheelchair Product Narrative, launched at GREAT 2019) – is a road map for investment and planned future interventions. The proposed strategies will differ by product area, but often opportunities exist to:

- Strengthen the integration of AT provision into health systems;
- Strengthen procurement processes to rationalize assortment and enhance quality;

- Work with buyers and suppliers to achieve efficiencies in the supply chain that could significantly reduce manufacturing and handling costs; and
- Accelerate the adoption of new technologies that can make the provision of assistive products in low- and middle-income countries more cost-effective.

The Product Narratives being developed through AT2030 will become an essential guide for further activities of the programme, in order to test new approaches to market shaping. They will ultimately be used to shape the investment by ATscale, the Global Partnership for AT, in order to drive sustainable large-scale changes in these markets.

Country Implementation Scoping

The sub-programme is also conducting scoping work in Kenya, South Africa and Indonesia through the CHAI country offices, with partners. In Kenya this has focused on the development of a strategy for improving wheelchairs access; in Indonesia this work is focused on how AT provision can be developed as a strategic priority for the Government as part of the Medium-term Plan; and in South Africa this work is focussed on how innovative approaches to screening and funded-demand for AT products, could offer new solutions.

This early mapping, and the Product Narrative Research, has backed up the initial assumption that funded demand for AT is low across many low- and middle-income countries, and it will be critical to understand opportunities at the country level to partner with governments. As a first step to understand and map a country's 'maturity' toward, and capacity for, providing AT services and inform the development of a road map for AT provision.

For this reason, CHAI is supporting WHO, UCL and partners to enhance and validate a set of the Assistive Technology Capacity Assessment tools – intended as a system level assessment that collects information on the current state of access to AT in a country. Over the next 6 months, the programme will aim to test and validate this tool in more than 10 countries across different regions.

Open Up Market Access (led by WHO GATE with LSHTM and UNICEF)

Priority Assistive Product Specifications & Procurement Guide

WHO GATE led and coordinated the initial draft development of 30 priority assistive product specifications to support countries in procuring high-quality and affordable products. Fifty AT experts from the globe contributed to the initial drafting. The Swedish Standard Institute (SIS) and the China Assistive Devices and Technology Centre for Persons with Disability (CADTC) supported GATE in coordinating the review process, during which the team learnt the importance of having a balance between the comprehensiveness and the practical usability of the specification especially in low resource settings.

Meanwhile, GATE has developed a draft procurement guide to support countries building their capacity, especially in public procurement of AT through competitive process (tender). The draft has been reviewed by colleagues of WHO, UNICEF, CHAI, and ICRC. The draft has

been revised with extended practical examples to demonstrate how to apply the core principles in AT procurement. In late 2019, AT2030 procurement workshops will be jointly organized by UNICEF, WHO and CHAI in Tajikistan and South Africa. During the workshops, we will gather participants from the regions to raise the awareness of the challenges and importance of AT procurement. We expect to learn how to further improve the assistive product specification and procurement guide at the workshop, so that they can be effective tools to support AT procurement in countries. If this is successful, UNICEF – who are working closely with WHO and CHAI as part of the team - will select a few top priority products to add to their supplier catalogue. UNICEF are also trialing innovation in AT for the humanitarian space.

Development of the online AT Training Package for community workforce

The need to move appropriate tasks, such screening or the provision of basic AT, from the realm of a very few University-educated professionals, to well-trained community health workers (or ‘task-shifting’ as it is known) is one of the opportunities the AT2030 programme is exploring. AT2030 investment has enabled the WHO GATE team to expedite and expand development of an online training package, targeted at community-level workforce to equip them to provide basic assistive products (aligned with the 30 product specifications mentioned above). Vision-related modules were piloted in Papua New Guinea in June 2019 and further module development and piloting are planned in the United Republic of Tanzania and Tajikistan within the next 6 months.

Key learning so far is that mainstream health workforce, such as nurses and community health workers, see provision of assistive products as relevant and useful to their role and work; and that an enabling environment (including training) is critical for successful implementation.

‘1-stop’ Service Provision Pilot: Tajikistan

The WHO GATE team is leading (with input from other programme partners) a pilot of a ‘1-stop’ model of service provision in one district in Tajikistan, with the Ministry of Health and Social Protection. Lessons learned will be used to inform future development of similar models in future countries, as well as expand provision to the whole of Tajikistan. Policy reforms have already been implemented, to expand coverage beyond disabled people to other AT users. Procurement of the assistive products is in progress, with workforce training is planned for January 2020. A second pilot country, in WHO African region, will be identified through country capacity assessments.

Development of a Mobile Tool for Population AT Need

The London School of Hygiene and Tropical Medicine (LSHTM) is developing a mobile tool to determine the overall population need for AT by consolidating learning from existing mobile tools that measure the presence of visual impairment (Peek) and hearing impairments (HearScreen). Through survey assessment, the team are also developing ‘decision trees’ to support professionals. Vision and hearing impairment flow charts have been completed;

training has also been delivered and data collection has commenced for example through an eye-health survey in the Republic of the Gambia which includes both self-report and clinical assessment of vision and hearing impairments. LSHTM will conduct a Philippines hearing survey with a pilot of functional hearing loss questionnaire during August. With UCL, LSHTM will develop a portal to collate and disseminate learning from this work and other academic work on AT so that is more readily accessible to practitioners and researchers alike.

Build Capacity and Participation (led by UCL Development Planning Unit with Kota Kita, SLURC and GDI)

The UCL Development Planning Unit (DPU) is looking at community-led solutions and access to AT for people living in Informal Settlements. The team is working with local partners: SLURC in Freetown, Sierra Leone and Kota Kita in Banjarmasin, South Kalimantan, Indonesia to undertake a participatory research programme to understand the aspirations of disabled people living in the settlements selected and their access to AT. It is anticipated that in the later phases, solutions to the priorities of disabled people will be co-designed by the programme experts (drawing in other partners from across AT2030) and the community. The teams undertook initial scoping in Freetown and Banjarmasin during March and April 2019 to identify the case studies and establish the partnerships. Since then, the Sierra Leone Urban Research Centre and Kota Kita have been working in the informal settlements; mapping the neighbourhood, identifying Disabled Peoples Organisations (DPOs), and reaching out to key stakeholders. Initial participatory research session began in July. DPU will present the methodology to the Human Capabilities and Development Association conference in autumn.

In September, the teams will be conducting the household survey 'Rapid Assistive Technology Assessment' (RATA) with 4,000 people. Developed by WHO GATE, RATA is intended to identify the need, use, supply and impact of AT. The teams have been able to feed directly into the testing and refinement of this tool.

Informality and AT

In the Scoping Report it was felt that having a significant aspect of the AT2030 programme focused on the poorest communities was fundamentally important for two key reasons. First, only focusing on 'what works' to understand AT access deficiencies within formal systems and markets would likely miss the realities of everyday lived experience of many/most poor disabled people leading to less well designed or even unworkable solutions. Data is exceptionally poor but we know disability and poverty are mutually reinforcing and both consequence and cause of each other (10) and hence unmet need for AT by the poorest communities is probably higher.

Second - and less well-envisaged at Scoping Report stage – was the role of informal markets in the provision of AT products and maintenance. On study suggests that as many as 46% of assistive products are 'home-made, self-made or made by family members' (11) and up to 37% of people said that they or their family maintained the devices (12) which indicates a

substantial impact of this sector which cannot be ignored. It is this second aspect which we intend to explore more through two supplementary studies led by DPU, focused on the role of informal markets. This research will be conducted alongside the Country Capacity Assessment but with a more appropriate methodology for this kind of data collection and will inform the final CCA tools that are validated and shared publically.

Grow a Global Partnership (led by GDI for the AT2030 programme with ATscale, the Global Partnership on AT)

Support for ATscale set up

AT 2030 has been able to support the set-up of ATscale, the Global Partnership for AT (13) in a number of different ways, including by supporting the work partners feeding into ATscale (UNICEF, WHO, CHAI, and GDI) and the ATscale secretariat staff, from Autumn 2019. AT2030 has also been able to provide resources toward emerging partnerships aligned with the development of ATscale's strategy and priorities including team members to develop partnership approaches with the Chinese Disabled People's Federation (CDPF) and resources to enable the Government of Kenya to participate in key face to face meetings of the group.

What has been particularly successful so far is the funding of CHAI through AT2030 to develop Product Narratives (see also, above) which will inform the near-term priorities for ATscale's action and investment plan for market building and market shaping.

The initial Scoping Research, as well as activities in the first 10 months of the AT2030 programme delivery have contributed in a meaningful way to the ATscale strategy development (14). Having this 'quick-start' programme in place has significantly aided and resourced the set-up of ATscale; facilitated it becoming operational; guided strategic planning; and continues to provide test cases for strategic and global activity.

Supporting other partnership approaches

Also emerging are flourishing partnerships with Indian network (through UCL); Asian Development Bank; East Africa Innovators and Tokyo 2020, which will be developed further into year two of AT2030.

Discussion

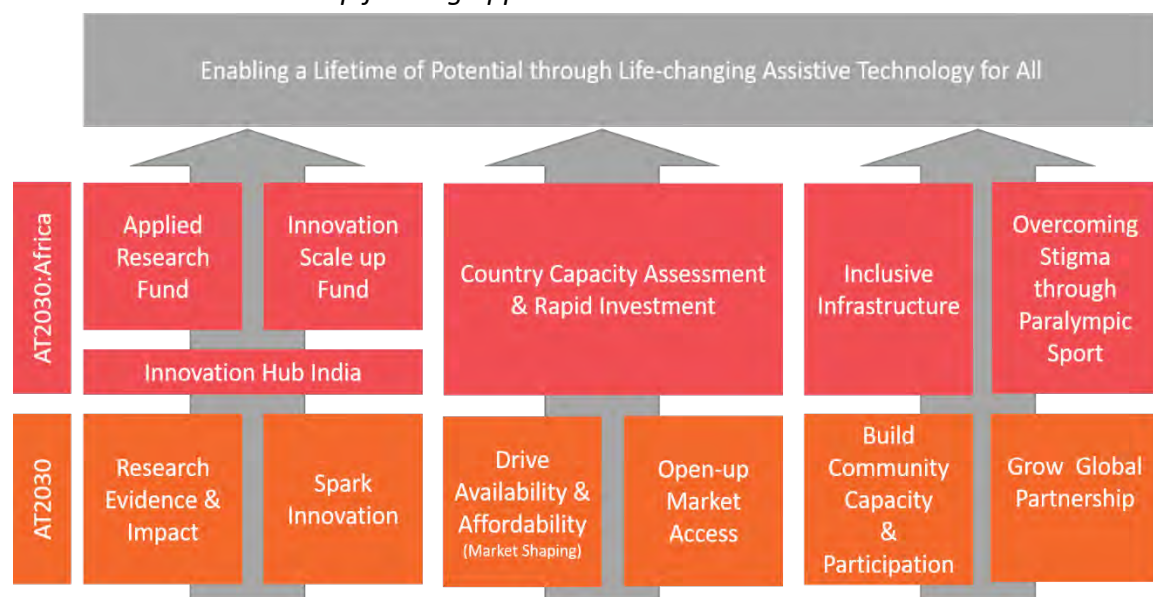
Refining the methodology and programme extension

As a result of learning from the first ten months of programme delivery, a second Business Case for AT2030 (called AT2030 Africa, as it has a stronger geographical focus here) was approved by DFID (in late July 2018). The additional resource will extend into the following areas of enhanced investment:

- Applied Research Fund (GDI, WHO, UCL and Royal Academy of Engineering): support for the World Report on AT and a research call to address evidence gaps.

- A larger Innovation Scale Fund (GDI, UCL and delivery partners): to back AT innovations to scale
- Exploration of an Innovation Hub in India
- Country Capacity Assessments Pilots in 10 countries and a new rapid implementation fund (WHO, CHAI, UCL and GD with National Delivery Partners) to allow two countries to trial the National AT provision model
- Inclusive Infrastructure in six case study cities (GDI and RCA) – a frequent result from AT2030 research is the need for improved accessibility of the built environment, building on the 2012 accessibility approach (15)
- Overcoming Stigma through Paralympic Sport (Loughborough University, with GDI and the IPC) harnessing effect of the Paralympics 2020 to shift in attitudes

Figure 3. AT2030 and Scale-up funding approach



A tighter focus on impact

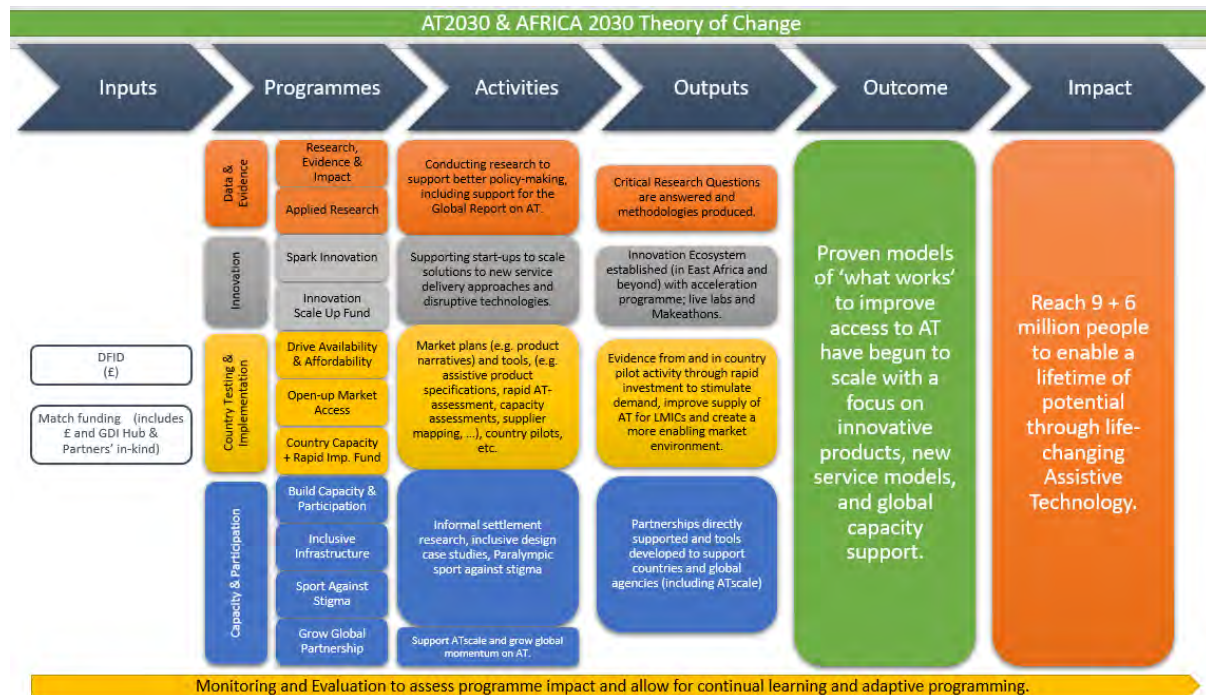
Building on rapid learning from AT2030, the additional £9.8m will reach 9m people directly and 6m indirectly through the core programme, which will now deliver:

- 40 new disruptive technologies with potential for life-changing impact and 25% on track to scale;
- 10 innovative service delivery models, frameworks and methodologies created;
- 80 new start-ups supported;
- 20 entities (countries or organisation) implementing AT2030 ideas
- 20 research questions answered;
- 10 Country Capacity Assessments undertaken; 5 country action plans and 2 rapid investment pilots
- 10 consortia or partnerships supported to strengthen systems

- 6 cities/countries supported on inclusive design so that AT can be used in the built environment;
- A programme to tackle stigma and discrimination across Africa (6)

The Theory of Change (ToC) has been re-worked, refined and simplified though the underlying logic remain unchanged:

Figure 4. AT2030 Theory of Change



Participation as method as well as outcome

In 'Development as Freedom' Amartya Sen states that "the enhancement of human freedom is both the main object and the primary means of development" (16), understanding the expansion of freedom as the removal of the primary sources of 'unfreedom' (poverty, poor economic opportunities, social deprivation, inequality, repression, and lack of public facilities) (ibid, p3). Assistive Technology is essential for those of us that need it in order to experience this freedom and to live lives of value - to ourselves, to our families, to our communities, and to our nations. If we understand human freedom as our normative approach, initiatives which are primarily concerned with enabling people to do, or be, whatever they wish to - by expanding their capacity with AT - necessarily require their participation in the process as a *means* as well as *end*.

The AT2030 programme is still in its early stages, but our working assumption is that the participation of AT users, and other non-traditional partners, is essential for the design of the disruptive solutions which will bring AT to more of the 900 million people that currently lack it. A mission of this size and scale can only be successful if it affords opportunity for all to turn their talents toward a common solution. AT2030 is just one of many programmes that will be needed to catalyse change, but we are determined to play our part.

One thing is certain; however necessary it is to increase the availability of AT products (and it is) the evidence so far suggests that alone this will not be sufficient to ‘enable a lifetime of potential’ for AT users. For that, we must ground our global mission within a systematic approach to inclusion which has the capacity to flourish over time.

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Assistive technology innovation ecosystem design: A Kenyan case study

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Abstract

Innovations within the AT space frequently fail to get to market and therefore to the people who could benefit from the products. The Scoping Report which underpins the AT2030 programme identified the need to test and develop “what works” for AT innovation to ensure new products, services and approaches are able to scale and reach people, especially people living in low- and middle-income countries. This paper sets out the initial thinking for an East Africa Innovation Ecosystem. We present the emerging thinking from initial scoping exercises and product trials which have helped to shape the newly launched Innovate Now ecosystem. We outline the ecosystem including the core elements – the accelerator programmes and Live Labs. Live labs will allow for rapid innovation testing and user feedback. Thus, increasing user-involvement in the design and development process, and reducing the time to market. The Innovate Now ecosystem is growing and is being led by AMREF. Successful graduates of innovate Now will be connected into the Innovation Scale Fund which will be launched by AT2030 next year (2020).

Keywords

Inclusion, Innovation, Assistive Technology

Introduction

As part of the AT2030 programme, an inclusive innovation ecosystem in Nairobi, called Innovate Now, is being developed with a focus on Assistive Technology (AT) and disability inclusion. The aim of AT2030, which is funded by UK AID (United Kingdom’s Department for International Development) is to test “what works in AT” to create a lifetime of potential. The Innovate Now ecosystem is being led by AMREF Enterprises and has been co-developed with a wide range of actors in east Africa and beyond. Those consulted include policy makers, entrepreneurs, academics, manufacturers and investors. The investigations have been led by University College London (UCL), the Global Disability Innovation (GDI) Hub and

the University of Nairobi with support from non-governmental organizations (NGOs), industry collaborators (e.g. Group Special Mobile Association, GSMA), Tech Hubs, Investors and the Kenyan Government.

This paper briefly reviews the context for establishing the Innovate Now ecosystem, explaining the approach taken, and describes the elements which make up Innovate Now along with the future plans for AT innovation within the broader context of AT2030. In the remainder of this introduction the background to Innovate Now is explored. In section 2 we present the approach taken to designing and developing Innovate Now, including the use of interviews and initial trial designs and in section 3 the findings are given. Section 4 discusses next steps for disability interaction through novel innovations.

The changing nature of AT

Innovators are increasingly being encouraged to take challenge-led approaches to the design of new technologies. Tackling inclusion for people with disabilities is one such challenge (1). This is helping to change the nature of assistive products (APs). This change is also being driven by advances in digital technologies which are enabling new methods of screening, manufacture and distribution of devices; as well as new devices themselves. Furthermore, there is a trend for increased inclusivity in mainstream products through the application of universal design principles (1). Examples of recent innovations in this space include Office 365's new range of accessibility features which allow for automatic captioning of presentations as well as compatibility with eye-tracking devices. Finally, change is being driven by new forms of interaction which are now possible (e.g. gesture control).

Within the more traditional spaces of AT e.g. wheelchairs and prosthetics, digital manufacturing practices are enabling new approaches to the design, development and distribution of products. For example, Motivation (2) has leveraged 3D printing to design new wheelchair seating and AMPARO (3), NONSPEC (4) and DREV (5) are driving innovations in prosthetics. However, despite this progress, 90% of people do not have access to essential priority assistive products (6). Within the AT2030 programme we are looking to understand the reasons for innovation bottlenecks and develop tools and approaches to overcome these.

AT is also being influenced by the ubiquitous nature of mobile. Within the last decade, mobile phones have become one of the most ubiquitous piece of technology in the world (7). Driven by a low entry price, flexibility of application and reduced need for physical infrastructure to support network operations, several low- and middle-income countries (LMICs) have leapfrogged directly to mobile phones. This is in contrast to the relatively low rates of adoption of earlier technologies such as broadband Internet and the Personal Computer. This has created a unique situation which Governments, NGOs and the private sector have sought to leverage. They have worked to use the power of mobile technology to roll out innovative products and services that can a widespread audience in a very short time span. The most notable case is the diffusion of mobile banking services in Sub-Saharan

Africa which enabled an unprecedented number of people to access better financial services which have subsequently led to significant reductions in poverty levels of individuals (8).

National and international organizations in the private and public sector have been quick to grasp the potential for mobile to spearhead innovation. Several initiatives for mobile developments have been established around the world. The most notable is the “Mobile for Development” initiative led by the GSMA that aims to promote sustainable businesses working in the mobile space that have the potential to deliver significant socio-economic impact towards all 17 Sustainable Development Goals (SDGs). In the 10 years of operation “Mobile for Development” has supported social enterprises operating in mHealth, agriculture, digital identities and women's rights. Over the past year, and in collaboration with GDI Hub through AT2030, increasing attention has been placed in understanding the potential role of mobile phones as ATs and how mobile technology could deliver a significant impact on the lives of people with disabilities across the world. Example innovations include new screening approaches - Hear X(9) and Peek (10) which use mobile as a screening tool for hearing and sight loss respectively. Despite these and other advances, many innovations remain focused on high income countries and only available to smartphone users which are not predominantly used by people with disabilities especially in low income settings (11).

One area which will drive the future of innovation is where the innovation takes place – we therefore next review the emerging innovation hotbed that is Silicon Savannah to assess its ability to deliver an AT Innovation ecosystem.

Leveraging Silicon Savannah for AT Innovation

Tech Hubs are expanding rapidly in Africa. Research for the 2016 World Development Report tracked 117 individual Tech Hubs across Africa (12). The Nairobi innovation ecosystem started in approximately 2010 with the establishment of iHub and has thrived in part due to the decentralised nature of the Hubs, which follow a “Community-centred approach” (12). This community-centred approach is driven by demand and market need and has flourished with limited involvement from Government. Similarly, most of the Kenyan-based Tech Hubs sit outside of academic institutions. Despite this, recent analysis from the World Bank shows that a “balanced partnership” with Government and academic institutions “boosts sustainability for both hub and incubator models”. The same report singles out the opportunity for tech hubs to partner with academic institutions to ensure a deeper connection to the innovation community and ensure connectivity to operating models which are better able to harness the burgeoning innovation within the ecosystem (12). This therefore shows an opportunity for Innovate Now to create a balanced partnership of Government and academic institutions as well as Disabled People’s Organisations (DPOs), NGOs and the private sector actors within the AT space. We propose to do this through the creation of an innovation ecosystem.

What is an innovation ecosystem?

An innovation ecosystem (IE) comprises two distinct and traditionally separate economies – the research economy and the commercial economy (13). Innovation ecosystems are diverse in type and can mean different things to different people. A challenge of innovation ecosystems is that they can frequently fail to define upfront their success criteria, which makes it difficult to compare them to one another or to understand when they have been or haven't been successful (13).

To overcome these potential challenges, Innovate Now aims to use initial research to set a definition of Inclusive Innovation and develop metrics which we will be measured against to derive how successful we have been, and where we need to improve. In taking this approach we hope to build on the following advantages of IE thinking identified by (13):

- Allow for a geographical shift in innovation activity - in our case to East Africa;
- Motivate successful projects;
- Develop helpful systems thinking in our case across the AT space;
- Contribute to high-tech economic regional development in Nairobi and East Africa;
- Contribute to the global thinking on technopolis and innovation.

This broader community of innovation (which has become Innovate Now) has and will embrace knowledge/research ecosystems which exist within the Universities and public research institutes within Nairobi. Furthermore, it looks to develop close ties with Charities, DPOs and NGOs who are frequently best connected to AT users and know best the benefits and limitations of the systems and environments in which APs are used.

The need for an inclusive innovation ecosystem?

Diversity and inclusion (D&I) are known levers for driving innovative products, services and business solutions (14). However, evidence of successful inclusive innovation is patchy (14). In the initial scoping work undertaken for the AT2030 programme a recurring theme was the need for user-involvement across the design, development and deployment of AT. The lack of user-involvement in the design of APs has been shown to increase abandonment rates (15). Abandonment rates in high-income settings such as those across Europe are high – the generally accepted rate of abandonment is 30% (16). This figure could well be higher in lower-income settings where drivers, such as poor infrastructure, hinder the usefulness of products and poverty can drive short-term gain in the form of sale of the AP for cash. Sale of the AP can also be driven by a lack of usability of the product due to limited training and a hostile environment making it unusable.

User-centred design can take on different levels of involvement from informants to full co-design. Full co-design is known to be much more successful however it takes time and there is a learning curve between designers (who need to better understand the users) and users (who need to better understand the jargon used by designers) (17). Methods can be developed to help bridge this gap such as those proposed by (17) who shared information

with both sides ahead of a co-design session leading to increased efficiency in the co-design process. It should be noted that co-design must take account of the full ecosystem of service delivery and should therefore also engage healthcare professionals (who will provide AP selection support, training and rehabilitation care). Ensuring close cooperation in the early stages of design between healthcare professionals and designers is known to make the products much more usable (18).

This upskilling of people – both designers and users – must be incorporated within the ecosystem, and it must go further, empowering users to become designers and well-informed co-designers by providing open access to digital skills development and business curriculum. Digital skills development must provide access to new manufacturing and prototyping methods such as 3D printing but also skills to take advantage of mobile. This is one element of Innovate Now which will help ensure innovations better reach the marketplace – by providing the testing resourced through co-design to give space for design iteration and also for failing. Failing fast and going ‘back to the drawing board’ must be encouraged if we are to see the best ideas reach people who need them.

Designing to overcome the Valley of Death

Once a design has been proven – there is a proof-of-concept – the next huge hurdle for innovators is to show a market fit for their innovation. This hurdle is a part of the Valley of Death (VoD). The VoD for AT is known to be longer and deeper for AT (19). This is in part because it has often been seen as a “niche” market and niche markets are known to require outside entities to provide the necessary resources to enable the transfer of technology from producer to consumer (20). It is further compounded by the fact AT is often delivered through a Service Delivery Method (SDM). This problem is discussed by (21) who highlight that end users are not the ones who decides whether their needs have been met, and products are chosen from a prescribed list. This results in the SDMs themselves becoming a barrier to innovation (21). Furthermore, ‘chicken-and-egg’ challenge can result in AT marketplace – industry, especially SMEs are “reluctant to invest in products without an expressed demand from service providers, whereas service providers cannot get engaged unless there are products to work with” (21). We intend for Innovate Now to address the full ecosystem in which AT is provided, included the service delivery methods.

Approach

Scoping the ecosystem: Innovate Now

Innovations within the AT space frequently fail to get to market and therefore to the people who could benefit from the products. The Scoping Report (22) which underpins the AT2030 programme identified the need to test and develop “what works” for AT innovation to ensure new products, services and approaches are able to scale and reach people, especially people living in low- and middle-income countries.

The initial business case for AT2030 made provision for an Inclusive Innovation Hub development within Nairobi. However, following a 3-week scoping trip in Nov 2018 the idea of a Hub was transformed into one for an ecosystem. The reasons for this were:

1. There are already a number of hubs within Nairobi all of which have the potential to support AT innovators. However, only one AT innovation was identified that had been supported by the Tech Hubs within Nairobi despite great enthusiasm to better support such innovations.
2. Hubs noted turning away innovators with ideas who were disabled due to a lack of facilities to support the innovator including one case of a lack of sign language interpreters. This supports the need for a wider inclusion agenda across the Tech Hubs in Nairobi and beyond.
3. There is both a top-down (i.e. has the support of the Kenyan Government) and bottom-up desire to support AT innovation. This is demonstrated thorough the recent formation of the Association of Start-up and Small and Medium Enterprises (SMEs) Enablers of Kenya (ASSEK, www.assek.ke)
4. AT innovation and inclusive innovation more broadly are seen as exciting areas to explore and ripe for investment within the African context, and the Government of Kenya were supportive of the ecosystem approach.

Key criteria for leading the Innovate Now ecosystem were developed. These are:

- Experience of delivering accelerator programmes;
- An East Africa network;
- Experience within the AT (or health) sector;
- Access to AT users;
- Desire to become part of a global programme.

Possible lead partners were approached and the idea for Innovate Now discussed. Following this initial round of discussions AMREF Enterprises were selected as lead partner for Innovate Now and a Director was identified. AMREF are now building the wider ecosystem partnership with the support of the University of Nairobi, Government of Kenya, GSMA and GDI Hub.

In parallel with the scoping trip a number of interviews were conducted with innovators, investors and AT experts. These interviews helped to develop our investment thesis for the Assistive Technology Innovation Scale Fund (AT-ISF). The AT-ISF will issue grants to innovators to enable them to gather the required evidence necessary to scale their AT solution. The AT-ISF will be available to graduates of Innovate Now as well as innovators globally.

Learning from the early Product Innovation Trials

The Innovate Now ecosystem has been further enhanced through learning from the design of two trials of novel AT. One, the design of a thermoplastic socket for lower-limb amputees,

and the other supporting testing of 3D printing and local manufacturing of wheelchairs. The product innovations have been led by AMPARO, an innovator-led start-up, and Motivation (an NGO and Social Enterprise), respectively. AT2030, through the UCL-led team, has worked to develop trials which would enable the impact of the innovations to be tested with AT users. Conducting these trials before starting the Innovate Now ecosystem allowed us to fully understand “what works” when developing testing protocols in Kenya/East Africa? These early trials have also allowed us to develop partnerships with testing sites. The trial partners are shown in Table 1.

Table 1. Partnerships used to test products

	AMPARO	Motivation
Study Design Support	GDI Hub & Oxford Clinical Allied Technology and Trial Services Unit (OxCATTS)	GDI Hub
Testing partners (trial sites)	APDK & Cure Hospital	Bethany Kids
Local research partners	APDK & Cure Hospital	University of Nairobi

Through the initial trials with AMPARO in particular we have discovered:

- Start-ups and NGOs have benefit from assistance in developing detailed protocols for clinical trials and implementing these
- A partnership co-design approach ensures a robust strategy to collect strong evidence for research purposes, which develops investment case
- Obtaining ethics approval requires time and support from both the research team at GDI and in-country organisations
- Setting up collaborations with sites for trials can be difficult for individual organizations and could be facilitated by the Innovate Now Ecosystem once in place
- Development of guidelines and walkthroughs explaining requirements for research and study designs could be extremely valuable for future start-ups supported by the Innovate Now Ecosystem.

We are currently conducting the Motivation trial which will conclude this year and will further enhance our learning.

Developing focus through Innovation Deep Dives

The Innovate Now ecosystem has been and will continue to be informed by other areas of the AT2030 programme. Specifically, the innovation deep-dives are helping us to develop challenges and specific areas which require focussed innovation. These are being conducted alongside work to develop product-specific narratives (‘product narratives’) of marketplace conditions globally for wheelchairs, hearing aids, glasses, lower-limb prostheses, and mobile with accessible software. The product narratives work is being led by the Clinton Health Access Initiative.

The innovation deep dives consist of a series of interviews with innovators within a specific AT domain. By interviewing current start-ups, innovators, established manufacturers and key opinion leaders in each field, we aim to scope out the current innovations occurring in each technology field with a focus on products and services aimed at LMICs. We are looking to assess what technologies and innovations are driving major changes, what products will be available in the next 10-15 years, and what aspects of design and delivery are stagnating or causing barriers to the successes of related innovation, and their potential to scale up. As these are completed new innovation challenges will emerge for innovate now to tackle. We welcome collaboration on these and will be publishing results on the AT2030 website (www.AT2030.org).

Findings

The design of Innovate Now: from Hub to Ecosystem

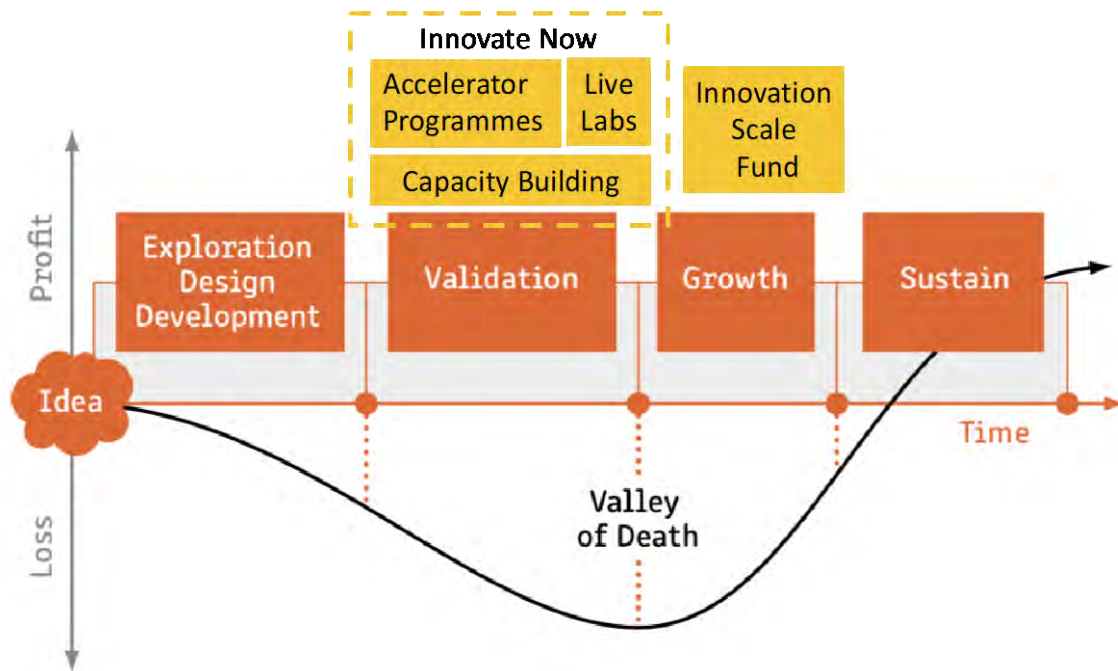
The innovate Now ecosystem has three areas of work - all of which help to overcome the valley of death for AT innovation (see Figure 1).

Figure 1 shows the journey of an idea from concept (left) to sustainable growth (right). When an idea is formed it is at the origin of the graph it has not yet made a profit or loss. However, as the idea is explored through design and development losses are incurred, these are often subsidised by grants, which often develop an idea to proof-of-concept. The proof-of-concept then needs to demonstrate a product-market fit through the validation stage. This is where Innovate Now will be active through three elements:

1. **Accelerator Programme for AT entrepreneurs:** the first call will support 10-20 innovators in the later part of 2019 providing business and marketing development; supporting the design of experiments; legal and IP support; as well as the provision of domain specific expertise and study design (building on what has been learned from the early product trials).
2. **Live Labs connected to the Accelerator will be series of Live Labs:** these are spaces where AT users can test and give rapid feedback to innovators on new AT ideas. Live Labs will be established in places where there is already a large number of potential AT users e.g. hospitals, which are willing to support testing) and the idea is to cluster innovators around live labs themed by area of intervention.
3. **Capacity Building of the Innovation Ecosystem in East Africa** through the creation of an inclusive innovation mission across the ecosystem is the final element of Innovate Now. The Innovate Now Director will advocate for AT innovation and network and connect existing programmes of work. A Steering Committee of key regional partners and investors will make recommendations for investment and backing of approximately 2-3 businesses per year who graduate from the Accelerator.

These three elements will be essential in ensuring validation of a product-market fit. Growth will be available through the Assistive Technology Innovation Scale Fund innovators globally, including those coming out of the Innovate Now ecosystem.

Figure 1. Innovate Now Ecosystem



Innovate Now was launched earlier this year and showcased at the Mobile 360 global conference in Kigali. Applications for its first accelerator programme are now open. Over the next 6 -9 months a second call will go live and our first round will graduate. Each round will further inform our model and research findings.

As was shown earlier for an ecosystem to be successful there must be clear impacts and outputs. We have defined the following metrics, which will determine if we are successful or not over the next three years:

- Supported over 64 start-ups creating 40 sustainable businesses
- Reached (impacted) 300,000 people
- Ensures 25% of start-ups are scaling

Developing the details of Innovate Now

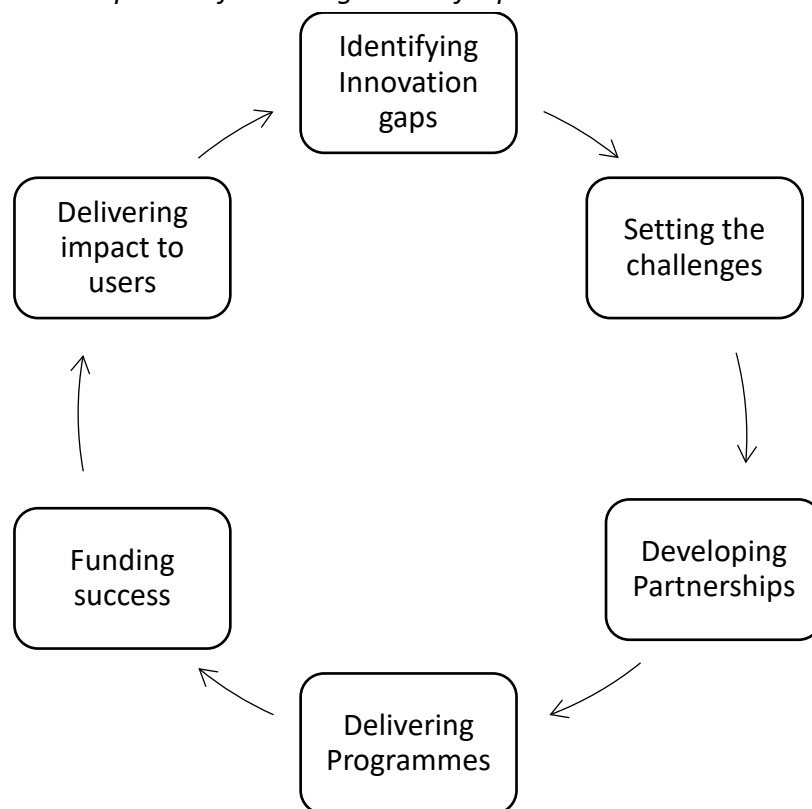
The Innovate Now ecosystem will draw upon a wide range of partners to be able to deliver the expertise needed to prove a market fit for innovations. A key part of this is developing the clinical testing protocols in such a way that they provide the level of evidence needed with minimal cost. For this the Innovate Now programme will continue to draw on the expertise of Oxford Clinical Allied Technology and Trial Services Unit (OxCATTS) based at Oxford Brookes University. OxCATTS will provide multidisciplinary expertise in clinical trial case development design, set up, management and translation for the accelerator programme in a smart modular format so innovators can choose individual or a suit of modules to meet their bespoke needs. The support will be tailored to individual businesses, organisations or projects, working in close partnership to configure the trials, the service activity modules delivered and the level of support. Support covers bespoke modular units for individualised customer needs, through to full-suite trial management, providing rapid

cost-effective solutions. Expertise of OxCATTS includes: design, health economics, statistics and data management and analysis, regulatory and governance needs, trial management alongside stakeholder involvement and engagement. The Innovate Now ecosystem will also offer a range of testing sites, each with a dedicated product or disability focus.

The second core strength of innovate Now will be in AT business model development and new financing possibilities which are being co-developed by AMREF and GDI Hub. Financing will be available through the ecosystem including access to the AT-ISF to provide investment to businesses which demonstrated a market fit, received initial investment, and have some revenue stream but require further investment to scale. Finally, the AT innovators will have access to global expertise through the AT2030 partners.

The AT2030 partnership and the programme will continue to identify innovation gaps, which in turn will be answered through Innovate Now through new challenges. These in turn will drive innovations, which, through unique partnerships, will be helped to reach the marketplace and ultimately impact AT users lives in a positive way. As more AT users engage more actively in society, new challenges will be presented. This cycle is detailed in Figure 2.

Figure 2. Innovate Now process for driving successful products to market



Discussion

Helping to foster a global AT innovation ecosystem

The future success of Innovate Now will be determined not only by what happens in East Africa, but also by the global landscape of investment into AT. We aim to work with the research sub-programme of AT2030 to help drive a reimagining of the financial-political

landscape. This work has recently been set out in a working paper (23). It will explore industrial and innovation policy landscapes which will be able to enable the thriving of the AT value chain through challenge led missions. Such challenge-led policies are able to embrace the barriers that often exist when interacting with multilevel systems (23). This is essential when dealing with ATs as such innovation crosses into multiple sectors and requires the participation of a range of stakeholders as has been demonstrated already within the formation of Innovate Now. Innovate now's success will ultimately be found through partnerships which deliver evidence and leverage investment.

Conclusion

The core elements of the Innovate Now ecosystem have now been established and are the accelerator programmes and Live Labs. The accelerator will provide both commercial and research support. Live labs will allow for rapid innovation testing and user feedback. Thus, increasing user-involvement in the design and development process. The innovate Now ecosystem is growing and is being led by AMREF. Successful graduates of innovate Now will be connected into the Innovation scale fund which will be launched by AT2030 in 2020.

The innovation ecosystem will continue to take a challenge-led approach to deliver new forms of disability interaction and new AT. In doing so it will drive the thinking behind *undisciplined* research, which looks to go beyond traditional thinking to tackle the wicked problems facing the achievement of the SDGs (1). Through a partnership approach it will deliver new AT to market with the aid of the new Assistive Technology Innovation Scale Fund. Finally, it will actively pursue new challenges as they emerge – many of which will have a digital focus.

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Applying market shaping approaches to increase access to assistive technology: Summary of the wheelchair product narrative

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Abstract

To accelerate access to assistive technology (AT), we need to leverage the capabilities and resources of the public, private, and non-profit sectors to harness innovation and break down barriers to access. Market shaping interventions can play a role in enhancing market efficiencies, coordinating and incentivizing the number of stakeholders involved in demand and supply-side activities. Across health sectors, market shaping has demonstrated its potential to enhance national governments' or donors' value-for-money, diversify the supply base, and increase reliability – ultimately increasing product and service delivery access for end users. These market-shaping successes in other health areas have led practitioners to hypothesize that market shaping could also be applied to assistive technology markets. ATscale, the Global Partnership for AT, aims to mobilise global stakeholders to shape markets in line with a unified strategy. To inform this strategy, it is critical to identify specific interventions required to shape markets and overcome barriers. The first product undergoing analysis by ATscale is wheelchairs. The market for appropriate wheelchairs in low-and middle-income countries (LMICs) is highly fragmented and characterized by limited government interest, investment, and a low willingness-to-pay. Moreover, the market is dominated by cheaper, low quality wheelchairs which fail to meet the needs of end-users. Non-profit organizations have attempted to fill the need for context-appropriate wheelchairs, but market uptake is limited. These initial findings led ATscale to believe that market shaping could support increased access to appropriate wheelchairs. This paper outlines what market shaping is, and how it can be applied to assistive technology at large – using the aforementioned wheelchair product narrative as an illustrative case study and presents the proposed market shaping strategy for wheelchairs. ATscale will develop a framework to evaluate short-term interventions identified to achieve a healthy market and increase access. This paper provides an opportunity to obtain

feedback from interested stakeholders on the market shaping strategy for wheelchairs, as well as the product narrative process to be undertaken for other priority AT.

Keywords

Market shaping, wheelchairs, ATscale, access

Introduction

Overview of ATscale, the Global Partnership for Assistive Technology

Globally, while progress has been made in improving many aspects of assistive technology (AT) delivery, the sector has been fragmented and under-resourced. Today, there is increased momentum and interest in bringing together different perspectives and voices to focus on AT. ATscale, the Global Partnership for Assistive Technology, was launched in 2018 to accelerate access to AT, coordinating around a common agenda. As described in its Strategy Overview released in February 2019:

“ATscale, the Global Partnership for Assistive Technology is a cross-sector partnership for AT that brings new energy and strategic focus to a significant global challenge. Building upon the foundation that leaders within the sector have established, ATscale looks to revolutionise access to AT through a collective effort, supporting the global community to have an impact greater than the sum of its individual parts... A global partnership, such as ATscale, enables partners who work in distinct sectors to collaborate within a unified strategy and facilitates complementary approaches, innovation, and capacity building. This coordinated approach, convening a broad range of leading stakeholders across sectors, will increase access to affordable, appropriate, and high-quality AT products and services, all while supporting a strong enabling environment.” (1)

This initial strategy was prepared by the ATscale Forming Committee to guide ATscale through the initial phase of its development and early activities, as well as to inform the establishment of its long-term structure and operating model. ATscale’s strategy proposes a twin-track approach that seeks to:

- Develop an enabling environment across all AT, which includes growing political will, advocating for and informing policy reform, mobilising investment, and strengthening systems and service delivery at global, regional, and national levels
- Identify targeted, catalytic interventions to address both supply and demand barriers to access for priority products via the development of detailed market scoping, called product narratives.

Analysis of approaches in other health areas reinforced this twin-track approach.

Role of Market Shaping in Increasing Access to AT and Accompanying Service Delivery

Development outcomes are inextricably linked to the health of the marketplace that delivers products and services to low-income populations. A well-functioning healthcare market, with public and private sector participation, requires manufacturers to produce

high-quality products, distributors to deliver the necessary quantities, providers to deliver them correctly, and patients to be educated and active participants in their own health. However, markets can fall short. Research and development may not see enough demand to develop a new product, manufacturers may not know how much to produce, and distributors may not see enough profit to justify delivery. The reality is that a single breakdown in this complex system can keep life-saving and life-enabling products and services from those most in need (2).

Market shaping is designed to improve a market's outcomes by targeting the root causes of market shortcomings. Actors at both ends—for example, producers on the supply side and purchasers on the demand side—can face high transaction costs, critical knowledge gaps, and/or imbalanced risks that hamper participation in the market, leading to market shortcomings. These include lack of affordability, availability, assured quality, appropriate design, and/or awareness. Market shaping, grounded in health ecosystem-level thinking, reframes issues, boundaries, and constraints to better align incentives across all stakeholders in the market to potentially overcome these shortcomings. Designed to be transformative, market shaping aims to reduce long-term demand and supply imbalances to achieve sustainable health benefits. It requires participation from countries, donors, procurers, distributors, service providers, end users, and beyond (2).

Market shaping has been successfully implemented in a variety of contexts, including global health. For example, with the support of PEPFAR, the United Kingdom's Department for International Development (DFID), the Clinton Health Access Initiative (CHAI), and others, South Africa conducted careful analysis of the market landscape and reached out to suppliers in India and China to increase supplier competition. In doing so, they were able to negotiate better prices, incentivize timely delivery, and improve transparency. In aggregate, the collective efforts of all parties helped cut the cost of antiretrovirals for HIV treatment by more than 50 percent in the initial post-intervention tender and by nearly 30 percent in the second, saving an estimated \$700 million and \$260 million, respectively (2)

The design of successful and sustainable market shaping interventions requires analytics to pinpoint the underlying root causes of the aforementioned shortcomings. For example, unaffordable prices can lead to low product uptake; however, high prices can stem from a variety of causes, including expensive inputs, high supplier margins, high transaction costs, uncertain demand, or a combination of these factors. Only by identifying the relevant root causes of a market shortcoming can a market shaping intervention target the shortcoming effectively. Market shaping interventions typically use three types of levers to reduce market shortcomings:

- Reducing transaction costs: reducing transaction costs seeks to lower structural hurdles to interacting in the market, such as simplifying, smoothing, or rationalizing purchase orders.

- Increasing market information: increasing market information seeks to generate new data, align existing analyses, and/or improve the visibility of existing data to reduce asymmetries of information, such as demand forecasting, pricing information exchange, or market landscape analyses.
- Balancing supplier and buyer risks: balancing supplier and buyer risks seeks to offset financial risks borne by suppliers and shifting them to donors/purchasers in order to make market engagement more attractive, such as advance market commitments, volume guarantees, or guideline inclusion (2).

Market shaping alone does not address the multitude of product or serve uptake challenges in low- and middle-income countries. It is only a powerful nudge toward further market optimization. Thus, market shaping relies heavily on ongoing programmatic interventions to implement and effect change. Not every situation calls for market shaping; it is important to consider all the options. When used appropriately, market shaping can accelerate the market to a more optimal equilibrium in terms of improved health outcomes and sustainability, playing a critical role in delivering life-saving and life-enabling products and services to those most in need. Market shaping successes in other health areas have led practitioners to hypothesize that market shaping could also be applied to assistive technology markets.

Wheelchair Product Narrative

Overview

In support of Objective 2 of ATscale’s Strategy Overview, a wheelchair product narrative, was delivered under the AT2030 Programme, funded by United Kingdom’s aid from the United Kingdom government. The product narrative defines a proposed approach to sustainably increase access, availability, and affordability to high-quality, low-cost AT in LMICs. The goals of this narrative are: 1) highlight the current market landscape; 2) illuminate the barriers to access; 3) set the long-term strategic objectives for a market shaping approach; and 4) identify immediate opportunities for investments. The next sections provide a summarized version of the approach, the market landscape, and market challenges that limit access to wheelchairs.¹ The final section provides the proposed Market Shaping Strategy, including initial activities and long-term outcomes, to create a sustainable, healthy market for wheelchairs in LMICs.

Summarized approach

Desk research, market analysis, key informant interviews, and site visits with relevant partners and governments informed a robust understanding of the market landscape and the viability of the potential interventions. Stakeholders interviewed included representatives from non-governmental organizations (NGOs), service providers,

¹ The full results of these sections can be found at atscale2030.org within the wheelchair product narrative.

governments, commercial entities, as well as academic experts, wheelchair users, and partners of the AT2030 programme and ATscale.²

Summarized Findings: Market Landscape

Globally more than 75 million people need an appropriate wheelchair, however 85-95% of those in need do not have access.






World Health Organization (WHO) estimates that 1% of the population, approximately 75 million people globally, require a wheelchair (3). Four in five people who need a wheelchair live in LMICs (4) with an estimated 65 million people needing a wheelchair. The need for wheelchairs will only continue to grow globally, especially in LMICs, due to aging (5), increasing rates of injuries (6), and the growing burden of NCDs (7).

Access to an appropriate wheelchair is critical to increasing civic and economic engagement and preventing negative health outcomes

An appropriate wheelchair is defined as one that meets the user's needs and environmental conditions, provides proper fit and postural support, is safe and durable, is available in the country and can be obtained and maintained, with services sustained, at an affordable cost (4). Proper fitting prevents various secondary health conditions such as: pressure sores and progression of postural deformities or contractures; respiration and digestion complications; and premature death (8). Table 1 outlines different wheelchair types available in the global market.

² The full list of those interviewed and consulted can be found at atscale2030.org within the wheelchair product narrative

Table 1. Wheelchair Types

Temporary Use	Indoor/urban/ even-surface	Outdoor/rural/ rough-terrain	Dual use/ indoor-outdoor (for Long- term or active use)	Postural support
<ul style="list-style-type: none"> - Depot, transport, orthopaedic or “hospital” chairs, - Does not provide the user with additional fitting, postural support or pressure relief. - Often pushed by attendant or carer. 	<ul style="list-style-type: none"> - Lightweight - Has a fixed/rigid or foldable frame - Transportable - Easy to manoeuvre in small spaces - Adjustable for proper fit, provides pressure relief, and basic postural support needs; postural support devices may be added to fit user needs - Divided into <i>manual</i> and <i>powered wheelchairs</i>. 	<ul style="list-style-type: none"> - Designed to be robust and stable - Easier to propel over uneven ground - Often three wheeled with longer wheelbase - Adjustable for proper fit, provides pressure relief, and basic postural support needs; postural support devices may be added to fit user needs - Divided into <i>manual</i> and <i>powered wheelchairs</i>. 	<ul style="list-style-type: none"> - Have level of compromise for both environments - E.g., robust wheelchair with large castor wheels, but with a short wheelbase - Adjustable for proper fit, provides pressure relief, and basic postural support needs; postural support devices may be added to fit user needs - Divided into <i>manual</i> and <i>powered wheelchairs</i>. 	<ul style="list-style-type: none"> - Designed for users requiring a higher degree of postural support - Highly adjustable - Comes additional postural support systems such as back support, head support and a positioning cushion
				
<p>LMICs: ~US\$80 HICs: US\$100-800</p>	<p>LMICs: US\$150-300 HICs: US\$2,100-3,500</p>	<p>LMICs: US\$150-300 HICs: rarely found</p>	<p>LMICs: US\$200-300 HICs: rarely found</p>	<p>LMICs: US\$180-350 HICs: US\$2,200-4,000</p>

Note: Wheelchair images provided as reference only (Source: clasphub.org)

Common guidelines exist to ensure the provision of appropriate wheelchairs in less resourced settings

The *WHO Guidelines for the Provision of Manual Wheelchairs in Less Resourced Settings* emphasise eight steps for appropriate wheelchair service (known as the **WHO 8-Steps**; see Figure 1) to assist stakeholders in developing an appropriate wheelchair provision service in different country contexts (4). Uptake by country governments has been low due to lack of awareness of the *WHO Guidelines*, a lack of existing service provision systems for wheelchairs or AT, and limited donor support for the dissemination and adoption of the *Guidelines* worldwide.

The global market for wheelchairs largely focuses on high-income markets and is largely fragmented

The global market for wheelchairs was estimated between US\$4.0-4.5 billion (9) in 2018 with the United States and Western Europe accounting for about 40% and 20%, respectively. Manual wheelchairs make up about 60% of the sales revenue globally, with sales projected to grow 6% year-on-year. The powered wheelchairs segment is projected to grow faster at 15-20% (10).

The supply landscape is relatively fragmented with the five largest manufacturers controlling less than 50% of the global mobility market. Leading global players are: Invacare (USA), Sunrise Medical (Germany/USA), Ottobock (Germany), and Permobil (Sweden).

Figure 1. Poster on Wheelchair Service Steps



Global manufacturers mostly enter into LMICs through distributors, but this adds costs

The production of active wheelchairs for high-income countries (HIC) is highly customized and localized, which limits the product range that could be provided cost-effectively in LMICs. Suppliers, such as Invacare, Sunrise or Permobil, have a limited presence in LMICs

and mostly operate via local distributors. The final price offered to LMIC buyers increases due to high shipping costs, and in some cases, import duties. Small volumes and limited competition among distributors further raises the price.

There is limited public funding for procurement and provision of wheelchairs in LMICs; where procurement within the public sector exists, it is often fragmented and/or erratic

Generally, LMIC governments allocate insufficient and/or variable financial resources for the procurement and provision of wheelchairs. Wheelchairs are typically tendered at the country or regional level, generally based solely on cost. Procurement and distribution or provision is often fragmented across different ministries, such as health, social welfare, education, and defence.

As the primary global manufacturers do not focus on LMICs, NGOs have filled the gap to design, produce and provide wheelchairs that are appropriate for use in low resource settings (LRS)

Leading global suppliers have limited interest in LMIC markets due to low and erratic funding and demand, a reliance on a distributor network that is often poorly developed in LMICs, and a need to develop products with specific design features for use in LRS. Various NGOs and faith-based organizations (FBOs) fill that gap and deliver low-cost, manual wheelchairs that are specifically designed for LMIC environments.

These organizations typically have full control over the value chain from product design to service provision. In most cases, the NGOs are structured as social enterprises and will contract third-party manufacturers. Income from wheelchair sales is used to support wheelchair access programs. Such a model allows the NGO to raise funds for overhead and operational costs while keeping a minimum margin and therefore reducing the price of the final product. In addition to providing wheelchairs and services to users through their local service partners, they also sell their products to donors, other NGOs, and governments.

Charitable organizations that donate product dominate funded wheelchair demand in LMICs

Most wheelchairs in LMICs are donor-funded with delivery models ranging from organization distributing refurbished wheelchairs with limited services to mass distribution campaigns to organizations providing quality appropriate wheelchairs with services that meet WHO Guidelines. Regardless of the model, almost all chairs are delivered at little or no cost to the user.

Free Wheelchair Mission (FWM) and LDS Charities are the largest donors of wheelchairs in LMICs, but volumes are still low compared to need. For example, it is estimated that >80% of the 5,000 wheelchairs delivered annually in Kenya (<5% of need) were delivered via donor-funded programs with FWM and LDS Charities making up >50% (9). Because these organizations deliver larger quantities, it allows them to have full control over the design, manufacturing, transportation, and inventory management of the primary products that

they donate, while also reducing cost per wheelchair provided. To achieve higher volumes and the lowest possible cost, a limited range of products is supplied.

Local manufacturing to meet LMIC demand has seen varying levels of success

Enabled by favourable government policies, incentives to manufacture locally, and perception that wheelchairs are a low-tech product, local manufacturers exist in LMICs. The wheelchairs are often designed for local context and can be customized to match users’ needs, though the manufacturing process is labour-intensive, expensive to initiate, and requires materials or parts from abroad, limiting scalability.

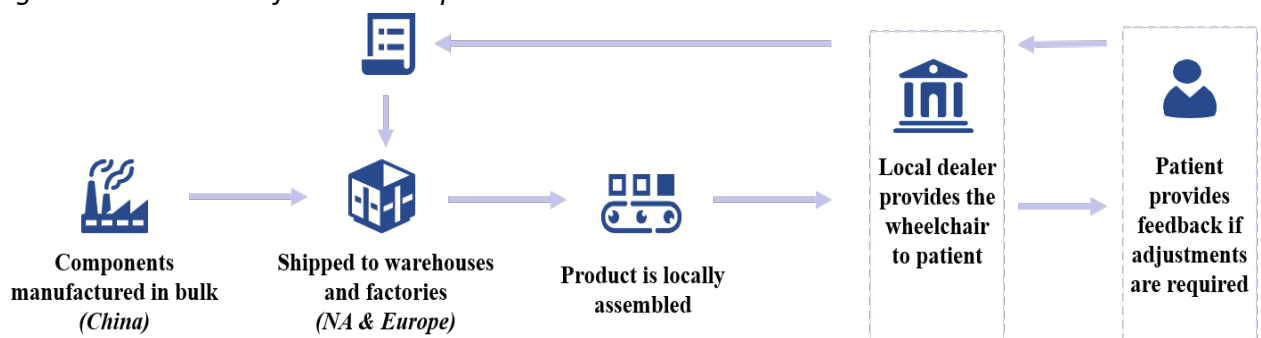
Local manufacturers struggle due to low and erratic demand, resulting in low production capacity planning and utilization and difficulties in sustaining production levels. Additionally, quality in production can be hampered by low investment, training, available equipment, skills, and quality mechanisms.

Key success factors for local manufacturing include: 1) quality and competitive pricing; 2) receiving support from the local government in the form of tender purchases; 3) selling both domestically and through regional exports; and 4) ability to provide a more diverse wheelchair product-offering.

While not heavily utilized in LMICs, localized assembly of component parts could support a cost-effective supply of appropriate wheelchairs

Bulk manufacturing of parts with regional assembly is the standard manufacturing model employed in HICs. In this model, wheelchair parts are manufactured at a centralized manufacturing site - usually in China - and then shipped to a warehouse or facility that is specialized to do final assembly of certain models (Figure 2). Given the pressure on profit margins, suppliers optimize warehousing and production costs while maintaining the ability to offer a highly customized final product. One supplier suggested that an assembly approach reduces shipping costs to 25% of the total cost of shipping assembled products. Most assembly of lower-cost wheelchairs happens in China, while more expensive, high-end products are commonly assembled in Europe or North America, closer to the end-user. Some NGOs have developed an approach that involves ‘localized’ assembly of wheelchairs in LMICs.

Figure 2. Illustrative of wheelchair production in HICs



Generic suppliers that serve as contract manufacturers for NGOs and FBOs produce quality wheelchairs that may be able to supply LMICs cost-effectively but lack market visibility or scale

Wheelchair manufacturing has largely shifted to Asian countries. For example, China's large bicycle industry, together with an extensive and diverse supply chain, indigenous supply of raw materials, high investment in production technology and volume manufacturing infrastructure, makes for an effective production base.

Asian-based companies, used as contract manufacturers by NGOs and FBOs, also manufacture their own brand and have the manufacturing capabilities and excess capacity that could be used to serve LMIC markets, but lack understanding on what products are needed for these markets, who are potential buyers, and potential market size.

Product standards and specifications for wheelchairs in LRS have been developed or are in development, though use in guiding purchasing and design has been limited

The *WHO Guidelines* include guidance on minimum product quality standards for products based on ISO 7176, the international standards for wheelchairs that evaluate the product's safety, durability, performance, and product dimensions. However, ISO 7176 does not test for factors typical for LRS, such as rough terrain, or environmental conditions, such as high humidity, exposure to water and sand, and high temperatures.

To improve reliability and usability of wheelchairs in LRS and guide product design, the International Society of Wheelchair Professionals developed the *Design Considerations for Wheelchairs Used in Adverse Conditions (11)*. It complements the *WHO Guidelines* by providing detailed information in designing wheelchairs for adverse environment and common pitfalls. ISWP developed protocols and equipment to test casters, rolling resistance and corrosion for adverse conditions, labelling it the ISO-Plus, but no specific pass/fail thresholds have been determined thus far.

At the moment, most LMICs include limited specifications in their tenders, often even restricting the request to a single word, such as "wheelchairs". As a result, these countries may buy products that are inappropriate for their settings or are of limited quality. The WHO, under the GATE Initiative, is developing Assistive Product Specifications (APS) for all assistive products listed in the Priority Assistive Products List (12), including wheelchairs.

A lack of clarity on the ideal products required to serve the highest proportion of the population, as defined by a preferred product profile (PPP), contributes to a fragmented market space.

PPPs for different types of wheelchairs that would be appropriate for use in LRS can rationalize demand and increase market transparency. A PPP that contains preferred criteria and specifications for a product that is appropriate for LMICs can, when backed by funders, provide strategic guidance for development and purchasing. While the *WHO Guidelines* give providers and program managers a framework for product selection, there is no mechanism

to evaluate products against its criteria. The APS will help buyers with procurement but doesn't include guidance on the desired price points and specific performance standards for LRS.

To address the challenges of a fragmented market landscape, USAID funded the development of a global distribution hub of context appropriate wheelchairs

Consolidating Logistics for Assistive Technology Supply and Provision (CLASP) is a USAID-funded global consolidation or distribution hub launched in 2014 offering access to a variety of products. It was designed to address challenges faced by service providers in LMICs. Advantages of CLASP as a procurement mechanism included: increased access to a variety of products; increased market visibility of available appropriate, quality products; reduced lead-time; and acting as a pooling mechanism for small/fragmented ordering. Challenges include: limited feedback loop from users; limited working capital; limited space and additional overhead from contracting third-party logistics company for warehouse management; and a limited buyer base.

Summarized Findings: Market Challenges

LMIC markets for wheelchairs are nascent, with a need to focus on demand creation. Table 2 summarizes the demand and supply dynamics that challenge the development of a wheelchair market.

Table 2. Challenges in Wheelchair Market

Demand	
Awareness	There exists a lack of awareness around the need for and importance of appropriate wheelchairs among end-users, service providers and policymakers.
Political Will:	Government involvement is low. Donor funding that fills this gap and supports 'free' product inhibits the development of a public market.
Provision	Due to a lack of awareness, prioritization and investment in this sector, the capacity for service provision in line with the WHO Guidelines is limited
Financing	There is a lack of financing - both public and private - for the purchase of appropriate wheelchairs. Financing often supports the cheapest product available
Preferred Product Profile	Limited consensus on a range of preferred product classes and no commonly accepted objective standards on what is a quality, appropriate wheelchair has contributed to a proliferation of products.
Supply	
Appropriate design	Limited feedback loop from end-users to inform product design and innovation.
Production economics	Manufacturing economics for current appropriate products are unfavourable with small volumes and wide range of SKUs lead to inefficient manufacturing schedules and increased production costs.

Competitive landscape	Leading global manufacturers have limited interest in entering LMIC markets, while Governments have a preference for locally manufactured products.
Cost-efficient supply chain	Limited use of cost-effective supply mechanisms, such as local assembly, combined with high import taxes increase price to final payer.
Enablers	
Quality	Limited quality assurance mechanisms at the demand and supply side. Buying is not driven by quality standards
Procurement	Fragmented funding drives fragmented procurement and limits the ability to aggregate demand, effective forecasting and incentivize volume- and value-based procurement. It contributes to a lack of visibility and data on actual demand.
Market visibility	There is limited to no data for suppliers on unmet need and funded demand for appropriate wheelchairs in LMICs and for buyers on available and quality suppliers and pricing.

Proposed Market Shaping Strategy for Wheelchairs

To overcome these market challenges, a multi-pronged approach that is informed by a long-term vision towards a sustainable market for appropriate wheelchairs and their provision in LMICs is required. This section describes the proposed strategic objectives and long-term target outcomes to achieve this. For each strategic objective, an initial set of activities is proposed that would deliver the outputs required to support the target outcomes. Many of the activities are interconnected.

Table 3. Strategic objective 1

Strategic Objective 1: Build and stimulate demand through the integration of wheelchair services, including procurement & provision, into healthcare systems	
Barrier addressed	Low and erratic demand in LMICs with limited government engagement and funding.
Rationale	<ul style="list-style-type: none"> • There is limited awareness within government on the need for and return on investment for appropriate wheelchairs. • Integrating the provision of wheelchair services into the health sector could drive regular purchases from government, leveraging existing infrastructure and capacity for service provision, product distribution and procurement. • Health systems are well suited to support user identification, service delivery and procurement in particular for remote settings in LMICs. • Buying appropriate wheelchairs and pressure relief cushions can be cost-saving overall to the health system by offsetting negative health outcomes.
Proposed Activities	Support the integration of wheelchair provision into the health system at country-level: In a sub-set of identified countries [framework for country selection TBD], increase provision through integration, expanding and further developing proven models for delivery. This includes: 1) mapping the provision landscape and need, where appropriate; 2) developing a roadmap or strategy to integrate wheelchair services into the national health system; 3) developing or expanding personnel and capacity for service provision,

	including follow-up and maintenance. Document learnings to inform the global toolkit.
	Develop advocacy and implementation toolkit to be used by decision-makers to integrate wheelchair provision into the health system: Develop and disseminate tools to support the implementation and advocacy at government level, including: 1) tools to model the need; 2) investment case for integration of wheelchairs, including financial and societal ROI; 3) a road map template including policy, guideline development, procurement guidelines and operational management guidance that can support countries with the integration of services; and 4) a sample budget impact model for scale-up.
Target Outputs	<ul style="list-style-type: none"> • Unmet need better understood and quantified • Improved awareness of the need for, and value of, appropriate wheelchairs • Demand generated (sustainably and predictably) in a number of countries • Model for integration tested and evaluated for scaling to meet need that: <ul style="list-style-type: none"> ○ Improves ownership and coordination ○ Provides quality-assured product through services
Long-term Outcome	Predictable, sustainable and sufficient demand for appropriate, quality wheelchairs which leads to positive outcomes for wheelchair users

Table 4. Strategic objective 2

Strategic Objective 2: Pool resources to catalyse increases in funded demand and to limit fragmentation in the market	
Barrier addressed	Fragmented market driven by a lack of coordination of among buyers of wheelchairs for LRS and a limited focus on deploying the available resources to effectively support the development of a public-sector market
Rationale	<ul style="list-style-type: none"> • Across various LMICs, donors operate parallel delivery systems that often lack coordination with the government; • Successes in other health areas show that viable LMIC markets can be developed through partnering with governments, and with targeted support from donors • Opportunities exist to expand domestic expenditure and catalyse government participation for both product procurement and service delivery, potentially using innovative financing mechanism (e.g. results-based financing & co-financing). • Pooling the available resources - both donor and government - allows for the channelling of resources to a single payer, thereby strengthening purchasing power, increasing market visibility to suppliers and predictability in funded demand.
Proposed Activities	Test model(s) to pool resources from key donors: Facilitate and test innovative models with select donor(s) to leverage available resources. This may include, match funding, subsidy, product purchasing support, etc.
	Leverage donor funds (e.g. from FBOs) to activate government purchasing and unlock additional resources: Work with donors and government to commit resources (in line with innovative funding model, such as match

	funding) towards wheelchair purchasing or provision, supporting integration into government-owned supply chain.
Target Outputs	<ul style="list-style-type: none"> • Government payer activated • Purchaser landscape consolidated and buyer power strengthened • Increased funding predictability • Increased market visibility • Key donors commit to taking proven innovative funding approach to scale
Long-term Outcome	Donor funding is effectively deployed to catalyse funded public demand and strengthen systems for the provision for appropriate wheelchairs

Table 5. Strategic objective 3

Strategic Objective 3: Strengthen procurement via adoption of specifications and standards, improved tendering and increased market information	
Barrier addressed	<ul style="list-style-type: none"> • Proliferation of low-quality products that do not meet end-user needs • Inability to support value-based negotiations • Opaque market environment with limited information available to suppliers and buyers
Rationale	<ul style="list-style-type: none"> • Aligning on product specifications and/or a PPP that establishes product quality standards, specifications and target pricing can increase transparency for purchasers, such as government programs, and suppliers. Thus, making procurement easier for governments, potentially supporting value-based price negotiations, centralized contracting or donor co-financing. • A procurement or distribution hub that rationalizes supply and negotiates directly with suppliers may serve as a step toward centralized contracting.
Proposed Activities	<p>Develop PPP to be adopted into countries' procurement:</p> <p>a. Establish baseline set of standards and specifications for products in LRS;</p> <p>b. Develop key strategic document that communicates PPP requirements for products that fulfil priority needs. The PPP includes desired specifications and requirements, including on environmental conditions, quality and cost;</p> <p>c. Develop standards in line with PPP that would be applied to support quality testing and implement testing body with easy to access testing canters. Promote the adoption of new wheelchair standards by ISO;</p> <p>d. Advocacy with donors/funders (donors, UNICEF SD, governments, NGOs, FBOs, etc.) should be targeted to emphasize buying only products meeting the minimum requirements and specifications as outlined in the PPP.</p>
	<p>Increase market visibility: Develop a market intelligence platform that tracks supply and buyer landscape, including data from UNICEF, CLASP, ATscale and AT2030 initiatives, and other field practitioners and NGOs.</p>
	<p>Strengthen procurement and distribution mechanisms to ensure the ability to meet market needs:</p> <p>a. Work to increase market information, including upcoming tenders and volumes, available to procurement mechanisms, such as UNICEF SD, CLASP and others;</p>

	<p>b. Include products meeting PPP specifications (and future products meeting PPPs) within UNICEF SD catalogue; increase country knowledge on product availability;</p> <p>c. Assess and further develop distribution hub models, such as CLASP, by increasing its independence, diversifying its funding base, reducing product acquisition cost and supporting capacity to increase scale, product range, reach and responsiveness.</p>
Target Outputs	<ul style="list-style-type: none"> • Increased visibility of quality suppliers in the market with products that meet PPPs • Demand rationalized as the requirements of buyers is standardized • Buyers have adopted standardized product specifications and standards (in line with PPP) and implemented procurement principles to adopt quality, appropriate product
Long-term Outcome	Transparent flow of information on demand and supply enables the market to grow in a cost-effective manner.

Table 6. Strategic objective 4

Strategic Objective 4: Identify and support cost-effective supply systems	
Barrier addressed	<ul style="list-style-type: none"> • Unfavourable manufacturing economics and high shipping costs significantly increase the cost to LMIC payers. • Governments may prefer 'local products', therefore limiting international supply and uptake of international distribution mechanisms (e.g. CLASP).
Rationale	<ul style="list-style-type: none"> • Proven models of affordable, quality, localized supply exist. • Manufacturers of quality, low-cost wheelchairs or wheelchair components exist that could meet LMIC market needs. • Increasing the use of globally recognized minimum quality standards may help filter out lower quality manufacturing in support of new mechanisms for cost-effective supply.
Proposed Activities	Improve understanding of the economics of local manufacturing versus local assembly: Conduct detailed analysis on the economics of local assembly versus local production in specific countries to support government decision makers and private sector business development units.
	Test models for localized cost-effective supply systems: Work with (local) suppliers already operating in LMICs and/or with large global suppliers to test approaches for the supply of products that meet quality and price goals. This may include – for example – facilitating a joint venture, supporting licensing agreements between social enterprises and contract manufacturers or supporting the development of a (regional) distribution network.
Target Outputs	<ul style="list-style-type: none"> • Governments have the tools and information required to make informed investment and procurement decisions regarding localized production • Proven model for a responsive and cost-effective supply of appropriate wheelchairs in country
Long-term Outcome	A healthy supplier base of quality, appropriate products for LMICs that are delivered at optimal prices that can efficiently service market needs.

Conclusion and next steps

This product narrative was developed to support identification of activities that will increase and sustain access to appropriate, affordable wheelchairs. ATscale is currently in the process of developing a prioritization process to inform which of the market shaping activities proposed above will be incorporated into the Partnership's overall investment and implementation plan. While that is underway, some of these proposed activities will be undertaken in the immediate term by the United Kingdom's aid-funded AT2030 programme in line with its aim to test what works to increase access to affordable AT. Additionally, ATscale welcomes feedback on the articulated approach and seeks collaboration with partners interested in aligning their activities with the proposed market shaping strategy.

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Frugal innovation and what it offers the assistive technology sector

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Abstract

This paper defines and summarises the contemporary concept of Frugal Innovation. As a novel approach to address market-shaping, investment and supply, Frugal Innovation is highly relevant to developing and developed countries or regions, particularly in resource-constrained environments. Frugal Innovation has a close relationship with disruptive models in that it offers a distinct way to address needs, “striv[ing] to deliver more economic and social value to more people using fewer financial and natural resources”. In addition to this ‘doing more with less’ mindset, frugal innovation focuses upon both: innovation processes and outcomes. Evidence suggests that Frugal Innovation offers a holistic and novel paradigm of innovation addressing issues of assistive technology market shaping. Authored by experts from the fields of Frugal Innovation and assistive technology (AT) and drawing on the literature and market-shaping concepts, this paper offers the first systematic application of Frugal Innovation to the assistive technology arena. Practical examples of Frugal Innovation are provided to offer a clear perspective on similarities between Frugal Innovation and assistive technology.

Keywords

Frugal innovation, assistive technology, market-shaping, systems thinking, five P’s

Introduction

The World Health Organization (WHO) has highlighted the urgency to address issues of access to Assistive Technology (AT), estimating that ‘more than one billion people worldwide need [basic] assistive products’ (1). Priority assistive products are spectacles, hearing aids, communication software, orthoses, wheelchairs, and many others (see the Priority Assistive Products List (2)). AT’s are critical as they ‘maintain or improve an individual’s functioning and independence, thereby promoting their well-being’ (3) alongside having socio-economic benefits at the country level.

Despite their critical value, access to assistive products is limited due to ‘...high costs, limited availability and inadequate financing in many settings, as well as a widespread lack of

awareness and suitably trained personnel' (2, p.1). While such challenges also exist in industrialised countries (4), research publications on AT in developing and emerging countries have been critically sparse in the last two decades. With approximately 3.5 articles published annually between 1995 and 2011 (5), there is a need to close this gap. Holloway et al. (6) suggest to 'harness innovation' 'with a focus on leapfrog technology, looking beyond the traditional understanding of products or services, and bringing in new players' (p.56).

To respond to this gap, this paper analyses current relevant innovation and AT practices, in, particularly, how frugal innovation can be a strategy of the concept of market shaping. Frugal innovation is one of the most relevant and modern innovation approaches when targeting the world's poorest in both developing and developed countries. Frugal innovation tackles affordability, accessibility, functionality and adaptability challenges, by modifying the paradigm underpinning the innovation mindset, process and outcomes (7,8). A frugal innovation 'mindset' can refer to several approaches such as the 'jugaad' mindset, which means 'the gutsy art of spotting opportunities in the most adverse circumstances and resourcefully improvising solutions using simple means' (9).

In terms of processes, frugal innovation is a bottom-up, market-driven approach, which relies on cheaper, less sophisticated, more local and resource-constrained activities (10-12), contrasting with expensive R&D, breakthrough technology and profit-oriented innovation activities (7). These activities generally result in the development of frugal products or services, which Cadeddu et al. (11) define as solutions '... for [base-of-the-pyramid (BOP)] markets with optimised core functionalities at affordable price-point, embracing usability and durability [attributes]. Frugal products offer alternative solutions to existing products developed for high-income consumers' (p.23). The alternatives often supplant existing products where they effectively address user/consumer aspirations. Frugal innovation activities are often drivers for disruptive innovation, where this approach seeks to 'wipe the slate clean' (13). Frugal innovation may in fact start from a clean slate, when traditional approaches have failed to engage with communities.

Additionally, the frugal innovation concept is increasingly discussed in relation to healthcare (14), offering a significant opportunity to bring frugal innovation and AT together. Numerous examples of affordable medical devices can be cited such as the Jaipur Foot, a rubber-based prosthetic limb (15), General Electric's affordable, portable and simple to use electrocardiogram Mac 400 (16). In the area of digital technologies, where software-based assistive technologies delivered on mobile phones are replacing traditional hardware-based devices. Software such as Coughdrop is a flexible alternative to existing speech-generating devices for those with speech and language impairments (16). Handheld electronic magnifying devices are being replaced with apps for phones with similar functionality. In these cases, not only the technology products but the means of delivery is disrupted, as many such apps are available directly from handset manufacturer online stores rather than traditional centralised processes of procurement. Examples of frugal innovation for

healthcare delivery are the Indian Narayana Hrudayalaya for affordable heart surgery and Aravind Eye Care System offering 50-dollar cataract surgery, both providing high-volume and high-quality care (11,17,18).

In addition to increasing interests for frugal innovation in healthcare, a range of AT practitioners, communities of practice and scholars have also developed frameworks and recommendations to address access issues of quality and affordable AT solutions. For example, MacLachlan et al. (19) discuss the important role of market-shaping and system thinking to increase access to high-quality affordable assistive products (AP). These consist of 'the potential to shape the market towards greater social inclusion and greater supply to those with weak or little purchasing power' (19, p.5). In other words, instead of accepting that 'people are disabled by their impairments or differences', the discussion should lean towards the idea 'that disability is caused by the way society is organized' (20) and that this view of the market for AT should 'shape' the access to AP. Another example of work relates to current barriers for people with impairments categorised across five key *P*'s – *People, Product, Provision, Policy, Personnel*. These have emerged as position papers (e.g. Desmond et al. (21) for *People*; de Witte et al. (22) for *Provision*), and cover 'the systems and services related to the delivery of assistive products and services' (3) that are key challenges in providing access to high quality and affordable AT worldwide.

Therefore, drawing knowledge from sustainable business thinking like frugal innovation (product, service, process, business models) into the domain of AT will be beneficial to address AT provision issues in developing countries. The following section seeks to tie frugal innovation with the AT market-shaping concept to draw similarities between the two concepts and display the significant value in combining both.

Synergies between frugal innovation and market shaping?

Both the AT field and frugal innovation seek to tackle challenges encountered by disadvantaged, low-income populations within resource-constrained environments. These complementary approaches respond to and are influenced by the market supply and demand, enclosing parallels between frugal innovation and the concept of market-shaping and system thinking discussed by MacLachlan (23).

MacLachlan (24) defines market-shaping as 'understanding the broader social context of the market, working cooperatively with other stakeholders, and exploring different types of systems to suit different contexts'. Market shaping has the potential to address 'market traps' (e.g. privatisation and centralised health system) by 'recogniz[ing] that the state of the health and social care system is directly connected to the effectiveness and reach of the markets on which it depends' (19, p.3). Market shaping approach in combination with the concept of 'system thinking' brings in the idea that AT depends on an ecosystem and that AT should be addressed holistically. Banes (25) builds upon this notion by describing such an ecosystem comprising eight factors that need to be addressed to ensure that innovative technologies are successfully implemented. These factors are defined as Policy, Awareness,

Advice, Assessment, Provision, Training, Support, Accessible content and further research and development. The essence of the ecosystem is that such factors are integrated and coordinated.

Similarly, frugal innovation offers a distinct way to address needs in a disruptive way, aiming to 'deliver more economic and social value to more people using fewer financial and natural resources' (26). Like the market-shaping concept, the frugal innovation's mindset of 'doing better with less' seeks to reconcile quality and availability criteria from the supply side, and value and awareness from the demand side, while in a resource-constrained environment. As with market-shaping, the frugal innovators' activities require the convergence of the following triad: the context, the innovator and the users. This holistic fusion within the local ecosystem brings attention to the *context* in which institutional voids, and geographical and societal market constraints exist; the *innovator's* new product development capabilities to respond to these constraints; and the various *users* and other stakeholders orchestrating these available and limited capabilities.

Three exemplars of the synergistic offerings of Frugal Innovation and market-shaping are provided below. Firstly, frugal innovation has a strong market-pull approach, which facilitates the innovator's intention to stem from problems (unmet needs) observed within BOP markets and their local constraints (11). Constraints can include BOP markets' income, low institutionalisation and poor infrastructure in the country (27). The main reason for prioritising unmet needs is that BOP users in developing countries have distinct requirements and environmental contexts that require innovators to change many aspects of their innovation approach (11, 28).

Secondly, a key Frugal Innovation technique is to leverage established institutions' initiatives, including the United Nations' Sustainable Development Goals (SDGs) or the Bill & Melinda Gates Foundation (BMGF), to identify BOP markets' unmet needs. An example of this is Geldom, an affordable condom with unique anti-HIV hydrogel material for developing countries derived from the BMGF. BMGF identified that the pain points of condom's acceptance and uptake were the sensation reducing the sexual experience and restrictions of use from stigmas and discrimination (29,30). Similarly, the growth of the use of some assistive technologies has been driven by initiatives related to increasing access to education and employment. In Rwanda, increased uptake of the open screen reader NVDA was facilitated by the employment initiatives of Rwanda Assistive Technology Access (RATA) (31).

The third connection concerns the degree of inclusiveness stemming from the collaboration with local users, suppliers, manufacturers, NGOs and local informal groups in developing frugal products are within local social contexts. Empirical studies with innovators in Indonesia, Cadeddu et al. (11) demonstrates the development of frugal innovation engages innovators and local stakeholders in 'informal' collaborative relationships, offering time, cost, and quality advantages for the firms and the users. For example, faster decision-making and product iterations can occur over components/materials and design due to

stakeholders' local knowledge and location. Costs can be reduced from avoiding product failures of too advanced prototypes, as well as reducing end users' cost of ownership through local repair. Quality stems from better mutual consent towards the functionality of the products, prioritising the primary performance of the product, which is opposed to the often prioritised 'cost reduction' approach of firms and suppliers. Again, this shows that the development of AT should be shaped by the market, empowering some local groups as well as considering local contexts.

In other words, frugal innovation is a clear market-driven approach which intends to offer an alternative, affordable and high-quality solution to BOP markets in developing countries. The main question remains the practicality of applying such business concept around the market-shaping concept and more particularly the Five P's.

Methods

As frugal innovation has demonstrated its value and feasibility in low-and-medium income countries (LMIC), this paper established relevance and application to assistive technology. Looking at the frugal innovation literature and case studies, the potential of the approach to support the aims and aspirations of the WHO Global Cooperation on Assistive Technology (GATE) initiative, across all five P's described above and the full ecosystem is significant. This paper employed the authors' familiarity with the frugal innovation literature combined with a focused literature search strategy for the most recent best practices and experience in the delivery of assistive technologies in a range of settings. This seeks to identify implications with current themes in AT provision – market-shaping, disruptive innovation and system thinking. Practical and relevant examples and lessons learned from the frugal innovation field will also be showcased.

Key words and synonyms were used for this literature search such as 'frugal innovation' AND 'product'/'process', 'frugal engineering', 'frugal innovation' AND 'healthcare'/'health'. The databases used were Google Scholar, Proquest Central, EBSCO Host. The search was in English and publications years were limited from 2014 due to the frugal innovation literature being nascent and refined throughout the last few years in particular (32). For the AT perspective, key position papers such as Desmond et al. (21) for *People*; de Witte et al. (22) for *Provision*; Smith, et al. (33) for *Personnel*; and MacLachlan et al. (34) for *Policy*, were also reviewed due to each of these being seminal studies elaborating the elements pertaining to each P. Additional seminal papers and secondary data (e.g. practitioners' website) were utilised to triangulate information. Snowballing was an additional strategy to track back the evolution of the frugal innovation literature and position papers.

Results

This study is a first attempt to combine frugal innovation with the concept of market-shaping through the WHO's five Ps. This section will discuss frugal innovation in terms of key innovation activities occurring as processes and outcomes. While confusion remains around

frugal innovators' processes, studies explore this phenomenon from various perspectives including business models, disruptive innovation management philosophy, supply chains and innovation process, which all result in a frugal product or service (11, 26).

Soni and Krishnan (8) define 'process' using other studies' terms like the 'lean' approach or 'frugal engineering', which the latter was summarised as '[a] clean-sheet approach to product development that aims at maximizing value for the customers while minimizing non-essential cost' (p.34). While this definition provides the 'what' answer, we extend 'process' to incorporate 'how' answers, taking account of key decisions regarding bottom-up approach process, non-traditional frugal distribution channels through local collaboration, local production system, leveraging digital platforms, open-source technology and the maker movement. These provide more details into the key innovation decisions that allow for a frugal innovation outcome, which is the second nature in which frugal innovation can exist, such as a product or a service. The process of developing new products in resource-constrained environments should lead to affordable, robust, usable, and functionally optimised outcomes. With this in mind, there are substantial synergies noted between Frugal Innovation and the Assistive Technology five 'P's, which will be presented below. Empirical case studies will be leveraged when possible to extend current debates in the AT field.

Bottom-up approach for needs assessment

One of the key frugal innovation practices is its bottom-up approach. This is particularly observed in the way users' unmet needs are assessed at an early stage, highlighting the important role that users play in the development of frugal innovations. This process relates strongly to the need to engage with end-users described in the P 'AT People', which is defined as end-users 'who would benefit from AT and their circle of support (including family, carers, personal assistants, educators, practitioners and possibly others)' (21, p.2). A major LMIC's challenge to AT delivery is the customisation of assistive products to users' requirements which includes their culture, context, condition, and technology. Such an approach was described in the work of the Tawasol Arabic symbol set for Alternative and Augmentative communication where symbols users and their support network were directly engaged in the design and choice of symbols as decision-makers (35).

Frugal innovation facilitates this customisation through the integration of non-traditional needs assessment at an early stage in the innovation process. These untraditional needs of both the user and context are then integrated into the product at the early concept stage, including the perception of affordability (e.g. cost of use); complementary needs (e.g. aspirational, psychological needs); and those related to the product usage context (e.g. geographical, cultural, societal characteristics) (11). From an AT perspective, Desmond et al. (21) pinpoint the importance for 'personal meanings and perspectives on AT use' (p.1) including self-construction when using AT; this is in line with frugal innovation processes that consider complementary needs as opposed to traditional needs only. Desmond et al. (21) and Holloway et al. (6) also assert the importance of understanding discrimination and

stigma for disabilities as well as ensuring a supportive environment. For those engaged in frugal innovation considerable weight is given to needs related to the context within which a product will be used.

Equally, frugal innovators often develop through a process of 'co-design' a concept highly relevant to AT (36). The integration and understanding of such needs would not be effective without direct interaction with users. Cadeddu et al. (11) empirically reviewed various techniques that are critical in the sustainable development of frugal innovation. Examples are immersion within users' environment for needs assessment; concept testing and criteria for the technical evaluation and acceptance of an early concept; and field trial in the local context testing an advanced prototype. Looking at the AT literature, Desmond et al. (21) assert that these direct interactions with users not only help in assessing patients' risk, resources, intrapersonal and social-ecological factors. They also helped taking account of users' physical, cognitive and adaptive competencies to a new product at the provision stage. These co-design techniques can help with device uptake, as well as the measurement of impact and outcomes of AT in users' lives and the broader context (21). In addition to these advantages to co-designing, frugal innovation studies highlight the development of community trust through building strong relationships throughout the innovation process.

An example of both frugal innovation practices is the Jaipur Foot, a frugal below-knee prosthetic, with a flexible ankle and foot. The former was developed at the Sawai Mansingh Hospital in Jaipur (India) based on the observation of Dr. Sethi and Ram Chandra Sharma that Western-designed prosthetics were poorly accepted by local Indian amputees (37, 38). The uptake of the Jaipur Foot relied on the integration of untraditional patients' needs in its design, in line with the considerations that Desmond et al. (21) suggested for self-construction and users' perception of the use of AT. The Jaipur Foot took account of 1) aspirational needs such as self-esteem and pride to wear an adapted solution, 2) usage context requirements at both a) the environment level such as considering humid rice farming jobs and uneven roads in villages, and b) cultural level such as the possibility to squat and sit cross-legged (39,40). Rehabilitation and testing of the Jaipur Foot was done at the main hospital and they also have implemented 50 provisional fitting camps and 50 mobile clinics in remote areas to reach more people (41,42). While bottom-up approaches in the conceptualisation of frugal innovation and AT appear critical, another important practice related to distribution channels is further discussed below.

Non-traditional distribution (provision) channels

The frugal innovation literature suggests that to deliver the total value of a frugal solution to those who need it, it needs to be affordable, available, accessible, and that users are aware of its existence (i.e. Four A's: affordability, availability, accessibility, awareness) (27). Correspondingly, accessing affordable AT has become a human right for people with disabilities. This led to the creation of legal national and regional obligations in many countries for AT *Provision*, focusing particularly on 'promoting the availability, knowledge and use of AT (article 4(1)(g) and Article 26(3))' (22, p.468). In addition, *Provision is* defined

as ‘everything that is needed to assure that a person with a disability who might benefit from AT actually obtains it and obtains the most appropriate AT solution for that individual’ (22, p.468). This focus has thus clear connections with the frugal innovation’s four A’s, as in both cases, obtaining an adequate affordable product through increasing users’ awareness of its availability and valuable use is critical for the product success. Increasingly the ecosystem that supports the implementation of AT is shifting and was the subject of wide discussion at the ICCHP/AAATE workshop in Linz on Excellence in the Process of ‘AT Provision’ in 2018 (summarised at 43). The increased use of social media, peer support, curated content and online delivery led to a significant change in the model of delivery from traditional to decentralised and frugal.

Provision is strongly related to *Personnel*, which relates to the lack of a trained workforce in the delivery of AT (33). ‘[A] shortage of trained personnel to fit the devices and provide maintenance and repair services...’ has a critical influence on provisioning AT (44). Trained personnel are ‘essential for the proper assessment, fitting, user training, and follow-up of assistive products. Without these four key steps, assistive products are often of no benefit or abandoned, and may cause physical harm’ (1). The low AT accessibility can also come from market factors such as high price, which is often a display of market dependency on a low number of producers, or low-demand due to unawareness of AT devices (45). Similarly, to the frugal innovation four A’s, overcoming *Provision* and *Personnel* barriers would thus ensure ‘last-mile delivery’ (46, p.145) in a beneficial and safe way for local communities. However, with the shifting models of delivery engendered by disruptive and frugal innovation, the role of the workforce is changing in some cases. Where the user’s health is not an issue or risk, the workforce is increasingly addressing high incidence/low impact needs through curating and sharing content on an advisory basis, offering indirect services supporting the self-determination of needs, rather than seeking to work directly with every person with a disability. Such approaches allow the workforce to address the breadth of need through frugal service models, with traditional models accessed as a form of escalation and referral.

Cadeddu et al. (11) highlight key frugal innovation practices related to these issues, including leveraging local networks through, for example, trusted formal and informal groups (e.g. non-governmental organisations [NGOs], postal shops, informal loan saving groups). However, for the latter group, these may not be feasible in the healthcare sector which is highly regulated with several steps for clinical testing rendering the process long and costly. The role of NGOs in the provision of AT has been critiqued due to their limited capabilities to reach people with disabilities and to deliver a wide range of AP (see 22). NGOs may have limited capabilities to scale new products, yet, they ‘carry a legitimacy that businesses may lack, and their status as a trusted member of the community can be leveraged for local contacts, knowledge and expertise’ (47).

In line with both views, frugal innovation practices demonstrate the important role of NGOs in the first step of commercialising new products, alongside non-traditional distribution

channels. Other institutions that can complement NGOs' actions are government agencies, foundations, provisional camps, or mobile clinics. For example, the Leverage Freedom Chair (LFC) is an affordable, all-terrain wheelchair developed by Massachusetts Institute of Technology (MIT) engineers who leveraged, for its *Provision*, NGOs, governments and aid agencies with operations focused on people with disabilities in developing countries (48). Another example of a frugal innovation with a non-traditional *Provision* model is Solar Ear, a low-cost digital hearing aid who has national distributors worldwide including auditive centers and specialised NGOs focusing on social inclusion for people with disabilities. Moreover, the *Personnel* are young impaired people employed for the production of the Solar Ear product, and those in charge of delivering the listening programs must be 'hearing healthcare professional or the manufacturer' (49). While these frugal innovation examples demonstrate various suggestions of sustainable delivery models for the AT field, another issue related to the easiness to repair AT products also influenced users' acceptance and is further discussed below with local production.

Localised production systems

Frugal innovation practice often draws upon local and available resources including local production or fabrication, which enable easy repair and maintenance of frugal products. The choice of the components of the frugal product is influenced by the availability of local components in their design, yet without compromising on the product performance; this enables fixing on the spot by accessing components at local shops in nearby villages (11,50). This practice can address AT *Provision*; in particular de Witte et al. (22) encourage research into 'new production techniques and supply chain efficiencies, including local production to shorten the delivery chain and save costs for transport, etc.' (p.468). These authors also term this consideration as the development of a schedule, a mechanism, or simply an 'infrastructure for maintenance and repair' (p.468). This consideration goes along the WHO (45) recommendations in the provision of manual wheelchairs in less-resourced settings, which highlight the low-scale and large-scale production of AT solutions with local production systems. Moreover, this practice of the local production system also addresses another AT 'P' factor, *Products*, as it also influences product design specifications. Therefore, frugal innovation provides support to leveraging existing local production sites.

An example of a frugal product that has available local components integrated into its design is the LFC Wheelchair, which led to numerous advantages. The components providing power to the driving wheels are made out of off-the-shell bike parts that can be found in rural villages in developing countries, simplifying and reducing costs of production (51,52). These bike components are cheap and easy to find locally rendering the repair of the LFC chair convenient, which made possible the development of an affordable chair. Local production is at the heart of the 'maker movement' and is discussed below.

Digital platforms, open-source and makers movements

Frugal innovation seeks to give underserved markets access to solutions adapted to their unmet needs, and we have suggested that this may be facilitated through the use of mainstream technology including digital platforms and information technology (IT), which can be freely accessible for all through open licencing. Ahuja and Chan (53) demonstrated the importance of IT platform as an enabler for frugal innovation. The key advantages of integrating IT capabilities in firms is the possibility of reducing costs; also, digital products are increasingly cheaper, thus available to a wider population. de Witte et al. (22) recognise the important role that such mainstream technology can have in giving access to new alternatives to people with a disability that are usually not able to utilise them.

Furthermore, we suggest that these digital solutions could address issues related to *AT Personnel*, providing professionals, non-professionals and other types of carers and workers with appropriate, independent, information and tools (22).

An example of a frugal innovation that provides an alternative to traditional training is Solar Ear's focus on a cloud-based app for hearing loss diagnosis in areas that are not accessible by carers. This seeks to engage local entrepreneurs to complete a \$1 hearing diagnosis with results on a cloud linked to Solar Ear's team (54). Then, personalised treatment is sent back to the entrepreneur, to provide the impaired user with a program adapted to his or her hearing loss. While this addresses both *Personnel* and *Provision* issues, Solar Ear also aims to target *People* differently by identifying and preventing hearing loss at an early age whilst familiarising people with the technology. This Frugal Innovation example illustrates the potential for prevention as well as remediation and management. Furthermore, this innovation has an open-source element, as Solar Ear seeks to develop 'a low cost, simple to use, Android smartphone-based, open-source, OAE testing device, for babies and infants called Baby Ears' (49,55).

Open licencing can be applied throughout the delivery chain. In recent visits to Nairobi, it was noted that open licences had the potential to accelerate the availability of assistive technology by 1) using open source code to support the development of widely available software and hardware devices; 2) using creative commons licences to facilitate the distribution of information and knowledge between organisations and communities; 3) using Open Education Resources (OER) to support the creation of open training material that can be distributed and localised for community usage. An example of such resources being made widely available includes EU funded projects such as 'access-interact' which provides training materials on reducing barriers to inclusion of people with a disability that can be freely distributed, translated and used (56). There is a strong link with the maker movement, as exemplified at ATmakers.org (57). AT Makers develop instructions and videos on the manufacture of various forms of assistive technology including switches and interfaces for computer access. Such resources are available freely online and can be used as the basis of local fabrication.

Discussion

These findings contribute to the complex but important work of drawing knowledge from sustainable business thinking into the domain of assistive technology. Traditional approaches to AT access have not been successful to date in meeting the global demand. Even within existing markets increasing demand suggests that traditional approaches cannot address the scale of need. Disruptive and frugal innovations are essential in seeking to address unmet need within existing markets and those that are emerging. The authors recommend that Frugal Innovation is an alternative and compatible approach to addressing this shortfall.

We have demonstrated that empowering *People* is critical in the Frugal Innovation process. Frugal Innovation recommends prioritising users' primary needs as a starting point at the AT product conceptualisation and co-design techniques allow for detailed needs assessment, impact measurement, testing of the broader context. *Provision* and *Personnel* of AT are intertwined, demonstrating the importance of an ecosystem which includes local production, digital innovation for services and remote support, NGOs' networks, community-based channels/social infrastructure, and collaborative learning via training local users and other stakeholders. In relation to *Products*, Frugal Innovation considers local resources and contextual factors of low and middle-income countries in new product development processes. For example, it strengthens AT recommendations for easier repair and maintenance by proposing product design techniques, including design for maintenance and customisation based on supply chain decisions, such as with the presence of local repair shops.

Table 1 maps a range of Frugal Innovation practices to four of the GATE five 'Ps.

Table 1. Frugal Innovation Practices and People, Provision, Personnel and Products

Frugal innovation practices	People	Provision	Personnel	Product
Bottom-up approach	X			X
Untraditional distribution channels		X	X	
Localised production		X	X	X
Digital platform		X	X	X

We propose that *Policy* is the conduit / mechanism to realise the potential of Frugal Innovation for AT. While Frugal Innovation is at its infancy, governments have demonstrated interest at a *Policy* level such as in Europe and developing countries. For example, the United Nations Conference on Trade and Development (58) seeks to develop strategic innovation policies which favour marginalised communities, local initiatives, open and collaborative digital technologies in addressing the SDGs, just as Frugal Innovation proposes.

Whilst recognising limitations, it is suggested that such an approach is essential to address demand in low and medium resourced environments, in particular as frugal innovation has overcome traditional barriers when reaching BOP markets in developing countries. We have

sought to leverage the frugal innovation literature as a concept that can help to resolve, when intertwined with AT, some of the most fundamental problems faced by the community of therapist, end-users, policy-makers, manufacturers and other stakeholders.

For AT practitioners we suggest that Frugal Innovation offers an alternative model which brings together the development, production and sustainable delivery aspects of the AT continuum, and this is of substantial value to AT practitioners. It offers a way to bring together person-centred principles, wholistic research and design approaches, and community-based way of doing business. It couples the reality of the business cycle with humanistic principles and provides a way forward for our AT communities to deliver great outcomes.

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Accelerating access to eyeglasses by leveraging government platforms

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Abstract

The purpose of this paper is to highlight opportunities to scale proven models of eyeglasses delivery through government systems and platforms with the goal of closing the gap in access to eyeglasses. It is estimated that the affected population living with vision impairment correctable with a pair of eyeglasses is approximately 1.5 billion – 89% of individuals living with vision impairment live in low and middle-income countries (LMICs) (1). Creating a world with equitable access to eyeglasses will require national scale of successful solutions. In order to address a problem of this magnitude government systems will need to be optimized to identify children and adults with poor vision, provide eyeglasses outside of healthcare settings, and connect those in need of more advanced eye care, with treatment. This paper shares operational research that indicates eye care delivery models, pioneered and proven at the district level by non-governmental organizations (NGOs) and inclusive business, could be scaled nationally if embedded into existing government systems and platforms. More specifically, data and lessons learned by NGOs and inclusive business indicate that government facilitated, and managed community health worker programs and public schools can be cost effective platforms to identify cases of vision impairment and poor vision. The vast majority of cases of uncorrected refractive error can be treated with a pair of glasses on-site in schools (86%) and near vision impairment can be corrected in communities with a pair of reading glasses. This paper will consolidate operational evidence and lessons learned by practitioners to promote opportunities to integrate proven models of eyeglasses delivery into government systems and will provide insights into unlocking government resources to scale school eye health initiatives, and outline financing options for delivery of reading glasses through national community health worker programs. In addition, the approaches outlined in the paper highlight opportunities to identify new cases of uncorrected refractive error while simultaneously creating referral pathways for adults and children who require more advanced care, so they can access treatment at the appropriate facility.

Keywords

Eyeglasses; school children; Community health workers; Uncorrected refractive error; low- and middle-income countries

Background

While poor vision correctable with eyeglasses, or uncorrected refractive error, will affect half the global population during their lifetime, access to the solution is far from equitable. In high income countries (HICs), most of those whose vision could be improved with a pair of glasses are able to obtain an eye exam and affordable glasses either through public health systems, private-sector optical shops and online optical companies, or at pharmacies and retail outlets if they only need a pair of reading glasses. Yet access to affordable, properly prescribed eyeglasses remains limited in LMICs with many individuals living with vision impairment and poor vision that could be easily corrected with a pair of eyeglasses. Unlike other public health problems, the disparity in access to the solution is not the result of costly medical treatment.

In fact, the cost of sourcing new frames and lenses for glasses can be as low as \$0.60-2.50 per pair (2). Rather, the current unmet need for glasses in LMICs stems from a long history of neglect. For many years, a lack of epidemiological data resulted in inaccurate sizing of the affected population. Prior to 2008, data was only collected on the number of individuals whose vision could be restored with medical interventions. As a result, governments and the global health community had data on how many people needed surgery and medical treatment, but no information on the number of people whose vision could be corrected with glasses. Without clarity on the scope of the problem, governments could not commit adequate resources to train eye health workers, or fully integrate the identification of poor vision and correction of vision with glasses into public health systems.

In addition, optical companies in LMICs have traditionally been concentrated in major cities and market primarily to high-income consumers. Furthermore, because of a widespread lack of eye doctors, skilled professionals are in high demand and frequently migrate to major cities where they can earn a higher income. For example, in Sub-Saharan Africa, 67% of ophthalmologists and 66% of optometrists are more likely to be employed in capital cities, and many leave their countries altogether for opportunities overseas (3). With so few eye doctors and a lack of competition, private optical companies have opted to focus on a small segment of urban populations who can afford to buy higher-priced glasses.

Despite new models pioneered and proven by international NGOs and inclusive businesses, these organizations collectively address only 0.3% of the global need for glasses in LMICs (4,5)¹. Without further intervention, this gap will only widen, as the prevalence rates of myopia in children are expected to rise dramatically over the next three decades. Yet, research has shown that correcting vision in primary school students yields an increase in test scores by at least 0.11 standard deviation (6), in some cases this is the equivalent of a third to a half year of additional schooling (6).

¹ Analysis of EYelliance Investment Case Research Survey (4): Past eyeglass distribution estimates derived from Survey Analysis' Question 1, "How many eyeglass/spectacles did your organization distribute over the last four years?". Current need and 2030 projected need derived from Essilor estimates (5).

According to UNESCO, one extra year of schooling increases earnings by as much as 10% (7). A 2007 World Bank policy research working paper noted that an increase of one standard deviation in test scores of international literacy and math assessments is associated with a 2% increase in annual growth of GDP per capita (8). These findings support the conclusion that providing properly prescribed glasses for children could potentially increase personal earnings by 5% over a lifetime and raise GDP by 0.2%.

The lost productivity from not addressing uncorrected refractive error has been calculated to cost the global economy at least \$269 billion annually (9), with LMICs disproportionately affected. Correction of near vision loss with a pair of reading glasses has been shown to lead to a 21.7% increase in productivity and for workers over the age of 50 productivity can increase by up to 31.6% (10,11). Further, studies show that 74% of illiterate adults fail one or more parts of a vision screening, highlighting an opportunity to save the global economy \$1.19 trillion each year due to illiteracy (12). The ancillary benefits of correcting vision in adults include safer drivers and safer roads, as well as increased participation in the digital economy.

Introduction

Addressing uncorrected refractive error at global scale will require investment in public health systems strengthening as well building capacity of human resources by training of sufficient new eye health professionals. It is not surprising that in the parts of the world with high rates of uncorrected refractive error optometry schools are virtually non-existent and the years of schooling and residency required to obtain an ophthalmology degree can be prohibitively expensive. While this long-term investment in eye health infrastructure is critical to creating equitable access to quality eye care and eyewear, it can be very resource intensive to establish new professional institutions and will take decades to strengthen public health systems to offer refractive services in district level facilities. Therefore, there is an opportunity to concurrently leverage platforms for delivery of basic eye care and eyeglasses outside the public health systems setting.

The historical lack of attention and resources allocated by the public and private sectors to address uncorrected refractive error led NGOs and inclusive business to innovate and implement new eye care delivery models to meet the need for vision care. These models, pioneered and proven by NGOs and inclusive business, could be scaled nationally if embedded into existing government systems and platforms. This paper will consolidate evidence that proven models of eyeglasses delivery can be integrated into government systems and will provide guidance on unlocking government resources to scale school eye health initiatives, and outline financing options for delivery of reading glasses through national community health worker programs. In addition, the approaches outlined in the paper highlight opportunities to identify new cases of uncorrected refractive error while simultaneously creating referral pathways for adults and children who require more advanced care, so they can access treatment at the appropriate facility.

The promise of school eye health

Without glasses, children with poor vision are at a major disadvantage in school. Poor vision limits children's ability and their motivation to learn (13); as a result, their academic performance often suffers. Hundreds of millions of children who need glasses do not have a pair, and many of them have not received a vision screening because they live in communities with limited eye care options. Fortunately, school-based interventions have been proven to be a cost-effective (14) approach for identifying children with vision problems. From Latin America to Sub-Saharan Africa, to East and South-East Asia, school eye health programs demonstrate that appropriately trained teachers can safely and accurately identify children with vision problems. Providing glasses to children who need them is a simple intervention that ensures children with poor vision have an equal opportunity to succeed in school – a condition critical for attaining goal 4 of the UN global goals for sustainable development: “Ensure inclusive and equitable quality education for all and promote lifelong learning”.

Accordingly, the eye care community of practice has coalesced around a set of best practices for school-based eye health interventions for children, or school eye health. In 2017 the London School of Hygiene and Tropical Medicine, Sightsavers International, and the Brien Holden Vision Institute came together to draft the Standard School Eye Health Guidelines for low and middle-income countries (15).

School Eye Health Pilot in Cambodia

Following the completion of a national prevalence study on disabilities and impairment among children in Cambodia, the Global Partnership for Education (GPE) recognized the opportunity to test school-based eye care delivery. The study on disabilities and impairment study, conducted by the Ministry of Education with technical assistance from Handicap International Belgium, found that many children who dropped out of school – or who never enrolled – suffered from poor vision (2). Therefore, GPE partnered with the Ministry of Education, the World Bank, Sightsavers, the Partnership for Child Development (PCD) of Imperial College London, and The Fred Hollows Foundation to launch a school eye health pilot in Cambodia 2012. In conjunction with the ministry's existing school health interventions, the pilot ran in 56 schools in Siem Reap province, in both urban and rural settings, and provided teachers one full day of training to conduct basic vision screenings. A team of visiting eye health professionals examined children identified with poor vision and provided those who did not need fully customized glasses with a ready-made pair on-site. Children who required fully customized eyeglasses received them within days following their exam. While 13,000 students and out of school children aged 11-15 were screened, some teachers also asked to be screened during this process. Although this was not part of the original programme design, the project aimed to improve the quality of education, with the teachers' vision being critical for an effective learning environment (2).

A six-month follow-up to evaluate accuracy found that teacher conducted screenings were 100% aligned with those of trained eye health workers, demonstrating the method's effectiveness and safety. Evaluators also found that providing eyeglasses to children within a matter of days was an effective approach for maximizing adoption and usage. The pilot provided data on eye health that helped the Ministry of Education plan and budget for appropriate interventions. Accordingly, the ministry incorporated the school eye health model into its new five-year national education sector plan and hired The Fred Hollows Foundation to provide technical assistance in implementing vision screening in three provinces (2). This seminal collaboration in Cambodia demonstrated the potential to include school eye health into national education sector plans developed by GPE partner countries thereby paving the way to unlocking government resources.

Liberia: A collaborative approach to national school eye health

In 2017, Sightsavers, an international non-governmental organization, that had been working in Liberia for 17 years was conducting school eye health programs at the district and county level in the Southeastern part of the country. The year prior, the L V Prasad Eye Institute, also a INGO, had partnered with the Government of Liberia to establish the country's first tertiary eye hospital and beginning to launch community screening efforts that included school eye health, to identify new patients living in and around Monrovia in need of eye care.

In 2017 EYElliance, a multi-sector coalition that drives the global strategy to address uncorrected refractive error, met with the sitting President of Liberia, Ellen Johnson Sirleaf, to make the case that she considers utilizing the country's community health worker program to dispense reading glasses to those in need living in remote communities. President Sirleaf recognized the opportunity to increase productivity and improve quality of life by creating access to reading glasses, but she also made the request that school children be included in the new eye health initiative. She reflected back on the hundreds of schools she had visited during her 11 years as President and noted that she had never seen a student with a pair of glasses. President Sirleaf requested that EYElliance convene a delegation of INGOs that had established best practices within their area of expertise to advise the Ministry of Health and Ministry of Education on a comprehensive eye health strategy. Three months later a memorandum of understanding was executed with both ministries, 4 INGOs, 1 inclusive business, and 1 local NGO to establish a continuum of eye care that connects patients to primary, secondary, and tertiary care.

National Scale

This government-led consortium in Liberia implements an approach to school eye health that involves training teachers to conduct vision screenings in schools to identify children who require comprehensive eye exams that was pioneered by NGOs and proven by the Government of Cambodia. According to the Liberian Ministry of Health, in 2017, there were six practicing ophthalmologists and one optometrist in a country of 4.7 million people. The

lack of eye health professionals capable of performing comprehensive eye exams on-site in schools necessitates a model in which the L V Prasad Eye Institute supports the training of appropriate cadres of eye health professionals. This upskilling is currently conducted at the L V Prasad Eye Institute's Centres of Excellence in India while they work to establish a six-month training program for physician assistants in Monrovia. As the initiative scales up from two counties to 10 counties, the consortia will adopt an approach where school children from multiple schools who have failed the vision screening will receive a comprehensive eye exam at one centrally located school to streamline the number of site visits made by eye health professionals. By the end of 2021, 500,000 children in 2,000 public schools will have received a vision screening, a pair of eyeglasses if needed, and treatment for more serious eye conditions or disorders for free at the tertiary eye hospital in Monrovia.

Without affordable quality frames available locally, OneSight, a INGO and consortia partner, has trained a local team to work within the tentoria eye hospital system to manage procurement for the school eye health initiative. This includes facilitating an in-kind contribution of children's ready-to-clip frames and lenses committed by 2.5 New Vision Generation –another consortia partner. Ready-to-clip frames and lenses enable eye health professionals to dispense eyeglasses on-site in schools within minutes to 86% of all children whose vision can be corrected with eyeglasses (the remaining 14% will require customized eyeglasses).

School children who have been identified with more serious eye conditions or disorders will be referred to either a public health facility if appropriate, or to the tertiary eye hospital in Monrovia. The tertiary eye hospital in Monrovia provides comprehensive eye care services and performs surgeries free of charge for those unable to pay –as part of the national school eye health initiative all children referred through the public-school system will receive treatment for free. This access to advanced eye care is proving immensely valuable as children who are Ebola survivors have a very high incidence of cataracts – a potentially blinding condition that is normally extremely rare in children.

In Liberia, the Ministries of Health and Education are actively collaborating to collect and share data across the two agencies. District and county-level staff from both ministries are compiling the number of students screened, the number of students who will require comprehensive eye exams, those whose vision problems can be corrected with a pair of eyeglasses, and those who will require more advanced care. Relevant data will be integrated into the Health Management Information System and the Education Management Information System. Donor driven school eye health programs not led by government have historically implemented data collection methodologies managed entirely by NGOs with minimal integration into government systems.

Liberia is one of GPE's 70 partner countries where multi-year education plans drafted by Ministries of Education are evaluated and funded by GPE and other development partners. In 2018 the Liberian Ministry of Education validated its first national school health policy –

which includes eye health. Similarly, the Liberian Ministry of Health has prioritized school eye health in its policies and hired the first ever national eye health program manager. The Ministry of Education has committed to including school eye health in their 2021 national education sector plan enabling the ministry to include ongoing operational expenses into their next multi-year budget. Consortia partners in Liberia are in the process of conducting two costing analyses, one detailing the incremental costs incurred by adding eye health to school health initiatives, and the other will seek to understand costs savings associated with bundling teacher training for multiple school health interventions –upon completion both evaluations will provide governments with a useful decision-making tool.

This collaborative model with partners bringing relevant expertise and resources to address any gaps in capacity within the eye health infrastructure, is particularly effective in low income, and lower middle-income countries that are also GPE partner countries.

Botswana: Technology-enabled national scale of school eye health

Peek Vision is a social venture that has developed technology-enabled tools and processes to improve eye health services that have been specifically designed for low resource and remote settings. Peek’s technology was initially developed in Kenya and has since been implemented in five countries in partnership with eye health professionals.

Affording to a rapid assessment of avoidable blindness conducted in 2015 Botswana has high prevalence of blindness (16). Accordingly, Botswana has made significant investments in eye care resources and have developed a National Plan for Eye Health to reduce avoidable blindness by 30% and all visual impairment by 25% by 2020 –in line with commitments to the WHO Global Action Plan (17).

In 2016 Peek Vision began conducting a donor supported school eye health pilot in Botswana at the district level. Initial results from the pilot prompted interest from the Government of Botswana and led to Peek and its partners making a case for further action and investment.

Peek synthesized initial findings along with existing research on the impact associated with correcting vision with glasses and other interventions to build an economic case for addressing eye health for a generation of children. The increase in earning potential and ensuing growth in GDP was an important factor in securing the Government commitment to funding a national school eye health initiative.

National Scale

The model that the Government of Botswana is implementing involves use of Peek’s evidence-based design process to optimize health service delivery including use of a smartphone app to facilitate vision screenings in schools. The clinically-validated app enables teachers or other users to not only screen students using graphics displayed on the phone, it also streamlines and automates the data collection process, sends personalized messages to carers, notifications to service providers and real-time healthy system level

analytics to support data driven decision making. Botswana is fortunate to have a relatively high number of eye health professionals (compared to other nations in the region) and comprehensive eye exams conducted at or near schools will be performed by a combination of private optometrists and public eye health professionals employed by the Ministry of Health & Wellness. The Ministry of Health & Wellness issues tenders to private sector optometrists outlining the scope of the engagement. In three years 500,000 children will receive a vision screening, a pair of eyeglasses if needed, and be referred for appropriate treatment if non-refractive eye conditions or disorder is found.

Currently fulfillment of eyeglasses prescriptions for children is managed either by a local public health facility or the optometrist's business, however all school children are receiving their first pair of glasses free or subsidized as part of the Government commitment. The Ministry of Health & Wellness is exploring the opportunity to facilitate national procurement of eyeglasses for children over the long term. All school children who are identified with non-refractive eye disorders are generally referred to one of three eye health facilities in Botswana, with the most complex cases needing to seek treatment in South Africa.

In September 2019, the costs associated with the national school eye health initiative in Botswana will be assumed by the Ministry of Health & Wellness and the Ministry of Basic Education. This co-investment necessitates the active collaboration across ministries that is critical to the success of any government-led school eye health initiative. The technology-enabled tools developed by Peek promote seamless data collection that enables both ministries to manage their data inputs while accessing the results across the spectrum of the intervention, from 1) teachers and other cadres conducting vision screenings; 2) outcomes of comprehensive eye exams; 3) uptake of referrals for more advanced care and critically; 4) visibility of who is not being reached through screening; and 5) who is not adhering to referral.

It would follow that this approach to national, government-led school eye health that is being demonstrated in Botswana will be most applicable in upper middle-income countries or lower middle-income countries as defined by the World Bank (18) where ministries are adequately resourced and there is the requisite professional base either within the public or private sector. This model has the potential to optimize the existing eye health capacity in countries where ophthalmologists and other eye health professionals are spending a disproportionate amount of time addressing uncomplicated cases that could be treated at the primary and secondary level.

Creating a New Eye Health Workforce

Globally, approximately 1.1 billion individuals are presenting with functional presbyopia, meaning individuals are unable to see nearby objects clearly due to near vision loss and need to use reading glasses (1). Presbyopia, easily treated with reading glasses, usually develops when adults are in the prime of their careers affecting a vast range of activities and

professions from agriculture and food production, such as coffee- and cocoa-bean sorting, to garment and textile work. If left untreated, presbyopia causes gradual vision loss that can reduce productivity and lead to premature retirement. Correcting near-vision loss with glasses has been shown to yield an immediate increase in productivity of up to 30% – however, rates of correcting presbyopia are as low as 6% in LMICs, compared to 96% in Europe (10).

Low and middle-income countries offer few opportunities to obtain reading glasses outside of healthcare facilities. In an attempt to meet the enormous need for reading glasses, NGOs and inclusive business have begun training community level workers to conduct basic vision screenings and dispense or sell reading glasses for \$1.00-\$1.50 per pair (2). With proper training, community level workers are also able to identify more advanced vision disorders, such as cataracts and glaucoma, and connect individuals who might not have otherwise received proper eye care to the appropriate facility for treatment. Training community level workers to reach people in remote communities with basic vision screenings can potentially create significant impact by delivering reading glasses at the point of care, and establishing referral networks to maximize access to eye care (2).

In approximately 3.5 hours, an individual with no prior health training can learn to conduct basic vision screenings and dispense reading glasses. This approach has been implemented for over 10 years, initially proven in Bangladesh (2), and replicated by the Brien Holden Vision Institute and 2.5 New Vision Generation in China, Kenya, Uganda and Pakistan. Across these five countries, over 35,000 community level workers have been trained creating an entirely new eye health workforce to reach those without access to basic eye care. In recent years, there has been growing alignment within the global development community that in order to strengthen primary health care and promote integrated health models, government-led and managed community health worker programs must be supported. As noted in USAID's report, *Strengthening Primary Health Care through Community Health Workers: Closing the \$2 Billion Gap*, "parallel cadres focused on singular disease priorities miss opportunities to capture cost efficiencies and maximize effectiveness."

While funding for community health worker programs is currently disproportionately deployed based on disease priority, the global development community is calling for funding integration among countries and donors alike, both in community health and, more broadly, in global health (19). This shift has positive implications for correcting presbyopia in hundreds of millions of individuals.

Training community level workers to conduct vision screenings and dispense reading glasses was proven within the context of parallel cadres models. In order to drive efficiencies and achieve scale, it will be necessary to gain a better understanding of what it takes to integrate this approach into government systems in policy and practice. Specifically, pilot projects will need to test the following:

- Readiness of a community health worker system to add a new service offering;

- Determine the incremental cost of adding this new service to the existing community health worker platform? (Can Ministries of Health absorb these costs?);
- How to create efficiencies by including reading glasses into government managed supply chain systems?
- Is there a viable path to reading glasses coverage as part of a national insurance scheme?
- Is there potential to test a patient's ability to pay via mobile money?

Pilot: Training 150 community health assistants in Liberia

The government of Liberia is implementing a highly systematized and well-coordinated national community health worker model with centralized decision making. All 3,000 community health assistants receive the same training and provide consistent services and treatment across the country. Within this structure, there is the potential to move from county-level pilot to national scale in 14 counties relatively quickly. In under a year, the pilot in Liberia will generate learnings on including reading glasses into national supply chain system and inventory management and procurement processes. In 2016, an external costing evaluation was conducted by the Financing Alliance for Health on the national Liberian community health worker program, plans are underway to compare this baseline data with new information on the incremental cost of adding the new service offering of vision screenings and reading glasses enabling governments to make informed decisions.

Recommendations

- The national school eye health initiatives in Liberia and Botswana should demonstrate the viability of the approach and help other organizations and ministries to make the case for adoption of the model;
- As additional governments launch new national school eye health initiatives, data needs to be captured on which approaches are most appropriate for various contexts;
- Pakistan and Kenya offer compelling opportunities to test the viability of reading glasses coverage through national insurance schemes (Pakistan) and the potential to test a model where patients pay for reading glasses via mobile money.

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Development of a financing mechanism for assistive technologies through the Philippine Health Insurance Corporation

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Abstract

Background: About 1.5 million Filipino children require the use of assistive devices to carry out their activities of daily living. However, only 5% of these children have access to them (basic and supportive wheelchairs, optical devices, hearing aids and similar devices). A survey in 2017 among families with children with disabilities in southern Philippines showed that while 79% have access to specialized medical services, only 68% have assistive devices, mostly coming from donations. Moreover, among these families, only 60% sought consult after seeing the need to refer their child, while 83% of healthcare costs is shouldered by families as out-of-pocket expenses. This paper aims to discuss the development of the Philhealth Benefit Packages for Children with Disabilities. **Methodology:** The Philippine Health Insurance Corporation (PhilHealth) and Department of Health (DOH), through the support of Physicians for Peace Philippines (PFPP) and the United Nations Children's Fund (UNICEF), formed a committee to develop a benefit package for assistive devices. Three main methodologies were used for the study: 1) Evidence Synthesis; 2) Costing Analysis; and 3) Epidemiology Analysis. Relevant stakeholders including policy makers, experts, health providers, managers and patient groups were involved in dialogue and negotiation. **Results:** PhilHealth Circular No. 2016-0032 provided for Benefit Packages for Children with Disabilities covering specialized assessment, assistive devices and therapy sessions for children with mobility, developmental, hearing and visual impairments. The benefit packages cover professional fees for assessment and therapy, and provision of assistive devices. Potential users of benefit packages were determined through identifying the prevalence and incidence of the different types of disabilities. **Conclusion and Recommendations:** The development of the benefit package provides access for health services, assistive devices, and rehabilitation through health financing. New challenges in implementation include alignment to the new framework within the context of the 2019 Universal Health Care Act that provides for stronger primary care, and financing and management of services through networks. Capacity development; regulation; expansion of newly defined professional and technical staff (e.g. prosthetists-orthotists, audiologists,

speech therapists and wheelchair service personnel); and robust regular costing analysis are important steps to ensure effective provision of services.

Keywords

Health Insurance, Disability, Assistive Devices, Health Financing

Background

People with disabilities are considered to be the world's largest minority. An analysis of data from the World Health Organization (WHO) Global Burden of Disease Report in 2004 estimates that about 15.3% of the world population or about 978 million had moderate to severe disability while about 3% (185 million) had a severe disability (1). Among this number, 5.1% and 0.7% are children, aged 0-14 years, or about 93 million and 13 million, respectively. When the data is further examined, the picture becomes even more alarming as statistics show that about 80% of persons with disabilities live in developing countries (2). According to the United Nations Children's Fund (UNICEF), this is because disability is linked with poverty (3). Poverty reduces a person's access to treatment and in effect may disallow working abilities. Paired with a childhood disability, a person faces the likelihood of a lifetime of poverty. Additionally, in developing countries where access to healthcare is a known problem, children with disabilities are likely to be excluded throughout their life. When disabled children are given proper healthcare and supportive services and technology, their functioning is improved, allowing them to participate in their society and contribute to their family and community (4).

The Philippine Statistics Authority estimates that 1 in every 5 persons with disability in the Philippines is a child aged 0-14 living with disability (5). According to the Philippine Health Insurance Corporation (PhilHealth), there are 1.5 million children who need assistive devices to help them carry out their daily activities and facilitate community participation (6). However, only 5% of these children have access to them. This number is highly associated with poverty and the lack of health care services available. UNICEF reported that, in 2017, 25.56% of poor Filipinos with disabilities were children (6). Disability has direct costs to children, such as reduced school attendance and lower quality of life, in addition to indirect costs to their families. Caregivers' reduced work productivity and the vulnerability of children with disabilities to catastrophic health expenditures both have a huge impact on the family income, among others.

Children with disabilities are considered to be one of the most marginalized sectors, experiencing social and economic disadvantages. Children with disabilities from poor families tend to have no access to appropriate health programs and basic education, compared to their richer counterparts who can avail of these services (7). Children with disabilities not only encounter physical disadvantage but also have to struggle with the social connotation of the disability, affecting not only the child, but the family as well.

Access to health services are also often restricted by the limited understanding about the needs of children with disabilities.

A survey in 2017 among families with children with disabilities in southern Philippines showed that while 79% have access to specialized medical services, only 68% have assistive devices, mostly coming from donations. Moreover, among these families, only 60% sought consult after seeing the need to refer their child, while 83% of healthcare costs is shouldered by families as out-of-pocket expenses.

As a response to these challenges, PhilHealth and the Department of Health (DOH), in collaboration with Physicians for Peace Philippines (PFPP) and UNICEF, introduced a benefit package for children with disabilities. This covers assistive devices and rehabilitation services for children with vision, hearing, mobility and developmental disability. This paper aims to discuss the development of the PhilHealth Benefit Packages for Children with Disabilities.

Methodology

PhilHealth and DOH, through the support of PFPP and UNICEF, formed a steering committee tasked to provide technical oversight in the development of a benefit package for children with disabilities. At the start of the development, services were categorized based on four types of impairment: hearing, vision, mobility, and developmental disability. In the development of the benefit packages, a series of methods were conducted including evidence review, epidemiological analysis, and costing analysis. Relevant stakeholders including policy makers, technical experts, health providers, managers, and patient groups were involved in dialogue and consultation of inputs throughout the process of package development. Each major methodology is discussed below:

Evidence synthesis

As the first step in package development, the team conducted a literature review on the algorithm of care and list of services provided based on the four types of impairment. Results from the review were validated by technical experts. After the finalization of the algorithm and list of services, standards of care were determined based on practice guidelines and inputs from consultations of service providers, hospital administrators, government agencies, and patient groups. During this process, an important consideration in designing the benefit packages is the availability of assistive devices and services in the local context. The main products of the evidence synthesis are algorithm of care, list of services, and standards of care. At the end of evidence synthesis, proposed package inclusions were identified and categorized into two groups: basic services and ideal.

Epidemiological Analysis

The main objective of the epidemiological analysis is to determine the disease burden of the four types of disability. The project team originally planned to conduct a national survey to determine the prevalence of disability. However, due to the unavailability of the confirmatory tools and logistical requirements, the researchers decided to estimate the

prevalence and incidence of disabilities through the WHO DisMod II program (8). Data was collected through systematic literature review and the results of the estimation were reviewed through a series of validation meetings with technical experts.

Cost Analysis

The cost analysis aims to determine cost of services identified through evidence synthesis. This will serve as a cost basis to determine the estimated cost of services included in the benefit packages. To analyze the cost of services, a facility survey was conducted for all types of disabilities to collect data on the availability of services, practices, compensation to health professionals, and cost of services. After establishing the proposed services and assistive devices, a costing survey tool was developed and pre-tested. The survey tool covers service provision, health personnel, and facility expenses. Each type of disability had one survey tool, except for hearing disability which required three types of tools because of different treatment settings. Health facilities providing services indicated in the proposed benefit packages were included in the survey. Since most health facilities are not providing assistive devices, manufacturers and suppliers were requested to participate in the cost estimation. Inputs were collected based on market and production costs. After costing of individual services, packages were costed based on a set of basic services and set of services in an ideal setting.

Results

Evidence synthesis

The review of interventions and evidence was based on three categories of services: assessment services, assistive devices, and rehabilitation services. The assessment services covered tests that would confirm the impairment and the need for assistive devices or rehabilitation. Screening services were not included in the benefit packages since these are targeted to be implemented in tertiary facilities. Screening services were still compiled but were targeted to be included in separate packages for primary care. All types of impairment included assistive devices except for developmental disabilities, which is focused on developmental assessment and therapy services.

The review of assessment services resulted to the same tests for both basic and ideal setting services. *Table 1* summarizes the inclusions of the proposed benefit package for hearing impairment. While several tests were identified in the review, the type of test to be used will depend on the age of the child. The assessment services covered include Auditory Brainstem Response Test, Age-Appropriate Behavioral Audiometer, Pure Tone Audiometry, and Audiological Assessment. In terms of assistive devices, basic services cover for the provision of hearing aids, while services in the ideal setting set include hearing aids, bone anchored hearing aid, cochlear implant, and middle ear implant. In terms of rehabilitation services, speech therapy is covered in both sets. For assistive devices, batteries, earmold

replacement, and other maintenance consumables required were included in the proposed services for inclusion. Moreover, hearing aid replacement every five years was also included.

Table 1. Proposed inclusions for the benefit package for hearing impairment

	Basic Services	Ideal Setting
Assessment Services	Auditory Brainstem Response Test Age-Appropriate Behavioral Audiometry Pure Tone Audiometry Audiological Assessment	Auditory Brainstem Response Test Age-Appropriate Behavioral Audiometry Pure Tone Audiometry Audiological Assessment
Assistive Devices	Hearing Aid	Hearing Aid Bone Anchored Hearing Aid Cochlear Implant Middle ear implant
Rehabilitation Services	Speech therapy	Speech Therapy

The proposed package inclusions for mobility impairment also includes assessment services, assistive devices, and rehabilitation services. *Table 2* shows the proposed inclusions for the benefit package for mobility impairment. Assessment of mobility impairment covers physiatrics assessment. In terms of assistive devices, the proposed package covers seating device, basic wheelchair, intermediate wheelchair, spinal bracing/orthosis, upper extremity prosthesis, lower extremity prosthesis, and lower extremity orthosis. For all orthoses, the difference between the two standards is the frequency of changing the assistive device. Patients with spinal bracing can avail of the service for a maximum of four replacements for those with idiopathic scoliosis and a maximum of 10 replacements for those with other spinal disorders. Rehabilitation services under ideal setting provide more sessions than for basic services set. Meanwhile, the difference for lower extremity prostheses is the type of foot included in the package (Solid Ankle Cushion Heel or SACH foot for minimum standards and Dynamic foot for maximum standards). Patients with prostheses, regardless of type, will be eligible for replacements following a yearly schedule for those 0 to 5 years old, every two years for 6 to 12 years old, and every three years for those 13 to 18 years of age.

Table 2. Proposed inclusions for the benefit package for mobility impairment

	Basic Services	Ideal Setting
Assessment Services	Physiatric Assessment	Physiatric Assessment
Assistive Device	Seating Device Basic Wheelchair Intermediate Wheelchair Spinal bracing/orthosis Upper extremity prosthesis Lower extremity prosthesis Lower extremity orthosis	Seating Device Basic Wheelchair Intermediate Wheelchair Spinal bracing/orthosis Upper extremity prosthesis Lower extremity prosthesis Lower extremity orthosis
Rehabilitation Services	Physical Therapy	Physical Therapy

Assessment services included in the benefit package for visual impairment are Visual Acuity Testing, Visual Field Testing, Contrast Sensitivity Testing, Color Vision Testing, Retinoscopy and Refraction, and Functional Vision Assessment. Table 3 shows the proposed inclusions for the benefit package for visual impairment. The different permutations of optical devices are based on their power and the type of material the optical device is made of. The last type of assistive device is the white cane for Categories 4 and 5 visually impaired patients which patients can claim up to two times depending on their needs. For ideal setting services, categories 1 to 4 visually impaired patients are entitled to two optical devices – one near device and one distance device. The power, material, and lens type will be determined by the child’s needs and as assessed by the prescribing health professional. Eligible category 5 visually impaired patients can avail of ocular prosthesis.

The proposed services for inclusion in the benefit package for developmental disability covers physiatric and developmental assessment under assessment services. Table 4 summarizes the proposed package inclusions for developmental disability. Under rehabilitation services, the proposed inclusion covers physical therapy, occupational therapy, and speech therapy sessions. There is no assistive device covered under developmental disability package. The main difference between the basic and ideal category is the number of therapy services provided.

Table 3. Proposed inclusions for the benefit package for visual impairment

	Basic Services	Ideal Setting
Assessment Services	Visual Acuity Testing Visual Field Testing Contrast Sensitivity Testing Color Vision Testing Retinoscopy and Refraction Functional Vision Assessment	Visual Acuity Testing Visual Field Testing Contrast Sensitivity Testing Color Vision Testing Retinoscopy and Refraction Functional Vision Assessment
Assistive Device	Technology Based Assistive Device Non-electronic Aid: Low Power, Near Non-electronic Aid: High Power, Near Non-electronic Aid: Low Power, Distance Non-electronic Aid: High Power, Distance Assistive Device Ocular Prosthesis White Cane	Technology Based Assistive Device Non-electronic Aid: Low Power, Near Non-electronic Aid: High Power, Near Non-electronic Aid: Low Power, Distance Non-electronic Aid: High Power, Distance Assistive Device Ocular Prosthesis White Cane
Rehabilitation Services	Environmental Adaptation Visual Skill Training Training on Activities of Daily Living Orientation and Mobility Training	Environmental Adaptation Visual Skill Training Training on Activities of Daily Living Orientation and Mobility Training

Table 4. Proposed inclusions for the benefit package for developmental disability

	Basic Services	Ideal Setting
Assessment Services	Physiatrics Assessment Developmental Assessment	Physiatrics Assessment Developmental Assessment
Assistive Device	None	None
Rehabilitation Services	Physical Therapy Occupational Therapy Speech Therapy	Physical Therapy Occupational Therapy Speech Therapy

Epidemiological Analysis

The literature search yielded six papers that can be utilized for the DisMod analysis. All retrieved articles provided sufficient data for the DisMod analysis, except for mobility impairment. The prevalence was modeled based on data on self-reported difficulty in moving from a study by De Guzman et al (9) since incidence on mobility impairment was not available. The full details of the epidemiological study can be retrieved from the Prevalence of Children with Disabilities in the Philippines Report by Wong (10).

Based on the estimation, the prevalence of visual impairment across the different categories is 18.4 per 10,000, corresponding to about 75,000 cases. *Table 5* enumerates the prevalence rate and prevalence cases of visual impairment for children aged 18 and below based on the analysis. Most cases of visual impairment fall under WHO Category 1 with about 29,100 cases, immediately followed by WHO Category 3 with about 29,000. WHO Category 2 has about 16,800 cases, while WHO category 4 has 9,600 cases. Lastly, WHO Category 5 visual impairment covers about 3,800 cases. Based on the results of the estimation, the prevalence of visual impairment decreases as the impairment becomes more severe.

Table 5. Prevalence rate and prevalent cases of visual impairment for children aged 18 and below (2016)

Severity of Visual Impairment	Prevalence per 10,000	Prevalent Cases
WHO Categories 1, 2, and 3	15.1	61,437
Moderate (WHO Category 1)	7.2	29,134
Severe (WHO Category 2)	4.1	16,817
Blindness (WHO Category 3)	3.8	28,975
WHO Category 4	2.4	9,658
WHO Category 5	0.9	3,830
Total	18.4	74,926

The prevalence of hearing impairment among children 18 years old and below is 368.9 per 10,000, which is estimated to represent 1.5 million children. *Table 6* shows the prevalence rate and prevalence cases of hearing impairment for children aged 18 and below based on the analysis. Based on the results of the epidemiological analysis, moderate hearing impairment represents about 96% of hearing impairment cases. Severe hearing impairment has a prevalence of 12.1 per 10,000 or 48,990 children. Lastly, profound hearing impairment has a prevalence of 3.8 per 10,000 corresponding to about 15,290 cases.

Table 6. Prevalence rate and prevalent cases of hearing impairment for children aged 18 and below (2016)

Severity of Hearing Impairment	Prevalence per 10,000	Prevalent Cases
Moderate (31 - 60 dB for 0 - 14 years old; 41 - 60 dB for 15 and above)	353.0	1,434,654
0 - 2 years old	412.5	281,357
3 - 5 years old	412.8	276,727
6 - 18 years old	323.3	876,570
Severe (61 - 80 dB)	12.1	48,990
0 - 2 years old	11.6	7,881
3 - 5 years old	12.2	8,157
6 - 18 years old	12.2	32,952
Profound (80 dB)	3.8	15,290
0 - 2 years old	3.7	2,501
3 - 5 years old	4.0	2,682
6 - 18 years old	3.7	10,107
Total	368.9	1,498,934

Based on the results of the study, mobility impairment has a prevalence of 31.3 per 10,000 or about 127,356 cases. Most of the cases can be found among children 10 years old and older. The prevalence of developmental disorders is 374.2 per 10,000, corresponding to 1,520,792 cases. *Table 7* shows the prevalence rate and prevalence cases of mobility impairment and developmental disability for children aged 18 and below based on the analysis.

Table 7. Prevalence rate and prevalent cases of mobility impairment and developmental disorders for children aged 18 and below (2016)

Age Group	Mobility Impairment (Prevalence per 10,000)	Mobility Impairment (Prevalent Cases)	Developmental Disorders (Prevalence per 10,000)	Developmental Disorders (Prevalent Cases)
0 - 4	18.3	20,802	335.9	381,871
5 - 9	17.8	19,159	361.1	389,563
10 - 14	45.3	46,946	391.7	405,610
15 - 18	49.8	40,449	405.93	329,953
Total	31.3	127,356	374.2	1,520,792

Cost Analysis

The costs presented in *Table 8* are the total cost of each benefit package for hearing impairment. As discussed during the project, the technical committee guiding project implementation, maintained that the objective of the benefit packages is to cover what are provided based on basic or minimum standards of care as opposed to the ideal setting or maximum standards. As a result, the costs presented below are based on the list of basic services for each type of disability.

Benefit packages under hearing impairment integrates the assessment services with assistive device provision. The cost of batteries, earmold replacements, and other consumables for five years are already integrated in the costs indicated above. Packages are disaggregated based on age since the type of tests would depend on the age of the child. Furthermore, a different type of hearing aid was prescribed for moderate impairment as compared to hearing aids for severe to profound hearing loss. Speech therapy sessions were included in separate benefit packages and cover more sessions for severe to profound hearing loss, as compared to the sessions covered in moderate hearing loss.

Table 8. Costs of proposed hearing impairment benefit packages. (Conversion rate: 1 Php = 0.020 USD)

Benefit Packages	Rate (Php)	Rate (USD)
Assessment and hearing aid provision (0 to 3 years old with moderate hearing loss)	53,460.00	1,047.74
Assessment and hearing aid provision (0 to 3 years old with severe to profound hearing loss)	67,100.00	1,315.06
Assessment and hearing aid provision (3 to 6 years old with moderate hearing loss)	45,400.00	889.77
Assessment and hearing aid provision (3 to 6 years old with severe to profound hearing loss)	54,100.00	1,060.28
Assessment and hearing aid provision (6 to 18 years old with hearing loss)	43,880.00	859.98
Speech therapy sessions for moderate hearing loss	22,100.00	433.13
Speech therapy sessions for severe to profound hearing loss	63,420.00	1,242.94

Mobility impairment benefit packages are categorized based on the type of assistive device that will be provided. *Table 9* summarizes the total cost of each benefit package for mobility impairment. Assessment services, assistive devices, and rehabilitation services are already integrated in each benefit package. The costs indicated in the package rate is based on a single lateral side. If both sides would require assistive devices at the same time, the package rate is multiplied by two. Exemptions to this are the benefits for Talipes Equinovarus or clubfoot and spinal bracing/orthosis where laterality is not applicable.

Benefit packages for visual impairment already integrated assessment services, assistive devices, and rehabilitation services for each benefit package. The packages are divided based on the type of assistive device they will receive according to the type of visual impairment category of the child. *Table 10* shows the total cost of each benefit package for mobility impairment.

The developmental disability benefit packages are divided into assessment by a physician and allied health professionals. *Table 11* shows the costs of the benefit packages under developmental disability. Rehabilitation therapy services are included in the benefit package and would depend on the prescribed number of sessions during assessment. The cost indicated in the benefit package covers 10 sessions of therapy services for each set. Each set can be availed for a maximum of nine sets of therapy sessions.

Table 9. Costs of proposed mobility impairment benefit packages (Conversion rate: 1 Php = 0.020 USD)

Groups of Products	Benefit Packages	Rate (Php)	Rate (USD)
Upper Extremity Prosthesis	Shoulder Disarticulation	132,300.00	2,592.88
	Above Elbow (AE)	67,300.00	1,318.98
	Below Elbow (BE)	47,300.00	927.01
	Finger glove (for 1 finger)	17,300.00	339.05
	Hand glove (for more than 1 finger)	22,300.00	437.05
Lower Extremity Prosthesis	Hip disarticulation	163,540.00	3,205.14
	Above knee or with knee disarticulation	61,940.00	1,213.93
	Below knee or ankle disarticulation	31,540.00	618.14
	Partial foot	26,540.00	520.14
Lower Extremity Orthosis	Talipes Equinovarus or clubfoot	17,860.00	350.03
	Ankle foot orthosis (AFO)	13,110.00	256.94
	Knee ankle foot orthosis (KAFO)	29,210.00	572.47
	Hip knee ankle foot orthosis (HKAFO)	50,810.00	995.80
Spinal Bracing or Orthosis	Spinal bracing/orthosis	32,180.00	630.68
Seating Device / Wheelchair	Seating device, for ages six months to less than seven years old	15,470.00	303.19
	Basic Wheelchair, for ages seven to less than 18 years old	12,730.00	249.49
	Intermediate wheelchair, for ages seven to less than 18 years old	29,450.00	577.18

Table 10. Costs of proposed visual impairment benefit packages (Conversion rate: 1 Php = 0.020 USD)

Benefit Package	Rate (Php)	Rate (USD)
Optical aid 1: Low Power Distance, Categories 1, 2, 3, 4 visual impairment glasses + low power optical aid	7,350.00	144.05
Optical aid 2: High Power Distance, Categories 1, 2, 3, 4 visual impairment progressive eyeglasses + low power optical device	13,820.00	270.85
Optical aid 3: Colored Filter Categories 1, 2, 3, 4 visual impairment	2,940.00	57.62
White Cane, category 5 visual impairment	1,000.00	19.60
Ocular prosthesis	20,250.00	396.87

Table 11. Costs of proposed developmental disability benefit packages (Conversion rate: 1 Php = 0.020 USD)

Benefit Packages	Rate (Php)	Rate (USD)
Developmental and functional assessment by a medical specialist only	3,626.00	71.06
Developmental and functional assessment by a medical specialist and three allied health professional or rehabilitation therapist	5,276.00	103.40
Rehabilitation Therapy (PT, OT, and ST)	5,000.00	97.99

Discussions

After the conduct of the evidence synthesis, costing analysis, and epidemiological analysis, the financial cost of each benefit package was determined. Alternative scenarios were developed to determine alternative policy options for health financing. The alternatives developed provided a less comprehensive benefit package but would still be open for inclusion of other components after initial implementation. The results of this study were submitted to Philhealth to serve as inputs for the actuarial studies. The actuarial studies assessed the potential impact of the benefit packages and provided insights on the sustainability of benefit package implementation from Philhealth perspective. This is conducted by the office of the actuary of Philhealth in collaboration with the Benefits Development and Research Department (BDRD).

In 2016, PhilHealth Circular No. 2016-0032 provided for Benefit Packages for Children with Disabilities covering specialized assessment, assistive devices and therapy sessions for

children with mobility, developmental, hearing and visual impairments. Overall, the development of benefit packages for children with disabilities facilitated the coverage of assistive devices and rehabilitation for children with disabilities. *Table 12* summarizes the inclusion of the approved benefit packages.

Table 12. Summarized inclusion of the approved packages.

Benefit Package	Assessment and Diagnostic Services	Assistive Devices	Rehabilitation Services
Hearing	<ul style="list-style-type: none"> • OAE • ABR • Age-Appropriate Behavioral Audiometry • Puretone Audiometry 	<ul style="list-style-type: none"> • Hearing Aid 	<ul style="list-style-type: none"> • Speech Therapy
Mobility	<ul style="list-style-type: none"> • Physiatric assessment 	<ul style="list-style-type: none"> • Upper extremity prosthesis • Lower extremity prosthesis • Lower extremity orthosis • Spinal bracing or orthosis • Seating device/wheelchair 	<ul style="list-style-type: none"> • Physical Therapy • Training on use of device
Vision	<ul style="list-style-type: none"> • Visual Acuity Testing • Visual Field Testing • Contrast Sensitivity Testing • Color Vision Testing • Retinoscopy and Refraction • Functional Vision Assessment 	<ul style="list-style-type: none"> • Technology Based Assistive Device • Non-electronic Aid: Low Power, Near • Non-electronic Aid: High Power, Near • Non-electronic Aid: Low Power, Distance • Non-electronic Aid: High Power, Distance • Ocular Prosthesis 	<ul style="list-style-type: none"> • Environmental Adaptation • Visual Skill Training • Training on Activities of Daily Living • Orientation and Mobility Training
Developmental Disability	<ul style="list-style-type: none"> • Developmental Assessment • Physiatric assessment 	<ul style="list-style-type: none"> • None 	<ul style="list-style-type: none"> • Physical therapy • Occupational Therapy • Speech Therapy

The development of a PhilHealth benefit package provides financial risk protection to families of children with disabilities. Since the cost indicated in the approved issuance

covers for basic services, PhilHealth allows health facilities to propose a co-payment mechanism if patients want to avail more comprehensive services. Through co-pay mechanism, patients are allowed to avail of services or devices with higher or better specifications than what is covered by the package, provided that they will shoulder additional costs which should not be higher than the amount indicated in each rate.

Throughout the process of package development, three stakeholder consultation meetings were conducted, while several consultation workshops and meetings were held. Professional societies, academic institutions, national government agencies, regional offices, patient groups, suppliers, and hospital managers were invited to participate in the consultations. Critical points discussed during the consultations are basic and ideal set of services, standards of care, roles and responsibilities of health workers, and guidelines for implementation.

An important consideration in the package development is the participation of stakeholders. A total of three major stakeholder consultations were conducted throughout the benefit package development. The first consultation was conducted during the development of the initial of services to be considered to be included in the proposed package inclusions. The second consultation was done during the development of standards of care for the benefit package. In this consultation, the project team ensured to include representatives from professional societies and technical experts. During the development of standards of care, an important consideration is the applicability of the benefit package in the Philippine context. The last consultation was conducted after the conduct of epidemiological analysis and costing analysis. During the consultation, the benefit package prototypes and costs were presented to the participants. Throughout the consultative process, the members of disabled people's organization and patient groups participated and provided inputs in the package development.

Conclusion and Recommendations

The proportion of disabled people is rising and now stands at about one billion worldwide. The situation becomes even more alarming with data showing that 80% of these people reside in developing countries. This will persist if health care interventions and assistive devices remain inaccessible to the majority, especially to children whose experiences influence the course of their entire life. Initial steps were taken to ensure inclusive and encompassing benefit packages for children with disabilities. A total of four PhilHealth benefit packages for children with disabilities were introduced to cover specialized assessment, assistive devices and therapy sessions for children with mobility, developmental, hearing and visual impairments. These packages provide financial risk protection for disabled Filipino children and their families ensuring accessible health care interventions and assistive devices.

Following these achievements, it is important to ensure effective and efficient implementation of these benefit packages. In ensuring the implementation of benefit

packages, the capacity of health facilities to deliver services for children with disabilities should be enhanced. At present, the government does not have posts for new professions including allied health professionals such as certified prosthetists-orthotists, audiologists, and wheelchair service personnel. Since the benefit packages require these personnel, human resource policies should be developed to include new professions to ensure the availability of health services.

The development of monitoring and evaluation framework is significant to monitor service delivery, improvement in health status, and impact on financial risk protection. Additionally, while this is a big leap in achieving equitable health care, new challenges in implementation exist to include alignment to the new framework within the context of the 2019 Universal Health Care Act that provides for stronger primary care, and financing and management of services through service delivery networks.

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