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# Uncovering unexpected impacts: the case of digital manufacturing of wheelchairs in Kenya

Giulia Barbareschi<sup>1, 2</sup>, Sibylle Daymond<sup>3</sup>, Jake Honeywill<sup>3</sup>, Dominic Noble<sup>3</sup>, Nancy Mbugua<sup>4</sup>, Ian Harris<sup>3</sup>, Catherine Holloway<sup>1, 2</sup>

<sup>1</sup>University College London Interaction Centre, <sup>2</sup>Global Disability Innovation Hub, <sup>3</sup>Motivation UK, <sup>4</sup>Motivation Africa

## ABSTRACT

To address issues around the provision of appropriate wheelchairs in low-and-middle income countries Motivation developed a new method for producing customized wheelchairs leveraging technologies such as Computer Aided Design and 3D printing. To test the feasibility and acceptability of this new provision system alongside the quality of the wheelchair manufactured, a 5-month study was carried out in Kenya. Five local members of staff and 8 expert wheelchair users were recruited as participants. The results of the study show that in general both the local members of staff and the wheelchair users had extremely positive opinions concerning this new delivery system. However, technical and logistic challenges will have to be taken into account in future wider implementations. Beyond the measurable outcomes recorded as part of the study, the project had a considerable impact on participants. The inclusive assessment process made wheelchair users feel empowered and increasing both their confidence and their knowledge about appropriate wheelchairs. Similarly, the staff at Bethany Kids reported that their involvement in the study changed the way they approach their clinical practice, making them more prone to listen and proactively involve users when prescribing a new wheelchair or adapting an old one.

## INTRODUCTION

According to the WHO's Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings a wheelchair must meet the user's individual needs and environmental conditions, provide postural support, and be safe and durable [1]. The wheelchair must be also available and affordable and it must be possible to maintain the product in country through a sustainable system [1]. In Kenya, there are more than 500'000 people with physical disabilities, many of whom are likely to be wheelchair users in need of appropriate wheelchairs [2]. Although there are organisations and institutions in Kenya that have received WHO wheelchair provision training and are committed to providing appropriate wheelchairs, reliance on intermittent supply chains and the continued donor supply of inappropriate wheelchairs remain a very significant problem [3,4].

Currently, wheelchair provision in LMICs follow one of three models: 1) importation, or donation, of complete wheelchairs, new or recycled; 2) importation, or donation, of wheelchair components for local assembly, or; 3) local manufacturing of wheelchairs both at large and small scale. Overall, there is no model which consistently outperforms the others and all of them can be applied to provide good services. However, all of them are affected by unique challenges that can compromise their effectiveness. Models that are heavily reliant on imports are susceptible to supply disruptions which can potentially lead to the provision of intermittent services [5]. Furthermore, imported or donate wheelchairs designed for different environments can be unsuitable to the local conditions [4]. On the other hand, local manufacturing might fail to provide products that consistently meet standards of quality [6].

Leveraging the use of novel digital technologies could help to transform the way in which wheelchairs are designed and manufactured [7]. Through the use of Computer Aided Design (CAD) and 3D printing it is possible to manufacture bespoke assistive products in locum for a relatively contained cost [8]. This de-centralised approach to manufacturing could enable clinicians and technicians in LMICs to take ownership of wheelchair provision, with the potential to tailor appropriate solutions for the end user, manufacturing on demand and within proximity to their point of use. At the same time, the use of CAD software and digital manufacturing technologies would ensure consistent quality standards across different sites, minimising room for error. Such a model also lends itself to sustainability as the expertise for repair would also be locally based.

Over the last three years, Motivation UK has developed a new method to design and produce custom wheelchairs using a parametric model that combines 3D printed nodes and metal tubes. The system enables clinicians to position and take accurate measurements of the client using a wheelchair simulator and input measurements and preferences of the clients in a simple computer interface. The programme feeds the data into a parametric model that creates different geometry of the nodes, constructing the full set of wheelchair joints in a file format suitable for 3D printing. The parametric model also gives the 'blueprint' for the chassis tubes in terms, enabling technicians to fully manufacture a wheelchair chassis locally with the desired specifications (see Figure 1). As the system is still under development, the model is currently only suitable for designing and manufacturing three-wheeled wheelchairs.

We carried out a 5-month research project in collaboration with Bethany Kids (Joytown, Kenya) to explore the acceptability and feasibility of this new wheelchair provision method from the perspective of both users and service providers, and to evaluate the quality of the wheelchairs manufactured with this method. A local team was trained to provide wheelchairs using this innovative model, and 8 local expert wheelchair users evaluated the service provision model alongside the products that were manufactured by the local team.



**Figure 1 Wheelchair chassis of different configurations made according to the measurements and specifications collected from the clients**

## **METHODS**

### Training phase

During this phase of the project a clinician and two designers from Motivation UK trained two wheelchair technicians and three clinicians from Bethany Kids. Under trainers' supervision, the trainees first manufactured three initial test wheelchairs using themselves as models to familiarize themselves with the new procedures and technology. Subsequently, two additional wheelchairs were manufactured, also under supervision, for two wheelchair users. Structured observations were conducted during training to document the difficulties encountered by trainees, and semi-structured interviews were carried out after each phase of the training to capture their experiences.

### Independent service delivery phase

Throughout this phase the trainees independently manufactured 6 wheelchairs for selected wheelchair users. A technical officer from Motivation Africa was present to observe the process and offer support when required. Furthermore, technical support for any 3D printing or manufacturing issues was provided remotely by the designers in Motivation UK. Interactions between the trainees and the support team were logged to understand the difficulties encountered throughout this phase. Semi-structured interviews were conducted at the end of the study to gather the experience of the trainees and their opinions about future implementations of this model of service provision.

### User evaluation

Eight bespoke wheelchairs for were manufactured as part of the project. Users were asked to trial and evaluate the wheelchair according to a set procedure. First, they completed the Wheelchair Skills Test (WST) 5.0 with the new prototype to enable a trial of the wheelchair across different tasks. At the end of the test users filled in the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) version 2.0 to record their overall satisfaction with the wheelchair. This was followed by a semi-structured interview in which the researcher sought to collect feedback about the wheelchair and the experience of the user throughout the service delivery journey. At the end of the project we carried out a focus group with all the users to enable an open discussion and exchange of opinions about the wheelchair design, potential design improvements and implications of this novel service delivery model.

## **RESULTS**

### **Performance and satisfaction with the new wheelchair**

All users except for one were able to complete the WST. Unfortunately, User 5 was unable to carry out the WST as her wheelchair had some structural issues and the clinicians decided that completing the WST could have put the client at risk. As none of the wheelchair users who were part of the study reported ascending or descending stairs with their wheelchairs normally, we did not include these skills in the WST. Furthermore, as the wheelchair could not be folded, but the seat could be detached from the frame, skill 11 (folds and unfold the wheelchair) was adjusted to reflect the change (see Figure 2).

Overall, scores in the WST were high for all participants with only one user scoring below 60% (50.5% User 6). All participants encountered some difficulties in assembling and disassembling the seat from the wheelchair due to the weight of the seating unit. All users scored highly on basic propulsions skills, transfer skills and advanced propulsions skills, such as negotiating soft surfaces, slopes and gaps. Although four users were unable to complete any wheelie (skills 27-31), three (Users 4,6 and 7) stated they were also unable to do so with their own wheelchairs;

User 2 found it more difficult to perform a wheelie in the new wheelchair as the weight distribution of a that particular three wheeler was different from her usual 4-wheeled chair.

Users scored the prototype wheelchair highly on most of the QUEST 2.0 items. Considering a maximum score of 5, the lowest average score was attributed to “Ease of adjusting parts of the assistive device” (Mean  $4 \pm .82$ ) and “Weight of the assistive device” (Mean  $4.14 \pm .69$ ) as most users found the seating unit too heavy. Highest average scores were attributed to “Comfort of the assistive device” (Mean  $4.86 \pm .38$ ) and “Dimensions of the assistive device” (Mean  $4.71 \pm .49$ ). When asked about the most important aspects of their assistive device, users most often cited Comfort (6 Users), Durability (6 Users) and Safety (4 Users).



**Figure 2 Technician showing the users how to remove and fold the seating unit**

### **Acceptability and feasibility of the provision system for users**

Overall, wheelchair users rated the service provision system very highly. What excited the users most was the fact that a service provision model for customized wheelchairs takes into account not only their body dimensions, but also their living environments, lifestyles and mobility goals (“*This model of wheelchair provision is great because the wheelchair is made according to your needs and you have a chance to express what your needs are*” U3). Users acknowledged the fact that this service delivery model could potentially take more time and require multiple visits to the clinic. However, they clearly stated that a wheelchair that could better address their needs would be worth a potentially longer waiting time and the logistical challenges that might be linked to multiple visits. To mitigate difficulties, users proposed having mobile assessment clinics that could travel to the community so that the user would only need to reach the central distribution centre to collect the wheelchair at the fitting appointment (“*You could have, for the measurements stations coming near us, rather than only few of us travelling here you could have many people coming if the station was closer to us. And then you came here to get the wheelchair fitted*” U8). These findings are interesting, however, it is the unexpected outcomes of using a truly user-centered assessment process which we feel are most noteworthy.

First, users stated feeling at the centre of the fitting process – having their opinions listened to by clinicians during assessment in particular gave them an increased sense of confidence and self-worth. Second, learning about how different elements of wheelchair configuration (such as camber and front castor size) might affect their user experience, made them think about their needs, their own wheelchairs and how they could be improved. Third, some users stated that through the assessment process they learned more about their postural and seating requirements potentially affecting their choices around wheelchair setups in the future. Finally, all users stated that interacting with this new service provision model gave them a better understanding of what an appropriate wheelchair really could be; it motivated them to advise their local services and advocates for better provision in their communities (“*I have learned about the project... But I have also learned how appropriate wheelchairs are made and now I know that an appropriate wheelchair is very important. And if someone is asking for one, I’ll be very keen to educate them on appropriate wheelchairs*” U1).

### **Acceptability and feasibility of the provision system for providers**

The Bethany Kids staff were initially uncertain about this new service delivery system but, by the end of the project, they unanimously expressed positive opinions about it. The initial concerns about the provision model related to the technological aspects and the increased complexity of the assessment process. In particular, clinicians were worried about the need to take extremely accurate measurements during assessment, with the risk of “ruining” the production of the wheelchair if they were somehow inaccurate. On the other hand, technicians were worried about the dependency on sophisticated and potentially fragile 3D printers and the impact of breakages and likely power cuts on provision. However, throughout the project clinical staff found that taking accurate seating measurements was simplified by the use of the wheelchair simulator (see Figure 3) (“*One thing that I found easy was the measurement on the simulator because there are the arrows and it’s just easier than when you have to do it on the person with the blocks or what you have around*” T5). Furthermore, the wheelchair technicians gained increased confidence as they solved (with some remote support from the technical team in the UK) each of the issues that arose during the project, none of which had a severe impact on wheelchair production.

As for the users, the impact of the project on the participating Bethany Kids staff went beyond measurable outcomes. Clinicians stated that the experience gained as part of the project had a direct impact on their everyday practice. Learning about the importance of involving the users in the prescription of customized wheelchairs made them more prone to listen and proactively engage their clients to ensure better outcomes (“*I now know that if I want to give a*

wheelchair for a patient who wants maximum support these are the factors that I consider and if I have a patient with different needs how I can give him a right wheelchair for the situation. I listened and I know what are the important things I need to ask" T2). The technicians became more aware of how technology could become a part of their everyday work; this motivated them to investigate how similar approaches could be used to provide other customized devices, such as handgrips for crutches or smaller postural support devices. Finally, all participating staff stated that the training received as part of the research had a positive impact on their wheelchair provision skills in general, making them more competent and motivated to provide appropriate wheelchairs for their clients.

## DISCUSSION

In keeping with best practice, our team developed a research protocol to evaluate a new model for wheelchair provision according to a series of defined outcomes. The findings that directly related to these pre-selected outcomes helped us to identify flaws in the design of the wheelchairs, improve training content, methodology, and adapt various aspects of this innovative model of wheelchair provision to make it more feasible to this particular context. However, we believe that some of the most important findings originated from this research were "collateral findings" or "spill-over effects" that we did not specifically look for, but that strongly emerged from data collected. When further explored, these findings clearly indicate the value that participants attributed to the goals of the research project and the impact it had on them. Most of these findings could only emerge thanks to the flexibility granted by qualitative methods that enabled us to use a combination of exploratory and confirmatory approaches [9]. Furthermore, the fact that the researchers were not specifically looking for additional indicators of impact from the project likely reduces the chance of confirmation bias. Finally, the delivery of the project also strengthened the resolve of all partners involved to leverage local resources and place extra emphasis on training of clinicians, technicians and users in the quest for providing appropriate wheelchairs to people in LMICs.



**Figure 3 Clinicians positioning the client on the wheelchair simulator**

## CONCLUSION

Novel technologies can help provide appropriate wheelchairs to users living in LMICs. When implementing interventions trying to address these challenges, researchers should use flexible approaches and outcome measures or tools, that enable them to capture the wider impact of a product or service innovation on stakeholders beyond the explicitly stated outcomes of the project.

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## **Assistive Technology awareness and utilization of its potential among lower limb amputees of Delhi, India**

Chitra Chander<sup>1</sup>, Srinivasan Kannan<sup>2</sup>

<sup>1</sup>Independent Consultant, <sup>2</sup>Achutha Menon Centre for Health Science Studies,  
Sree Chitra Tirunal Institute for Medical Sciences and Technology

### **ABSTRACT**

Assistive Technology (AT) can do wonders in the life of the user but only one in every 10 people in need have access to assistive technology due to high cost and lack of awareness, availability, trained personnel, policy and financing. We conducted a study among 24 lower limb amputees in Delhi, India. We aimed to study the assistive technologies being used and their utilization. First author collected data and documented the experiences of users after amputation. We found that half of the participants were not aware of the AT options available initially and three quarter of them mentioned that they accessed the assistive technologies after an average time of one and half years after amputation. In this study, it was found that the awareness among the users on AT is dependent on the type of AT they use. Which makes it evident that many have lived through their productive age without a support and compromised both personally and professionally. Hence, the purpose of assistive technology lost to achieve its goal and due to lack of complete knowledge even after accessing people did not use the technology to its fullest potential. This is an example for the problems caused by adapting problem solving approaches in healthcare technologies that have limitations, which clearly raises a concern that, is making a solution available in the market enough? or are there more dialogues that need serious attention while introducing an AT to the marketplace. This reflect upon the knowledge gap between what is known and the assistive technologies available in place. Information, education and communication(IEC) is an essential element in any process of intervention development and distribution. Effective IEC determines the uptake and success of any intervention. The AT user must be made aware, educated and taught about the whys and hows of the technology to match and achieve optimal utilization of AT features. This paper highlights the importance of such interventions in a process of AT development and experiences of lower limb amputees in achieving the technological goals. This further has implication in users' life attainment outcomes. For the development of assistive technologies, the developers need to involve the users in every stage of development through adapting unconventional exploratory approaches to understand the needs of the user in a better way. Developers should also keep the social, economic and technological aspects of low-middle income countries in mind, along with engaging the users in all phases of the development of technologies to understand how to achieve utilization to the maximum extent when introduced at the right time and right place. That will improve the outcome and in turn would support the users to attain good life with empowerment, and will help in achieving social and emotional well-being.

### **INTRODUCTION**

Assistive technology, an umbrella term about the systems and services associated with the assistive products and services. Assistive products maintain and improve the user's functioning and independence to promote well-being. The facts on the Assistive Technology suggests only one in 10 persons in need access the assistive technologies [1]The reasons associated with poor access are poor awareness about the technologies, accessibility and availability of such technologies, non-availability of personnel for training and finance and so on. It is also heartening to note the low and middle income countries are far below in access to assistive technologies. [2]There issues associated with the uneven distribution of such technologies among such countries due to insufficient resources and existence of large gaps between haves and have-nots.[3] Other reasons for poor diffusion of the technology are, ineffective promotional campaigns, service provider characteristics and attitude, higher cost for the product, non-availability of timely information, and others. [4,5,6] In the present scenario, the awareness among the users on AT is dependent on the type of AT they use. This could reflect upon the knowledge gap in the AT available. Information, education and communication is an essential element in any process of intervention

development and distribution. Effective IEC determines the uptake and success of any intervention. There are limited number of publications focusing on awareness of existing interventions in the world, which could be a determining factor for lower uptake of assistive technologies. There is also dire lack of health promotion activities in regard to persons with disabilities. Studies are limited in the field of disability that entirely focuses on the element of awareness as a determining factor in the utilization of the intervention. Role of health promotion focusing persons with disabilities is very limited. The present paper is an effort to address the gap in awareness on the assistive technologies for the persons with disabilities, with the specific reference to lower limb amputees.

## **METHOD**

Using exploratory research design, total 24 lower limb amputees from 14 rehabilitation centers in Delhi and national capital region, India have participated in the study. There was homogeneity among participants from one center. Organization profile include, six privately run centers, four government operated centers, and four were run by non-government organizations. Data were collected during June to August 2018. Following ethical practices which included obtaining ethical clearance to conduct the study, all participants were consented to participate and the participation was voluntary. The participants profile includes they are in the age group of 18 to 49 years with the mean age of 35years. They hail from Delhi, Haryana, Jammu& Kashmir, Rajasthan, UP and Bihar. 70 percent are male, 50 percent unmarried, and with accident as major cause of accident. Using an interview tool questions on awareness about the assistive technologies, on utilization of such technologies, problems faced if any, and the availability and accessibility of such technology were asked. The first author conducted data collection and the interviews were recorded.

## **ANALYSIS**

The recorded interviews and field notes were analyzed, using Weft QDA software (1.0.1) after transcription and translation. Then codes were generated following patterns We followed axial coding following lumping and splitting. Side by side, we were also writing memos for each of the quotes. Based the codes we grouped them in to different themes. Validation of the codes were done by sharing the codes between the authors. [7] The codes were not shared with the participants for the purpose of validation. This helped us theorizing the problem.

## **FINDINGS**

The participants were of the age group of 18 to 60 years. Three quarter of them were below knee amputees, one of was bilateral amputee and the rest were above knee amputees. Only 20% of them had insurance coverage for the ambulatory care. The Assistive Technology used by the participants include, prosthesis, wheelchair, tricycle, crutches and cane sticks. However, there are instances that some used multiple assistive technologies in different circumstances. 22 of them used prosthesis which gives more mobility support and hence were considered better than other AT for amputees. While, others were still using cane sticks due to non-affordability of prosthesis, which are highly priced. The prostheses used were in the forms of modular prosthesis, ALIMCO (Artificial Limbs Manufacturing Corporation Of India) prosthesis [8]and Jaipur foot [9]. Based on the definition by the user in- local context, modular prosthesis is availed from a private center and has support higher activity levels, ALIMCO is the prosthesis that is produced and distributed under a national scheme which is deemed to provide moderate to high level activity support, and Jaipur foot is produced and distributed by a faith based non-governmental organization and has limited mobility and activity support.

About 17 percent of the participants were employed regularly prior to amputation and it was reduced to eight percent at the time of interview. The average time taken to seek care was 19 months which is very much higher than the recommended period for seeking ambulatory care (2 to 180 months). The reason for the delay was lack of financial assistance. The sources of financing for the users are, family saving, property mortgage, loans from unorganized money lender, personal savings. Two third of the assistive

technology users spent over ₹ 2,00,000(INR). It was found that exorbitant prices and no funding resources for such high cost were the reason for most of the participants to prefer the aids that support restricted mobility. For the question on the sources of information on the Assistive Technology providers, respondents majorly identified a) friends, b) acquaintances and c) other AT users, . No participant reported receiving any information either from the rehabilitative care provider or the general health care provider providing treatment. This finding indicates poor health information sharing by the healthcare providers.

## **DISCUSSION**

According to the science of sustainable consumptions, public awareness plays an important role. It is important to note that the awareness about the number of interventions available are shared and awareness created among the potential users will address the problem as well as achieve the purpose of developing such technology. The success of any assistive technology will depend on the effort put on creating awareness and knowledge among the users. [10] Even though on paper evidences suggest there are more number of high mobility supporting interventions or assistive technologies for people in need, the number of people using them are still not been documented.

### **Affordability and Accessibility**

This study found a majority of people with lower limb amputation are using lower mobility supporting assistive technologies and it is an important topic that needs to be addressed. It is also important to note that the technology options that are available for lower limb amputee with better functionalities are either unaffordable to many or if they are affordable then are not found to be appropriate. The cost, availability, knowledge about the features of assistive technologies with higher features still needs to be addressed. Another important issue emerged from the study was the assistive technologies are not locally available and people have to travel larger distances for availing them.

### **Awareness**

Even the sources of information on the assistive technology providers are mostly through informal communication channels. The healthcare providers who were engaged in ambulatory care did not inform the appropriate aids to be used by the users.

Outcomes of the assistive technology use could be best described by the uptake and utilization quantitatively but the performance improvement is a qualitative aspect which is not studied vigorously and could be important in accessing the success point of an intervention when used to its fullest potential.

Participants appear not to be aware of the basic uses of the prosthesis in terms of, the duration- how long is it advisable to use the prosthesis, what could be the cause of pain in daily use of prosthesis and does it need to be attended, what are the activities that can be performed while one uses the prosthesis. The change in the trend of the employment status of the user from being employed to unemployed or under employed after the amputation even after using assistive technology is an important scenario suggesting the lack of utilization of the technology to its fullest potential.

The development of an intervention is supposed to be user centric but the data presented in this study indicates that there are system failures system is failing in providing the awareness, knowledge about the product to the user which is resulting in the under-utilization of the intervention.

### **Lack or poor quality of User Training**

Participants who were using the prosthesis with higher mobility support mentioned not being able to carry out day to day activities such as, climbing up the stairs, sitting while using prosthesis for longer duration, walking without a support and so on. Completely making the activities such as physical exercise, cycling, jogging, brisk walking all out of reach and context for users. Though the investigator identified that the prosthesis had a potential to support all activities, the users were not aware of it. They were not provided with any proper training to carry out those activities and also there was a lack of motivation to do so. This clearly reflects to the social and economic outcome. People even after having the best service in terms of the assistive technology they own, were not utilizing it and were compromising on their comfort and their capabilities. This could be a reason that there is still a stigma attached to the persons with disabilities. Though a person with amputation can go back to normal life when fitted with a good prosthesis but when the person fails to use it, they fail in being a complete member of the society. It is still a wonder for people in lower middle income countries to see a person wearing a prosthesis and carrying out the daily life independently. This is indicative of the dire need of awareness raising and making the intervention more useful.

### **Need of the hour**

It would be necessary to work with the users to find a way to raise awareness on increasing the uptake, awareness and utilization of the intervention. Success stories would set out positive examples. Involving a user throughout the process of ideation, development, launch, strategizing, awareness building, and rehabilitation through an intervention is necessary.

Paying vigorous attention towards bridging the knowledge gap between what is available and known is as important as developing new technologies. Making the existing technologies available and accessible for anyone who need it would fill in a lot of void in the field of assistive technology and rehabilitation. Mapping the points of intervening for knowledge transfer and channeling the information through a systematic process is essential. Mass communication along with targeted, clear, concise, correct, coherent, complete and courteous communication is the key along with other approaches.

### **CONCLUSION**

Even after six years of Sustainable Developmental Goals (SDGs), we have not progressed much on inclusion of persons with disabilities on various aspects. The field of assistive technology is blooming with interventions to support persons with disabilities relapse to socially acceptable complete life. But even today there are districts which has no rehabilitation centers is an important thing to be addressed. With the rise in expenses of treatments, absence of any social security schemes and insurance, lack of knowledge and awareness potential AT users are still not utilizing the interventions. Structural changes without understanding the barriers in utilization will lead to non or under-utilization of such facilities.

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## THE VALUE OF VOCABULARY STANDARDS TO DISCUSS AT OUTCOMES AND IMPACT

Linda-Jeanne Elsaesser<sup>1</sup>, Sajay Arthanatz<sup>2</sup>, Stephen Bauer<sup>3</sup>, Emma Friesen<sup>4</sup>, Takenobou Inoue<sup>5</sup>, Emily Steele<sup>6</sup>

<sup>1</sup>Elsaesser Consulting, <sup>2</sup>University of New Hampshire, <sup>3</sup>National Institute on Disability, Independent Living, and Rehabilitation Research, <sup>4</sup>Raz Design, Inc., <sup>5</sup>Research Institute of National Rehabilitation Center for Persons with Disabilities, <sup>6</sup>Centre for Universal Design Australia

### ABSTRACT

Recognizing the need for effective access to assistive technology, the World Health Organization (WHO) published the Proceedings of the GReAT Consultation, Global perspectives on assistive technology 2019 [1]. The proceedings contain over 80 manuscripts presenting international perspectives on “the current need, demand and supply of assistive technology, as well as to outline good practices for innovation and recommendations to improve access” [1] (p. i). Accepted for publication in this document was the manuscript by the authors titled “*The value of vocabulary standards towards improving access to assistive technology (AT)*”.

This present paper justifies the need for a vocabulary standard comprising key concepts, terms, and definitions to ensure that communication in the domain of assistive product services is complete, unambiguous, and efficient within national and across international contexts. It illustrates important applications of this standard by stakeholders that include product users, product providers, service providers, systems administrators, policy makers, researchers, and academics. Exemplar applications include interdisciplinary AT service provision, professional capacity building, development of scientific tools, consistent gathering, analysis, and description of internationally comparable data, and support for coordinated global actions increasing access to AT.

The purpose of this paper is to describe development of an International Standards Organization (ISO) Assistive product services – vocabulary as a critical component of the infrastructure necessary to transform individual and system capacities. Methodology will follow international standards development guidelines and mandates. Development of this standard will be rapidly achievable through the aggregation of existing knowledge and international consensus. As with all standards, this vocabulary standard will be reviewed and revised as new knowledge becomes available including development on AT outcomes and impact.

### INTRODUCTION

Internationally, consensus is building that global research infrastructure for assistive technology (AT) is a priority and must include all stakeholders: users, industry, and services [1,2]. However, the field currently lacks consensus terminology, classification or taxonomy of devices, products or service models [3,4]. Global efforts to improve access to AT will remain inconsistent and inequitable while stakeholders lack a common language through which to build and translate knowledge. Semantic specificity is critical to facilitate data sharing, pooled computational analysis and comparisons, and measuring interdisciplinary AT outcomes and impact [5].

At the international level, the International Organization for Standardization (ISO) leads development of AT-related classification and terminology standards through *ISO/TC 173 Assistive products* [6], and specifically Sub-Committee 2, i.e. *ISO/TC173/SC2 Classification and Terminology*. In 2018, *ISO/TC173*'s scope expanded to include services for assistive products. *ISO/TC173/SC2* initiated discussion to establish a new standard related to classification and terminology of assistive product services.

This paper outlines the proposed content and methodology for developing a new ISO standard on *Assistive product services – Vocabulary*. This standard would fit under the broader umbrella of a standard envisioned on assistive technology fundamentals and vocabulary. This paper also discusses benefits of the proposed standard, including potential to facilitate successful collaboration and attainment of multiple United Nations Sustainable Development Goals (UN SDGs) [7].

### METHODS

ISO standards are developed through six stages: proposal, preparatory, committee, enquiry, approval, and publication [8]. Under ISO rules, new work items (NWIs) may be proposed by member bodies of ISO, TC secretariats, TC sub committees and working groups, organizations in liaison, the Technical Management Board or by one of the advisory groups, or the Secretary-General (ISO/IEC Directives Part 1, Clause 2.3.2) [8,9].

The authors are working on the first stage, “proposal”. This stage aims to confirm need for the standard. The proposed method established by *ISO Form 4: New work item proposal (NP)* states “The proposer(s) of the new work item proposal shall:

- make every effort to provide a first working draft for discussion, or at least an outline of a working draft
- nominate a project leader
- discuss the proposal with the committee leadership prior to submitting the appropriate form, to decide on an appropriate development track (based on market needs) and draft a project plan including key milestones and the proposed date of the first meeting” [8].

Upon satisfying Form 4 requirements, a new work item proposal (NP) for standards development is submitted for vote by members of the relevant TC or SC to determine inclusion in the program of work. NPs are accepted if (i) two-thirds of participating member countries (P-members) voted in favor and (ii) at least five P-members declare a commitment to actively participate [8]. The Standard development track can be either be 18, 24, 36, or 48 months in length [8].

## **RESULTS**

ISO protocols for the proposal stage are being followed to initiate this NP. The Americans National Standards Institute (ANSI) is the US Member Body of the ISO. Linda-Jeanne Elsaesser as Head of Delegation (HoD) to ISO/TC173/SC2 and ISO/TC173/SC2/WG12 discussed a working draft which addressed Form 4 requirements. The working draft’s proposed scope is modeled on the Scope of *ISO 26000:2010 Guidance on social responsibility* [9].

### Scope of the proposed deliverable

This International Standard is intended to ensure that communication in the domain of assistive product services is effective and difficulties in understanding are minimized. The standard will provide guidance to all types of individuals and organizations, regardless of their size or location on:

- a) Concepts, terms, and definitions related to assistive product services
- b) The background, trends, and characteristics of assistive product services
- c) Principles and practices relating to assistive product services
- d) The core subjects and issues of assistive product services
- e) Integrating, implementing, and promoting socially responsible behavior throughout assistive product services and, through its policies and practices, within its sphere of influence
- f) Identifying and engaging with stakeholders
- g) Communicating commitments, performance and other information related to assistive product services

### Purpose and justification of the proposal

The main purpose of this international standard is to provide a normative vocabulary through systematic identification of concepts and relations, designation of terms, and descriptive definitions for the field of assistive product services [4]. The standard will support the work of other committees by providing the terminology to draft linguistically and conceptually consistent standards and documents.

The manuscript, “*The value of vocabulary standards towards improving access to assistive technology*” providing evidence of need by five international key stakeholders was accepted for presentation at the WHO GReAT Summit 2019 and published in the proceedings [4]. The proceedings are considered a first step to inform development of the planned *Global Report on Assistive Technology 2021* on good practices for innovation and recommendations to improve access.

The proposed ISO document will meet the identified need for building global infrastructure to increase education, practice, information-sharing, and collaboration between countries.

### Work plan

The project team will comprise the international authors of the original manuscript. Additional content experts will be recruited to assure representation from stakeholders including academics, consumers, researchers, and providers of products and services, systems, and policies. Sajay Arthanat has been identified as project leader. The project will initiate immediately following project approval and resource allocation.

The project evidence base will include applicable ISO standards for terminology and concepts, the Oxford English Dictionary to ensure consistent understanding by international members, the Convention on the Rights of Persons with Disabilities, the United Nations Sustainable Development Goals, and publications from the World Health Organization, and other peer-reviewed sources. The project development track will be 18 months.

## **DISCUSSION**

While this standard will provide monolingual terminological entries, to facilitate communication in science and technology, cross-cultural communication, the exchange of good and services, as well as the formulation of policies and strategies at national, regional and international levels, the potential need for development of multilingual entries is recognized.

Development of a vocabulary standard is at the core of efforts to improve access to assistive products and services, for the vast portion of underserved individuals with disabilities. Examining and comparing the utilization of and demand for assistive products and services both within and across nations requires a consistent and replicable survey framework and language. For viable analysis and comparisons, it is important to implement a standard nomenclature to classify and denote AT products and services. Long term, a vocabulary standard can facilitate creation of: a) uniform funding codes that logically identify functional and contextual need for an assistive product; b) consumer-driven AT product databases; c) systems for tracking impact and outcomes, and; d) interdisciplinary and international education and training for AT workforces.

Prerequisites for reference standards include identification of theoretical background, target groups, and purpose. Terminology must be operationalizable, comprehensive, generalizable, extendable, flexible, unambiguous, and consistent. Use is intended to support connectable and interoperable domain-independent typology including causal, instrumental, and associated relations on a continuum of simplicity to complexity. While this may seem new to some AT stakeholders, these are established expectations in clinical terminology standards such as the Systematized Nomenclature of Medicine - Clinical Terminology (SNOMED-CT) published by the International Health Terminology Standards Development Organization (IHTSDO). Based on consensus, vocabulary standards are tools upon which to base good practice, guidelines, and regulations assuring effective, efficient, and satisfactory AT outcomes and impact. ISO notes in its guide to contributing to the UN SDGs that:

“To be successful, the process requires consensus, collaboration, and innovation with contribution “from all elements of society, including local and national governments, business, industry and individuals” [7].

Our manuscript published in WHO GReAT 2019, describes key concepts on the value of a vocabulary standard to include findings, opportunities and challenges by stakeholders representing:

- Clinicians- provider capacity, common language and framework, translation of research to practice, process standard, international collaboration
- Administrators – improve the efficiency and clarity of communication within and between government entities and improve data gathering, analysis and interpretation in support of evidence-based policy and administration
- Manufacturers- international trade, AT and medical device lifecycle management, medical device regulatory affairs (including pre-market authorization activities and regulatory compliance, specification & adjustment
- Academics – research, education, and policy development
- Engineers- AT development and innovation, co-creation, field-based innovation, classification and terminology [4].

Diffusion of Innovation (DOI) describes the steps, barriers, and facilitators governing the adoption and use of an innovation such as the vocabulary standard [10]. Reference to DOI concepts and success cases has potential to speed vocabulary standard adoption within and across international contexts [11]. International organizations such as the WHO GATE and the Alliance of Assistive Technology Professional Organizations will be engaged to inform and potentially to help carry out this strategy [11].

Diffusion of innovation strategies that include awareness, development of positive attitudes, decision to adopt, and continued use of standardized terminology will be critical for international stakeholders to effectively discuss evidence of AT outcomes and impact.

## **CONCLUSION**

Development of this International Standard is intended to ensure that communication in the domain of assistive product services 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 to strengthen capacity for development of international strategies advancing access to AT services and AT products.

## ACKNOWLEDGEMENTS

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**Person-centred approaches to evaluation of assistive technology products and outcomes:  
An Australian policy and practice perspective**

Natasha Layton <sup>1,2</sup>, Libby Callaway <sup>1,2,3</sup>

<sup>1</sup> *Australian Rehabilitation and Assistive Technology Association, Victoria, Australia*

<sup>2</sup> *Rehabilitation, Ageing and Independent Living Research Centre, Monash University, Victoria, Australia*

<sup>3</sup> *Occupational Therapy Department, Monash University, Victoria, Australia*

**ABSTRACT**

Australia is currently undergoing monumental reform. This includes the introduction of a \$22B no-fault National Disability Insurance Scheme for Australian residents who experience significant and permanent disability and are aged under 65 years at the time of Scheme entry, and a community-based ageing in place funding stream for those aged over 65, called My Aged Care. Both of these policy initiatives may provide government funding for assistive technology and other supports, based on a person's participation goals and associated support needs. These new funding streams have opened up person-centred approaches to assistive technology (AT) product selection, and the opportunity to examine both AT outcomes and impact achieved.

This presentation will provide an overview of current work of Australia's national peak body for AT stakeholders, the Australian Rehabilitation and Assistive Technology Association (ARATA). Members of the Board of ARATA will present two frameworks in development by ARATA members and their collaborators. One is designed to evaluate and guide selection of AT options (the Performance Enhancing Technology Evaluation Framework), and the other focuses on impact achieved from the perspective of the AT user (My Outcomes Framework). Both have been codesigned with AT users, practitioners, researchers and funders.

In the presentation, research underway to test and operationalize these two frameworks will also be discussed. Practical application of the frameworks will be presented. Knowledge translation resources that are in development to assist AT users, practitioners, developers, suppliers and funders to select, trial, and evaluate both outcomes and impact achieved over time using these frameworks, will also be presented.

**Relevance for the international session**

This presentation will contribute evidence of approaches to the assessment and evaluation of AT outcomes and impact, and the relationship between the two focus areas. A perspective will be offered from Australia, but the dialogue will be relevant and applicable to international AT practice, the Global Alliance of Assistive Technology Organizations, and government and other policymaking bodies.

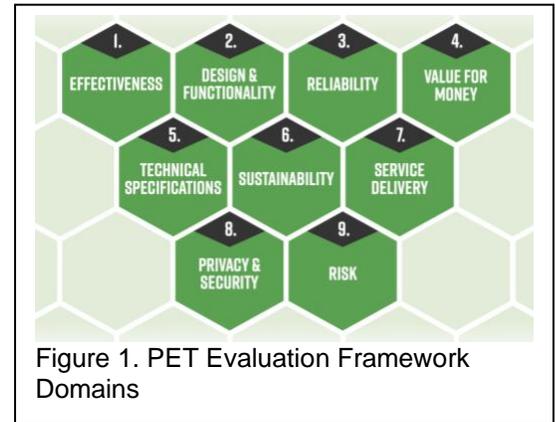
**INTRODUCTION**

Assistive technology is a key facilitator of human functioning and participation [1]. Effective assistive technology provision involves matching assistive products to person, to task and environment [2,3]. Assistive technology therefore includes both assistive products and services, delivered within an evidence-based set of service delivery steps [4,5]. There is substantial global interest in realizing the potential of assistive technology to deliver on public health [6] and human rights [7] agendas. Specific challenges include foregrounding ethics [8] and rights [9] in the use of emerging technologies, and enacting policy and service design which reconciles a cost effectiveness agenda with person-centered perspectives [10]. Articulating and measuring the process of assistive product selection is also challenging as this 'tacit' knowledge of allied health professionals and related workers is currently poorly evidenced [11].

The person-centered approaches described below endeavor to address these challenges, offering co-designed and internationally translatable ways to evaluate assistive technology products and outcomes. First, we present an evaluation framework for products. This framework may be used to augment, or at times replace, human input to address cognitive support needs a person may experience when completing daily tasks, and thus has been termed a 'Performance Enhancing Technology Framework'. Following, we will outline a global outcomes framework, called 'My Outcomes Framework', which integrates international classification systems, research evidence, and service delivery frameworks into eight tools to describe the impact of assistive technology from the AT user's perspective.

## Performance Enhancing Technology (PET) evaluation framework

The past decade has seen the development and use of mainstream technologies grow exponentially, and in contrast to the more specialized and costly AT solutions that were previously used. Electronic assistive technologies, including smartphones, tablets and their mobile applications, home automation systems, and wearable devices, may be considered essential components of everyday life [12]. One of the challenges of AT practice in the area of emerging technologies is that product development is occurring at a much faster rate than research to inform evidence-based approaches. For these reasons, AT users, their supporters, and those providing AT services may look to good practice steps to guide assistive technology provision [5]. The need for a framework for evaluation and selection of performance enhancing technologies that may be used for cognitive support has also been identified. It is in this context that the Performance Enhancing Technology Framework has been developed (Figure 1).



This framework can be applied by the technology user and practitioners in collaboration, when considering emerging technology interventions based on a person's goals and support needs. The framework design has been informed by an international scoping review, and grey literature and website scan on performance enhancing technologies. This desktop work was coupled with qualitative research methods, using indepth semi-structured interviews with AT users, practitioners, suppliers, funders and developers (n=18), to draft a set of domains. A final total of nine key domains, determined through thematic analysis and research participant and investigator consensus, have been identified. These domains guide consideration when exploring performance enhancing technology (see Table 1).

Effectiveness	The extent to which the functioning of the PET improves the user's living situation, as evaluated by the practitioner and as perceived by the user, including whether it enhances functional capacity and/or independence, improves safety and/or enables participation in meaningful activities.
Design and Functionality	The ease of learning to set up, operate and continue to use the PET through its functions and controls, together with the physical design, aesthetics, interface and capacity for personalisation.
Reliability	The extent to which the PET operates with repeatable and predictable levels of accuracy under all conditions of reasonable use <sup>1</sup> over an extended period of time.
Value for Money	Whether the investment of money, time or other resources to purchase, use, maintain and service the PET over time represents good value for money
Technical Specifications	The key technical specifications of the PET and how compatible it is with other PETs on the market
Sustainability	The currency of the PET and the sustainability of the technology over time (including operating system & network).
Service Delivery	The quality, timeliness, expertise and reliability of the professional services or PET supplier in providing customer support, repairs and servicing.
Privacy and Security	The usage, privacy, security and storage of data collected through regular use of the PET. Consider also regulatory and legal compliance.
Risk	The likelihood of device malfunction relative to the level of consequence to the user and/or their supporters.

**Table 1. Performance Enhancing Technology (PET) Framework Domain Definitions**

### Applications

The PET Framework provides a structure, definition and set of questions for use during product exploration. It also offers a list of questions the AT user or practitioner can seek answers to when making AT choices, and comparing products in specific technology domains (e.g. medical reminder devices). The Framework is provided in three formats: an interactive PDF, a Word document and a fillable Excel spreadsheet. The spreadsheet version converts question responses (yes, no, unsure) into a ranking of products across the nine domains, based on the answers provided. It also identifies where more information is required. This Framework, associated tools, a glossary of terms, and digital and written instructions to guide use are currently undergoing final user testing for publication. Interest to apply the Framework is welcomed.

### My AT Outcomes Framework

Global thinking on AT is progressing towards a systems view which encompasses AT people (users), policy, personnel, products and provision. A summary of AT outcome measures according to these system dimensions was published as background to the upcoming Global Report on Assistive Technology [13]. This summary discussed the range of challenges in synthesizing practice, research and policy in AT outcome measurement. It is in this context that the My AT Outcomes Framework (Figure 3) has been developed, empowering AT users to manage their own data and providing a flexible structure for people tell their stories in a systematic way. Needs analysis conducted by a consortia of stakeholders across disability and aged care sectors [14] identified the need for n-of-1 data capture formats to enable AT users to collate evidence regarding their support needs according to established criteria, and communicate this to AT practitioners and funders. Consensus was reached on the inclusion of six dimensions (see Table 2). An accessible PDF summary report of data entered is then generated. Before and after evaluation is recorded via rating of satisfaction, difficulty and time-use by the user, and measurement of participation by the AT practitioner, before and after the AT bundle is deployed. These measures are superimposed to gain a dynamic picture of the impact of AT bundles and their funding. From a utility perspective, the framework needed to be robustly accessible, to generate a useable report, to capture change with different scenarios, and to enable users to opt to aggregate their data to address the critical lack of person-defined outcomes data which identifies and evidences the impact of AT provision upon outcomes.

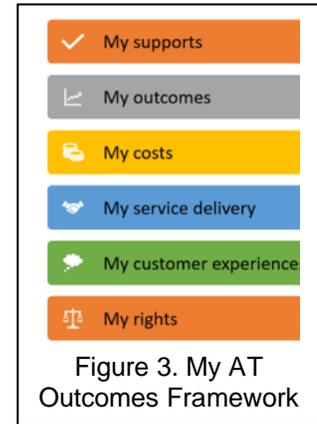


Figure 3. My AT Outcomes Framework

These measures are superimposed to gain a dynamic picture of the impact of AT bundles and their funding. From a utility perspective, the framework needed to be robustly accessible, to generate a useable report, to capture change with different scenarios, and to enable users to opt to aggregate their data to address the critical lack of person-defined outcomes data which identifies and evidences the impact of AT provision upon outcomes.

My Supports	Identify my bundle of assistive technology products and services, along with personal support and environmental modifications, using ISO 9999 [15]
My Outcomes	Articulate the full range of activity and participation chapters which are impacted by the AT bundle [16]
My Costs	An economic pathway analysis tool to identify costs and benefits for my AT bundle. This includes costing the AT bundle, and identify any cost offsets (direct cost savings and likely downstream cost savings) as well as social returns on investment
My Service Delivery	Capture the service delivery experience through the steps of initiation, assessment, trial and solution selection, procurement, implementation (delivery, setup, trial) follow up, review [17]
My Customer Experience	Identify whether, as a customer, the AT bundle meets expectations. This tool operationalizes nine values identified by AT users including flexible bundling; sufficient resourcing, lifestyle and lifespan considerations; support and resources; active involvement in decision making, and consideration of personal preferences and identity [18].
My Rights	Using the Articles of the UN CRPD [19] which specify AT, people can identify whether their rights are realized, or not yet realized, with their AT bundle [20].

Table 2. My AT Outcomes Framework - Tools

### Applications

My AT Outcomes Framework provides a structure for key outcome dimensions, expressed as practical tools in person-first language. The dimensions and questions illuminate 'what is' and 'what can be expected', enabling a robust and methodical capture of data points with optional qualitative narrative, at one or more points of time (see example in Figure 4). The tool topics are, we propose, universally applicable to AT users and their practitioners. As such, these can be used as 'key questions' to raise awareness of the full impact of AT. They may be used to educate stakeholders as to AT rights, outcomes, cost implications and measurement dimensions. They may also be used to hold up a mirror as to the effectiveness of AT policy, against international benchmarks and frameworks. Interest has been expressed by international research consortia in developing and piloting the Framework, and is welcomed by the authors.

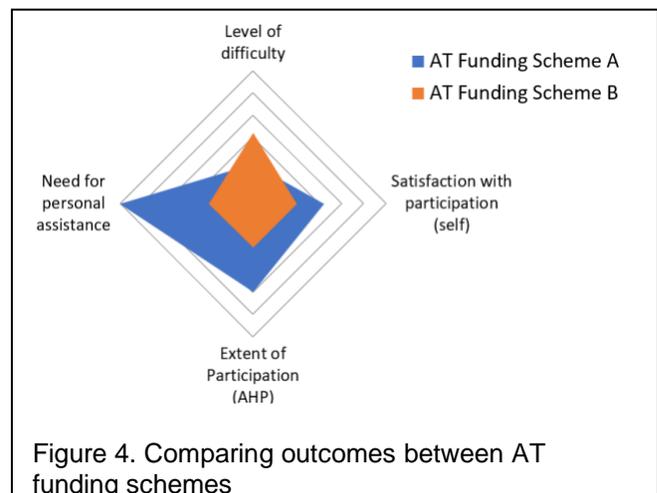


Figure 4. Comparing outcomes between AT funding schemes

## CONCLUSION

Australia's policy reforms have offered opportunity to re-think person-centred AT practice. This paper has presented co-designed tools to evaluate and guide selection of AT options and to document the impact achieved from the perspective of the AT user. Collaboration is welcomed with our global colleagues as we work towards equitable and measurable AT outcomes for all.

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## **Assistive Technology for People with Cognitive Disabilities**

### **A 5 year follow-up on an interdisciplinary cognitive rehabilitation clinic focusing on its development, evolution, and expansion**

Amy Pacos Martinez<sup>1</sup>, Timea Tozser<sup>1</sup>, Christopher Stavisky<sup>1</sup>, Nancy Dukelow<sup>1</sup>, Lisa Walther<sup>1</sup>, Sheryl Maier<sup>2</sup> and Jamie Campeau<sup>2</sup>

<sup>1</sup>*Department of Physical Medicine and Rehabilitation, University of Rochester Medical Center,* <sup>2</sup>*Department of Otolaryngology, University of Rochester Medical Center*

#### **ABSTRACT**

The ICRP program published an article in 2015 that discussed the theoretical frameworks and practical substrates of delivering cognitive rehabilitation interventions within an inter-disciplinary approach [1]. The 2015 article highlighted the clinical model, discussed the theory behind the approach, and identified specific treatment approaches. The purpose of this current review is to discuss the evolution and programmatic changes of this unique multidisciplinary cognitive rehabilitation program over time. The current review will also highlight a case example to demonstrate the current clinic model and highlight the use of technology within an integrative cognitive rehabilitation for individuals with mild to moderate cognitive impairment. The overarching goal of this submission is to shed light on the overwhelming benefits of collaborative practice of cognitive rehabilitation, emphasize implications for future research, inform public policy on practice, and demonstrate clinical program development in an existing outpatient clinic.

#### **INTRODUCTION**

Beginning in 2011, a clinical need emerged to better manage the cognitive and functional deficits of adult populations with acquired neurologic illness/disease. The Integrative Cognitive Rehabilitation Program (ICRP) was developed to focus on the assessment and cognitive rehabilitation treatment of adults with mild to moderate cognitive deficits and associated functional challenges within an outpatient medical setting.

The program highlighted integrative care from Occupational Therapy, Speech Pathology, and Neuropsychology and promoted an interdisciplinary approach to cognitive rehab, including initial comprehensive individual evaluation, collaborative goal setting, and patient-driven rehabilitation treatment [1]. The program focused on the shared partnership of these professions to assist individuals with mild to moderate cognitive impairments by identifying functional goals and then developing and implementing cognitive compensatory strategies, including support from assistive and everyday technologies, to maximize functioning for an adult population (ages 18+).

Current models of cognitive rehabilitation suggest the efficacy of inter-professional approaches in the assessment and treatment of individuals with mild to moderate cognitive impairments [2]. Since its inception, the ICRP program has evolved to maintain efficiency and address individual specific needs while maintaining the theoretical tenets of the Self Determination Theory (SDT), along with the Matching Person and Technology model and the Distributed Cognition model [2, 3].

Assistive technology (AT) has been widely used to support individuals with new onset cognitive impairment. A significant body of research supports the use of external aids/AT approaches to support recovery from brain injury and for patients living with general cognitive impairments [4]. Within the ICRP program, cognitive aids are used to promote independence and improvement in everyday functioning. The program features both low tech and high tech approaches to AT and promotes Scherer's MPT model of tailoring tools for specific users based on both purpose and environment [3].

The ICRP program begins with a one-stop-shop approach with an initial comprehensive evaluation by each discipline (occupational therapy, speech-language pathology, and neuropsychology). This assessment allows the providers to identify a specific profile for each individual's cognitive and functional needs. Discipline-specific objective measures are utilized during each evaluation to measure goodness of fit for the program, establish individual goals, and identify individual cognitive strengths and weaknesses through formal assessment. Each discipline also completes a formal interview process to assist with clinical decision making.

The ICRP program published an article in 2015 that discussed the theoretical frameworks and practical substrates of delivering cognitive rehabilitation interventions within an inter-disciplinary approach [1]. The 2015 article highlighted the clinical model, discussed the theory behind the approach, and identified specific treatment approaches. The purpose of this current review is to discuss the evolution and programmatic changes of this unique

multidisciplinary cognitive rehabilitation program over time. The current review will also highlight a case example to demonstrate the current clinic model and highlight the use of technology within an integrative cognitive rehabilitation for individuals with mild to moderate cognitive impairment. The overarching goal of this submission is to shed light on the overwhelming benefits of collaborative practice of cognitive rehabilitation, emphasize implications for future research, inform public policy on practice, and demonstrate clinical program development in an existing outpatient clinic.

## **METHODS**

### **Program Development**

This is a program review of the current integrative cognitive rehabilitation program at the University of Rochester Medical Center to determine changes and modifications that were required for program improvement and individual care. Review of current literature was considered as a part of the changes made within the clinic model as well as aspects of the program that has maintained over time. Future development will discuss research involvement to measure outcomes and consider future technology to incorporate in cognitive rehab treatment. Notable program changes from inception to current clinic function are cited below with related discussion.

#### Population

Clinical parameters of the ICRP program have been modified since the original articles publication in 2015 in order to meet the need of the serving population. The 2015 article discusses inclusion criteria for the program such as: "1) individuals ages 12 and over; 2) mild to moderate levels of cognitive impairment, with no specifications related to diagnoses or duration post injury; 3) the presence of intact insight and awareness into their cognitive deficits or the capacity to develop this insight and awareness with education; and 4) the ability to learn compensatory strategies for cognitive skills [1].

The current program continues to reflect inclusion criteria such as: the presence of intact awareness and insight, mild to moderate levels of cognitive impairment and the ability to learn compensatory strategies. However, the current program has shifted the inclusion criteria to include an adult population (18+), as the theoretical models framed by this program is best suited for an adult population.

Another change highlighted within the ICRP program regarded the specificity of the population served in the program. Over time, it became evident that this integrative cognitive rehabilitation program best benefited individuals with diagnosed acute neurological injuries or illness versus individuals with more remote injuries or neurological presentations. Rationale for this approach reflects the program's compensatory approach, which appears better suited for acute changes in function.

#### Initial ICRP evaluation protocol

The initial multidisciplinary evaluation session has been shown to be an invaluable part of the program's success in addressing individual functional complaints related to cognitive decline. Since the original article's publication, the ICRP program has utilized a series of formal measures and questionnaires to address individual and caregiver concerns [1]. The focus of the initial evaluation is to provide a subjective report of cognitive and communication complaints, along with identification on impact of activities daily function. Further, the evaluation serves to highlight psychosocial concerns and other stressors that might be impacting the clinical presentation of the individual.

Over time, the program has identified that the important role of both qualitative and quantitative information to inform treatment. Further, it has balanced the need for this person's information with the needs of the individual and their ability to tolerate lengthy written questionnaires or rating scale completion. In addition, the idea of discipline specific coverage was discussed to avoid over-burdening the individual with similar questions during the evaluation process.

#### Program coverage/program education

The main goal of the ICRP program has been to provide cognitive rehabilitation to address function based concerns. Over time, a clear need emerged to provide basic education on cognitive rehabilitation and general education related to the individuals' specific diagnosis. In an effort to improve individual understanding, all individuals are now provided with a comprehensive handbook at the beginning of their initial interdisciplinary evaluation. This handbook provides information on the specific approach to cognitive rehab (compensatory approach). At the end of the initial evaluation, individuals' are also provided a summary sheet of the team's to take with them. These tools are both new additions added to increase individual education and frame expectations for the cognitive rehabilitation experience.

#### Integration of technology

As the program has advanced, a need to define an individual's willingness to utilize technology has become a relevant need in the climate of advancing technology. In this vein, the program aims to provide interventions to aid towards criteria of the MPT model. The MPT measure [1] allows for individuals to be classified as either high tech or low tech users. This classification enables ICRP providers to utilize compensatory strategies surrounding the available low tech or high tech options. Following the MPT model, clinicians within ICRP utilize the Device Match Assessment within the Assistive Technology Device Predisposition Assessment to assist with determining appropriateness of assistive technology for individuals, and how well the device(s) targets preferred outcomes of the individual [7, 8, 9].

Over time, the program has built a library of high tech cognitive strategies and applications for use that aid individuals with improving cognitive performance during functional activities. These strategies and applications range in variety, and include reminder applications, calendar applications, smartwatches, and smart home devices. These devices and applications provide opportunities for individuals to offload information to assist with regulating cognitive overload during a task, attend to specific tasks that need to be completed during an activity, recall information necessary for the task, and engage in communication with other individuals also involved in the task or activity. The advancements and usability of the artificial intelligence within these applications and devices afford individuals strategies to efficiently organize, store, and retrieve information personally relevant to a daily task, and help the individual better participate in and complete the desired task.

#### Program enrollment/scheduling

If individuals are deemed appropriate candidates for cognitive rehabilitation, they are scheduled for the subsequent treatment sessions with the occupational and speech therapists. This was not highlighted in the original article and was implemented within the past few years. The program has also objectively tracked whether individuals were deferred program participation or if program participants declined at the end of the assessment. Many factors could lead to deferral or decline such as severity of individual needs that require a higher level of care, other health issues being the primary concern, mental health, lack of identified functional goals by the individual, among others. Providers within the program will often refer to auxiliary service to meet the needs of individuals who are deferred or decline participation for instance individual service (OT/SLP), mental health treatment, physical therapy, or a structured day program.

#### Duration of treatment

Frequency and duration of treatment has evolved over time, as the recognition of a compensatory strategy approach to cognitive rehabilitation was best suited with a short term treatment tactic. Once compensatory strategies have been successfully taught and/or a successful match of technology and education has been made, individuals are discharged from the program. This short term approach has shaped a person's expectations of cognitive rehabilitation and stressed the importance of using assistive devices to aid in everyday life activities.

#### Formalized follow up

The previous 2015 article discusses informal follow up's with treating providers (OT and SLP) on an as need basis [1]. At that time, there was no formal conclusion or discharge from the ICRP program and individuals were individually discharged from their respective treating providers. The Integrative Cognitive Rehabilitation Program has since added a formal follow up with the Neuropsychologist as a part of person's discharge from the ICRP program. This follow up has been added to provide a formal wrap up meeting and also identify any clinical concerns or additional referrals that might need to be implemented for the individual.

### **DISCUSSION**

As this integrative cognitive rehabilitation program continues to develop over time, future directions regarding program development should be considered. For instance, mental health has been identified as a barrier to cognitive rehabilitation for some individuals who engage in cognitive rehabilitation. The current model does not provide mental health in the associated treatment sessions. Although, mental health needs are assessed at the time of the initial evaluation, patients are typically referred to external providers for psychological support. The need for embedded mental health providers in conjunction with the delivery of cognitive rehabilitation treatment is viewed as both optimal and necessary for future care.

From a research perspective, this program is exploring pre and post functional focused objective outcome measures to measure utility and success in this type of cognitive rehabilitation program. The need for future collaboration to objectively measure outcome and benefit of short term compensatory cognitive rehabilitation is a necessary area of continued development.

With regard to public policy, there are a variety of assistive and everyday technologies that can be useful supportive tools. The availability of these products is not typically a problem; rather, it is the lack of trained providers and personnel who can provide specific recommendation, advise on set-up, and promote active use. Further, insurance reimbursement for cognitive rehabilitation services has historically been problematic. The delivery of cognitive rehab through tele-rehab has been limited by varying state laws and discipline specific regulations. Increased awareness of these obstacles needs to be made known to policymakers and legislators.

## CONCLUSIONS

In sum, programmatic development within this integrative cognitive rehabilitation program has evolved over time. Future exploration should consider how to implement advanced technology and research to improve the efficacy of outpatient cognitive rehabilitation programs.

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## **International Assistive Technology Service Case Report: Outcomes of a Romanian and Huntington University Collaboration**

Laryn O'Donnell, OTD, OTR/L<sup>1</sup>, Jeanne Sowers, OTD, MA, OTR<sup>2</sup>

<sup>1</sup>*Huntington University*

### **ABSTRACT**

Internationally, individuals living with disabilities are marginalized by the lack of mobility related assistive technology. Insufficient mobility devices impede individuals with disabilities and their caregiver's ability to participate within the community. Without access to a wheelchair for sufficient mobility, they and their caregivers are left at an economic and social disadvantage.

This paper describes a case study of Huntington University's Occupational Therapy Doctoral Program as it provides collaborative and culturally appropriate assistive technology interventions as an example for future practice. Under the supervision of licensed therapists, students provided 137 seating and mobility evaluations and devices to individuals with disabilities residing in Romania. This case report highlights the outcomes of these international collaborations and the program's impact on occupational therapy students.

### **INTRODUCTION**

Internationally, individuals living with disabilities are marginalized by the lack of mobility related assistive technology. Insufficient mobility devices impede individuals with disabilities and their caregiver's ability to participate within the community. Without access to a wheelchair for sufficient mobility, they and their caregivers are left at an economic and social disadvantage. This paper describes a case study of Huntington University's Occupational Therapy Doctoral Program as it provides collaborative and culturally appropriate assistive technology interventions as an example for future practice. Under the supervision of licensed therapists, students provided 137 seating and mobility evaluations and devices to individuals with disabilities residing in Romania. This case report highlights the outcomes of these international collaborations and the program's impact on both occupational therapy students and the individuals and families served.

### **BACKGROUND**

A team of occupational therapists, occupational therapy students, Romanian church members, interpreters, and journalists collaborated with Joni and Friends' Wheels for the World™, to deliver seating and mobility services to individuals with disabilities. The team convened in Romania, where services were provided at several clinical sites throughout the nation. Each team member learned to adapt to each clinic site, as each site was unique, many with limited access to materials and types and sizes of wheelchairs.

The World Health Organization (WHO) projects that globally one billion people are living with a disability. Disability prevalence continues to be on the rise due to population ageing and the increase of chronic health conditions. [2] A new understanding has emerged classifying a disability a human rights issue, due to the societal barrier's individuals with disabilities experience. Of the estimated disability population, 70 million individuals are in need of a wheelchair, with only 5-15% obtaining access to one. In addition to the unavailability of devices, WHO identified a shortage of healthcare personnel equipped with the knowledge and skills to provide wheelchairs that meet individual's specific mobility needs. [3] Lack of mobility can lead to limited engagement in meaningful activities and community mobility. [4]

#### **Disabled Persons in Romania**

An estimated 3.41% of the Romanian population lives with a disability. [5] Literature reveals an inconsistency between the reported low consensus of individuals living with disabilities in Romania compared to the 14 % European Union average.[6] Individuals are likely unaccounted for in the national census due to geographical and societal barriers. [7]

The primary ethnography served during the collaboration constitutes one of the European Union's largest minority groups, the Roma. Evidence reveals a higher association of disability prevalence within the Roma population due to higher rates of chronic disease and poor access to primary care and preventative health programs. [8] In recent years, Romania have strived towards inclusion for all, with a notable shift in perspective towards seeing disability as a human rights issue. Hurjui and colleagues urge for the

continuation of measures to facilitate the effective integration of individuals with disabilities into society, which they note will require maximum attention from all the world's countries. [9]

This significant need in Romania has challenged all current services. The collaboration between Joni and Friends' Wheels for the World™ and Huntington University depicts an opportunity for a continuation and adoption for future innovative service programs.

## **METHODS**

The researchers conducted a survey, which generated qualitative findings related to the impact of the Romania service trip on occupational therapy students. An exempt IRB application was submitted and approved for by the Huntington University Institutional Review Board.

A team consisting of licensed occupational therapists and students provided seating and mobility services to individuals with disabilities residing in Romania. Prior to the service trip, occupational therapy students engaged in a five-hour cultural competency training which included a course in cross-cultural learning. Additionally, students were enrolled in a six-hour seating and mobility instructional laboratory to ensure foundational competence in serving as a seating therapy assistant or seating mechanic. Interventions for the event included a seating assessment, fitting, and training to the client or family members on how best to utilize the mobility device. Each intervention varied in length due to complexity of each client, ranging from one hour to five hours of time spent with each client. In total, the team provided 137 custom seating and mobility devices.

To gather data regarding the impact of the service trip, students were asked to fill out a free-response question survey about their trip experience. The interview generated feedback on the qualities and program's impact on students' clinical expertise. Survey transcripts were analyzed using a four-step procedure: 1) removal of identifying information, 2) survey responses were iteratively reviewed while highlighting pertinent information and key words, 3) common themes were identified, 4) comparison of all interview transcripts.

### Free-response question survey to occupational therapy students:

1. How would you describe your service trip experience in Romania?
2. How was your clinical expertise as a future OT impacted by the trip?



**Image 1. Mobility devices at one of the clinical sites in Romania**

## **RESULTS**

Six out of seven occupational therapy students responded to the survey. Three themes emerged from the qualitative data: 1) life-changing experience, 2) improved ability in providing culturally competent care, and 3) impactful to future clinical practice. The six participants in the study will be referred to as Participant A-F to ensure confidentiality. Eight quotations provided specific examples related to cultural

experience and clinical practice. Two themes were excluded due to irrelevance to the assistive technology intervention. Example quotations from each of the themes follow.

#### Theme 1: Life-changing experience

Participant A: "I would say my experience impacted my career as an OT by experiencing hands on cultural competence and language barriers by making me more aware of others and their beliefs."

Participant E: "Serving people in Romania was a humbling experience. Living in America, I believe we often forget how fortunate we are to have a vast array of resources at our fingertips...Simply put, seeing how under-served those of Romania are has inspired me to use the resources I am able to offer for a greater good; what may be readily available and expected to us, could be significant and invaluable to someone else."

#### Theme 2: Improved ability to provide culturally competent care

Participant A: I think the most important thing I learned while on the trip was how to interact with people from a different culture. Learning how to communicate through a translator or using nonverbal communication will be very beneficial in the future as I work with families from various backgrounds.

Participant E: "When language is a barrier, it is vital to be able to read individuals' body language in order to build rapport. While in Romania, more times than not, we had to use a translator as a means to communicate. Although helpful, it was evident certain words/phrases did not translate equivalently. That's when being able to read facial expressions, posture, and even recognizing changes in tone, were extremely helpful and critical. What I gained certainly transferred to my clinical expertise as a future OT."

#### Theme 3: Impactful to future clinical practice

Participant A: "I would say my experience impacted my career as an OT..."

Participant C: "It allowed me to refine my clinical problem-solving abilities and communication strategies..."

Participant E: "The experience was a profound demonstration of how important nonverbal communication is during clinical practice... When language is a barrier, it is vital to be able to read individuals' body language in order to build rapport."

Participant F: "The clinical knowledge I gained while in Romania focused on seating systems to improve functional mobility in the community and to complete activities of daily living. This knowledge I have already been able to use during a level II rotation in a nursing home while working with ATPs during wheelchair assessments."

Over half of those surveyed expressed the impact the trip had on their improved ability to provide culturally competent care, and five of the six participants mentioned how the trip would benefit them in future clinical practice.

## **DISCUSSION**

Qualitative data revealed three major findings and implications for future assistive technology programs and clinical practice and exhibits a potential important model to expand assistive technology practice worldwide. Firstly, the intercultural programs in assistive technology directly impact clients lives and have a substantial impact on the clinical instruction in assistive technology. A secondary benefit to students would improve future clinical practice and competence working with clients globally. Lastly, service program's provide innovative and inexpensive ways to assist individuals with disabilities and provide services to countries with limited access to materials and mobility related assistive technology. The service-trip generated positive feedback from all participants interviewed, as well as statements classifying the trip as a life-changing experience.

## **CONCLUSION**

Results from the study align with prior research regarding the positive outcomes associated with providing international assistive technology services to individuals with disabilities as well as the team members who provided services.

The outcomes of the program support the findings of Short and colleagues on the short-term benefits of international service, including evidence of increased cultural competence. [1] The custom seating and mobility devices provided mobility freedom to individuals with disabilities and an impactful experience for the students that will carry on with them into future clinical practice.

University's should be encouraged to adopt and continue to operate programs such as this. Collaborations such as these are a promising way to advance the field of assistive technology, and the services highlight the role current and future practitioners can play in collaborative international programming. There is a continued need for innovative models for service delivery as the global implementation of assistive technology continues to improve.

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## EqTDs

Image 1.

Brief Description: Image 1 is a picture of mobility devices at one of the clinical sites in Romania.

Essential Description: Image1 is a picture used to demonstrate the types of mobility devices, including wheelchairs and walkers, at one of the clinical sites in Romania. The mobility devices are organized by device type and size.

## **Wheelchair User's Voice: Evaluation of Appropriate Wheelchair Provision in El Salvador**

Jonathan Pearlman<sup>1</sup>, Megan D'Innocenzo<sup>1</sup>, Yasmin Garcia-Mendez<sup>2</sup>, Perth Rosen<sup>2</sup>, Virginia Rodriguez<sup>3</sup>

<sup>1</sup>*Department of Rehabilitation Science and Technology, University of Pittsburgh*, <sup>2</sup>*United Cerebral Palsy, Wheels for Humanity, California, United States*, <sup>3</sup>*University of El Salvador, San Salvador, El Salvador*.

### **ABSTRACT**

There is a significant global unmet need for appropriate wheelchairs worldwide. Studies suggest that only 17% and 37% of WC users have access to appropriate WCs and assistive technology devices. [1] For people who have a mobility impairment, access to a WC is an important step towards independence and participation. The purpose of this study was to investigate the impact of the World Health Organization's guidelines for manual provision in less-resourced settings (WHO 8-steps) [2], on the socioeconomic status, quality of life, health, wheelchair skills, and caregiver burden of wheelchair users in El Salvador. Wheelchair provision according to the WHO 8-steps has the potential to improve outcomes for wheelchair users including increased quality of life, decreased poverty likelihood, and increased health-related to wheelchair use. More research on the benefits of providing wheelchairs following the WHO 8-Steps approach is needed. This research-based evidence is necessary to drive policy and wheelchair provision programs in LMICs toward more effective interventions that maximize benefits for wheelchair users.

### **INTRODUCTION**

There is a significant global unmet need for appropriate wheelchairs worldwide. Studies suggest that only 17% and 37% of WC users have access to appropriate WCs and assistive technology devices. [1] For people who have a mobility impairment, access to a WC is an important step towards independence and participation. The purpose of this study was to investigate the impact of the World Health Organization's guidelines for manual provision in less-resourced settings (WHO 8-steps) [2], on the socioeconomic status, quality of life, health, wheelchair skills, and caregiver burden of wheelchair users in El Salvador.

### **METHODS**

#### **Design**

This study used a within-subject longitudinal design to compare outcomes before and after wheelchair provision following the WHO's 8-steps. Data was compared at various points in time: at baseline, wheelchair delivery, and 3- and 6-months after wheelchair delivery.

A consecutive sampling method was used for ethical considerations to select participants from the waiting lists of the partner wheelchair service provider organizations in El Salvador.

Outcome measures tools were administered through personal interviews. Additionally, wheelchair maintenance reminders were sent twice a week through text messages to a sub-cohort of randomly selected participants to assess the utility of information technology to promote care and proper functioning of the wheelchair.

#### **Participants**

The study recruited two types of participants:

1. Wheelchair users, defined as a person with a mobility limitation requiring a wheelchair as a primary means of personal mobility and waiting to receive one<sup>1</sup>, 18-years or older, with the cognitive and verbal ability required to respond to the study questions or a proxy who could respond on his or her behalf, and desire to participate in the study. Only wheelchair users who did not require additional postural support to sit upright were included. All wheelchair users involved in the study provided informed consent.
2. Caregivers of wheelchair users, defined as those assisting the wheelchair users recruited for this study with activities of daily living. Caregivers involved in the study were required to be 18-years or older and the primary caregiver. All caregivers involved agreed to participate in the study and provided informed consent.

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<sup>1</sup> The study included wheelchair users that previously owned a wheelchair and those that did not own a wheelchair at the study baseline.

## Procedures

All wheelchair users were provided with a wheelchair and wheelchair services in line with WHO's 8-steps by a wheelchair provider previously trained in the basic and intermediate levels of the WHO's Wheelchair Service Training Package. Participation in the study was voluntary and wheelchairs were provisioned regardless of participation.

Wheelchair users or proxies were interviewed at the study baseline (2 months before wheelchair provision), at wheelchair delivery, and at 3- and 6-month follow-up visits. Data was collected using the following tools previously translated into Spanish: Poverty Probability Index (PPI), WHO-Quality of Life Short version (WHOQOL-BREF), the MIT-Health Status Questionnaire, Wheelchair Skills Test Questionnaire (WST-Q), and Breakdowns and Adverse Consequences Questionnaire (BAC-Q). Caregivers were interviewed using the Zarit Burden Interview (ZBI) tool to measure caregiver burden at the same time points.

Responses to study questions were entered into electronic devices using the KoboToolbox application, which did not require the availability of an internet connection at the time of the interviews.

The study was revised and approved by the National Ethics Committee for Health Research in El Salvador and the Institutional Review Board of the University of Pittsburgh.

## Analysis

All data was analyzed using descriptive statistics and graphics. For continuous variables, mean and standard deviation (mean  $\pm$  SD) is reported. For categorical variables, frequency and percentages are reported.

To detect significant changes within subjects over time, detailed graphical explorations were conducted for each result for the total sample and, after checking for test assumptions, paired t-tests or repeated-measures ANOVA were carried out. In cases where non-parametric data were analyzed, Wilcoxon signed-rank test and Friedman's ANOVA were used. The significance level was set at  $p < .05$  with Bonferroni corrections for subsequent post-hoc comparisons.

## RESULTS

**Table 1. Demographics**

	<b>All participants (N=247)</b>
Age, in years (mean $\pm$ standard deviation)	54.9 $\pm$ 19.7
Live with a spouse or significant other (% , n)	
No	55%, n=137
Yes	45%, n=110
Education level (% , n)	
None	18%, n=45
Primary school (first to third grade)	15%, n=36
Primary school (fourth to sixth grade)	14%, n=35
Primary school (seventh to ninth grade)	18%, n=45
High school (incomplete)	2%, n=5
High school (complete)	18%, n=44
Technical education (incomplete)	0%, n=1
Technical education (complete)	3%, n=7
College (incomplete)	4%, n=10
College (complete)	7%, n=17
Postgraduate education	1%, n=2
Employment status (% , n)	
Unemployed	57%, n=140
Student	3%, n=7
Homemaker/full-time parent	14%, n=34
Self-employed part-time	7%, n=18
Self-employed full-time	6%, n=16
Employed part-time	1%, n=3
Employed full-time	12%, n=29
Medical condition (% , n)	
Spinal cord injury	31%, n=76
Amputation	26%, n=64

Aging / Weakness	7%, n=17
Rheumatoid arthritis	5%, n=13
Stroke	5%, n=12
Spina Bifida	5%, n=12
Injury	5%, n=12
Consequences of Polio	4%, n=11
Brain injury	4%, n=9
Cerebral Palsy	4%, n=9
Other conditions	12%, n=12

## Demographics

A total of 247 wheelchair users were included in the study; 38% (n=93) were female and 62% (n=154) were male. The average age was 54.9 ± 19.7 years for all wheelchair user participants, 62.7 ± 19.7 years for female wheelchair user participants, and 50.1 ± 18.1 years for male wheelchair user participants. 67% (n=175) of participants previously owned a wheelchair

at study baseline. A summary of other demographic details can be found in Table 1.

## Socioeconomic and health indicators

On average, the likelihood of the wheelchair user households of living below the National and the USAID “Extreme” poverty lines was significantly reduced from baseline to 6-months after receiving a wheelchair,  $t(161)=2.90, p=.004$  and  $t(161)=2.55, p=.012$ .

Overall rates of quality of life and satisfaction with health significantly increased from baseline to 6-months,  $z=-4.41, p=.000$  and  $z=-3.43, p=.001$ . The physical health and environment domains of the WHO Quality of Life assessment at 6-month follow up had significant increases over baseline measurements,  $t(163)=-4.66, p=.000$  and  $t(163)=-4.51, p=.000$ .

Health-related to wheelchair use as defined by the presence of pressure sores, falls during wheelchair transfer and riding, injuries in upper extremities and hands, and back pain significantly changed over time;  $X^2(3)=9.74, p=.021$ ;  $X^2(3)=42.02, p=.000$ ;  $X^2(3)=28.58, p=.000$ ;  $X^2(3)=9.14, p=.027$ ;  $X^2(3)=14.81, p=.002$ ; and  $X^2(3)=46.01, p=.000$ ; respectively. Pressure ulcers were significantly reduced from baseline to delivery,  $z=-3.53, p=.000$ . Falls during wheelchair transfers were significantly lower at delivery, and 3- and 6-months in comparison with baseline;  $z=-4.42, p=.000$ ;  $z=-5.73, p=.000$ ; and  $z=-4.96, p=.000$ ; respectively. Falls during wheelchair riding were significantly lower at delivery, and 3- and 6-months in comparison with baseline;  $z=-4.13, p=.000$ ;  $z=-4.13, p=.000$ ; and  $z=-3.65, p=.000$ ; respectively. Injuries and pain in the upper extremities were significantly lower at 3- and 6-months in comparison with baseline,  $z=-2.90, p=.004$  and  $z=-2.89, p=.004$ . Injuries and pain in the hands were significantly lower at 6-months in comparison with baseline,  $z=-4.02, p=.000$ . Back pain was significantly lower at delivery, and 3- and 6-months in comparison with baseline;  $z=-4.06, p=.000$ ;  $z=-6.48, p=.000$ ; and  $z=-5.68, p=.000$ ; respectively; and significantly lower at 3- and 6-months in comparison with delivery,  $z=-4.62, p=.000$  and  $z=-4.22, p=.000$ . See Table 2 for more details on socioeconomic and health indicators.

**Table 2. Socioeconomic and health indicators**

	Baseline	Delivery	3-Months follow-up	6-Months follow-up
Poverty Probability Index (PPI) <sup>1</sup>				
National poverty line (mean ± SD)*	25.6 ± 19.6	-	-	21.8 ± 18.4
USAID “Extreme” poverty line (mean ± SD)*	9.0 ± 10.3	-	-	7.1 ± 10.5
Quality of Life (WHOQOL-BREF) <sup>1</sup>				
Overall quality of life (mean ± SD)*	2.7 ± 1.2	-	-	3.3 ± 1.3
Satisfaction with health (mean ± SD)*	2.7 ± 1.2	-	-	3.2 ± 1.0
Physical Domain (mean ± SD)*	11.9 ± 3.2	-	-	13.3 ± 3.2
Psychological Domain (mean ± SD)	13.1 ± 3.7	-	-	13.3 ± 4.5
Social Relationships Domain (mean ± SD)	15.0 ± 3.7	-	-	14.4 ± 4.8
Environment Domain (mean ± SD)*	11.9 ± 2.5	-	-	13.0 ± 2.6
Health status (MIT-Health Questionnaire)				
Pressure sores <sup>1,2,*</sup>	12%, n=30	5%, n=8	6%, n=13	5%, n=8
Falls during wheelchair transfer <sup>2,3,*</sup>	32%, n=56	15%, n=24	6%, n=11	7%, n=12
Falls during wheelchair riding <sup>2,3,*</sup>	21%, n=36	7%, n=11	7%, n=14	6%, n=10
Upper extremity injury or pain <sup>2,3,*</sup>	24%, n=42	15%, n=24	12%, n=24	10%, n=16
Hand injury or pain <sup>2,3,*</sup>	23%, n=40	12%, n=19	11%, n=22	5%, n=8
Back pain <sup>2,3,*</sup>	58%, n=101	38%, n=63	19%, n=38	19%, n=32

<sup>1</sup> Includes all wheelchair users in the study. <sup>2</sup> In the 3 months previous to the interview. <sup>3</sup> Includes participants who had a wheelchair at baseline.\* Significant differences found. SD= standard deviation

## Wheelchair skills, wheelchair breakdowns, and adverse consequences

Wheelchair users who had a wheelchair at baseline had a significant change in their capacity to use their wheelchair,  $X^2(2)=28.98, p=.000$ . There was a significant increase in the total capacity score from baseline (44.01

$\pm 27.01$ ) to 3-months ( $51.19 \pm 26.15$ ,  $z=-5.08$ ,  $p=.000$ ), and 6-months ( $48.70 \pm 26.47$ ,  $z=-2.65$ ,  $p=.008$ ), but a reduction in capacity from 3-months to 6-months ( $z=-3.38$ ,  $p=.001$ ).

The number of wheelchair breakdowns that required repairs was significantly different over time  $X^2(3)=51.99$ ,  $p=.000$ . At 3- and 6-months the number of breakdowns was significantly lower in comparison to baseline and delivery;  $z=-6.87$ ,  $p=.000$  and  $z=-4.15$ ,  $p=.000$ ; and  $z=-6.30$ ,  $p=.000$  and  $z=-3.46$ ,  $p=.001$ ; respectively. Receiving wheelchair maintenance reminders did not significantly influence the number of wheelchair breakdowns at 3- and 6-months,  $U=4566.50$ ,  $z=-.041$ ,  $p=.967$  and  $U=3075.00$ ,  $z=-1.35$ ,  $p=.176$ .

### Caregiver burden

Caregivers of users who received wheelchairs in line with WHO's 8-steps did not have a significant reduction in caregiver burden at 3-months ( $25.36 \pm 15.66$ ) and 6-months ( $25.54 \pm 14.63$ ) compared to baseline measurements ( $29.63 \pm 13.91$ ),  $F(2,54)=2.32$ ,  $p=.108$ .

### DISCUSSION

All wheelchair users participating in the study, including those without a wheelchair at baseline, were included in the assessment of poverty probability, quality of life, and satisfaction with health at baseline and 6-months. Due to the study design, which lacked a control group, improved outcomes may not be attributed directly to the WHO 8-steps provision process itself but may be related to the effects of increased personal mobility through access to a mobility device. Indicator analysis by wheelchair ownership at baseline found no significant difference in poverty likelihood at baseline and 6-months. However, higher baseline ratings of quality of life and satisfaction with health were seen in those who did have a wheelchair at baseline. Satisfaction with health ratings, remained significantly higher at 6-months for those previously owning a wheelchair, whereas the quality of life ratings showed no significant difference between these two groups at this time point.

The overall effects of wheelchair services may be observed from the start. Improvements in health factors related to wheelchair use were observed from baseline to delivery. This was likely because service providers began giving advice preventing health complications (such as pressure relieving, and transfer techniques, and proper posture) at assessment when first identifying a user at risk, thereby reducing their risk of developing health complications. Other phenomena may have influenced health-related results, such as knowing they were being followed up regarding the health complications or over-reporting them in the first interview to emphasize the need for a wheelchair. Subsequent analysis will be performed to assess factors that may have influenced these results.

Improvement in the wheelchair skills capacity score from baseline to 3- and 6-month follow-up were as expected as users received basic training on how to use their wheelchair as part of the services received. However, the improvements did not have a long-term effect as a significant reduction in capacity was found from 3 to 6-months presumably due to insufficient dose of training to ensure skill transfer, lack of practice, among other reasons that will be discussed further in another publication.

Reduction in the number of wheelchair breakdowns that required repair was also as expected as the wheelchairs provided during the study were new and more reliable. All wheelchairs provided in the study were ISO 7176-8 certified, which ensures the wheelchairs are high quality and more durable for less-resourced settings where the conditions of the environment tend to be rougher.

Even though a reduction in caregiver burden was observed, it was not significant, suggesting that providing a wheelchair may help with the mobility of the person being cared for but not necessarily reduce the level of assistance needed in all aspects of care.

The findings of this study indicate that people with mobility limitations in low- and middle-income countries (LMICs) are likely to benefit from the provision of a wheelchair and the associated wheelchair services. However, the benefits of appropriate wheelchair provision in line with the WHO's 8-steps are yet to be proven. More randomized controlled studies and systematic reviews evaluating the impact of wheelchair provision interventions, and more specifically the WHO 8-steps approach, are needed to make the case for wheelchairs to be provided following standardized processes [3].

It is recommended that governments, private-entities, and not-for-profits develop and operationalize standards related to manual wheelchair provision, to control for quality of wheelchair provision and rehabilitation interventions.

## **CONCLUSIONS**

Wheelchair provision according to the WHO 8-steps has the potential to improve outcomes for wheelchair users including increased quality of life, decreased poverty likelihood, and increased health-related to wheelchair use. More research on the benefits of providing wheelchairs following the WHO 8-Steps approach is needed. This research-based evidence is necessary to drive policy and wheelchair provision programs in LMICs toward more effective interventions that maximize benefits for wheelchair users.

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## **Outcomes or Impact? When the difficult to measure results appears: The experience in Spain.**

Thais Pousada<sup>1</sup>, Estíbaliz Jiménez<sup>2</sup>, Emiliano Díez<sup>3</sup>, Laura Nieto-Riveiro<sup>1</sup>, Betania Groba<sup>1</sup>

<sup>1</sup>*Universidade da Coruña. Research Center of ICT; TALIONIS Research Group*, <sup>2</sup>*Faculty of Padre Ossó. University of Oviedo*; <sup>3</sup>*INICO, University of Salamanca*

### **ABSTRACT**

Interventions based on the use of Assistive Technology (AT) are a common strategy to promote improved participation and quality of life. Access to appropriate AT is considered a fundamental human right. However, the potential advantages of using AT are limited by a wide variety of factors that must be taken into account when prescribing the use of a particular product. That is why research on outcome measurement is absolutely necessary, being essential to carry out an adequate assessment of the user's needs with reliable measurement tools to improve decision making for the prescription and adaptations of AT.

In Spain, the research related to outcome measures in AT is deficient, because there are not many specific measurement instruments that are validated in the Spanish population. A review of the state of the art about the application of outcome measures in Spain is presented and compared with other European countries. The main challenge is to design and implement a suitable proposal to improve the approach and quality of the AT system. That new approach has to get the consideration from all stakeholders (policymakers, health managers, health professionals and the community) to integrate the measurement of impact derived by the use of AT on the policy goals in the health and social system of the country.

### **INTRODUCTION**

Assistive technology (AT) is a wide and comprehensive group of products and devices designed to increase independence and contribute to the life quality of people with disabilities. These assistive devices constitute important supports that help in doing activities of daily living, being environmental factors facilitators to improve the functional performance of a person (activity & participation).

Literature reviews show that there are significant unmet needs for physical rehabilitation services, including access to appropriate AT across all regions of the world [1]. Otherwise, despite its great contribution, one AT doesn't always meet the specific characteristics of the final user [2].

Nevertheless, the World Health Organization (WHO) also estimates that only 1 in 10 people in need currently have access to assistive technology, owing to a lack of financing, availability, awareness, trained personnel and high costs [2]. An important part of the efforts towards universal coverage for assistive devices involves building national research capacity to generate a strong evidence base both for the real demand for AT in the communities and to prepare for the necessary investments in infrastructure and human resources [1]. Understanding the impact of AT on people's well-being, quality of life, inclusion, participation, empowerment, social and economic status is key to inform policy development, guide public investments and mobilize resources [1,4–6].

In Spain, the situation is complicated not only for the lack of equal access to affordable Assistive Technology but also the difficulty to get qualitative and quantitative data about the results derived from the AT service and intervention. In fact, there is a great lack and deficiency in the implementation of tools that allow obtaining quantitative data to justify the efficacy and effectiveness of the AT system in health services [3,4]. The application of the tools of outcome measures was published only in three research projects [8–10]

The purpose of this communication is to present the global perspective of the impact and outcome measure in Spain, a Mediterranean country where the use of AT is relegated to primarily the prescription of mobility devices. Also, the authors present their research work in the field of outcome measures to reflect on its usefulness in order to improve the provision of AT.

### **RESULTS**

The prescription of assistive technology in Spain isn't guided by a protocol or guidelines, and in the majority of regions, the provision of AT is circumscribed to devices for mobility. In fact, the government (through Public Health System) only funds those products for mobility, so people don't have to pay for them. Nevertheless, they

have to buy and pay for themselves the other devices that can need in other activities (for instance, adjustable beds, hoist or bath chairs). The high price of AT and the lack of expertise and knowledge leads to people don't get the assistive device that they could use to promote their independence [5,6].

On the other hand, rehabilitation professionals in public health, during the prescription of AT, don't consider the psychosocial characteristics of the person, nor his/her activities in lifestyle neither environmental factors nor contexts. They are limited to the consideration of the anthropometric characteristics and the economic aspects so that the person can receive wheelchair funding by the health system. That situation leads to the possibility of the early abandonment or non-use of AT, with the corresponding loss of resources, and the reduction of opportunities to participation and performance activities [7].

The expertise and use of outcome measures and models in Spain are really low. Only three research on that topic has been documented and the authors, also researchers in these, are presenting this communication [8–10]. It is known that few occupational therapists are using the tool Psychosocial Impact of Assistive Device Scale (PIADS) in their clinical practice, but their application is not standardized or protocolized, and of course, not linked to research projects. So, that practice conditions that no data in this field are available to compare results or to get evidence about the outcomes of AT in the lives of people with disabilities.

The lack of information between professionals and users about the available AT and the resources to get one of the needed devices is one of the causes of this low knowledge about the possibilities of outcome measures [5].

In fact, in Spain, we have only two adapted and validated tools for outcome measures: The Psychosocial Impact of Assistive Scale [11] and the Matching Person and Technology [12]. In Table 1 is showed the synthesized data about research done with these instruments in Spain [9,10,13].

**Table 1. Main data of research in outcome measures in Spain**

Study	Year	Region	Sample	Outcome Measures	
				Instruments	Main results
Psychosocial impact of communication assistive technology in people with hearing impairment and deaf people[9]	2016	All territory in Spain	291 people with hearing impairment / deaf people	PIADS	A positive psychosocial impact is associated with the use of support products for communication.  A greater perceived impact was verified in the group of cochlear implant users followed by hearing aids and finally, users of video intermediation systems.  A lower psychosocial impact was found for those participants who abandoned the support product one year after the evaluation.
				Survey of Technology Use (SOTU) of the Matching Person and Technology Model	The predisposition of participants to use communication assistive technology was high.  The predisposition was higher in the group of deaf people using a cochlear implant than in the people with loss hearing.
Psychosocial impact of wheelchair in the life of people with neuromuscular disorders [10,18]	2011	Region of Galicia	60 participants with Neuromuscular disorders	PIADS	The wheelchair has a positive social impact in terms of the perceived quality of life in persons with NMD. Among the different types of assistive tools, the electronic wheelchair offers improved competency and adaptability in users.
				SOTU and ATD PA from the Matching Person and Technology Model	The wheelchair and the user (afflicted with NMD) are matched correctly.  As the degree of user-device matching is increasingly optimized, the degree of the psychosocial impact associated with the use of the device becomes greater and with a higher positive value.
Need, predisposition and adjustment for the use of	2007	All territory in Spain	155 university students: 57 students without disability and	SOTU and ET-PA from the Matching Person and Technology Model	The percentage of students with disabilities in the Spanish University is low, mainly due to lack of adaptations, and the absence of assistive technology. The predisposition to technology use, in general, has been positive (the number of

assistive technology in university students with disabilities [19]			98 persons with disability		<p>positive answers was higher than the negatives or neutral).</p> <p>Students with physical and visual sensory disabilities indicated less experience with online learning systems</p> <p>The virtual learning platforms (like Moodle) aren't completely accessible.</p>
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## DISCUSSION

The authors highlight the special situation of outcome measures in AT in Spain, taking into account the low research projects related to that topic. It is noted that the availability of evaluation tools to help make decisions on the adoption of AT, based on the relevant factors, allows minimizing errors in decision making when matching people and technologies.

To improve that situation, it is necessary to convey the importance of the implementation of this perspective and practice based on the approach of outcome measures in assistive technology. The long term goal is always to optimize the resources and services, in equality, in order to offer and get the best solution for each person, independently of his/her condition.

This piece of work raises a set of challenges and opportunities. Tangible ways forward include [4,14]:

- Funded outcome global projects to get an international profile of AT practices.
- Mentorship/linkages to build knowledge and capacity between low- and middle-income countries and developed regions.
- Incorporation of research results into national catalogs of AT and take the results into account in the process of delivery of AT devices.

## CONCLUSIONS

It is important to make the effort to spread it among the community of rehabilitation professionals and to demonstrate the interesting contribution of these tools to get more efficiency and efficacy of the AT provision system in the country. Finally, the importance is not only concerning getting outcome results but also to generate a real impact in the community, from the evidence.

The present contribution opens the debate to discuss and to address, from a critical perspective, the situation of an obsolete system and the generation of new ideas for the change; as well as the challenges posed at the International Summit from GAATO.

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## Development, validation and impact of a suite of outcomes tools to give triangulated data on the appropriateness of wheelchairs designed for use in low-income settings

Karen Rispin<sup>1</sup>, Vicki Sheaffer<sup>2</sup>, Natasha Layton<sup>3</sup>, Larry Raymond<sup>4</sup>

<sup>1</sup>Assistive Technology Catalyst Project, <sup>2</sup> Monash University <sup>3</sup> LeTourneau University, <sup>4</sup> John's Hopkins

### ABSTRACT

Over the past ten years, we have been involved in research with the goal of providing data to wheelchair developers and manufacturers to improve the effectiveness of their chairs in low-resource settings. We focused on field studies on the function of wheelchairs designed for use in low-resource areas. We found that it was important to discriminate between different aspects of function. For example, a wheelchair could be durable and in good condition, but not at all appropriate for its current user. Or the seating was adequate, but the chair did not roll well on surfaces commonly encountered. In addition, wheelchair users have a different point of view than do wheelchair professionals, but both are essential. To that end, over a period of time, we developed and validated four outcomes tools. All are wheelchair specific and are designed so that feedback is explicit enough to spark beneficial changes to the design of wheelchair parts. To increase discriminatory ability, all use a mixed methods design including qualitative explanatory comments along with quantitative data. The quantitative data is suitable for powerful parametric analysis. Two of the tools are completed by wheelchair users: The Wheelchair Satisfaction Questionnaire and Aspects of Wheelchair Mobility. The other two are professional report tools: The Wheelchair Interface Questionnaire enables informed professional data on how suitable a wheelchair is to its user's needs; the Wheelchair Components Questionnaire enables feedback on the maintenance condition of a wheelchair. These outcomes have been validated and used in studies and are available open source on-line along with supporting research papers. Our hope is that these outcomes tools will enable feedback to improve wheelchair design and services globally.

### INTRODUCTION

Research directly comparing different health-related interventions is essential to confirm that the goals of those interventions are achieved. Laboratory studies that test wheelchairs to ISO standards are an important part of the picture, but they are incomplete. Field studies are necessary because the lab doesn't perfectly model the conditions in which wheelchairs are used, and especially because direct feedback from people involved in wheelchair use and provision is of key importance [1,2,3].

There are significant challenges to collecting data in the field. Wheelchair professionals have time constraints and are focused on the immediate needs of their clients. Any tool that is actually going to be of use must be brief and simple to use. Collecting data over time places a heavy load on busy clinicians and is less likely to be complete than data sets that can be obtained at one sitting. Outcomes tools which are not wheelchair specific are necessarily vague and unlikely to produce data about specific problems with design in a given wheelchair component or aspect of use. The design of questions and protocols also matters. If the results of a study are intended to spark evidence-based changes in wheelchair design, studies must produce data likely to serve that purpose. The type of data set produced by the tool also matters. Studies designed to produce data suitable for parametric statistical such as analysis of variance (ANOVA) are known to be more likely to discern differences. In addition, the power to discriminate meaningful difference is increased in mixed methods studies which include qualitative as well as quantitative data [4,5].

High variation among wheelchair users presents a challenge. Ideally, there should be a level playing field for all wheelchair users. If parts of the wheelchair are described as they relate to human body regions, almost everyone can complete all questions. In studies involving rolling on different surfaces, differences between participants may mask differences due to wheelchair design. A wheelchair user with a very strong upper body may be able to roll farther and more quickly in almost any chair on any surface than a wheelchair user with reduced upper body function. This can be solved by a within-subjects study design in which each participant uses two or more devices and is only compared to themselves [6,7,8].

Another challenge to providing data able to spark positive change is lack of clarity on the specific aspect of function addressed by an outcomes tool. Data to do with one aspect of function may mask data to do with another aspect of function. For example, data on durability is needed but should not obscure data on clinical appropriateness. Data from wheelchair professionals is needed, but it will likely differ from data provided by wheelchair users [1,9,10].

We hypothesized that wheelchair specific tools designed to provide clear data on specific aspects of wheelchair function would enable positive design changes on the part of manufactures and enable the provision of more appropriate wheelchairs.

## METHODS

Beginning in 2010, comparative studies were done in partnership with BethanyKids at JoyTown School for students with disabilities in Kenya with the goal of providing feedback to manufactures of wheelchairs intended for use in low-resource settings. Undergraduate teams prepared in the US and then traveled to Kenya on short trips. Given those limitations, we felt we could provide meaningful data on four topics: 1) Is it broken? 2) Does it roll well? 3) Does it suit its user? 4) Is the user satisfied?

Four outcomes tools were developed. Each was designed to provide a level playing field to all wheelchair users. Visual analogue scale (VAS) format questions were used to produce data suitable for ANOVA. To provide a shared understanding of the rating scale, emoticons were used as anchors underneath the visual analogue line. Each VAS question also solicited an explanatory qualitative comment (Figure 1)

1. Rate the seat, include cushions and other parts supporting the hips, buttocks and thighs.

POOR |  |  |  |  | EXCELLENT

Comment: \_\_\_\_\_

Figure 1. Format of the questions used in each of the tools described in this paper.

Each outcomes tool was brief so that it could be completed in a short time period, and it focused on only one of the four topics. It was designed to provide a snapshot of function at one moment in time. For the four outcomes tools validation studies have been published covering construct validity and reliability. Comparative studies on different wheelchair types have also been published and in those studies ideally 30 wheelchairs of each type were included. The tools are very briefly described below in the order of their development. For more information, related research publications are available at [www.atcatalyst.org](http://www.atcatalyst.org). All four outcomes tools are available open source on the same website.

### Wheelchair Components Questionnaire (WCQ)

The WCQ addresses the “Is it broken?” topic. It is a professional report tool for wheelchair professional to assess the maintenance condition of a wheelchair. The WCQ does not require the tracking of repairs over time and is brief with only eight questions. Questions are written to relate wheelchair regions to regions of the human body so that all questions can be completed for almost all wheelchairs in use. Figure 1 is a question from the WCQ [10,11,12,14]

- **Aspects of Wheelchair Mobility Tests (AWMT)**

The AWMT addresses the “Does it roll well?” topic. If the AWMT is used in a comparative study, 25 or more participants each roll in two or more wheelchair types on tracks that model three commonly encountered rolling environments: smooth surfaces, rough surfaces, and tight spaces. Each participant is compared only to themselves so that the impact of wheelchair design on mobility is not obscured by individual variation. After completing a track in each type of wheelchair, a participant answers a feedback [6,7,8,13,15]

- **Wheelchair Interface Questionnaire (WCQ)**

The WIQ addresses the “Does it suit its user?” topic. Therapists with wheelchair experience and training are the population most able to answer this question. The WIQ provides a moment in time assessment based on informed professional opinion on the quality of the interface between individual users and their wheelchairs. Because of the difficulties in interacting with non-verbal wheelchair users, or small children, or those who only speak a mother-tongue, interaction with the wheelchair user is encouraged but not required [3,9].

- **Wheelchair Satisfaction Questionnaire (WCQ)**

The (WSQ) addresses the “Are the users satisfied?” topic. It collects data on a wheelchair user's satisfaction with their own wheelchair at a given moment in time. This tool has 16 questions that cover satisfaction with regions of the wheelchair supporting different bodily regions. It also includes questions on other aspects of satisfaction with a wheelchair [1,15].

## **RESULTS**

Responses to our studies indicate that our goal of providing feedback specific enough to spark positive change in wheelchair design and provision was met. The AWMT and the WCQ were the first two outcomes tools to be developed, and these have been used in several comparative studies. There were responses on the part of the wheelchair companies whose wheelchairs had been involved in studies. Free Wheelchair Mission modified the attachment of footplates on their Gen 2 wheelchair. A designer who had been working with Hope Haven, has indicated that our study results were a key factor in his development of the concepts behind the BeeLine wheelchair initiative. Wheelchairs for Kids modified the design of their lateral trunk supports and castor bearings. Several manufacturers indicated that problems revealed in our studies had been due suppliers providing inadequate parts; for example, Whirlwind altered the subcontractor for the caster material when our study revealed failure of castor wheel material. A few manufacturers have not responded to significant problems revealed by our studies. Even in those cases, wheelchair provision was locally improved because our results confirmed a strong hesitancy on the part of several organization to order or use those wheelchair types.

## **DISCUSSION**

Although the snapshot like nature of these outcomes tools does facilitate quick and complete data collection, there are of course limitations. For example, WCQ data does not reveal exactly when the wheelchair was last repaired. However, to some extent, comments can give insight on the long-term reasons for the snapshot responses of those completing the WCQ, WIQ and WSQ. With the AWMT, participants sometimes mention other situation in which they've encountered problems rolling in a certain rolling environment.

Many studies have used visual analogue scale (VAS) format questions to produce data which was then found to be suitable for parametric analysis. However, the lack of an understanding of the scale can be a problem. Early on in the development of these measures, we had tried to use a VAS line without grades. Without anchors, we found that data was obscured. For example, for the WCQ, the score for maintenance condition of the push handles was scored higher than other wheelchair components for our study wheelchairs by all raters; however, this finding was obscured because of high variation in the way raters responded to the VAS line. Some raters marked all parts lower on the scale or higher on the scale, or closer together. The push-handles were consistently scored higher, but the actual scores were highly various, therefore ANOVA did not indicate statistical significance. For VAS format pain assessment questionnaires, ‘anchors’ under the scale help to give a shared understanding of what is meant [17]. However, emoticons indicating grief or pain seemed inappropriate for our purpose. When we paced symbols for school grades as anchors under the line, this solved the problem, presumably because of the shared understanding of these symbols. We have found that school grade symbols also provide a powerful communications tool when addressing the wheelchair manufactures. The statement, “your footplates consistently received an average mark equivalent to a failing grade,” has more punch than “your footplates received a mark on the lower end of the VAS scale”. Local culturally appropriate grading symbols need to be used as anchors to provide this intuitive understanding. Although we have done validation studies in Kenya and in the US which have slightly different grading symbols, additional validation with grading symbols from different cultures is still to be done.

The data for the WSQ and AWMT come directly from wheelchair users. This is of course essential for any assessment of the function of a wheelchair. Unlike the other measures, the AWMT provides hard data on distance traveled along with accompanying response questions. It may be a bit more difficult to implement because it requires following a protocol to set up the tracks and collect data. With the professional report data, we wanted to answer the “is it broken?” question separately from the “does it suit its user?” A wheelchair that is durable and in good condition may not be at all clinically appropriate. Therapists and other wheelchair professionals with wheelchair experience and training are the people who have base of knowledge to provide data on the maintenance condition of the wheelchair, and on the appropriateness of a wheelchair for its user. Professional report data from the WIQ and WCQ is also easier to collect than data directly from users. Wheelchair users may be non-verbal, or children, or only fluent in small mother-tongue languages. In contrast, wheelchair professionals almost universally speak the local language of education which is often a worldwide language. In our areas of study, wheelchair professionals are almost universally fluent in English.

The WCQ and the WIQ could be quickly completed by wheelchair professionals as part of a follow-up wheelchair assessment. At the same time, the wheelchair users who are verbal and able to complete a questionnaire could

complete the WSQ. The three tracks for the AWMT could be part of a wheelchair skills training area, and a four-minute roll test on each track could become part of wheelchair selection or follow-up assessments. Data from these validated outcomes tools could be used to as supporting evidence for wheelchair repair, modification or replacement.

## CONCLUSION

For a full picture of the function of a wheelchair or wheelchair type, it is helpful to be able to answer four questions: is it broken? Does it suit its user? Does it roll well? Is the user satisfied? The first two are completed by wheelchair professionals, the last two by wheelchair users. All are wheelchair specific and are designed so that feedback is explicit enough to spark beneficial changes to the design of wheelchair parts. To increase discriminatory ability, all use a mixed methods design including qualitative explanatory comments along with quantitative data. All four outcomes tools can and have been used successfully in studies on specific types or makes of wheelchairs, they can be used to improve local wheelchair services.

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Figure 1 is a question from the Wheelchair Components Questionnaire showing the user oriented clear wording and the format of questions utilized in these tools. The question says, “Rate the seat include cushions and other parts supporting the hips, buttocks and thighs.” It illustrates a visual analogue scale with emoticons as anchors and a comment line to explain the rating.

# **A partnership between researchers, an established NGO and an overseas manufacturer to address chronic problems with prosthetics supply in Uganda**

Rubango K, Ackers L, Ssekitoleso R, Kenney L, Howard D

*University of Salford, Joint Medical Store, Makerere University*

## **ABSTRACT**

In most LMICs, foreign donor programs are the major provider of Prosthetics and Orthotics (P&O) products, yet they are temporary. The beneficiaries of these donations are unable to access maintenance services or replacements after the donors exit due to lack of local supply chains. As a result, orthopedic clinics contact (typically foreign-based) manufacturers or distributors directly for each order, which significantly increases the products' cost. Cost is the most profound impediment to use of P&O products in LMICs. Therefore, the establishment of a sustainable local supply chain for P&O products has the potential to have a high impact on usage of P&O services.

This practice paper presents a case study of the introduction of a new supply chain model, offering a range of P&O products via a Ugandan non-profit distributor – Joint Medical Store (JMS). The introduction of P&O products at JMS involved key informant interviews and focus group discussions with stakeholders in the P&O supply chain to understand the needs and challenges being faced with the objective to design interventions that address them.

The lack of clarity on tax exempt P&O products and sufficient local stock of P&O products were found to be key challenges in Uganda. Direct-to-manufacturer sourcing and inclusion of end users and regulators in the product selection and supply chain design were found to be key for affordability and ensuring local stock availability of P&O products. These insights could inform similar initiatives by non-profits to develop a sustainable pathway to supply P&O products to groups of interest. Although up-to-date statistics are not available, a conservative estimate based on World Health Organization's (WHO) studies and estimates, suggests that the P&O unmet need is about 82,000 individuals in Uganda hence the JMS development has the potential to impact at least 5000 of them.

## **INTRODUCTION**

The International Society for Prosthetics and Orthotics (ISPO) in collaboration with the World Health Organization (WHO) advise that in the developing world, a reliable estimate for persons with disabilities who require P&O products and related rehabilitation services is 0.5% of the general population. [1] Using this estimate, as of 2018, about 32 million people with disabilities in the developing world would have been in need of P&O products. [2] Similarly, the current P&O need in Uganda would be 205,000 individuals. [3]

The most recent Ugandan nation-wide prosthetic need was reported by Staats et al in 1996. [4] These 5000 amputees were reported before the end of the Kony war in 2006 and the civil unrest in South Sudan, both of which are believed to significantly have contributed to the increase of the number of war-trauma related amputees in Northern Uganda. [5,6] In a study reported in the 2011 World Disability Report, the average unmet need for Assistive Devices was 77% among the study countries in the developing world. [7] Conservatively assuming that the unmet need in Uganda is a minimum of 40% of those in need, 82,000 individuals would represent the P&O unmet need.

Although there are few studies on the cost of prosthetic limbs, according to the 2015 Phillips et al and a 2013 article by ABC news, a prosthetic limb costs between 15 to 50,000 USD, requiring replacement between 3 to 5 years. [8, 9] According to the 2016/17 National Household Survey, Uganda's Average Monthly income is about 110 USD. [10] As such, it is highly unlikely that a typical Ugandan will afford a P&O product that costs more than their month's income. Unsurprisingly, a recent study in Tanzania investigating the barriers to prosthetic use found that cost is the biggest impediment to access of prosthetic devices. [11] The prohibitive cost of these P&O products is to the most part due to the lack of a reliable local supply chain to benefit from economies of scale, preferential pricing direct from manufacturers and tax exemptions.

Non-profits have been heavily involved in the funding of P&O product and service provision but they have not developed the local P&O supply chain to be self-sustaining post their intervention. [8] As such, there are multitudes who would afford P&O products through a reliable local supply chain but still have an unmet need. Of the estimated

82,000 individuals who have an unmet need in Uganda, this case study is assuming that at least 5000 of them will be able to afford certain P&O products when reliable local distribution by a non-profit organization – Joint Medical Store – is implemented.

## **METHODS**

This case study was conducted through focus group discussions and key informant interviews with different stakeholders in the P&O supply chain. These stakeholders involved orthopedic technicians, a leader of the biggest funder of P&O devices in Northern Uganda, a manufacturer of prosthetic devices, and regulatory bodies of P&O service provision.

### **Needs Assessment Field Trip to Northern Uganda**

A field trip to Gulu in Northern Uganda was made to a branch of an NGO, the AVSI Foundation- Uganda, and an interview was held with the Program Manager about the challenges, strategy and opportunities in the provision of P&O devices in Uganda. The Program Manager at AVSI then enabled a focus group discussion about the desired product attributes for P&O devices suited for the Ugandan context with the Orthopedic Technicians of Gulu Regional Referral Orthopedic Workshop, whose operational budget is supported by AVSI Foundation.

### **Academic Trip to the University of Salford, UK**

A visit to the University of Salford provided the opportunity for 3 interviews with: a PhD student designing a socket suitable for low-income settings, a Research Scientist researching techniques to capture real world use of prosthetic hands and with the lead of the Fit-For-Purpose project [12] and other members of the lead author's academic supervision team from Makerere University and University of Salford. Coincidentally, another member of the supervisory team was hosting 6 Orthopedic Technicians from Uganda with whom we had a Focus Group Discussion about the products needed and recommended brands for stock consideration by Joint Medical Store.

### **Manufacturer on-boarding trip to Nobel Prosthetic China Ltd Head Quarters in Guangdong, China**

Following the discussions with the NGO, the Orthopedic Technicians and academic supervision team, desktop research to identify manufacturers of prosthetic devices was undertaken and Nobel China Ltd was selected for a manufacturer on-boarding visit. At their company premises in China, a discussion was held about the introduction of prosthetic devices to the Ugandan market via the JMS-Nobel China Ltd partnership.

### **Uganda Association for Orthopedic Technologists Workshop**

Upon the confirmation of JMS as the certified distributors of Nobel China Ltd, JMS was represented in the Uganda Association for Orthopedic Technologists workshop which brings together Orthopedic Technicians from all over the country. The goal of JMS' representation in this workshop was to request the Orthopedic Technicians in attendance to select particular models of interest for JMS to stock them, with assurance of market acceptance prior to order placement and shipment. Fortuitously, the Ministry of Health Department of Disabilities was also in attendance and they too shared their insights regarding the P&O supply chain.

## **RESULTS**

Two major learnings were made from the interactions with the different P&O supply chain stakeholders and interventions are ongoing to address them as detailed below.

### **Stock depletion and inexistence of certain P&O products from the local market**

Stock outs from the only 3 local suppliers of P&O products and services in Uganda were common forcing the Orthopedic Technicians to improvise with non-ideal alternatives like melting jerrycans to replace polypropylene plastic sheets during socket fabrication or to place orders directly to the manufacturers which is now the norm. The stock depletion was due to the fact that the 3 local suppliers have a limited stock range and quantity that is by far insufficient to meet the demand. These small order quantity stock replenishments direct from the manufacturer lead to increased unit costs of the prosthetic devices since they do not benefit from economies of scale. In some cases, intermediate companies masquerade as manufacturers, thereby providing marked up prices for products since the Orthopedic Technicians typically do not make prequalification on-site visits to confirm that the seller is indeed a manufacturer and one who follows the standard Good Manufacturing Practices.

### **Lack of clarity on tax exempt P&O products**

It was noted that all P&O consumables are not tax-exempt since they are in a form that could be used for non-health related activities which makes them more expensive. This was noted to be a repercussion of conducting programs that involve the importation of P&O products without notifying and involving the regulatory bodies in the process. (Ministry of Health Department for Disabilities and the Uganda Revenue Authority) This is a clear indication of the lack of procurement expertise on the part of the Orthopedic Technicians and Workshops who attempt to import their own P&O products in-country.

## ONGOING INTERVENTIONS

In response to the stock depletion and inexistence of certain P&O products locally, Joint Medical Store (JMS) has partnered with Nobel China Ltd as their official distributor for P&O products in Uganda. In addition to Nobel China Ltd, JMS' plans to on-board two other P&O product manufacturers that have been recommended by the Orthopedic Technologists. Additionally, the translational research consortium (JMS, University of Salford and Makerere University) is planning to collect nation-wide data on the consumption of P&O products via a custom inventory management system to inform the demand of P&O products in the country which will in-turn inform JMS' stock quantities to ensure sufficient availability of stock quantities and stock range. More so, this data is envisioned to support the application for tax exemption for these products by clearly showing their use in the healthcare industry, which will in turn inform Policy design.

## CONCLUSION

In summary, the process of introduction of P&O products to the Ugandan market via Joint Medical Store is still ongoing. However, the learnings that have been made so far are informative to P&O product supply chain stakeholders like funding bodies to explore empowering local institutions for sustainability upon exit.

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## Different Strokes for Different Folks: Different Outcomes are Valued by Different Stakeholders

Marcia J. Scherer, PhD, MPH, FACRM, RESNA Fellow<sup>1</sup>, Roger O. Smith, Ph.D., OT, FAOTA, RESNA Fellow<sup>2</sup>

<sup>1</sup>Institute for Matching Person & Technology, <sup>2</sup> University of Wisconsin-Milwaukee

### ABSTRACT

This paper updates and extends an editorial written by the first author on “Technology Adoption, Acceptance, Satisfaction and Benefit: Integrating Various Assistive Technology Outcomes.” Additional stakeholders have been added as well as evidence-based outcomes measures applicable to each. It is critical for outcomes measurement developers, researchers, policy makers, people with disabilities, practitioners, funders, and service program administrators and managers to understand that each of their perspectives on outcomes is critical, but each of these unique perspectives is only one perspective of many. These many perspectives become even more important to consider when cultures, financial models, and service delivery programs, are unique as is the case across LMIC and MIC where many of the outcomes systems were not originally developed.

### INTRODUCTION

Measuring outcomes are crucial to any assistive technology (AT) service program. But the seriousness of this discussion is now more important than ever. The world level initiatives by WHO, the China Belt and Road, and others have elevated the attention to begin meeting a world level need. As new programs embark, this becomes a critical time for discussing how outcomes are best measured and systems developed. There is no better time to introduce new assistive technology outcomes systems as when new programs have the potential of collecting naturally occurring baseline data prior to service provision that can be compared longitudinally as services and device interventions are implemented.[1]

However, the value of assistive technology is not the same to everyone and this value is core to outcomes measurement. For example, to the user of technology it is only as valuable as what the person gains from using it, the benefits of use compared to the expenditures of procuring it, time learning to use it, fatigue in using it, embarrassment of using it, and so on. When a product or system meets standards of good design and usability, its use and realized benefit from use depends heavily on initial expectations of benefit, involvement in product and feature selection, and adequate training for use.

*“AT users may be satisfied with the clinic’s services, have the necessary funding for the device, received a product that is usable, looks good, functions well and meets all safety standards, and helped them achieve functional gain -- but if it is a hassle to use, set-up and maintain, if it doesn’t fit with their needs/preferences/lifestyle, if they feel self-conscious using it, insecure with use even though it is safe, if they are socially and physically and emotionally uncomfortable with use, then they are not realizing benefit from use and will not use it. It is not a good match of person and AT. Ultimately, it is the User Experience (UE) and realization of benefit that drives and determines whether or not a device is used, for how long, what percent of the time and in which environments” (Scherer, 2017, p. 1).*

As more and more technologies are becoming indispensable to people with disabilities, use is becoming less and less optional. This makes it even more important to assess realization of benefit, and whether use was prematurely or inadvisably stopped and why that occurred. But other AT stakeholders hold different perspectives and value different outcomes. [2,3]

### Different Views of Desirable AT Outcomes

These distinct perspectives of what outcomes are even extends to the point where some do not even have it in their vocabulary. In the U.S. where the concepts of “outcomes” are commonly used, it was found that consumers of AT devices and services may not even conceptualize the word for their device use, suggesting that perhaps the term is conceptualized by administrators, managers, funders and academics, not AT end users. [4]

Table 1 contains examples of key assistive technology stakeholders and what they view as key outcomes. While they do share common goals, they differ in the weight they place on the person, the technology, and situations of use.

Table 1. Examples of Various Assistive Technology (AT) Outcomes According to Stakeholder\*

Stakeholder	Focus	View of AT	Desired AT Outcome	Sample Outcome Measures
AT user	Comfort, function	Functional gain, use worthiness	Realization of benefit from use, enhanced well-being/QoL	ATD PA, ATUFS
Clinic director	Continued operation and funding	Functional gain	User satisfaction, cost containment	User feedback surveys, financial reports, SCAI
Funding agencies and payers	Minimization of financial losses	Functional gain	Functional gain, profit, cost containment	Accounting reports
Physical therapist	Mobility, movement, seating and positioning	Functional gain	Mobility, comfort, functional gain	FIM, WST
Occupational therapist	Task performance	Functional gain	Comfort, functional gain, personal well-being, underutilization/overutilization	log of AT use, SWBS, ATD PA, OTFACT
Speech Language Pathologist	Communication	Speech communication support or alternative	Communication	(Same as for OT), AAC TOM
Rehabilitation counselor, social worker, psychologist	Employment, personal factors, goal achievement,	Functional gain	Use worthiness, personal well-being, realization of benefit, underutilization/overutilization	(Same as for OT)
Special Educators	Academic achievement, social interaction	Academic and functional performance	Learning, class participation	MATCH-ACES, ET PA
Rehabilitation engineer, computer scientist, manufacturer, supplier	Device, system, and components, product sales	Functional gain, safety, operability, affordability	Usability, performance, technology adoption/acceptance/diffusion, user satisfaction	QUEST, log of AT use, TAM, UTAUT

\* all emphasize enablement and the performance of activities and participation, but vary in and weigh differently attention to the person, milieu/environments of use, and technology functions and features  
 Source: Authors as modified from Scherer, 2017 [5]

## INTERNATIONAL RELEVANCE

Different geographic areas, economies and cultures value some outcomes more highly than other outcomes and this can make global data sharing and strategizing challenging. Consequently, the identification of the most common elements of outcomes measurement systems and databases will be essential to use as an initial way to communicate across regions and disciplines.

## OUTCOMES MEASURES

Many lists of measures exist. A few AT assessments are listed here. Another compilation of instruments, all free when catalogued, exists on the R2D2 Center ATOM Project website: <http://www.r2d2.uwm.edu/atoms/idata/> [6] and in a scoping review of AT evaluation tools [7].

**AAC TOM:** Enderby P. (2014) Introducing the therapy outcome measure for AAC services in the context of a review of other measures, *Disability and Rehabilitation: Assistive Technology*, 9:1, 33-40, DOI: 10.3109/17483107.2013.823576

**Functional Independence Measure (FIM):** Hamilton BB, Granger CV, Shervin FS, et al. A uniform national data system for medical rehabilitation. In: Further MJ, ed. Rehabilitation outcomes: analysis and measurements. Baltimore: Paul H Brooks, 1987

**MATCH-ACES:** Zapf, SA, Scherer, MJ, Baxter, MF & Rintala, DH. (2016) Validating a measure to assess factors that affect assistive technology use by students with disabilities in elementary and secondary education, Disability and Rehabilitation: Assistive Technology, 11(1), 38-49. PMID: 26696460.

**Matching Person & Technology (MPT) Portfolio:** Scherer, M. J. (1998). Matching person & technology: A series of assessments for evaluating predispositions to and outcomes of technology use in rehabilitation, education, the workplace & other settings. Institute for Matching Person & Technology.  
<https://sites.google.com/view/matchingpersontechnology/>

**ATD PA:** Assistive Technology Device Predisposition Assessment (ATD PA), see Matching Person & Technology (MPT) Portfolio

**ATUFS:** Assistive Technology Use Follow-up Survey (ATUFS), see Matching Person & Technology (MPT) Portfolio

**ET PA:** Educational Technology Predisposition Assessment (ET PA), see Matching Person & Technology (MPT) Portfolio

**OTFACT:** Smith, R. O. (2002). OTFACT: A multi-level performance-based software instrument with an assistive technology outcomes assessment protocol. Technology and Disability, 14(3), 133-139.

**Psychosocial Impact of Assistive Devices Scale (PIADS):** Jutai, J., & Day, H. (2002). Psychosocial impact of assistive devices scale (PIADS). Technology and Disability, 14, 107-111.

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## DISCUSSION

We have an opportunity like never before and maybe never again as AT programs rapidly proliferate globally. While a local AT outcomes system will be of benefit to programs as they document their challenges and success, national [8] and indeed, global reporting and related databases are of immense benefit for comparison and informing each other. The recent COVID-19 is a clear example of how global data can be of mutual international interest. While AT is an intervention and COVID-19 is the challenge, the need to collect data around the need for intervention and the success of interventions is actually the same. We all learn from the experiences of others around the globe. We need common terminology, common data elements, common databases to best benefit from the work of our international colleagues and achieve global .

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## Addressing data gaps to improve evidence on AT outcomes – an update from Australia

Emily J. Steel<sup>1</sup>

<sup>1</sup>*Centre for Universal Design Australia*

### ABSTRACT

Australian governments are currently investing in a National Disability Data Asset (NDDA) as part of a Disability Research Strategy to inform policy and practice. This is an important opportunity to find out about the need for and use of assistive products for the first time. The NDDA is expected to address critical data gaps and help governments understand and address the needs of people with disability.

Many data collections exist across different agencies and sectors that provide assistive technology (AT) in Australia, but data gaps exist and inconsistencies in defining disability and AT limit the quality and comparability of data. There is a lack of information on what services people use (across mainstream and specialist areas), and how coordinated, timely and effective they are. There is also a lack of information on the unmet need for services and the quality and sustainability of the disability workforce. The Australian Institute of Health and Welfare (AIHW) has recommended improvements in the use of existing data sources (including surveys and administrative data), consistency of definitions across data sources, and the development of new data sources and data linkages.

The improvement and development of data sources in Australia will provide useful data for international comparison if it adopts standard terminology and concepts. Use of classification frameworks such as the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) has been recommended to improve consistency. A standardized terminology for assistive products and associated services, as proposed at the Global Research, Innovation and Education in Assistive Technology (GREAT) summit in 2019, would ensure that data collected in Australia contributes to international efforts to improve access to high quality, affordable assistive technology.

### INTRODUCTION

AT providers and researchers have discussed the challenges of meeting the needs of people with disability while also demonstrating fiscal responsibility to funding bodies [1]. It is important to identify and measure what AT is and how it is acquired, and its intended outcomes for individuals and society, in order to appropriately and efficiently allocate public and private resources [2].

In Australia, a lack of conceptual clarity and terminology to describe assistive products, AT services and other rehabilitation interventions has contributed to the conspicuous absence of outcomes measurement. There is a legacy of state-government run services providing subsidized assistive products, collecting data on outputs (e.g. number, type, and cost of products) rather than functional outcomes (e.g. participation in employment, education, and recreation). The introduction of the National Disability Insurance Scheme (NDIS) that funds reasonable and necessary supports (including assistive products and AT services) across the lifetime for Australians with permanent and significant disability (approximately 10% of all Australians with disability) provides the first opportunity to collect and analyze AT outcomes data. This is dependent however, on service providers and policymakers agreeing on and using terminology to describe AT interventions, which are often embedded in rehabilitation practices and not identified as discrete variables in outcomes measures [3].

Without specific reporting on AT and concurrent interventions (e.g. environmental modification, task modification, human assistance), any reported functional outcomes may be assumed to be the result of an assistive product alone. This is despite research showing significant associations between approaches and processes used in AT provision, and demographic factors of AT users, and outcomes reported by hearing-aid and wheelchair users [4]. Use of the ICF, complemented by standardized and more granular terminology for assistive products and AT services as environmental factors, may enable internationally replicable data collection techniques that can inform national policies and international reporting to progress the goals of the WHO's Global Cooperation on Assistive Technology (GATE). The purpose of this paper is to present the proposed approach to improving data sources and evidence on people with disability in Australia, and link this to the global agenda to improve access to high quality affordable assistive technology.

### METHODS

The AIHW acknowledges that, while there are many existing data sources on people with disability in Australia, the quality and usefulness of these sources varies [5]. Key challenges with the existing data include the inconsistent definitions of disability across sources, the limited availability of data that is collected but not shared

for statistical purposes, and the lack of integration of data across settings and domains of participation to understand pathways and outcomes for people with disability. The critical information gaps make impossible to report on the mainstream and specialist services that people with disability use, and their effectiveness, as well as the unmet need for services.

To improve the evidence, the AIHW have proposed work on three areas: maximizing the use of existing data sources; improving the quality and comparability of data across data sources, and; adding to data sources, including by developing new data sources in priority areas and through data linkage [5]. This will require agencies including the AIHW, the Australian Bureau of Statistics (ABS), Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA) to agree on and adopt consistent definitions. The ICF has been proposed as a useful framework for improving consistency and coverage between data sources to report more comprehensively on people with disability. Consistent terminology and data rules should also reduce the complexity, timeliness and cost of data cleaning currently required prior to linking data from various sources.

## RESULTS

Under the direction of the Australian Digital Council, several state governments are participating with the AIHW in a pilot of a new National Disability Data Asset (NDDA) that will help work through many of these issues. Consultation with people with disability, service providers, governments and the research community is anticipated. At the time of writing, there were no updates available since the 18 month pilot commenced in late 2019, but it is anticipated that interim findings will be reported by mid 2020 [6].

## DISCUSSION

The development of the NDDA is an important project to address the data gaps on people with disability in Australia, but should also be seen in the broader context of the international agenda to improve access to AT. Any new data asset on disability that doesn't collect and report data on AT needs, provision and use is a missed opportunity, but the limited awareness of unmet need for AT in Australia, and the lack of a shared language to communicate the issues between people with disability, practitioners and policymakers risks AT being left off the policy agenda again. Key documents that are guiding policymaking in the NDIS still refer to aids and equipment rather than assistive products, including the Applied Principles and Tables of Support (APTOS), which outline the roles and responsibilities of different sectors who deliver supports to people with disability [7].

As an insurance scheme, the NDIS relies on the aggregation of data to inform actuarial decisions about funding. This necessitates descriptions of the assistive products and services provided, as well as monitoring whether consumers received interventions as intended, and functional outcomes. Several service models and instruments to measure outcomes from AT provision have been developed and validated by researchers, but are not yet promoted or mandated for use in practice by policymakers, despite the ambition of the NDIA to "capture information and build an evidence base" [8 p.3]. A focus on assistive products and lack of a systematic data collection strategy to evaluate outcomes of AT provision jeopardizes the equity and sustainability of the NDIS.

## CONCLUSION

The development and pilot of an NDDA presents an opportunity to collect data on AT needs, interventions and outcomes for the first time across Australia. The AIHW's proposal to improve evidence through data linkage and improved quality and comparability should facilitate international reporting and comparison with countries providing AT in similar and different policy and practice contexts. Linking the NDDA to the WHO's global efforts to assess need and demand for AT may contribute to improved access to AT.

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