

Part II

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ICCHP-AAATE 2022 Open Access Compendium
"Assistive Technology, Accessibility and (e)Inclusion"



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Aim and scope: To communicate and complete knowledge on ICT, AT and Accessibility for/with people with disabilities and older adults and connect research in these domains with the necessary practical background and user related aspects.

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Editorial

Welcome to our Open Access Compendium “Assistive Technology, Accessibility and (e)Inclusion” published on the occasion of ICCHP-AAATE 2022.

The first Open Access Compendium was published for the ICCHP 2020 conference and its added value became immediately clear, just as the wish to continue what hopefully will become a long series of significant resource publications for the community of AT and accessibility researchers and wider stakeholder.

That first edition which came under the title “Future Perspectives of AT, eAccessibility and eInclusion” included 29 peer reviewed papers. The one we present today includes 78 contributions. that together present a 360° view on AT, Accessibility, ICT with and for people with disabilities and older adults.

The decision of AAATE and ICCHP to join forces for the organization of a major conference in 2022, provided an excellent opportunity for innovation. It was decided to create and offer a new venue for researchers and practitioners in assistive and access technologies, to showcase their work and mingle together.

After almost two years of living through a pandemic, during which AAATE 2021 had to be canceled and ICCHP 2020 was held online, the best way forward was to merge the individual bi-annual conferences for 2022, providing a single platform for exchanging ideas, stimulating conversation, and facilitating networking— at the Polo Territoriale of the Politecnico di Milano in Lecco, close to the most beautiful shores of Lake Como.

So, the Compendium got a brand-new name, highlighting this new, additional perspective. Its scope was broadened to include topics closer to the AAATE community and the conference themes. Each of the extended abstracts submitted underwent a rigorous review by at least 3 experts, making up the selection presented in this second edition.

Representing a multidisciplinary, multifocal approach was made easier by bringing the AAATE and ICCHP communities together to explore the common threads linking policy, practice, research and advocacy for people living with disabilities, as well as working together for a more equitable, and inclusive future.

The ICCHP-AAATE 2022 joint conference was open to everyone interested in new and original ways to put technology at the service of people living with a disability. Together with the traditional Young Researchers’ Consortium, this joint conference was a unique ecosystem for networking, exchange and connecting researchers and developers in all our field(s) to a stronger community.

This universal approach that has characterized the conference is also reflected in the different publications available: Technological-scientific conference proceedings published with Springer Lecture Notes in Computer Science; the scientific, more open and broader designed Open Access Compendium “Assistive Technology, Accessibility and (e)Inclusion”; and the ICCHP-AAATE Book of Abstracts collecting all submitted abstracts and additionally the descriptions of policy sessions and panel discussions, educational sessions; and the brand new Innovation Area with product presentations, demonstrations and poster sessions.

We hope this edition of our Open Access Compendium delivers memories, knowledge and also new insights to you – and is an incentive to join our future conferences.

Looking forward to meeting you 2023 at AAATE in Paris, France and at ICCHP 2024 in Linz, Austria.

Linz / Lecco, July 2022



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AT and Rehabilitation: Service Delivery and Policy



Shaking up Services

Reframing Service Delivery as a Self-Organising Complex Adaptive System to Sustain Innovation

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Abstract. This paper outlines a systemic understanding the innovative development of (e)Services in Ireland during the initial months of the Covid-19 lockdown in 2020. The pandemic posed a wicked problem which defied obvious solutions and had no clear stopping point. In response to the need to sustain contact with disabled people most at risk both of catching the virus and of social isolation, some services developed ad hoc responses. This research explored the practices that staff engaged in to craft that response. Interviews with a purposive sample of twelve staff supporting people with physical, sensory, and intellectual disabilities, across education and training, independent living, information and day services were held between July and September 2020. Four key technological factors were found to contribute to or inhibit the capacity to innovate: organisational technological capability, access to resources, organisational orientation to understanding the role of technology in people's lives and digital literacy skills amongst staff and disabled people. The response is consistent with understanding disability services as Complex Adaptive Systems (CAS), capable of self-organising beyond traditional hierarchies and boundaries, and dynamically adapting to external circumstances to craft unique contextualised responses. The imperative to build on the creative potential of (e)services will rely on sustaining a spirit of openness to innovating in real time and a continuous balancing of potential risks and social inclusion in online spaces. This is likely to be met with success where technology continues to be the tool for engagement rather than an end goal.

Keywords: (e)Services, Innovation, Complex Adaptive Systems

1 Introduction

This paper outlines a systemic understanding the innovative development of (e)Service Delivery in Ireland during the initial months of the Covid-19 pandemic. The WHO announcement of a global pandemic on the 11 March 2020 prompted governments to instigate lockdowns which impacted hugely on face-to-face services and supports for people with disabilities. No one was prepared for this rare 'black swan' event that occurred outside normal expectations characterised by uncertainty or the disruption it would bring [1]. The pandemic presented a "wicked" problem where there was not definitive formulation of the problem the pandemic posed, no stopping rule for when it

might end and no clear solutions or opportunities to test different kinds of interventions. Additionally, governments and service providers had no right to get the response wrong [2].

There were particular concerns that disabled people would be hardest hit by the pandemic and the UN urged countries to prioritise their needs [3]. The pandemic posed a double risk for many people with disabilities: some had a higher risk of contracting COVID-19 [4-6], relied on their peers and staff for their primary social interactions [7]. Mental health and wellbeing was a concern not just for people accessing services [8, 9], but also for their families, particularly where elderly parents were in caring roles [10]. While these reasons may have given a very strong rationale for the importance of sustaining contact, the logistics of doing so, required a new level of technologically driven innovation. Some disability services responded by setting up virtual services within weeks to ameliorate the worst of the effects of not being able to meet in person.

2 Methodology

This research explored the practices that staff in Irish disability services engaged in to improvise a response. Interviews with a purposive sample of twelve staff supporting people with physical, sensory, and intellectual disabilities, across education and training, independent living, information and day services were held between July and September 2020. The semi-structured interviews were designed to understand the staff perspectives in making the transition from face-to-face to virtual services. All interviews were transcribed, and analysed using reflexive thematic analysis [11, 12], using a systems thinking constructionist lens [13] to interpret the data.

3 Research Results

The findings point to a Complex Adaptive System (CAS) [14] characterised by emergence of new innovation where some staff improvised in a self-organised way to craft a response without top-down direction and with very limited means. CAS are constituted relationally by the interaction of the different elements of the system rather than the parts themselves and are considered radically open in terms of hierarchy and boundaries, allowing for greater engagement in interdependent activity [15]. It was this characteristic that allowed individual staff to adapt to the external environment and set up classes such as yoga sessions online, WhatsApp groups, record material for Facebook or Youtube, and in some instances negotiated the redirection of resources from management and funders. Over time, responses moved from being ad hoc to having a greater regularity and co-ordination within a more cohesive organisational response.

This research identifies four key defining factors relating to technology which enabled or inhibited innovation in staff practices: organisational technological capability, access to resources, organisational orientation to understanding the potential role of technology in people's lives and digital literacy levels amongst disabled people and front line staff. Each organisational response was unique and contextualised to their purpose, ethos and resources.

Organisations with technological capability continuously improved their internal IT infrastructure and were in a better position to respond both because they had the means to communicate internally via Microsoft Teams for example, but also because the experience of upskilling in one area gave staff the confidence to transfer learning to setting up and facilitating online. Outmoded IT infrastructures on the other hand, frustrated efforts to communicate in a timely and accessible way however, for example inaccessible websites made it difficult to share (e)Service weekly programmes or give condition specific updates relating to Covid-19.

The ability to access internal and external resources was another key driver of innovation. While some organisations with existing AT services were better equipped with hardware, and others rerouted grants or accessed support via small technology grants, not all organisations were similarly resourced. For some, negotiating with external funders was easier than with management in the same organisation; one service were operating with a free Zoom account and staff often used personal broadband accounts and phones to sustain an (e)service.

The degree to which organisations were able to pivot and embrace innovation initiated on the ground was often dependent on the cultural understanding held at an organisational level about the potential role of technology in people's lives. Organisations where AT was understood, were quick to respond, as was a Disabled Person's Organisation with an independent living ethos. Even so, many found themselves "raiding the shelves" for technology they had, and it did not guarantee that disabled people accessing services had the technology they needed at home or access to broadband. Phone usage and in particular smart phone usage was poor amongst attendees in many services, and social media was not encouraged, due to concerns around GDPR and safeguarding.

Digital literacy amongst frontline staff and disabled people posed an additional hurdle, with staff often struggling to stay one step ahead of the people they supported. While these factors played a significant role in outcomes, they did not stifle the impetus to innovate once the equilibrium of the organisational service delivery system was thrown out of synch by the pandemic. Those with enough agency to act, did so regardless of the external technological or organisational enablers or inhibitors, driven by a desire to sustain contact in the midst of a huge degree of uncertainty.

4 Discussion

While there is a call for systems approaches to understand health systems [16], and they are often understood as complex adaptive systems at a macro level [17], this approach is less often applied to understanding disability services and innovation at a micro level in a time of crisis. Covid-19 presented an opportunity to shake up services, rise beyond a complacency at all levels of the system, and force innovation and risk taking, not just amongst people with disabilities but in the design of services. It drove staff to improvise and take risks and demonstrate a level of creativity which often went beyond what they thought they were capable of. As time goes on, systems seek to recreate stability, and

this often comes at a risk to budding innovation. Formalising innovation, for example, may result in actions at one level of the system impeding innovation at another level.

The imperative to build on the creative potential of (e)services will rely on sustaining a spirit of openness to innovating in real time and a continuous balancing of potential risks with potential social inclusion in online spaces. It also calls for recognition of the dynamic adaptiveness that emerged during the pandemic where services could react in real-time to feedback loops, forming common patterns across different services, whilst acknowledging that services were often operating independently of each other. Reframing an understanding of innovation in the context of CAS can potentially create the conditions for effective innovation leading to a more resilient system into the longer term. Innovation is most likely to be successful where human connection is the driver of innovation and technology continues to be the means to that end.

4.1 Research Limitations

Participants were limited to staff who had successfully navigated the challenge of developing an online service, participants in services were not involved, and it is recognised that many staff were redeployed across services and in some instances did not have access to broadband or did not feel comfortable contributing to the (e)service response. Nor did online services suit everyone.

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References:

1. Taleb, N. N., *The black swan: The impact of the highly improbable*, Random House, 2007.
2. Rittel, H. W. J., and Webber, M. M. "Dilemmas in a general theory of planning," *Policy Sciences*, vol. 4, no. 2, pp. 155-169, 1973-06-01 1973, doi: 10.1007/bf01405730.
3. UN, "Pandemic Reveals How Excluded Are Society's Most Marginalized, Secretary-General Says, Launching Policy Brief on Persons with Disabilities and COVID-19," ed: United Nations, 2020.
4. H. K. Brown, H. K., et al., "Outcomes in patients with and without disability admitted to hospital with COVID-19: a retrospective cohort study," *Canadian Medical Association Journal*, vol. 194, no. 4, pp. E112-E121, 2022-01-31 2022, doi: 10.1503/cmaj.211277.
5. Kamalakannan, S., et al., "Health Risks and Consequences of a COVID-19 Infection for People with Disabilities: Scoping Review and Descriptive Thematic Analysis," *International Journal of Environmental Research and Public Health*, vol. 18, no. 8, p. 4348, 2021-04-20 2021, doi: 10.3390/ijerph18084348.
6. Lunskey, Y., Durbin, A., Balogh, R., Lin, E., Palma, L., and Plumpton, L., "COVID-19 positivity rates, hospitalizations and mortality of adults with and without intellectual and developmental disabilities in Ontario, Canada," *Disability and health journal*, vol. 15, no. 1, pp. 101174-101174, 2022, doi: 10.1016/j.dhjo.2021.101174.
7. Macdonald, S. J., et al., "'The invisible enemy': disability, loneliness and isolation," *Disability & society*, vol. 33, no. 7, pp. 1138-1159, 2018, doi: 10.1080/09687599.2018.1476224.

8. Lund, E. M., Forber-Pratt, A. J., Wilson, C., and Mona, L. R., "The COVID-19 Pandemic, Stress, and Trauma in the Disability Community: A Call to Action," *Rehabil Psychol*, vol. 65, no. 4, pp. 313-322, 2020, doi: 10.1037/rep0000368.
9. Lunskey, Y., Jahoda, A., Navas, P., Campanella, S., and S. M. Haverkamp, S. M., "The mental health and well-being of adults with intellectual disability during the COVID-19 pandemic: A narrative review," *Journal of Policy and Practice in Intellectual Disabilities*, vol. 19, no. 1, pp. 35-47, 2022-03-01 2022, doi: 10.1111/jppi.12412.
10. Wos, K., Kamecka-Antczak, C., and Szafrński, M., "Remote Support for Adults with Intellectual Disability During COVID -19: From a Caregiver's Perspective," *Journal of policy and practice in intellectual disabilities*, 2021, doi: 10.1111/jppi.12385.
11. Braun V., and Clarke, V., "What can "thematic analysis" offer health and wellbeing researchers?," *Int J Qual Stud Health Well-being*, vol. 9, no. 1, pp. 26152-26152, 2014, doi: 10.3402/qhw.v9.26152.
12. Braun, V. and Clarke, V. "Reflecting on reflexive thematic analysis," *Qualitative research in sport, exercise and health*, vol. 11, no. 4, pp. 589-597, 2019, doi: 10.1080/2159676X.2019.1628806.
13. Ison, R., *Systems practice: How to act: In situations of uncertainty and complexity in a climate-change world*, 2nd Edition ed. London: Springer, 2017. <https://doi.org/10.1007/978-1-4471-7351-9>.
14. Capra, F., "The web of life : a new synthesis of mind and matter," ed. London: London : HarperCollins, 1996. ISBN: 0006547516 9780006547518.
15. Preiser, R., Biggs, R. De Vos, A. and Folke, C., "Social-ecological systems as complex adaptive systems: organizing principles for advancing research methods and approaches," *Ecology & society*, vol. 23, no. 4, p. 46, 2018, doi: 10.5751/ES-10558-230446.
16. Kwamie, A., Ha, S., and Ghaffar, A. "Applied systems thinking: unlocking theory, evidence and practice for health policy and systems research," *Health Policy and Planning*, 2021-06-23 2021, doi: 10.1093/heapol/czab062.
17. Kwamie, A. "Balancing Management and Leadership in Complex Health Systems Comment on "Management Matters: A Leverage Point for Health Systems Strengthening in Global Health"," *International Journal of Health Policy and Management*, vol. 4, no. 12, pp. 849-851, 2015-08-14 2015, doi: 10.15171/ijhpm.2015.152.

“Timing is Everything”

Developing a New Assistive Technology Service Delivery Model in Israel During the COVID-19 Pandemic

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Abstract. Though technological solutions are often described as holding a great promise for the equal, dignified, and independent living of their owners, they seem to be short of reaching their full potential. This is the result of many intervening and interconnected factors such as lack of awareness, partial accessibility to solutions and services, funding policies and a crucial need of developing and implementing effective service delivery models. The COVID-19 pandemic erupted in early 2020, led to far-reaching consequences for all aspects of society, including the health and welfare systems. In such complex conditions, where many health services are delivered remotely and priorities change, people with disabilities who use Assistive Technology (AT) are likely to be highly effected. It is therefore, that especially during the pandemic, an AT ecosystem, including comprehensive and adaptive service delivery models, must be present to ensure optimal AT access, consultation, provision, and use. This article describes the design and implementation process of a new service delivery model for AT in Israel, that set into action with the beginning of the COVID-19 pandemic. Insights and lessons learned from previous models are highlighted, an outline of the new model is explained, the “Smart homes” program, as an exemplary program, is presented, and the interconnecting effects of the COVID-19 pandemic on the new service model are further explained. Recommendations regarding a hybrid service delivery model for AT are discussed.

Keywords. People with Disabilities, Assistive Technology, Service Delivery Model, COVID-19, Digital Platforms, Hybrid Models, Governmental Services, Funding Mechanisms.

1 The AT Service Delivery Model Landscape in Israel

Technological solutions for people with disabilities (PWD) that suit their unique abilities, needs and preferences, environmental context, and personal goals, can serve as a powerful enabler of independent functioning and participation. Though technological solutions are often described as holding a great promise for equal, dignified, and independent living, they have not reached their full potential. The WHO [1] reports that only one out of ten people globally have access to Assistive Technology (AT). This is the result of many interconnected factors such as lack of awareness of what solutions exist, partial accessibility to solutions and services, limited funding policies, and a need for developing and implementing service delivery models to increase access [2].

An AAATE position paper [3] identified seven basic steps for an AT service delivery model. A recent international review revealed that different countries adopt different models of access and provision of AT, which diverge in several aspects. Some are comprehensive programs offering an individualized package of services and solutions, in which AT is one of many possible solutions meeting individual needs; some focus solely on the provision of AT, and some are limited to several components of AT such as providing information, demonstrating the devices, or helping obtain a loan to purchase equipment. The programs also diverge at the level of individual involvement in the process, from choosing the technology, funding, and owning the equipment. Some are based on an itemized list of devices, some on categories of devices, and some dispense with a list of devices altogether [4]. In Israel, eligibility for AT services is divided between several ministries, depending on the relevant ministry that provides services to each disability and functional need. The models of AT provision vary considerably between those governmental ministries (see Table 1).

Table 1. Differences between Israeli ministries providing AT services

Ministerial office	Population	Type of support	Type of solutions
The National Insurance Institute – the Rehabilitation Department	PWD in a vocational rehabilitation program, job training, academic, or professional training	One time support, full or partial funding	Computer and communication solutions aimed at vocational rehabilitation
The Rehabilitation and Mobility Unit at the Ministry of Health	People with a permanent disability (visual, hearing, physical, psychosocial)	Long term lending, full or partial funding	Mobility devices, prostheses and orthoses, rehabilitation devices, augmentative, and alternative communication (AAC), hearing aids
The Department of Rehabilitation, Mental Health Division, at the Ministry of Health	People with a mental health disability	Services including courses and limited funding for products every five years.	Daily living products (Bed, couch, closet etc.), computer

The Administration of people with disabilities at the Ministry of Welfare and Social Services	PWD (visual, hearing, psychosocial, intellectual, and physical)	Subsidy for AT ranges between 10% to 90% every 4 years. Full of partial funding. Lending options	Mobility and seating, hearing, vision and communication devices, self-care and safety solutions, computer accessibility solutions
The Employment arm at the Ministry of Economy and Industry	Employers hiring PWD, PWD in job training	Matching funding between employer support and the ministry	Computer accessibility solutions, hearing and vision devices, aimed at improving work functioning
The Special Education Department at the Ministry of Education	Students with disabilities in special education (until age 21)	AT package according to disability – one time purchase with an option to apply for upgrade or changes if needed.	Computer and computer accessibility solutions, tablets, amplifiers, AAC
The Ministry of Defense	PWD due to a military or terrorism related injury	Full or partial funding	Mobility devices, prostheses and orthoses, orthopedic products, hearing and vision devices, for educational and vocational purposes

Long term and broad examination of the models, based on the lived experiences and insights of service recipients, and the experience gained by other stakeholders such as ministry officials, service providers and suppliers, has led to the understanding that the described process entails lacunas that should be addressed: 1. Limited list of eligible solutions – the existence of a fixed list, as wide and diversified as it may be, can never serve as a good enough answer for the different, continuously changing, and unique users' needs – "one size does not fit all". 2. Setting the level of subsidization per solution – it has been shown that when the different ministries set a bar for the maximal amount of funding per solution, it eventually interferes with the dynamics of the market. It has been found that the publication of the level of subsidization per solution can create a possible stagnation in market prices. 3. Low access to AT consultation and guidance – though users can receive AT recommendations from professionals or seasoned users, it is often not the case. Many users rely on general "word to mouth" suggestions and tend to report having experiences of frustration or disappointment due to a mismatch between their personal goals and the solution purchased. To prevent abandonment and misuse, the match between the user and the solution needs to holistically consider users' abilities and needs, goals, and preferences. In addition, it has been shown to be highly important that the person will be provided with multiple possibilities that he/she can choose from instead of having a sole "prescription" of a single solution. 4.

Lack of flexibility in proposed eligible technological solutions – technology is dynamic, developing, and upgraded continuously. If the ministry is interested in providing the relevant technology to the person, in any given time, flexibility is of an essence. In

the current model, the subsidized solutions are fixed, based on a bid for five years, that prevents opening the market towards this much-needed flexibility.

Considering these shortcomings, JDC Israel Unlimited, The Ministry of Welfare, Digital Israel, the Ministry of Health, and the Ministry of Education, have convened to re-examine current service delivery models for AT in Israel. Based on extensive market research and widespread client journey mapping, involving all stakeholders, a first detailed action plan was developed in 2019 and put into action. The plan included a digital transformation scheme, the reshaping of funding mechanisms, market opening steps and suggested training programs for service recipients and providers. Chronologically, the starting point for this groundbreaking process has aligned with the outbreak of the COVID-19 pandemic in Israel. This has given all stakeholders the unique opportunity of reevaluating service delivery models in a changing reality, when the need for efficient, online, digital services has increased significantly and the need for technological solutions for PWD could not be more important and crucial in all walks of life. As will be shown later in this article, the process of change has not only been free of additional delays and obstacles, as one would imagine the pandemic would cause, but rather has been further validated and encouraged because of the dominant role technology played in daily functioning of people during the pandemic and even more so for PWD.

2 COVID-19 Pandemic – Effects on Remote Services and AT

The COVID-19 pandemic erupted in Israel in February 2020, leading to far-reaching consequences for all aspects of Israeli society. Data collected during the crisis in Israel clearly shows significant effects on PWD and their families, especially due to the threat on the stability and continuity of services [5-6]. Changes to services delivery were also related to the increased use in remote treatment. Both clients and allied health professionals reported numerous advantages to this new mode, including flexibility, simplified logistics, maintaining continuity of treatment during lockdowns, the possibility of involving caregivers in the treatment and seeing clients in their home setting. Both groups also reported challenges, including difficulty maintaining concentration, reduced quality of the relationship, technical limitations, and unsuitability to some health conditions. These studies emphasize the importance of a hybrid model of therapy (digital + face-to-face) [7-8]. The restrictive measures have also influenced how families interact with and support their relatives living in residential settings. The findings indicated that most family members adopted remote communication technologies to contact their relatives. The families were able to provide emotional support and advocacy using digital technologies but were limited in their ability to provide significant social support [9].

In such complex conditions, where many health services are delivered remotely and priorities change, people who lack access to AT are likely to be specifically disadvantaged. It was therefore stressed that, especially during the pandemic, an AT ecosystem must be present for the safe and effective provision and use of AT, to ensure that products are available and fit for purpose [10]. It was similarly argued that governments

must coordinate policies to deal with underlying weaknesses in their systems and to assure good information, access to AT, benefits, and financial support to ensure more independence especially during such a crisis. Recommendations regarding the use of remote digital services, online AT purchases and capacity building of AT personnel were also provided [11]. Two such processes – of creating a full and seamless service delivery model from assessment to provision and building an ecosystem for AT in the shape of a generalized service – will be shown in two exemplary programs. These programs were developed prior to the COVID-19 pandemic and adapted in response to the challenges and opportunities created by the crisis. One is an intra-ministerial program, and the other is a cross-ministerial program, developed hand in hand to maximize the learning, while addressing the needs of various populations.

2.1 Intra-ministerial Service Design – Ministry of Welfare and Social Services

Since 2017, the Administration for People with Disabilities in the Ministry of Welfare and Social Services is implementing fundamental changes, towards a client centered, ICF based approach regarding clients' needs and goals. The field of AT has received a special attention and resource allocation. Today, a new service delivery model is designed regarding AT identification, selection, provision, and use, both for people who live independently in the community and for people who live in all kinds of residential settings. Based on an assessment of the current AT service model provided by the ministry, a list of insights and next steps for improvement were suggested (see Table 2).

Table 2. Insights and next steps for AT service model in the Ministry of Welfare

Topic	Insights	Next steps
AT consultations	There is a need for supporting systems to cope with integration of multiple considerations and large amount of data regarding AT needs	Interfacing with the Atvisor Digital Platform that has an updated list of technological solutions, mapped according to the ICF, and can match between the user profile and the technology [12]
Guidance and implementation support	Continuous professional support helps prevent AT abandonment and waste of public funds	1. Training of Instructors 2. Developing an Online Support Center
Funding and governmental support method	Subsidies for specific products can create a condition of price stagnations, AT fixed list prevents client-tailored customization	1. Creating new AT funding baskets based on personal budgeting rather than on a list of products. 2. Rewarding suppliers according to quality of products and services criteria

Trial opportunities	Trial opportunities help prevent AT abandonment and waste of public funds	Establishing loaning centers for expensive and unique AT
Re-used AT	There is a need to lower the cost of AT for people who have difficulty paying for it	Establish a mechanism for handling, maintaining, and providing reused AT
Information about rights	There is a need to provide clients with additional information relevant to the decision-making process and their rights regarding AT	<ol style="list-style-type: none"> 1. Atvisor platform 2. Customer Personal Area 3. Dedicated instructors

The development of the new service for technological solutions for PWD implemented in the Ministry of Welfare and Social Services includes the following components:

Digital literacy courses for AT users. A three-levels programs for digital orientation, adapted to the type of disability and necessary accommodations, to support AT use: Basic program – digital orientation in a smartphone and a computer. This program will offer basic operation principles and recommended techniques; Level 2 program – relevant to those with basic computer and smartphone skills. The program offers instructions on how to order relevant services via mobile or computer, filing digital forms, and more; Advanced program – relevant to those who have basic and level 2 digital orientation. The program offers techniques for creating social connections online, while acquiring social codes of conduct, safe purchasing online, options to expand knowledge through online resources, which emphasize critical thinking and responsible use;

Technological solutions for daily functioning. AT, accessible technologies, and mainstream technologies are funded for clients to support their various needs. The service model is a hybrid service, including a digital platform, Atvisor, that offers matches between the user's profile and the relevant technological solution, and a professional coordinator, that provides insights regarding the best solution from the offered choices based on the user's preferences and environment. The platform and service operate according to the AAATE model and steps and include: Needs assessment – In-depth intake to understand needs and functioning possibilities; Definition of the functioning domain and the activity the person is interested in; Selection of technology – includes the selection of the category and the selection of the product itself – a shared decision-making process between person and professional (if needed); Purchase – the purchasing process is conducted online, in a subsidized co-payment model; Delivery and installation (if needed); Training – how to use the product (if needed); Follow up and support provided by technical and professional experts;

Mainstream affordable and accessible technologies. Many solutions in the market are not designed specifically for PWD but are highly suitable and beneficial for people

with certain limitations and difficulties in functioning. Due to their popularity, they are affordable and highly available. It is important to make the public aware of such solutions, including information about suppliers and prices, through the Atvisor platform and other means of information delivery;

Support and funding of technological solutions. To avoid interference with market pricing, funding is designed to be given as a package to the person and not paid “per product” to the supplier. This method will also allow for an “open market” approach that will broaden user's options for choosing and purchasing technology. In parallel, efforts are being made to synchronize services with other ministries to avoid double-funding and optimize eligibility;

Follow up and support call-center. The use of technological solutions requires remote support in situations involving operating issues. The support center will be operated by AT professionals via phone, chats, or online video consultations;

Display and Demonstration Centre (DDC). This physical retail center, designed both as a shop and a display center, is designed to answer the need of clients to see or feel the product they are buying instead of choosing online. The DDC will be connected to the digital platform and every purchase done there will be operated digitally. Consultation kiosks with the hybrid solution of professionals available digitally will be provided in the physical center as in the virtual space;

Resource center for re-used technological solutions. Frequent changes in clients’ conditions and needs are resulting in a considerable amount of good quality products that are not in use. Since it is a high-cost market, it is very important to build a designated market for re-used technologies, that will be managed by a technical team that has the capabilities to examine the state of the products and whether they can be re-used. Such a center is a part of the process and will be set into action in the second phase of the program.

2.2 A Cross-ministerial Service Design - The “Smart Home” Model

The program was initiated by JDC Israel unlimited in partnership with Digital Israel, the Ministries of Welfare and Social Services, Health, Education, and Finance. A pilot program currently underway, aimed at promoting the independent living of PWD, examines the introduction of technological solutions to a wide range of populations. The goal of the program is to build governmental mechanisms for the assessment, provision, and funding of technological solutions while ensuring that the person is involved in choosing-getting-and keeping the solution that best fits their needs. The program is operated by Beit Issie Shapiro and the Atvisor digital platform. The Myers-JDC-Brookdale Institute conducts long-term research to accompany the development and testing process. The program services people with multiple disabilities and different levels of functioning, living in different environments, ranging between 15-67 years of age. The program team includes seasoned occupational therapists, aiding in the

matching process between users' needs, activity goals, environment, and preferences, and the technological solutions that can be of interest and relevance to them. Their role is also to provide guidance and training following the provision and installation of the technology to ensure sustainability. The service provided in the program is based on the principles of the [3], with the following steps: Introductory meeting with user – assessing goals, preferences, and needs; Technology “hunt” – looking for the right AT category and solution; Provision and delivery – of the solution selected; Installation – provided by a technical team and electricians; Training and follow up support – provided by AT Coordinators. The whole process, from registration through assessment and selection, is facilitated by the Atvisor platform that supports the matching between the personal profile and the technology. The platform is based on the ICF taxonomy and contains technological solutions that can be purchased online and offline. During COVID-19 outbreak, steps 1,2 and 5 were operated remotely, using video calls and the Atvisor digital platform. Step 3 was made possible thanks to the definition of AT suppliers and technical teams as necessary staff, which enabled physical delivery and installation. Comprehensive work protocols were developed and disseminated among team members, webinars for professionals and users were facilitated to increase awareness and use, and a digital call for action titled “smart home goes online” was published on social media to encourage participants to join the program.

Special attention is given in the program to those populations with disabilities who are rarely perceived as needing AT for their needs, such as people with autism, people with mental health conditions, etc. The collaboration with the Department of Rehabilitation, Mental Health Division at the ministry of Health, enabled in-depth learning of the needs and possible solutions relevant to these populations. In an information packet [13] currently in press, several needs were identified amongst people with mental health conditions in which technology might assist in their daily functioning and independence. This process is a part of a larger, long-term design of services towards technology implementation done in the ministry. As an example, in the last two years, especially during the pandemic, designated courses for digital orientation were executed, taking into consideration varied personal needs and goals, and offered together with a financial support for educational purposes. One of the main conclusions reached during the piloting of the "Smart Home" program was the need to raise awareness and knowledge in this area. A webinar on technologies and applications for Mental Health was held successfully with almost 300 participants – clients, professionals, and family members. 31 clients with mental health conditions have participated in the program so far.

Accompanying research. The “Smart Home” program is accompanied by a formative evaluation research, done by the Myers-JDC-Brookdale research institute. This research began in the pre-pilot phase in 2018 and continues today. Its goal is to identify the influence of the technological solutions on the quality of life, independence level and sense of security of participants and their caregivers, as well as identifying barriers in the program's implementation and goal achievement. So far, the research has included an international review of services for AT provision and an assessment of the pre-pilot. The pre-pilot assessment included qualitative interviews with different stakeholders, mainly clients and caregivers. Currently, the research team is assessing the

pilot phase, that includes: An online questionnaire answered independently before and after the provision of the selected technological solution. This is answered by the participant or on their behalf if needed; Comprehensive interviews with participants done in their homes; Interviews with relatives and caregivers; Shared observation conducted with the participant on the use of the selected technological solution provided by the program. This research is currently at its data collection stage, which is estimated to end by July 2022. So far, 20 participants have answered the questionnaire after receiving the selected solution – 13 participants responded regarding two solutions and seven responded regarding one solution, totaling in 33 AT solutions, that data were received about. The initial findings provide the following insights: High percentages of technological solution are being used every time or almost every time the person need them (94%); No difficulty or very mild difficulty in adjusting to the technological solution (97%); For 88% of the solutions, participants confirmed the product is fitted to their needs. These high percentages suggest that there is a good fit between the participant and the selected technology, as well as emphasize the importance of proper guidance, training and follow up and support using the technology. As to the influence of the technological solutions on the life of the participant, for 33 solutions, it was found that: for 73% of the technological solutions, it was stated that they are enabling the participant to do things they couldn't do before; for 85% of the technological solutions, it was stated that they make the participant feel more independent; for 79% of the technological solutions, it was stated that they make the participant feel more safe and secure; for 76% of the technological solutions, it was stated that they save time or other resources for the participants; for 85% of the technological solutions, it was stated that they improve the quality of life of the participants; for 79% of the technological solutions, it was stated that they make the participant feel more self-confident during use. In general, it can be suggested that based on the initial data collected, the technological solutions selected and used in the framework of the hybrid design of the service model (digital + expert), allows more independence in functioning, while improving the quality of life of clients.

3 Discussion and Recommendations

The development of a framework that integrates a client-centered approach with the ICF model, using a digital platform, shared decision processes and AT service delivery models, was accelerated due to the COVID-19 pandemic. As timing is an important agent of change, it seems that igniting the process on a system level and on the ground during the COVID-19 pandemic has only highlighted the core components of the model being developed and emphasized its value. Moving forward, a cross-ministry AT service model will be designed and implemented based on the lessons learned from the two projects described in this article. The core principles for the new Israeli model are:

1. Establishment of a hybrid service for AT – human resources (users, AT experts and technical team) and a digital platform (clinical decision support system and marketplace components).

2. One stop shop – enabling a full process in one place – from assessment to provision and use.
3. Connecting all stakeholders to one platform for best coordination and communication.
4. Personal tailoring – solution search and selection stems from the personal profile of each user.
5. Interface with government funding and provision systems – for online immediate funding.
6. Reshaping funding mechanisms – moving to a personal budget concept based on tailored recommendations instead of a general list of approved solutions.

References

1. World Health Organization Website. Assistive Technology, <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>, (2018).
2. Holloway, C., Austin, V., Barbareschi, G., Ramos Barajas, F., Morgado Ramirez, D., Frost, R., et al.: Scoping research report on assistive technology on the road for universal assistive technology coverage. Global Disability Innovation Hub, UK (2018).
3. Andrich, R., Mathiassen, N. E., Hoogerwerf, E. J., Gelderblom, G. J.: Service delivery systems for assistive technology in Europe: An AAATE/EASTIN position paper. *Technology and Disability*, 25(3), 127-146 (2013).
4. Pur, Y., Yabo, M., Barlev, L.: Provision of Assistive Technology Devices to Promote Independence among People with Disabilities – International Review (In Hebrew). Myers-JDC-Brookdale, Israel (2020).
5. Admon-Rick, G.: "Leave no one behind": Protecting the rights of people with disabilities during emergency times and the COVID-19 crises (In Hebrew). *Disability and Society, Research and Practice*, 1(1), 9-22 (2022).
6. Tilovich Levi, S., Shavit, N., Aspler, S., Geva, G.: COVID-19 Crises: estimations, policy, services development and coping in the Administration for people with disabilities (In Hebrew). *Disability and Society, Research and Practice*, 1(1), 23-36 (2022).
7. Roth D., Raviv-Carmi, D., Refua, M.: Remote Treatment (Telehealth) for Allied Health Professions during the Coronavirus Outbreak (COVID-19): A Global Perspective. Beit Issie Shapiro, Israel (2021). <https://tinyurl.com/yzxvdc3>
8. Roth D., Raviv-Carmi, D., & Refua, M.: Research Summary: Client experience of Remote Allied Health Treatment (Telehealth) during the Coronavirus outbreak (Covid-19) in Israel. Beit Issie Shapiro, Israel (2020).
9. Shpigelman, K.N, Araten-Bergman, T.: Adults with disabilities in residential institutions during the first wave of COVID-19 pandemic: Non-formal connection and support of relatives (In Hebrew). *Disability and Society, Research and Practice*, 1(1), 53-68 (2022).
10. Layton, N., Mont, D., Puli, L., Calvo, I., Shae, K., Tebbutt, E., et al.: Access to assistive technology during the COVID-19 global pandemic: Voices of users and families. *International Journal of Environmental Research and Public Health*, 18(21), 11273 (2021). <https://doi.org/10.3390/ijerph182111273>
11. Mont, D., Layton, N., Puli, L., Gupta, S., Manlapaz, A., Shae, K., et al.: Assistive Technology during the COVID-19 Global Pandemic: The Roles of Government and Civil Society in Fulfilling the Social Contract. *International Journal of Environmental Research and Public Health*, 18(22), 12031 (2021).

12. Ran, M., Banes, D., Scherer, M. J.: Basic principles for the development of an AI-based tool for assistive technology decision making. *Disability and Rehabilitation: Assistive Technology*, 1-4 (2020). <https://doi.org/10.1080/17483107.2020.1817163>
13. Tsabar, O., Grinstein, O., Shaked Koprak, R., Ran, M.: Technology and Apps in mental health (In Hebrew). JDC Israel Unlimited & Health Ministry, Israel (forthcoming).

The Non-discrimination and Accessibility Public Policy Practices and Approaches to Assistive Technology and Inclusion

The Implication on the Coverage of AT solutions

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Abstract. The review of the secondary data on the Assistive technology (AT) Public policies and laws revealed the Non-discrimination and Accessibility approaches to Assistive technology and Inclusion (NSH, 2007). The Convention on Rights of Persons with Disabilities (CRPD) recognised the Non-discrimination approach to AT as it stated that the use of Universal Design shall not exclude the assistive technology needed by persons with specific disabilities (UN, 2006; article2). The CRPD recognised accessibility as both a human rights principle and a Right under articles 3 and 9 respectively. Assistive technology was also one of the Accessibility and reasonable accommodations recognised by the CRPD. The Multiple research methods composed of case study and mixed research methods were used to collect empirical data on the validation of the Non-discrimination and Accessibility practices and approaches. The qualitative data was collected through key informant interviews. The survey data on the validation of the AT legal and public policies approaches was collected and analysed. The findings reveals that Majority of students were not aware of the AT related public policies and laws. All students recommended the provision of AT based on non-discrimination principle and other CRPD human rights principles. The 2005 Disability Act and the 2015 Equality Acts prohibited discrimination of persons with disabilities in Ireland and provided for reasonable accommodations including provision of AT products and services. Ireland ratified the CRPD in 2018 and committed to the Accessibility and Non-Discrimination approaches and practices. Ireland was a state party to the 2019 European Accessibility Act.

Keywords: Assistive technology, Non-Discrimination, Accessibility

1 Introduction

The review of the secondary data revealed the Non-discrimination and Accessibility approaches to the Assistive technology (AT) and Inclusion of Persons with disabilities [1]. The United Nations Convention on Rights of Persons with Disabilities (UNCRPD)

[1] recognised the Non-discrimination and Accessibility approach to AT through articles 2, 3 and 9. The CRPD under article 2 noted that Universal Design of goods, products, environments for all shall not exclude the assistive technology needed by persons with specific disabilities [1]. This confirmed the Non-discrimination approach to AT. Non-discrimination and Accessibility were Human rights principles under article 3 of the UNCRPD.

2 The AT Accessibility and Non-Discrimination Approaches

The UNCRPD recognised accessibility as both a human right under articles 9 and Human right principle under article 3. AT was also one of the Accessibility and reasonable accommodations recognised by the CRPD. The CRPD makes the most reference to assistive technology solutions than any other eight international Human Rights instruments that do not make any reference to assistive technology. The CRPD makes specific references to AT solutions in seven articles, and these were articles 2, 4, 9, 20, 26, 29 and 32. The CRPD article 2 requires the application of universal design to not exclude the use of assistive technology solutions that requires adaptations and flexibility. The CRPD article 4 provided the general obligations for member states under clause G and I to provide and promote assistive technology solutions including supporting research and providing information about AT solution information. Article 9 on Accessibility requires member states to support the production, supply and availability of AT solutions at a low cost for persons in need or persons with functional difficulties. The CRPD makes reference to AT solutions in Article 20 on personal mobility. The CRPD requires member states to ensure that manufacturers and suppliers of assistive technology solutions produce and supply a wide range of AT products that addresses the diverse personal AT needs of different categories of group of people in need or users of AT.

The CRPD under article 26 makes a reference to Health Assistive technology solutions and their role in Rehabilitation of persons with functional difficulties. The CRPD recognised the role of AT solutions in promoting Political and public life participation of persons with functional difficulties under Article 29 on Participation in political and public life. The CRPD article 32 on international cooperation also recognised assistive technology solution. The CRPD requires member states to collaborate and support in each other through transfer of assistive technology knowledge, solutions and technical assistance. The CRPD indirectly makes references to AT solutions through provision of reasonable accommodations in article 24 on education and article 27 on work and employment. While the secondary data revealed the Non-discrimination and accessibility approaches to assistive technology and inclusion. The empirical data and research studies on accessibility and non-discrimination approaches and practices towards AT were limited. The research study therefore validated the accessibility and non-discrimination approaches and practices to AT and Inclusion of Persons with disabilities in the Higher education environments and others.

3 The Methodology

The multiple research methods composed of case study research method and mixed research methods were used to collect empirical data. The qualitative data was collected through key informant interviews with University College Dublin students using hearing and Ear assistive technology solutions, UCD officials in charge of AT related policies and provision of assistive technology, representatives of government officials in charge of AT related policies and provision and representatives of Non-State Actors providing AT services to students in Higher Education Institutions. The survey data was collected from the audiologists, users of hearing and ear assistive technology and organisations of persons with hearing loss or Hard of Hearing in Ireland and around the world. The research study was approved by the University Ethics committee. The data collection was delayed by COVID-19 pandemic between 2020-2021. The research paper considered AT Public policies and programmes as socially constructed objects and used the Constructivist Ontology to analyse the data. The Critical discourse analysis was also used to analyse the behaviours of the AT service delivery system as they interacted with the UCD students using Hearing and Ear Assistive Technology (HEAT) and environment [5-8].

The semi structured interviews and survey questionnaires were used to help the research participants to respond to the research study. Over 50 users of HEAT solutions from 21 countries around the World responded to the survey of the research study [6]. The survey participants were from Ireland, Austria, Australia, Canada, Czech Republic, Denmark, Germany, Georgia, Italy, Nepal, Norway, Philippines, Poland, Lithuania, Rwanda, Serbia, Uganda, United Kingdom, Vietnam, and Zambia. The 17 qualitative interviews including three key informant interviews with users were used to collect empirical data in Ireland. The data collection was delayed by the COVID-19 pandemic. This research paper used the secondary and empirical data collected from Ireland.

4 Results

One of the UCD students using HEAT solution stated that “ I consider the AT I use as accessibility accommodation that enables me to perform learning activities in lecture room and participate in other activities outside the lecture rooms”. This empirical data confirmed that the accessibility approach to AT. Assistive technology was considered as one of the accessibility solutions that facilitate participation and inclusion of persons with hearing difficulties in Higher education learning environment.

The UCD Assistive Technology Officer stated that “ We consider AT as one of the reasonable accommodations we provide to all UCD students in need.” The Assistive technology specialist further stated that “ The fund for students with disabilities supports reasonable accommodations for only EU citizens and residents who are students and does not cover International students outside EU. The UCD Global fund supports international students in need of AT from outside EU to acquire AT”. This empirical data shows that Assistive technology was considered as a reasonable accommodation and was provided to all through different programmes. While the reasonable

accommodation approaches pushes the biggest burden to users and person in need of AT and less burden to the duty bearer. The consideration of AT as an accessibility accommodation was based on recognition of accessibility as a human right and human right principle. This implied the States as a duty bearers have the biggest burden and the responsibilities to fund and provide Assistive technology. The empirical data provides evidence of practice of the non-discrimination principle in provision of assistive technology to all students. The UCD global fund covered AT access for International students that were not covered by the fund for students with disabilities from Higher Education Authority.

The 100% of the survey participants using HEAT selected AT as an accessibility solution. 80% of the survey participants selected Non-discrimination Principle as one the principles for the Rights +Capability based oriented Assistive Technology service delivery system. This empirical data confirmed the accessibility and Non-discrimination approaches and practices towards AT.

5 The Recommendations

The Accessibility and Non-discrimination practices and approaches to assistive technology and Inclusion should be used to develop and review Assistive technology public policies and programmes.

References

1. United Nations, , Convention on Rights of Persons with Disabilities, (2006)
2. Ireland, Disability Act, (2005)
3. Ireland, Equality Acts, (2015)
4. European Union, European Accessibility Act, (2019).
5. Leeds-Hurwitz, W, Social Construction of Reality, (2009), In S. Little john, & K. Foss (Eds.), *Encyclopaedia of Communication Theory* (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>.
6. Robert K Yin, *The Case study Research*, 6th edition, (2018).
7. Fairclough, N, *Critical Discourse Analysis*, (1995).
8. Fairclough, N, *Peripheral Vision. Discourse Analysis in Organization Studies: The Case for Critical Realism*. *Organization Studies*, (2005).

WeeWheel

End-users' Satisfaction of a Storybook, Posters and Training Workbook to Enhance Manual Wheelchair Skills Training in Pediatric Rehabilitation Settings

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Abstract. Background. The Wheelchair Skills Training Program (WSTP) is effective for teaching the wheelchair skills required for everyday mobility but is underutilized in pediatric rehabilitation settings. Clinicians expressed concerns regarding the complexity of the manual and the lack of guidance on how to train the skills with children. Three complementary WSTP knowledge transfer tools were developed (storybook, posters, training workbook) to address these barriers. Objective. Document OTs and pediatric manual wheelchair users' (PMWUs) satisfaction with and perception of the usability, relevance, and feasibility of the three tools. Methods. A descriptive qualitative design was used. OTs and PMWUs were recruited from the Marie Enfant Rehabilitation Center and affiliated schools using a convenience sampling method. A focus group (OTs) and interviews (PMWUs) were conducted online (Zoom videoconferencing platform) to obtain participants' feedback on the tools and suggestions for improvements. Deductive analyses were performed using the Framework method. Results. 8 OTs and 5 PMWUs described the tools as attractive, playful and easy to use for training wheelchair skills among younger or novice PMWUs. OTs expressed the desire to use the tools in their clinical practice and three PMWUs felt the tools could help them learn new skills/improve their techniques. Both groups suggested modifications to refine the tools (e.g., increased precision of illustrations depicting the characters in the wheelchairs). Discussion. OTs and PMWUs were satisfied with the tools and perceived them as applicable in pediatrics. Conclusion. The tools could contribute to facilitate the use of the WSTP in pediatrics.

Keywords: Wheelchair, Training, Pediatric Rehabilitation, Knowledge transfer, User-centered approach.

1 Background

Independent manual wheelchair (MWC) mobility fosters the participation of children with physical disabilities in physical, leisure, and school activities, which are essential for their growth, development, social participation, and overall health [1,2]. The provision of a MWC alone does not guarantee safe and efficient use, and many children need help from their parents to navigate their MWC in the community [3,4]. In fact, the World Health Organization recommends MWC skills training as one of eight critical steps when providing MWCs [5]. However, children receive an insufficient amount and quality of training. Two surveys conducted in Canada revealed that, due to lack of time, knowledge and resources, more than 50% of clinicians provide less than 3 hours of training and fewer than 30% use a validated program [6,7]. Innovative solutions to support high-quality MWC skills training practices in pediatric rehabilitation settings are thus warranted.

Sixty-four studies, including 16 randomized control trials and two meta-analyses, have demonstrated that the Wheelchair Skills Training Program (WSTP) is safe and effective for improving wheelchair mobility among adults [8,9]. The mean improvement of wheelchair skills capacity in WSTP groups was 14% higher than the no intervention or standard care groups ($p < 0.0001$) [8,9]. However, the program is not frequently used in pediatric rehabilitation settings. Only four pilot studies documented its use in pediatric populations, and the mean relative improvements in MWC skills (ranging from 4.5 to 32%) were lower than in adults (mean = 21.2%) [10–13]. Pediatric-specific adaptations, including resources tailored for children, may increase the utilization of the WSTP by clinicians and children's engagement in the training process [14]. In the long term, this could facilitate increased training practices in pediatrics and improve MWC skills.

In Canada, occupational therapists (OTs) are health professionals responsible for MWC skills training. Daoust et al. (2021) documented OTs' perceptions of the barriers limiting the utilization of the WSTP in pediatrics. When considering their time constraints for planning interventions and their sense of competency using the program, OTs were discouraged by the density and complexity of the manual [14]. They expressed concerns regarding the playfulness of training activities and material, the few considerations on children's development and the lack of guidance on how to train the skills with children [14]. Recognizing the importance of MWC skills training and the potential benefits from using the WSTP, OTs identified a need to develop knowledge transfer tools tailored to children that could support the utilization of the program in pediatrics [14].

Three complementary WSTP knowledge transfer tools tailored to children were created using a user-centered approach (see Figure 1). Following this approach, primary end-users' feedback were incorporated throughout an iterative design process, evaluation, and implementation (Figure 1) [15]. First, a team of experts, including 4 OT students, 1 adult MWC user, 5 researchers with expertise in MWC skills training or knowledge transfer, 2 pediatric OTs, 2 rehabilitation services managers, collaboratively developed three types of tools (ie., storybook, posters, workbook). The three types of tools teach children four basic MWC skills frequently required for everyday life

activities (i.e., roll forward and backward a short distance, pick objects from floor, turn while moving forward). The second step, on which this presentation focuses, involved a qualitative evaluation of the tool prototypes to document primary users' satisfaction and obtain their suggestions for improvements.

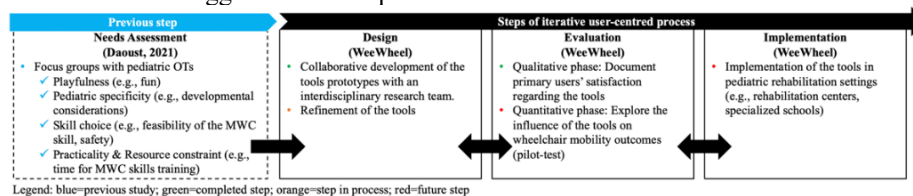


Fig. 1. Iterative design process, evaluation and implementation of the WSTP training tools

2 Objectives

The objectives were to document OTs' and pediatric manual wheelchair users' (PMWUs) satisfaction with and perception of the usability, relevance, and feasibility of the three tools.

3 Methods

3.1 Design

A descriptive qualitative study was conducted.

3.2 Participants

A convenience sampling strategy was used to recruit OTs and PMWUs from the Marie Enfant rehabilitation center and its affiliated schools (Montreal, Canada). To be eligible to participate, OTs had to provide MWC skills training interventions in their practice. To be eligible to participate, PMWUs had to be aged between 5 and 15 years old, use a MWC (minimum 4 hours/day during the last 6 months), and have the cognitive and language abilities to participate in a 60-minute discussion online in French.

3.3 Procedures

Sociodemographic information was collected from OTs (e.g., gender, years of practice) and PMWUs (e.g., age, years of MWC experience). A 90-minute focus group (OTs) and 60-minute semi-structured interviews (PMWUs) were conducted online (Zoom videoconferencing platform) to respect the COVID-19 public health restrictions at the time. At the beginning of the focus group and interviews, the tools were presented to the participants. Then, open-ended questions based on the indicators of the *Guide to Monitoring and Evaluating Knowledge Management in Global Health Programs* were asked [15]. These indicators included satisfaction (e.g., first impressions, favourite or disliked elements), usability (e.g., aesthetic, content clarity) and relevance (e.g., tools facilitate learning) [16]. Questions documenting the feasibility of using the tools in

clinical practice were also asked (e.g., capacity to use the tools regarding time constraints or personal characteristics).

3.4 Analysis

Sociodemographic information was summarized (mean, standard deviation, median, interquartile range, percentage, frequency). Qualitative data were deductively analyzed using the Framework method according to which data are coded in the categories of a matrix (i.e., satisfaction, usability, relevance, feasibility) [17].

4 Results

4.1 Participants

Eight OTs, who had between 2 to 29 years of experience working with PMWUs (mean=8.1 +/-9.3) and provided MWC skills training on an occasional basis (62.5%), participated in the focus group. Three girls and two boys, ranging from 6 to 12 years of age and who had between 3 and 9.5 years of experience using a MWC, were interviewed.

4.2 Satisfaction

All OTs expressed overall satisfaction when first seeing the tools. However, PMWUs had mixed impressions. Three PMWUs expressed the tools could help them improve their MWC mobility, but the two others felt the tools would be better suited to younger children with lower MWC skills levels.

4.3 Usability

OTs and PMWUs mentioned the tools were attractive and colourful. Both groups particularly liked the characters, that PMWUs described as “cool” and OTs as “inclusive” (age, gender, nationality). OTs perceived the content as easy to understand for PMWUs, as the tools contain verbal cues frequently used with children (e.g., push, push, push). OTs commented that the breakdown of MWC skills into small steps and the illustrations used to depict the movement required to execute the skill were appropriate for PMWUs. Most PMWUs required support from a parent to use the tools, especially to understand the tips and tricks suggested to perform the MWC skills (e.g., rainbow visual cue showing the arm movement for self-propelling). When understood, PMWUs thought that the tips and tricks would be helpful.

4.4 Relevance

All OTs were ready to integrate the tools in their clinical practice immediately. OTs and PMWUs felt that the tools would be useful for training MWC skills with younger or novice PMWUs.

4.5 Feasibility

OTs mentioned that it would be feasible for them to use the tools in their work environment. Given the structure for planning and delivering MWC skills training, OTs believed the tools could help them provide their interventions more efficiently.

4.6 Improvements

The most common suggestions for improvements provided by OTs and PMWUs were: a more exciting story plot, increased precision of illustrations depicting the characters in the MWCs, and consistency between the visual and verbal cues provided in the three tools.

5 Discussion

This is the first study to explore providers' and users' satisfaction with wheelchair skills training resources specifically designed for children, and it responds to OTs' and parents' needs for learning materials supporting the development of MWC skills in PMWUs [12,14]. The WSP website and YouTube channel offer educational resources to facilitate MWC skills training (e.g., posters and videos) that are widely accessible, with respectively 154,415 users from 196 countries and 179,324 views up to January 2022 [18]. However, all available resources are tailored to adult populations (e.g., only depicting adults performing MWC skills, high language level) [18]. Resources that are adapted to the needs of the patient population and the practice context of clinicians tend to be better accepted and more easily implemented [19,20]. The results of the present study support this finding as OTs' and PMWUs' perceptions felt that the pediatric-friendly wheelchair skills training tools could facilitate the implementation of the WSTP in pediatric rehabilitation settings. As a few differences in OTs and PMWUs' points of view regarding the tools were observed, this study highlights the importance of giving children with disabilities a voice to express their perspectives on the rehabilitation services they receive. Children with disabilities are one of the most excluded populations from partnering in the research, but their involvement is essential for ensuring the uptake of the tools in pediatric rehabilitation settings [21].

5.1 Future Research

Given the positive response from OTs and PMWUs about the first three tools, the research team has considered and incorporated the suggested modifications in the design of additional tools for community and advanced skills. Tools supporting the training of skills such as getting through hinged doors, getting over obstacles, and ascending or descending inclines are currently being designed and tailored to the needs of more experienced PMWUs and adolescents. OTs and PMWUs' feedback regarding these new tools will be obtained following the same qualitative evaluation process. When all tools will be refined, they will be pilot-tested in pediatric rehabilitation settings to explore their influence on MWC mobility outcomes.

6 Conclusion

OTs and PMWUs were satisfied with the three pediatric-specific WSTP knowledge transfer tools they perceive as usable, relevant and feasible to use when training MWC with children. Incorporating primary end-users feedback throughout the steps of the design process, evaluation and implementation appears essential to ensure satisfaction with the tools.

References

1. Rousseau-Harrison, K.; Rochette, A. Impacts of Wheelchair Acquisition on Children from a Person-Occupation-Environment Interactional Perspective. *Disability and Rehabilitation: Assistive Technology* 2013, *8*, 1–10, doi:10.3109/17483107.2012.670867.
2. Bray, N.; Noyes, J.; Edwards, R.T.; Harris, N. Wheelchair Interventions, Services and Provision for Disabled Children: A Mixed-Method Systematic Review and Conceptual Framework. *BMC Health Serv Res* 2014, *14*, 309, doi:10.1186/1472-6963-14-309.
3. Rodby-Bousquet, E.; Hägglund, G. Use of Manual and Powered Wheelchair in Children with Cerebral Palsy: A Cross-Sectional Study. *BMC Pediatr* 2010, *10*, 59, doi:10.1186/1471-2431-10-59.
4. Barnard, A.M.; Nelson, N.G.; Xiang, H.; McKenzie, L.B. Pediatric Mobility Aid-Related Injuries Treated in US Emergency Departments From 1991 to 2008. *Pediatrics* 2010, *125*, 1200–1207, doi:10.1542/peds.2009-3286.
5. World Health Organization *Guidelines on the Provision of Manual Wheelchairs in Less Resourced Settings*; World Health Organization (WHO): Geneva, 2008;
6. Best, K.L.; Routhier, F.; Miller, W.C. A Description of Manual Wheelchair Skills Training: Current Practices in Canadian Rehabilitation Centers. *Disability and Rehabilitation: Assistive Technology* 2015, *10*, 393–400, doi:10.3109/17483107.2014.907367.
7. Daoust, G.; Rushton, P.W.; Demers, L. Bridging the Gap in Wheelchair Skills Testing and Training in a Canadian Paediatric Rehabilitation Context.; In: Oceania Seating Symposium, p. 77, Melbourne, AUS (2019).
8. Tu, C.-J.; Liu, L.; Wang, W.; Du, H.-P.; Wang, Y.-M.; Xu, Y.-B.; Li, P. Effectiveness and Safety of Wheelchair Skills Training Program in Improving the Wheelchair Skills Capacity: A Systematic Review. *Clin Rehabil* 2017, *31*, 1573–1582, doi:10.1177/0269215517712043.
9. Keeler, L.; Kirby, R.L.; Parker, K.; McLean, K.D.; Hayden, J.A. Effectiveness of the Wheelchair Skills Training Program: A Systematic Review and Meta-Analysis. *Disability and Rehabilitation: Assistive Technology* 2019, *14*, 391–409, doi:10.1080/17483107.2018.1456566.
10. Sawatzky, B.; Rushton, P.W.; Denison, I.; McDonald, R. Wheelchair Skills Training Programme for Children: A Pilot Study. *Australian Occupational Therapy Journal* 2012, *59*, 2–9, doi:10.1111/j.1440-1630.2011.00964.x.
11. Best, K.L.; Wilson, D.; Miller, W.C. Peer-Led Approaches for Improving Satisfaction with Participation, Wheelchair Skills and Self-Efficacy among Children Who Use Manual and Power Wheelchairs.; In: International Seating Symposium, p. 129, Vancouver, CA (2020).
12. Gowran, R.J.; Collins, M.B.; McGlanaghy, J.; Shanahan, E.; Cleary, Y. Wheelchair Skills Education and Training for Children with Spina Bifida and/or Hydrocephalus and Their Parents: A Pilot Study. *Disabilities* 2022, *2*, 96–118, doi:10.3390/disabilities2010009.

13. Kirby, R.L. Training a Parent in Wheelchair Skills to Improve Her Child's Wheelchair Skills: A Case Study.; In: RESNA Annual Conference, pp. 1-5, Las Vegas, US, (2010).
14. Daoust, G.; Rushton, P.W.; Racine, M.; Leduc, K.; Assila, N.; Demers, L. Adapting the Wheelchair Skills Program for Pediatric Rehabilitation: Recommendations from Key Stakeholders. *BMC Pediatr* 2021, *21*, 103, doi:10.1186/s12887-021-02564-9.
15. Abras, C.; Maloney-Krichmar, D.; Preece, J. User-Centered Design 2004.
16. Ohkubo, S.; Sullivan, T.M.; Harlan, S.V.; Timmons, B.K.; Strachan, M. Guide to Monitoring and Evaluating Knowledge Management in Global Health Programs 2013.
17. Gale, N.K.; Heath, G.; Cameron, E.; Rashid, S.; Redwood, S. Using the Framework Method for the Analysis of Qualitative Data in Multi-Disciplinary Health Research. *BMC Med Res Methodol* 2013, *13*, 117, doi:10.1186/1471-2288-13-117.
18. Dalhousie University Wheelchair Skills Program 2021.
19. Graham, I.D.; Logan, J.; Harrison, M.B.; Straus, S.E.; Tetroe, J.; Caswell, W.; Robinson, N. Lost in Knowledge Translation: Time for a Map? *Journal of Continuing Education in the Health Professions* 2006, *26*, 13–24, doi:10.1002/chp.47.
20. *Knowledge Translation in Health Care: Moving from Evidence to Practice*; Straus, S.E., Tetroe, J., Graham, I.D., Eds.; 2nd ed.; John Wiley & Sons: Chichester, West Sussex, 2013; ISBN 978-1-118-41357-9.
21. Bradbury-Jones, C.; Isham, L.; Taylor, J. The Complexities and Contradictions in Participatory Research with Vulnerable Children and Young People: A Qualitative Systematic Review. *Social Science & Medicine* 2018, *215*, 80–91, doi:10.1016/j.socscimed.2018.08.038.

Clinical Applicability of the COMET Intervention

An Innovative Power Wheelchair Training Approach

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Abstract. Objective: To evaluate the clinical applicability of the COMET (cognition, occupation, mobility, evaluation and training) intervention. Design: A case series was conducted. Participants: Adults who were being considered for PWC provision and who had been identified by an occupational therapist to benefit from a PWC training were included. Intervention: The COMET intervention a goal directed, client-centered and occupation-based, was provided to all participants. Outcome measures: Clinical applicability indicators were collected for: process, resources, management and treatment. Clinical outcomes included the Goal Achievement Scale (GAS), the Canadian Occupational Performance Measure (COPM), the Power Mobility Indoor Driving Impairment (PIDA) and the Wheelchair Skill Test (WST). Applicability indicators were evaluated as binary responses ('successful/unsuccessful'). Results: Four females (62.5 ± 3.5 years) with cognitive impairment participated. Among the thirteen clinical applicability indicators defined, ten were successfully achieved. Indicators that did not meet the criteria for success were adherence rate, safety and treatment for the PIDA. Two of four participants completed all 5 sessions. Two adverse events were reported, with one minor injury. Related to treatment response, participants demonstrated better than expected results on the GAS and the COPM performance and satisfaction scores. All participants demonstrated improvement of more than 9% at the WST. Only two reported an improvement beyond 4% of the PIDA. Conclusions: With few modifications, the COMET intervention will be applicable in clinical practice. Individuals with complex cognitive and mobility impairment demonstrated abilities to learn PWC use. Further investigation of the COMET intervention is required to evaluate its efficacy.

Keywords: clinical applicability, power wheelchair, cognitive impairment.

1 Introduction

Power wheelchairs (PWC) allow mobility[1], engagement in meaningful activities[2], and social life[3] for individuals with mobility limitations. Such increased autonomy and independence in mobility may also reduce the caregiver burden[4]. An eight step process for the provision of wheelchairs (referrals and appointments, assessment, prescriptions, funding and ordering, product preparation, fitting, training of users, families and caregivers, and follow-up, maintenance and repair) has been published by the World Health Organization[5]. Occupational therapists are health professionals commonly in charge of PWC service provision. They commonly evaluate the individual's diagnosis and prognosis, skills and abilities (including physical, cognitive and perceptual abilities), and its environment[6]. Occupational therapists also provide clinical judgements regarding safety issues (e.g., ability to avoid collisions), ability to negotiate the environment, and insight to recognize when assistance is needed[6].

Training is one of the eight steps recommended by the World Health Organization and there is lots of evidence showing the effectiveness of training to enhance capacity for PWC skills (e.g. driving background, turning right and left, maneuvering in small spaces), address the challenges PWC users may face, and to diminish the potential risks of incidents[7,8]. The Wheelchair Skills Program (WSP) is an evidence-based program with lots of evidence for effectiveness documented. It demonstrated effectiveness for improving PWC skills capacity for individuals with neurological conditions[9]. However, after being trained using the WSP, PWC users did not demonstrate long-term improvement in PWC skills[10]. Although the WSP includes some consideration of the cognitive ability required to drive a PWC, one explanation may be that conceptualization of the WSP did not specifically consider how individuals with cognitive impairment learn. As a result, current best practices may not respond to the specific needs of PWC users with complex mobility and cognitive impairment. Therefore, individuals with complex mobility and cognitive impairment, who need more in-depth or tailored learning opportunities, are often precluded to be provided a PWC before they get a chance to be trained[6,11].

Results of a scoping review [12] and a cross-sectional study [13] demonstrated that individuals with complex cognitive and mobility impairment have the ability to learn how to use a PWC and that cognitive level and self-efficacy directly influence performance using a PWC. A developmental study using focus groups and a Delphi survey including stakeholders (PWC users, occupational therapists and researchers) suggested that training individuals with cognitive impairments should apply a client-centered, goal directed and occupation-based approach. The COMET (cognition, occupation, mobility, evaluation and training) intervention was developed in response to this need for alternative approaches that specifically consider the needs of individuals with complex mobility and cognitive impairments who may benefit from a PWC[11]. Conducting an evaluation of clinical applicability represents a preliminary step of evaluation before conducting a large clinical trial. Even if the COMET intervention is effective in improving PWC driving, if it is not clinically applicable, it will not be used by OTs when providing PWC to this clientele. Clinical applicability refers to suitability for being put to practical use and gives an emphasis to the subject reaction. The objective of this study was to evaluate the clinical applicability of administering the COMET intervention.

2 Methodology

2.1 Design

A case series design was conducted. The study was approved by the local research ethics committee of the 'Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale' (MP-13-2020-1841CA). Informed consent and agreement to be filmed were obtained from all participants.

2.2 Participants

Adults with cognitive impairment who were being considered for PWC provision, or who were recently provided a PWC, and who had been identified by an occupational therapist to benefit from a PWC training.

2.3 Intervention

The COMET intervention applies a goal directed, client-centered and occupation-based approach. The intervention consisted of a maximum of six 1-hour sessions, was conducted by a trained occupational therapist and occurred at a convenient location chosen by the participants (e.g., home, rehabilitation center, long-term care facility). All procedures were defined in collaboration with the occupational therapy clinical practice leader in the seating and mobility department.

2.4 Outcome Measures

Sociodemographic information were collected (age, experience using a PWC, MoCA). Thirteen applicability indicators were defined a priori and collected for: process (consent and retention rates); resources (time to complete data collection, training time); management (study duration, adherence rate); and treatment (number of adverse events during training, treatment response of clinical outcomes). Clinical outcomes included the Goal Achievement Scale (GAS), the Canadian Occupational Performance Measure (COPM), the Power Mobility Indoor Driving Impairment (PIDA) and the Wheelchair Skill Test (WST)) and were evaluated after each training session. Applicability indicators were evaluated as binary responses ('successful/unsuccessful') according to a priori parameters of success.

3 Results

Four females (62.5 ± 3.5 years) with cognitive impairment participated in the study. Among the thirteen clinical applicability indicators defined, ten were successfully achieved. Indicators that did not meet the criteria for success were adherence rate, adverse events and treatment for the PIDA. Two of four participants completed all 5 sessions. Two adverse events were reported, with one minor injury (ie., small lesion on the

leg). Related to treatment response, participants demonstrated better than expected results on the GAS and the COPM performance and satisfaction scores. All participants also demonstrated improvement beyond the minimal clinically important difference of the WST. However, only two reported an improvement beyond the minimal clinically important difference of the PIDA.

4 Discussion

This study presents findings about the clinical applicability of the COMET intervention. Specifically, indicators for treatment adherence, mitigating risk due to adverse events and using the PIDA as a clinical outcome must be considered before conducting larger trials. Conducting research with older adults can be challenging, specifically related to recruitment, participant burden and treatment adherence[14]. Unforeseen event should be considered when conducting research with older adults with complex impairments and is in accordance with previously documented challenges during clinical trials with older adults[14]. The two adverse events that occurred during the nineteen training sessions were reported to the ethics committee and did not impact the study. One minor injury occurred that was not beyond potential injuries expected during PWC use, and the participant wanted to continue training. The proximity of the trainer at all times, as defined by the COMET intervention, increased safety and allowed for small errors to be made being and corrected during training. Acknowledging that adverse events are likely for this population, there is a need to optimally balance safety and challenge, as challenging situations and optimal amount of difficulty are needed to enhance learning[15].

Related to treatment effect indicators, all participants improved their COPM scores (performance and satisfaction) and WST-Q confidence scores by more than the minimal clinically important difference. They also improved by more than two points on goal attainment, demonstrating that all participants achieved their identified goals. Moreover, all participant improved their PWC skills after training, with improvements on the WST more than the minimal clinically important difference of 9.3%. These results are supported by previous research demonstrating that occupation-based interventions have the potential to enhance global performance and specific skills. However, the PIDA as a clinical outcome did not meet the criteria for success.

The result of the present study demonstrated that with few modifications the COMET intervention will be applicable in clinical practice. The next step would be to work with clinicians to realize an implementation trial of the COMET intervention.

4.1 Limitations

The results should be interpreted with caution as only four older women were recruited. Moreover, a heterogenous sample included individuals who already had PWC and individuals who were not yet approved for PWC. Examining only individuals who were originally precluded from PWC provision will be important to understand the potential for the COMET intervention to enhance PWC service provision process. Despite the limitations, this study provided preliminary evidence supporting the clinical

applicability of the COMET intervention and may guide clinical practices for PWC training for people with complex motor and cognitive impairments.

5 Conclusions

With few modifications, the COMET intervention may be applicable in clinical practice. Individuals with complex cognitive and mobility impairment demonstrated abilities to learn how to use a PWC. Further investigation of the COMET training approach is required to evaluate its efficacy and implementation in clinical practice.

References

1. Sund T, Iwarsson S, Anttila H, *et al.* Effectiveness of Powered Mobility Devices in Enabling Community Mobility-Related Participation: A Prospective Study Among People With Mobility Restrictions. *PM&R* 2015;7:859–70. doi:10.1016/j.pmrj.2015.02.001
2. Pettersson I, Törnquist K, Ahlström G. The effect of an outdoor powered wheelchair on activity and participation in users with stroke. *Disability and Rehabilitation: Assistive Technology* 2006;1:235–43. doi:10.1080/17483100600757841
3. Fomiatti R, Richmond J, Moir L, *et al.* A Systematic Review of the Impact of Powered Mobility Devices on Older Adults' Activity Engagement. *Physical & Occupational Therapy In Geriatrics* 2013;31:297–309. doi:10.3109/02703181.2013.846451
4. Frank A, Neophytou C, Frank J, *et al.* Electric-powered indoor/outdoor wheelchairs (EPI-OCs): users' views of influence on family, friends and carers. *Disability and Rehabilitation: Assistive Technology* 2010;5:327–38. doi:10.3109/17483101003746352
5. World Health Organization, International Society for Prosthetics and Orthotics, United States. Agency for International Development. Guidelines on the provision of manual wheelchairs in less resourced settings. *Guide pour les services de fauteuils roulants manuels dans les régions à faibles revenus* 2008;:128.
6. Mortenson WB, Clarke LH, Best K. Prescribers' Experiences With Powered Mobility Prescription Among Older Adults. *American Journal of Occupational Therapy* 2013;67:100–7. doi:10.5014/ajot.2013.006122
7. Kirby RL, Coughlan SG, Christie M. Could changes in the wheelchair delivery system improve safety? *CMAJ* 1995;153:1585–91.
8. Mountain AD, Kirby RL, Eskes GA, *et al.* Ability of People With Stroke to Learn Powered Wheelchair Skills: A Pilot Study. *Archives of Physical Medicine and Rehabilitation* 2010;91:596–601. doi:10.1016/j.apmr.2009.12.011
9. Keeler L, Kirby RL, Parker K, *et al.* Effectiveness of the Wheelchair Skills Training Program: a systematic review and meta-analysis. *Disability and Rehabilitation: Assistive Technology* 2019;14:391–409. doi:10.1080/17483107.2018.1456566
10. Kirby RL, Miller WC, Routhier F, *et al.* Effectiveness of a Wheelchair Skills Training Program for Powered Wheelchair Users: A Randomized Controlled Trial. *Archives of Physical Medicine and Rehabilitation* 2015;96:2017–2026.e3. doi:10.1016/j.apmr.2015.07.009
11. Best K, Smith E, Pellichero A, *et al.* International research priorities on the role of cognition in power mobility device use: In pursuit of informed clinical practices and knowledge translation. *Assistive Technology* 2021;:1–8. doi:10.1080/10400435.2021.1956638

12. Pellichero A, Kenyon LK, Best KL, *et al.* Relationships between Cognitive Functioning and Powered Mobility Device Use: A Scoping Review. *IJERPH* 2021;18:12467. doi:10.3390/ijerph182312467
13. Pellichero A, Best K, Leblond J, *et al.* Relationships between cognitive functioning and power wheelchair performance, confidence and life-space mobility among experienced power wheelchair users: An exploratory study. *J Rehabil Med* 2021;53:jrm00226. doi:10.2340/16501977-2869
14. Provencher V, Mortenson WB, Tanguay-Garneau L, *et al.* Challenges and strategies pertaining to recruitment and retention of frail elderly in research studies: A systematic review. *Archives of Gerontology and Geriatrics* 2014;59:18–24. doi:10.1016/j.archger.2014.03.006
15. Cicerone KD, Goldin Y, Ganci K, *et al.* Evidence-Based Cognitive Rehabilitation: Systematic Review of the Literature From 2009 Through 2014. *Archives of Physical Medicine and Rehabilitation* 2019;100:1515–33. doi:10.1016/j.apmr.2019.02.011

Perspectives on 3D printing technology for manufacturing customized assistive technology in rehabilitation by occupational therapists

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Abstract. Emerging technologies such as 3D printing offer promising opportunities to manufacture assistive technology to support activities of daily living for and in co-creation with clients in rehabilitation. Little is known about the impact and requirements of implementing 3D printing in rehabilitation, including competencies of occupational therapists, viable business models and financial, ethical, practical and/or legal considerations. The aim of this study was to explore the perspectives of rehabilitation professionals, 3D printing experts and clients in rehabilitation on the potential of 3D printing technology for manufacturing assistive technology to support activities of daily living. An exploratory qualitative study design was adopted to explore different perspectives on 3D printing for occupational therapy in rehabilitation. Interviews were audiotaped, transcribed verbatim and analyzed using content analysis. In total, 30 interviews were conducted with users, engineers, health care professionals and (rehabilitation) managers. No clients were found. Participants' actual experience with using 3D printing technology was limited, but they mentioned, knew or used a broad spectrum of 3D printed devices. Participants did see added value for 3D printing of custom-made assistive technology. Seven main themes could be identified in the data regarding participants' views on the implementation of 3D printing in the rehabilitation setting, including critical factors that should be taken into account: 3D printing technology, mindset, collaboration, competencies, requirements, business case, and legal aspects.

Keywords: Occupational therapy, qualitative research, 3D printing, implementation, rehabilitation

1 Introduction

In interdisciplinary rehabilitation, occupational therapists have a central role in advising their clients on assistive technology. Assistive technology is used to support all kinds of daily activities, e.g., aids for self-care, household and school activities, devices to perform work or play/leisure activities, orthoses (and prostheses) to support mobility, digital devices for communication and social interaction. In the Netherlands, occupational therapists use a standard guideline for the provision of assistive technology [1].

This guideline describes the steps to be taken, in cooperation with the client, to achieve the most optimal fit between the experienced problem on the one hand and the assistive device to solve or cope with the problem on the other hand.

To find suitable and commercially available assistive technology, occupational therapists can consult several national and international databases, such as the EASTIN database (<http://www.eastin.eu/en/searches/Products/Index>). Many assistive products in these databases are generic, however, and although aids are often made for people with specific conditions or disabilities, these are not tailored to individual needs. Assistive technology often not entirely matches the individual needs of the user regarding functionalities and/or aesthetics, which has been found to negatively affect acceptance and adoption by the user [2,3].

In this respect, emerging digital fabrication technologies, such as 3D printing, offer promising opportunities as 3D printing allows for the design and creation of personalized aids, and for active involvement of the end-user in the design process. It has been recognized that 3D printing offers several advantages compared to regular and commercially available aids [4-6]. In particular, 3D printed objects may be of lighter weight, can be easily adjusted, may have a more appealing aesthetic look, have lower production costs and are produced in a more sustainable manufacturing process [3,7]. Co-creation of assistive technology together with clients, may also empower them and improve the adoption process [2,8].

A study by Patterson et al. [9] showed that occupational therapists providing hand therapy interventions recognize these benefits and are optimistic about the potential use of 3D printing technology. Moreover, they perceive more benefits than challenges of using 3D printing and expect that, in time, 3D printing will be mainstream in hospitals and clinics. As such, 3D printing seems to be a promising technology for rehabilitation professionals to support clients' daily activities.

Despite the shared enthusiasm about the potential of 3D printing for rehabilitation, scientific literature reporting on the implementation of 3D printing in rehabilitation is still limited in scope and quality. Although examples of 3D printed assistive technology have been published, this mainly involves studies on prostheses or orthoses. Literature reporting on 3D printed assistive devices supporting activities of daily living, such as functional objects, individualized toys, or practical tools such as pen grips, grip holders for eating utensils, key turners, sponge holders, etcetera is much more scarce [3, 10-12]. The few studies published on 3D printed aids, indicate that the available technology needs further improvement before application in rehabilitation can be realized in practice. In particular, further research and improvement is needed on techniques for designing 3D models, bio-compatible printing materials, interdisciplinary co-creation workflows that facilitate collaboration between rehabilitation professionals and engineers, 3D printing experts [11,13].

In addition, little is known about the impact and requirements of implementing 3D printing in rehabilitation, including viable business models and financial, ethical and/or legal considerations that should be taken into account. From a rehabilitation perspective, more insight is needed into the liability of designing and making customized assistive technology using 3D printing, the role of occupational therapists, clients and 3D printing experts in this process, competencies but also support needed by occupational

therapists, and influencing factors for implementation of such technology in daily practice [10,14,15]. To gain a better understanding of these issues, we have explored the perspectives of both rehabilitation professionals and 3D printing experts on the potential of 3D printing technology for manufacturing assistive technology to support activities of daily living.

2 Methods

2.1 Study Design

An exploratory qualitative study design was adopted to explore perspectives on 3D printing for occupational therapy in rehabilitation. Purposeful sampling was used for identification and selection of 30 information-rich participants.

2.2 Setting and Study Population

Participants were required to be either users of customized (3D printed) devices, professionals in occupational therapy and/or rehabilitation or experts in 3D printing. Additionally, they were to have a vision on the role 3D printing might play in rehabilitation occupational therapy. Health care organizations, 3D printing companies, researchers, client organizations, and professional and representative national bodies of occupational therapy, rehabilitation services and engineers were approached to recruit participants for the study. When suitable participants who met the inclusion criteria were identified, additional participants were identified by snowball sampling. Inclusion criteria were as follows:

1. Users/people with experiences in using, designing, making of customized 3D printed devices to support daily activities i.e. (former) clients of rehabilitation services regarding assistive aids provision;
2. Professionals (such as OTs) and persons knowledgeable regarding rehabilitation and rehabilitation services (management, admission and rehabilitation processes, interdisciplinary corporation, financial matters etc.);
3. Experts in the field of (Do-It-Yourself) technology, 3D printing (developers, manufacturers, engineers etc.) and/or with expertise regarding juridical, financial and/or ethical aspects involved in advising and using assistive technology in rehabilitation settings.

2.3 Data Collection and Data Analyses

Semi-structured individual interviews were conducted (by RJ) to explore participants' perspectives on 3D printing technology for manufacturing customized assistive technology for clients in rehabilitation settings. An interview guide was used, including topics such as experiences, possibilities, challenges, and prerequisites. Sub topics and probing suggestions were included in the interview guide as well [16]. Examples of these questions include: What are your experiences with 3D printing, and if applicable

with 3D printed assistive aids? What is, according to you, the value of 3D printing in manufacturing assistive aids? What are according to you possibilities or threats of 3D printing in rehabilitation?

Two pilot interviews were carried out with members of the project team, who met the inclusion criteria, to test the interview guide. No adaptations of the interview guide were needed. The subsequent interviews were recorded and transcribed verbatim. Member checks were executed by sending each participant a summary of their interview to check whether their visions were described correctly. Data analysis was conducted using content analysis [17]. Two researchers (EH, RJ) coded the same two interviews independently from each other. They compared their codes and discussed differences to reach consensus on a coding tree. Subsequently, the two researchers (EH, LH) coded the remaining interviews. The main themes based on the codes were finally discussed with the entire project team and results were written down by the researchers (EH, LH).

2.4 Study Procedure

An invitation, including a brief description of the study, the inclusion criteria for participants and contact information was distributed online using the networks of project members, such as the Dutch association of occupational therapists. Participants who indicated to be interested in taking part in the study received an extensive information letter and informed consent form. After given written informed consent an appointment was set for the interview (1-1,5 hours) at a location of choice of the participant or online when a face-to face meeting was not possible due to the measures related to the COVID-19 pandemic.

The study was approved by the Medical Ethics Committee (METC-Z; project number METCZ20200109). The project was granted by the Dutch Taskforce for Applied Research SIA, project number RAAK PUB06.013.

3 Results

In total, 30 people with different kinds of backgrounds and expertise were interviewed, i.e. 3 users, 11 professionals (OTs n=6, rehabilitation professionals n=5) and 16 experts (researchers, entrepreneurs, engineers etc). For a description of participants' characteristics, see Table 1.

Table 1. Characteristics of participants.

Variables	Outcomes
Gender	
- Male (n; %)	22 (73.3)
Age (mean; SD)	40.6 (12.2)

Function	3
- Users	11 (OTs n=6; rehabilitation ex-
- Professionals/ rehabilitation expert	perts n=5)
- 3D printing experts	16
Years of experience in current function (mean; SD)	12.0 (9.5)

Although participants' actual experience with using 3D printing technology was rather limited, they mentioned, knew or used a broad spectrum of 3D printed assistive technology, including arch inlays, splints, (finger/shoulder) orthoses, and (breast) prostheses, 3D models of body parts for education (anatomy) or for surgeons to prepare for surgery. Additionally, examples of assistive aids to support activities of daily living were mentioned, used or made by participants such as cup holders, an adapted tray, a bar magnifier, parts to repair a broken wheelchair, grip for cutlery or for a hand bike.

Engineers, health care professionals and (rehabilitation) managers did see added value in 3D printing of custom-made assistive technology. Many advantages but also some disadvantages of 3D printing were mentioned in the interviews. Most advantages were related to the ability to customize devices to individual clients, for example to exactly fit a device to a client's body, or to print new devices when children have grown. Furthermore, as 3D printing is believed to be a relatively cheap technique, it is considered suitable for developing 'rapid' prototypes in an interactive, co-creation process together with the client. Additionally, other benefits of customization that were mentioned included the possibility to choose different colors and materials, and the possibility to vary the weight by adapting the density of the material used to print. These options to tailor assistive technology to users' needs are expected to result in better fit, increased treatment outcome, and also better user acceptance and lower non-adoption. Other advantages relate to sustainability due to the possibility of in-home printing, less waste, and the increasing availability of durable, biodegradable printing materials. Disadvantages interviewees came up with were required technical competencies needed for 3D designing and the fact that the design part is very time consuming.

Seven main themes could be identified in the data regarding participants' views on the implementation of 3D printing in the rehabilitation setting, including critical factors that should be taken into account. We outline each of these seven themes below.

3.1 Technical Aspects of 3D Printing

The first theme involves the participants' perspectives on the technical aspects of 3D printing, including printing technologies, hardware, software (for designing and printing), materials, and the quality of 3D printed products.

Participants indicated that before considering to make a new device, commercially available assistive technology should be used (according to regulation) if suitable for the intended purpose. For situations in which no suitable assistive devices are available,

participants differed in the extent to which they believe that 3D printing provides a potential solution. In this respect, several participants indicated that 3D printing may not always be the most obvious or appropriate solution due to characteristics related to the printing material and printing technique. For instance, the Fused Deposition Modeling-technique (FDM) that is used in 3D printing may not be strong enough for some forms of assistive devices, as prints made with this technique consist of individual layers. These layers, which are quite visible and tangible, may also yield aesthetic and hygiene issues (i.e. adhesion of bacteria), making 3D printing less suitable for assistive devices that are used in public or that come in contact with user's skin or mouth. Whether 3D printing may be a good solution depends, also depends on safety issues, such as whether it comes in contact with skin or mouth of the user.

Moreover, participants talked about various 3D designing techniques, such as 3D modelling, 3D scanning, 3D computer design, including adaptation of already available designs. In particular, the 3D modelling and scanning technique participants expected to be valuable to occupational therapists (in the future), while others believe that the design process is very/too complicated and maybe not feasible for occupational therapists. On the other hand, participants also frequently mentioned aspects that are still unclear to them such as if the occupational therapist is able to design devices by themselves, or the ability to adapt designs, for example if a device no longer fits. In summary, 3D printing technology is believed to be valuable for manufacturing customized assistive devices.

3D printing expert: "Today, we can already make pretty good 3D scans using a hand scanner. If the interface and computer software would be even more user friendly, then with some education and training, I believe, occupational therapists should be able to learn how to make simple assistive aids".

3.2 Mindset

The second theme encompasses stakeholders' awareness of the existence of 3D printing technology and its possibilities, and their attitudes towards new innovations. In general, participants expect that occupational therapists who are not familiar with innovative technologies like 3D printing, and who have never experienced its benefits themselves, might be hesitant at first. Therefore, participants suggest that 3D printing should not be presented as something extraordinary, but as a technique that is inevitably going to be part of regular practice in the future to stimulate its acceptance. They also expect that acceptance of 3D printing technology could be accelerated by showing examples of what has been made so far. As such, (groups of) people who act as ambassadors and who actually start printing devices might be of essence in convincing others of the benefits. However, expectation management may be important in this respect, as participants who actually had some experience themselves indicated that they encountered many failures, especially in the pioneering phase, which may be time consuming and frustrating. Therefore, perseverance seems an important characteristic for such ambassadors. Additional important personality traits mentioned were being courageous, inventivity, or willingness to think out of the box, digitally proficiency, willingness to learn and being open to trial and error, and willingness to cooperate with other

disciplines. Additionally, on an organizational level, participants stressed the importance of management being at least aware of the existence of 3D printing and developing a vision and policy regarding 3D printing.

3.3 Collaboration

As mentioned above, willingness to collaborate was considered an important prerequisite for the successful implementation of 3D printing in rehabilitation settings. According to the participants this means that developing a 3D printed assistive device requires an interdisciplinary design team. In this respect, participants stressed the importance of collaboration between end users/clients, paramedics (such as occupational therapists, but this may also be supplemented with e.g. physical therapists in case of e.g. ankle-foot orthoses etc), and engineers/3D experts, all with their own responsibilities. A rehabilitation physician may be included as well, e.g. as prescriber of the device. In such an interdisciplinary design team, speaking each other's language seems very important for all stakeholders to guarantee an optimal fit between clients' need and wishes and the functional and technical requirements to come to the best solution.

Engineer: "The technician and the occupational therapists both have their own responsibilities. It's the technician's responsibility to make a high-quality 3D printed product which is working properly. It's the occupational therapist's responsibility to make sure that the product matches the needs and wishes of the individual client".

3.4 Competencies

The theme labeled 'competencies' regards perspectives on the knowledge and skills required by occupational therapists about 3D design and 3D printing, but also training, support and tools they need to acquire or compensate for technical skills.

In general participants feel that being able to 3D print assistive devices requires complex technical skills, such as using design software, applying mechanical principles, spatial ability, etc. Even working with a model downloaded from a database like Thingiverse.com., participants indicate, requires basic design skills that many occupational therapists do not have. Moreover, participants mentioned that occupational therapists may not have sufficient understanding of the basic principles of 3D printing to determine for which cases 3D printing would be a good solution. As such, it is essential to have some level of design skills, but also knowledge of printing materials and 3D printing techniques (for example which materials are required when certain forces will be exerted on a device, how a device should be physically designed in order to withstand such forces, or which materials or coatings could be used for devices for which hygiene is crucial).

3D printing expert: "We start with a 3D design, so you have to be able to generate a spatial concept in your mind. The 3D design is your starting point for making a model in 3D computer software to make the concept tangible. Then you can start playing with shapes and sizes and you rotate a model 360 degrees to see if it's feasible. And then you set up the basic lines and after some post-editing you can make a test print with as

little material as possible. You create a prototype to test whether it works. Then you print it again in the final version and material”.

Participants seriously doubt whether designing 3D devices should actually be part of OT’s competencies, since in particular the design process requires complex technical skills and is rather time consuming. All participants stressed the importance of collaborations between occupational therapists, engineers/3D printing experts and clients. The integration of knowledge from a health care perspective (occupational therapist and client) and a technical perspective (engineer, 3D printing expert) is deemed crucial for successful implementation of 3D printing in rehabilitation.

3.5 Organizational Requirements

Another theme that was frequently discussed during the interviews concerned organizational or infrastructural aspects of 3D printing in rehabilitation settings. This includes, amongst others, participants’ perspectives on the access to a 3D printer and printing materials, the physical location in which a printer is set up, availability of time and resources in terms of training, education and to practice working on and with new innovations.

Learning and using 3D printing technology is considered to be a highly time-consuming process by the participants. Currently, occupational therapists lack time to for manufacturing customized assistive technology, with or without the use of 3D printing. In general, it is believed that organizations should support and facilitate their employees in exploring new developments, e.g. time and resources (training, education). Access to other tools such as instruction manuals or movies, a digital library with pictures, available designs and examples of solutions to support occupational therapists were frequently mentioned. Moreover, availability of design software, 3D printers, printing materials and a physical workplace and guidance and support of the process seems required for successful implementation. Additionally, consultation of experts in the field of engineering or 3D designing and printing should be available as well, within the organization or in collaboration with an external organization such as an 3D printing company.

3.6 Business Case

Related to infrastructural requirements, participants also addressed several financial aspects related to implementing 3D printing as a standard tool in rehabilitation settings, such as reimbursement, material costs, time investment, etc.

Participants seem to feel that the costs of 3D printing should be divided into technical costs (e.g. design software, 3D printers and scanners, printing materials) and time spent on designing and printing assistive devices (modelling, scanning and/or 3D computer design). Costs related to materials are in general perceived as low, whereas costs related to the time spent on designing devices are considered to be quite high, in particular in terms of time investment. It was also mentioned that costs related to time investment for the 3D design process might decrease in the future as this technique is rapidly emerging and improving.

The business case and reimbursement of customized 3D printed assistive devices seems challenging, since individual new devices have to be developed and manufactured each and every time for single clients. The added value of customized assistive device has to be proven. Is it possible for clients to receive high-quality devices that provide an optimal solution for their problems, produced in short amounts of time and against relatively low costs? Questions raised by the participants in this respect concerned e.g. how to assess the added value of a custom-made device, how to gain insight into the costs and benefits, are clients willing to pay for a device, what is the role of health insurance companies?

Manager in rehabilitation: “To make customized products for individual clients, 3D printing seems a promising technique since, in my opinion, printing materials are quite cheap. However, I doubt if occupational therapists have enough time to make designs and use the 3D printer themselves during their working hours?”

3.7 Legal Aspects

The final theme that we established from our dataset regards legal aspects. Most importantly, this theme includes participants’ perspectives on the meaning of and compliance with the newly adopted medical device regulation (MDR) for customized assistive technology, awareness and paying attention to risks, and intellectual property of 3D designs and prints.

Based on the interviews, we learned that the meaning and implications of the MDR on manufacturing of customized assistive technology in rehabilitation is mostly unclear to all participants. Moreover, knowledge of legal matters seems currently lacking by (therapists) in the rehabilitation setting, including awareness of one’s responsibility and of liability issues. Furthermore, participants wandered about aspects such as the need for certified production procedures and/or (bio-compatible) materials, the need for measures and tools for risk assessment, guidelines to produce and guarantee high quality assistive devices, copyrights and quality of available 3D designs on websites (e.g. Thingiverse.com). It was also suggested by some that clients could print the AT product themselves which transfers liability to the client and that the OT should be involved in order to be co-labile, or by distinguishing between using 3D printed AT as part of the therapy (intramural) and at home.

Engineer: “I am not quite sure whether the Medical Device Regulation also applies for this type of assistive devices and adaptations often made to regular devices, like hand grips for cutlery, for clients in rehabilitation”.

4 Discussion and Conclusion

The interview study presented in this paper explored the perspectives of users of assistive devices, of engineers/3D printing experts, and of health care professionals, on the potential of 3D printing technology for manufacturing customized assistive devices. Although the participants’ hands-on experience with 3D printing was rather limited, all

participants in this study indicated to see added value for 3D printing of assistive technology in rehabilitation.

Seven main factors were identified that may be important when considering implementation of 3D printing technology in rehabilitation settings. These factors can be divided into internal and external factors. The internal factors are related to the users and the organizations within the rehabilitation setting. External factors refer to e.g. policies and regulations. Factors related to the users include the mindset and competencies of end-users of the 3D printing technology, in our case clients, health care professionals and engineers, 3D printing experts. Factors of organizations that should be taken into account are technical aspects of 3D printing, collaboration between all people involved, and the requirements for assistive devices that are printed. External factors that are important for implementation are related to the business case and to legal aspects of 3D printing.

Based on the results, recommendations for practice are to raise awareness for the potential of 3D printing technology, to educate health care professionals, such as occupational therapists, technical knowledge and skills and to make sure that health care professionals and technicians learn to speak each other's languages. All participants consistently stressed the crucial importance of interdisciplinary collaboration between engineers and occupational therapists when designing and 3D printing assistive technology, in co-creation with clients. Future research should, amongst others, focus on further improvement of 3D printing technology and materials, on how to set optimal interdisciplinary collaboration and on how to comply with the Medical Device Regulation.

Currently, ongoing follow-up research aims at further exploration of the collaboration between occupational therapists, clients, engineers and 3D printing experts in rehabilitation centers. This research focuses on the development and description of a workflow and an accompanying toolbox to support occupational therapists with manufacturing customized 3D printed assistive devices, in which collaboration with engineers and 3D printing experts is deemed crucial.

References

1. Heerkens Y, Bougie T, Claus E.. The use of the ICF in the process of supplying assistive products: discussion paper based on the experience using a general Dutch prescription guideline Prosthet Orthot Int. 2011 Sep;35(3):310-7.
2. Hurst A & Tobias J. Empowering individuals with Do-it yourself assistive technology. Conference paper. Dundee Scotland. Assets, 2011.
3. Ganesan B, Al-Jumaily A and Luximon A (2016). 3D Printing Technology applications in occupational therapy. *Physical Medicine and Rehabilitation - International*. 3:1085.
4. Hofmann M, Williams K, Kaplan T, Valencia S, Hann G, Hudson S.E., Mankoff J, Carrington P. "Occupational therapy is making": clinical rapid prototyping and digital fabrication. CHI 2019, May 4-9, 2019, Glasgow, Scotland UK.
5. Holloway C & Dawes H. Disrupting the world of Disability: the next generation of assistive technologies and rehabilitation practices. *Health Technol Lett*. 2016, 3(4):254-256. doi: 10.1049/htl.2016.0087.

6. Schwartz JK, Fermin A, Fine K, Iglesias N, Pivarnik D, Struck S, Varela N and Janes WE. Methodology and feasibility of a 3D printed assistive technology intervention. *Disabil Rehabil Assist Technol.* 2020; 15(2):141-7.
7. Jimenez M, Romero L, Dominguez I.A, Mar Espinosa del M, Dominguez M. Additive Manufacturing Technologies: an overview about 3D printing techniques and future prospects. *Complexity*, vol. 19, 2019.
8. Sandri G, Gherardini F, Anastasio C, Bettelli V, Bottini A, Mascia MT. Customised construction of devices as integration of occupational therapy intervention in rheumatology by 3D printing technology and co-design: further development and verification of long-term effectiveness. 2018. Scientific Abstract. *Ann Rheum Dis.*
9. Patterson RM, Salatin B, Janson R, Salinas SP, Mullins MJS. A current snapshot of the state of 3D printing in hand rehabilitation. *J Hand Ther.* 2020;33(2):156-163
10. Lunsford C, Grindle G, Salatin B, Dicianno BE (2016). Innovations with 3-dimensional printing in physical medicine and rehabilitation: a review of the literature. *PM R.*;8: 1201-12.
11. Gherardini F, Petruccioli A, Dalpadulo E, Bettelli V, Mascia MT, Leali F. A methodological approach for the design of inclusive assistive devices by integrating co-design and additive manufacturing technologies. *IHSI 2020, Intelligent Human Systems Integration 2020*, 816-22.
12. Wagner JB, Scheinfeld L, Leeman B, Pardini K, Saragossi J, Flood K (2018). *J Med Libr Assoc.*;106:370-6.
13. Mikołajewska E, Macko M, Ziarnicki Ł, Stańczak, S, Kawalec P, Mikołajewski, D (2014). 3D printing technologies in rehabilitation engineering. *Journal of Health Sciences.* 4(12):78-83.
14. Slegers K, Kouwenberg K, Loucova T, Daniels R. Makers in healthcare: the role of occupational therapists in the design of DIY assistive technology.
15. Thorsen R, Bortot F, Caracciolo A. From patient to maker – a case study of co-designing an assistive device using 3D printing. *Assistive Technology 2019*, 306-12.
16. Polit, D.F. and Beck, C.T. (2012) *Nursing Research: Generating and Assessing Evidence for Nursing Practice.* 9th Edition, Lippincott, Williams & Wilkins, Philadelphia.
17. Hsieh H, Shannon SE (2005). Three approaches to qualitative content analysis. *Qualitative health research.* 15; 1277-88.

Challenges in the Provision Process of Assistive Products for Donning/Doffing Compression Stockings as Perceived by All Stakeholders

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Abstract. In 2019, 2.3 percent of the Dutch population wore Compression Stockings (CS). Despite positive effects, clients and caregivers experience bottlenecks in the daily use of CS. The compliance of clients is low and related to the ability to independently don and doff CS. Studies show that only 37 percent of CS wearers can do this independently. If these people do not receive home care or a suitable assistive product, this leads to noncompliance with the risk of complications, reduced autonomy, quality of life (QoL) and increased healthcare costs. Research has shown that by using an appropriate assistive product for donning/doffing, more people are able to don or doff their CS independently. The delivery process of these products in the Netherlands is not functioning well and should be optimized. As a first step in the optimization, the aim of this study was to identify challenges in the provision process as described in the literature and perceived by all stakeholders. The review detected 13 articles, and 4 national reports were included. The results from a scoping review were supplemented by stakeholders' experiences shared in personal conversations and an expert meeting. All bottlenecks from the literature were recognized by the stakeholders. Some were added or additional explanations were given to the bottlenecks presented. They can be categorized into 5 main themes; awareness, information provision, competencies, client involvement and reimbursement arrangement. All bottlenecks and explanations form the basis for the optimization of the provision process of assistive products for donning/doffing CS.

Keywords: compression stockings, assistive products for donning and doffing, provision process, qualitative research

1 Introduction

With 7 million euros in 2019, Compression Stockings (CS) compression class 2-4 belong to the top 10 assistive products in the Netherlands in terms of costs related to provision [1]. CS aim to reduce swelling and pain [3] in for example patients with varicose veins, venous insufficiency, chronic wounds and after thrombosis [2]. In 2019,

2.3 percent of the population of the Netherlands wore CS. In exact numbers 389,500 people [1]. The total population of the Netherlands is over 17 million people.

Despite positive effects of CS [3], clients and caregivers experience bottlenecks in the daily use of CS. The compliance of clients who received CS is low, for compression class 2 and 3 it is estimated between 44 and 65 percent. The ability to independently don and doff CS is related to compliance. Studies show that only 37 percent of CS wearers can don and doff them independently [5]. In particular elderly people and people with obesity or conditional/cognitive impairments or limited joint movement experience problems with independently doffing and donning CS [4]. If these people do not receive home care or a suitable assistive product, this leads to noncompliance [6] with the risk of complications such as chronic wounds, erysipelas, reduced mobility, pain and thus reduced autonomy, quality of life (QoL) and increased healthcare costs [7]. For donning and doffing, approximately 15 [4] - 25 percent [5] of CS wearers rely on professional care such as home care. In addition, 38 percent of CS wearers depend on informal care [5]. Additionally, due to the clients high dependence the physical strain on (in)formal caregivers is high [8], as well as the cost of using home care. In a group of CS wearers with deep vein thrombosis, the costs were estimated to be about 20 million euros, primarily spent on home care to put on or remove the CS [9].

Research has shown that by using an appropriate assistive product for donning/doffing, more people are able to don or doff their CS independently. The number of elderly people who could put on CS independently increased significantly from 60 to 88 percent by using the correct assistive product for doffing and donning [10]. Research shows that fewer donning/doffing products are provided than warranted based on clients' needs [11]. Persons who have to wear a CS often do not obtain any assistive product for donning/doffing. This is also reflected in the number of provisions. In the Netherlands in 2019, 49,700 declarations for doffing and donning assistive products to health insurance companies were registered with a total cost of 2.2 million euros. Despite the fact that doffing and donning assistive products are often used for more than one year, this implies underuse [1].

Another problem is that the wearers of CS frequently obtain an assistive product that does not match their wishes and needs, as not every assistive product is appropriate for everyone. This implicates that the delivery process is not functioning well and that there are bottlenecks. Therefore, it is important to optimize the provision process of assistive products for donning and doffing CS. As a first step in the optimization, the aim of this study was to identify challenges in the provision process as described in literature and perceived by all stakeholders namely clients, physicians, CS suppliers, oedema physiotherapists, skin therapists, occupational therapists, district nurses and health insurance companies.

2 Methods

The identification of bottlenecks started with a scoping review, for which Medline PubMed, CINAHL and DiZ (a search engine at Zuyd University of Applied Sciences for the library catalog and a large number of electronic files) were searched. The search

strategy was partly based on the strategy described in Balcombe et al. [12]. Using terms for the population: (ulcer* OR venous* OR lymph*), and for the intervention: (device* OR tool* OR aid [OR self-help device (PubMed) OR Assistive Technology Devices+ (CINAHL) OR assistive technology or assistive devices or devices or adaptive technology (DiZ)) AND (compression AND garment* OR stocking* OR hosiery) AND (appli* OR remov* OR don OR donning OR doff*)). Then the search terms for population and intervention were combined with AND.

Based on the small number of studies, all outcome measures and levels of evidence were included and no methodological filters were applied. The search generated 119 hits in Medline/PubMed, 60 hits in CINAHL, and 212 hits in DiZ. In addition, the references of relevant publications were reviewed (hand search) and Dutch experts in the field of compression care were asked about relevant national reports. The results from the scoping review were supplemented by the experiences that the stakeholders shared in a personal conversation.

During the kick-off meeting of the HASHTEK project, the bottlenecks gathered in the review and personal conversations were presented to the participating representatives of interest groups and professional organizations of the above stakeholders. Based on their feedback the bottlenecks were further supplemented and adjusted so that they can form the basis for a new optimal way of providing. Below preliminary results of bottlenecks in the provision process of assistive products for donning and doffing CS are presented. In the coming months, a qualitative study will be conducted on experiences of users of these products. This will provide more in-depth insights into the bottlenecks as outlined below.

3 Preliminary Results

The review detected a total of 13 articles, 2 unpublished and 2 published national reports were included. With the exception of one RCT and two literature/systematic reviews, the studies did not have a high level of evidence. In the literature, only a few reasons could be found why the use of assistive products for doffing and donning CS is not widespread. According to Kapp et al. [13], several barriers exist to the successful application of CS, mostly related to the physical or cognitive abilities of the client. Dिल्s and colleagues mentioned that it generally was hard to gather information about the number of assistive products available [14]. Gelderblom and colleagues [15] identified reasons specifically applicable to the Dutch situation: (1) Users were of course aware of their dependence in relation to the CS but badly informed about the availability of solutions to don and doff CS independently in the form of assistive devices, (2) Physicians focused on the compression therapy itself, not on devices supporting this therapy, (3) Home care organizations were primarily interested in improving the working conditions of their employees; making their work superfluous was for understandable reasons no appealing strategy to them. (Note: over the intervening years, there has been a shortage in the labor market for caregivers, making home care agencies more likely to motivate clients to doff and don CS themselves.) (4) Manufacturers and suppliers are logically involved from a commercial perspective and therefore any implementation

supporting activities from their side are suspected to be initiated for financial gain only. (5) The overall effects of implementing assistive products for doffing and donning CS will not directly benefit any of the direct stakeholders and therefore responsibilities towards the implementation are unclear. (6) Another problem is that suppliers of CS are supposed to supply suitable assistive products for doffing and donning CS together with the CS but in some cases this is paid for in a defined price arrangement, the money is paid whether or not an assistive product for doffing and donning CS is delivered. Verschooten [16] reported that the use of an assistive product seems a simple intervention: indicate an assistive product for doffing and donning CS and instruct the client how to use it. However, an extensive range of competencies (knowledge, attitude and skills) of the caregiver is required for proper handling of cases (e.g., analytical skills, being able to motivate, observe, instruct, to work in a structured way according to protocols, showing a proactive attitude and taking care of the communication within a district/team) [16]. Van den Berg [8] reaffirms what is described above and argues that the caregiver should be trained at least at nursing level. When clients receive care for an extended period of time, hospitalization can occur. These clients are often physically able to put on and off CS independently. However, due to habituation to home care there is no motivation (anymore) to perform these tasks independently. This is not determined by age: it has been noticed that many people aged over 80 and even 90 are still interested in independence. On the other hand, clients seem to appreciate home care visits, due to their feelings of loneliness. Fear of not being found in case of an accident played also a role in this [16].

All bottlenecks from the literature were recognized by the stakeholders and participants of the expert meeting. Some additional bottlenecks were mentioned or additional explanations were given to the bottlenecks presented.

The results of the review and the results of the personal conversations and the expert meeting finally resulted in the following bottlenecks in the provision process of assistive products for doffing and donning of CS in the Netherlands.

They can be categorized into 5 main themes; awareness, information provision, competencies, client involvement and reimbursement arrangement.

1. Lack of awareness of the importance of wearing CS by clients. Clients often do not know the importance of wearing CS, so the motivation to wear CS and finance assistive products for donning and doffing CS themselves is minimal. In addition, there is low adherence to wearing CS if doffing and donning them is difficult.
2. Insufficient attention to donning/doffing during the provision process of CS. Being obliged to wear CS can be perceived as intense and the client may be emotional at a first provision. There is often too little attention paid to the emotional aspects of being provided with CS and the practical aspects of donning/donning and wearing CS. And if attention is paid to donning and doffing CS, it often eludes clients because of their emotions.
3. Once wearers of CS receive home care they become accustomed to it and it is more difficult to achieve independence. Due to a frequently experienced sense of loneliness, elderly appreciate when someone comes to visit every day which also minimizes their fear of not being found in case of an accident [16].

4. Lack of appropriate information for all stakeholders. The information available on assistive products for donning and doffing CS is not always suitable for people who are low-literate or non-native speakers. The care providers choose, in principle, from the entire range of products in order to provide the most appropriate device for an individual client, but they are often not aware of the entire range of products including their functional and technical capabilities.
5. Insufficient familiarity with assistive products of both clients and health care professionals. Assistive devices for doffing and donning CS are not always known, so the help of family or home care is accepted and no further action is taken to learn to put on and off CS independently.
6. Difficulties in matching needs and wishes of the user and the possibilities of the assistive products. It is difficult to make a proper match between the aid and the user. Little is known about the usability of the devices in the case of co-morbidity and prerequisites for using certain assistive products. The knowledge gap makes it also difficult to motivate the choice of a more expensive assistive device.
7. Lack of active involvement of clients in the process. The client is often not actively involved in the provision process (e.g. due to limited information). There are still hardly any tools that support the client in shared decision making.
8. Reimbursement for one assistive product for donning or doffing only. A number of health insurers reimburse only one assistive device for donning or doffing, even when complete independence would require a donning device and another doffing device.
9. No reimbursement for the supplier of CS for providing training and instruction on assistive devices for donning/doffing. The supplier of CS is not reimbursed for certain services such as selecting the device and providing instruction and training, as this is considered the task of occupational therapist with their expertise in teaching ADL and the use of assistive devices. Therefore, training to use an assistive device is reimbursed for an occupational therapist, but not for another healthcare provider. This means that the CS wearer will have to deal with even more health care providers.
10. High administrative workload for the request of assistive products. Many health insurers require a recommendation from both an occupational therapist and a physician.
11. Fixed reimbursement fee for fitting and delivery the CS with or without assistive product for doffing or donning. The contracts of a number of health insurance companies include the provision of a standard fee for fitting and the delivery of CS incl. any necessary donning/doffing devices. A simple aid such as a sliding bag is included in the reimbursement for the provision of the CS. This makes the provision of a donning/doffing device financially unattractive for the supplier.
12. Revenues resulting from the improved functioning of a client end up in another department within the health insurance company than the department that reimburses the assistive devices. One department exceeds the budget and the other department has the revenues. This complicates the provision of the assistive devices.

4 Discussion

The bottlenecks form the basis developing a protocol for the optimal provision process of assistive products for donning and doffing CS. This protocol will be developed in 6 co-creation meetings with all stakeholders. Additionally, we strive to solve these bottlenecks by 1) developing information materials for clients and professionals that will be distributed through interest groups, professional associations, magazines, congresses and social media, 2) developing tools to identify the care need, the match between the capabilities and wishes of the user and the characteristics of the assistive devices, and evaluation tools. Caregivers will learn to work with these tools during an additional training course to be developed. The bottlenecks around reimbursement of the assistive products are beyond the scope of the HASHTEK project, but we hypothesize that the new provision process of assistive products for donning and doffing CS is effective. If it turns out that this hypothesis can be accepted, the reimbursement should reasonably be adjusted by the health insurance companies.

References

1. Zorginstituut Nederland. GIPdatabank Internet]. Available from: <https://www.gipdata-bank.nl/>
2. Rabe E, Partsch H, Hafner J, Lattimer C, Mosti G, Neumann M, et al. Indications for medical compression stockings in venous and lymphatic disorders: An evidencebased consensus statement. *Phlebology*. 2018;163-84
3. NVDV. Richtlijn Lymfoedeem. [lymphedema guideline] Utrecht: Nederlandse Vereniging voor Dermatologie en Venereologie [Dutch Society for Dermatology and Venereology]; 2013
4. Hagedoren - Meuwissen E, Berkel van M, Arkesteijn S, Steeghs F, Heugten van C. Implementatieplan 'Steun de steunkous' [Implementation plan "Support the compression stocking"]. Bunnik: Stichting Fonds en Arbeidsmarktbeleid en Opleidingen Thuiszorg; 2005.
5. Hampton S. Acti-Glide: a simple method of applying compression hosiery. *Br J Community Nurs*. 2004;10(5):244-6.
6. Wassall A. Compression hosiery: donning aids and garment removal. *Br J Community Nurs*. The Lymphoedema Supplement. 2007 October:S10-16.
7. Bouman AC, Ten Cate-Hoek AJ, Dirksen CD, Joore MA. Eliciting patients preferences for elastic compression stocking therapy after deep vein thrombosis: potential for improving compliance. *J Thromb Haemost*. 2016;14(3):510-7
8. Van den Berg H. Eindverslag ZonMw Koplopers in Kwaliteit en Kostenbesparing: Invoer steunkousenhulpmiddelen. Final Report Leaders in Quality and Cost Savings: Introduction of devices of doffing and donning compression stockings [Projectnummer 330010010]. 2012
9. Bouman, A. Post thrombotic syndrome, exploring aspects of pathophysiology and personalized management. Maastricht: Uitgeverij BOXPress. 206. <https://doi.org/10.26481/dis.20160218ab>
10. Sippel K, Seifert B, Hafner J. Donning Devices (Foot Slips and Frames) Enable Elderly People with Severe Chronic Venous Insufficiency to put on Compression Stockings. *Eur J Vasc Endovasc Surg* 2015;49:221-229.

11. Schwahn-Schreiber C, Marshall M, Murena-Schmidt R, Doppel W. Outpatient treatment of venous diseases with medical compression stockings in Germany. *Veins and Lymphatics* 2018;7:7560
12. Balcombe L, Miller C, McGuiness W. Approaches to the application and removal of compression therapy: A literature review. *Chronic Oedema* 2017; S6-14.
13. Kapp A, Sayers V. Preventing venous leg ulcer recurrence: a review. *Wound practice and research*. 2008 (15): 2.
14. Dilks A, Green J, Brown S. The use and benefits of compression stocking aids. *Nursing Times*. 2005; 101:32
15. Gelderblom GJ, Hagedoren E, Heugten van C Gelderblom GJ, Hagedoren E, Heugten van C. Implementation of Assistive Devices for Putting on and Off Therapeutic Elastic Stockings in Assistive Technology. In: Pruski A, Knops H. *From Virtuality to Reality*. Amsterdam: IOS Press, 2005. 468-473.
16. Verschooten I. Eindverslag ZonMw Zorg voor Beter: Invoeren van innovaties in de care; Steunkoushulpmiddel. Final Report Care for Better: Implementing innovations in care: assistive devices for compression stockings [Projectnummer 88100207]. 2012

Towards Rights + Capability Oriented Assistive Technology Service (OATS) Delivery System

The Implication on the Assistive Technology Public Policy and Practice

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Abstract. The research studies revealed that the Disability models influenced the person's freedom of choice for selection of Assistive technology (AT) products and services. The interaction of the Disability Models and AT resulted into the Oriented Assistive Technology Service (OATS) delivery systems (AAATE, 2012; Sebastian Van der Peijl and et al, 2011). The AT Medical, Social, Medical-Social, Charity or Donor, Capability, Rights, and Rights + Capability based models or OAT systems emerged as outcome of the interaction between Disability models and AT. These OATS delivery system determined the freedom of choice and decision-making powers for selection of AT products and services between the AT users or Person in need of AT and health, social and other AT related workers. The research study methodology was composed of multiple research methods. The mixed research methods such as qualitative and quantitative research methods were used to collect and analyse data. The case study research method was used to examine the data from Ireland. The data shows that Ireland used the Medical -Social OATS delivery system. The Model provided more decision-making powers for selection of AT products and services to Health and social workers. It provided limited freedom of choice to the AT user or person in need of AT to select AT products and services of choice. Research recommends the use of Rights Capability OAT delivery system. The model provides more decision-making powers to the User or a person in need of AT to select AT products and services of choice.

Keywords: Freedom of Choice, Assistive technology, Disability Models.

1 Introduction

The World Health Organisation [3], Bickenbach, Jerome E. [3], and Patricia Welch Saleeby [11] noted that the International Classification of Functioning, Disability and Health (ICF) recognised Assistive technology (AT) as one of the environmental interventions that responded to the complexity of disability. The AAATE [1] and Sebastian

Van der Peijl and et al [14] research studies revealed that the Disability models influenced the Person's freedom of choice for selection of AT products and services. The AT Medical model, AT Charity/ Donor model, AT Social model, AT medical -social model or AT Biopsychosocial model, AT Rights based model, AT Capability based model and AT Rights-Capability model emerged from interaction of the Disability models with the AT as both environmental and personal factor. The AT models were used by the research study to measure the shares of decision-making powers between the person in need of AT or AT user and the health workers, social workers, AT specialists and others [11] (Retief, M. & Letšosa, R., 2018).

2 Limited Freedom of Choice for Selection of AT

The AAATE [1] observed that the Disability models influenced the AT service delivery programmes in health, education, employment, and others. These AT delivery programmes (ATDPs) were within the framework and orientation of the AT Medical, Social, Biopsychosocial, and Rights based models and capability approach. However, the AAATE [1] and Sebastiaan Van der Peijl and et al. [14] research studies did not separate the influence of the Disability models on the Person's freedom of choice to select AT products and services of choice and the Institutional and sectoral AT delivery programmes. The Medical and Charity OATS delivery system did not provide any freedom of choice to a person in need of AT or AT user to select an AT product and service of choice. The two OATS delivery systems gives all the decision-making powers to medical workers and the Donors or charity givers respectively to select the assistive technology products and services on before of the Person in need of AT or AT users [1,14].

The Medical-Social model OATS delivery system provided some decision-making powers and freedom of choice to Person in need of AT or AT user to select AT. The medical or social workers or AT officers remained with the more decision-making power to select the AT products and services needed by person in need or AT users. The Rights based OATS provided most of the decision-making powers to the persons in need of AT and AT users to select the AT products and services of choice funded by the State. The Capability based OATS recognised AT as equal opportunity that facilitates participation and wellbeing of the AT users. The Rights -Capability based OATS provided freedom of choice to a person in need of AT and AT users to select AT of choice and considered AT as an equal opportunity to facilitate full participation and wellbeing of the person in need of AT or AT user [1,2, 9, 13, 15, Retief, M. & Letšosa, R., 2018].

The impact or influence of the disability models on the Person's freedom of choice to select AT product and services of choice was referred to as the Oriented Assistive Technology Service (OATS) delivery systems This research paper distinguished the OATS delivery systems from the AT delivery programmes (ATDPs) such as health, education, and employment and others. The influence of the Disability models on the AT service delivery in different sectors and institutions was referred to Assistive Technology delivery programme/Provision system (ATDPS). This research paper categorised the ATDPS based on education, health, employment, culture, political

participation, and other sectors defined by the Convention on Rights of Persons with disabilities. The institutional Assistive technology delivery programme system was a subcategory of the sectoral ATDPs. The researcher paper analysed the types of Oriented Assistive Technology service (OATS) systems used by University College Dublin's AT delivery Programme system and Higher Education ATDPS in Ireland and their impact on freedom of choice of UCD students using Hearing and Ear Assistive technology (HEAT) solutions [1,10,14, 16].

The 2005 Disability Act of Ireland recognised Assistive technology as one of the reasonable accommodations to facilitate participation and wellbeing of the persons with disabilities. The Higher education Authority Ireland [5] established the fund for students with disabilities to support provision of reasonable accommodations including assistive technology. However, both the 2005 Disability Act and the fund for students with disabilities in Ireland under the National Plan of Equity of Access to Higher education for the underrepresented learners in Higher education institutions did not define the freedom of choice of students in need of AT.

This research paper examined how the disability models affected the freedom of choice of the Person in need of AT or AT user to select the AT product and service of choice. The research paper also examined the OATS delivery system used by University College Dublin (UCD) and Higher education Authority Ireland to provide AT products and services. The research study was based on hypothesis that stated that all the AT delivery programmes in Ireland used Rights +Capability based OATS delivery system and provided more decision-making powers to Person in need of AT to select AT products and services of choice. The hypothesis was based on the policy and practices in Norway. Terje sund [16] and the Nordic Center for Rehabilitation technology [10] noted that the Norwegian AT service delivery system provided freedom of choice to a person in need of AT to select a public funded AT products and services of choice.

3 The Methodology

The multiple research methods composed of case study research method and mixed research methods were used to collect empirical data. The qualitative data was collected through key informant interviews with University College Dublin students using hearing and Ear assistive technology solutions, UCD officials in charge of AT related policies and provision of assistive technology, representatives of government officials in charge of AT related policies and provision and representatives of Non-State Actors providing AT services to students in Higher Education Institutions. The survey data was collected from the audiologists, users of hearing and ear assistive technology and organisations of persons with hearing loss or Hard of Hearing in Ireland and around the world. The research study was approved by the University Ethics committee. The data collection was delayed by COVID-19 pandemic between 2020-2021. The research paper considered AT Public policies and programmes as socially constructed objects and used the Constructivist Ontology to analyse the data. The Critical discourse analysis was also used to analyse the behaviours of the AT service delivery system as they

interacted with the UCD students using Hearing and Ear Assistive Technology (HEAT) and environment [8,12,19,20].

The semi structured interviews and survey questionnaires were used to help the research participants to respond to the research study. Over 50 users of HEAT solutions from 21 countries around the World responded to the survey of the research study (Robert Yin, 2018). The survey participants were from Ireland, Austria, Australia, Canada, Czech Republic, Denmark, Germany, Georgia, Italy, Nepal, Norway, Philippines, Poland, Lithuania, Rwanda, Serbia, Uganda, United Kingdom, Vietnam, and Zambia. The 17 qualitative interviews including three key informant interviews with users were used to collect empirical data in Ireland. The data collection was delayed by the COVID-19 pandemic. This research paper used the secondary and empirical data collected from Ireland to respond to the early highlighted research questions.

4 Results

The data findings revealed that the funding cap of 500 Euros for each of the two hearing aids funded by Health Service Executive for medical card holders limited the person's freedom of choice to select an Hearing aid of choice funded by the State in Ireland. The representative of Health Service Executive (HSE) Audiological services stated that "HSE covers two hearing aids for each at 500 euros for all persons in need with medical card". This data confirmed that a person in need of a hearing aid that costs more than 500 euros was funded by the public health Insurance managed by HSE Ireland. This implied that medical card holders in need of hearing aids were forced to take the 500 euro hearing aid funded by HSE Ireland. The health AT delivery programme in Ireland was a medical Oriented service delivery system that was characterised by selection of hearing aid by the medical officer or social worker on before of the person in need of AT or AT user.

The findings also shows that Ireland used the Medical -Social model OATS delivery system in higher Education Institutions. This was characterised by the medical assessment of body functional loss and funding only education related assistive technology products and services. The UCD AT specialist stated that "The UCD students in need of AT are required to present a recent medical assessment record of their hearing loss from the medical officer. When we receive the medical assessment record, we do another assessment for assistive technology and other reasonable accommodations needed by the student to learn in UCD".

The UCD Assistive Technology specialist also stated that "UCD funds only educational assistive technologies and does not fund medical assistive technology such as hearing aids". The requirement of the medical assessment of the hearing functional loss in the context of Higher education institutions confirmed that the UCD used a Medical-Social model OATS system. However, UCD AT funding system did not fund medical devices such as hearing aids because these were considered to be Health or medial AT products. These were not considered as educational assistive technology solutions. The hearing aids were provided in hospitals and other Health centres.

One of the UCD students using Hearing and Ear AT stated that “I had limited information about Assistive technology before I interacted with the Assistive Technology specialist at UCD Access and lifelong learning centre”. The same student further stated that “The Assistive technology specialist in UCD Access and lifelong learning centre consulted me in the selection of my AT and managed the purchase of the AT products for me”. The data confirmed that most of the decision-making power to select AT product for student was in hands of the Assistive technology specialist.

Another research participant or UCD student using HEAT stated that “The UCD website does not provide specific information on the different types of hearing and Ear Assistive technology. It was difficult to make a choice on the selection of AT based on the limited information on website”. The data further confirmed that the AT specialist had more decision-making powers and selected the AT products on behalf and in consultation with UCD students in need of AT.

The representative of Higher Education Authority Ireland, Access office stated that “the fund for students with disabilities funds assistive technology and other reasonable accommodations. The 2005 Disability Act requires the provision of reasonable accommodations in all Higher education institutions in Ireland”. The data confirmed that Assistive technology was one of the reasonable accommodations supported by the state funding programmes. The 2005 Disability Act was a medical -social model policy legislation that shifts the biggest burden of disability and cost to Persons in need of AT. This contributed to limited freedom of choice to select AT products and services of choice.

The 65% of the survey participants using HEAT products and services outside Ireland stated that the hearing and ear assistive technology products they used were influenced by their ENT, audiologists, and AT service providers to select AT products. This confirmed that the Medical-Social or Biopsychosocial and the donor/Charity OATS delivery system were the common OATS delivery system used around the World.

The representative of the National Disability Authority Ireland stated that “The AT service delivery system in Ireland is fragmented and managed by different actors ranging from health care and social care service providers, education institutions and others”. This empirical data confirmed the findings of the Enable Ireland and Disability Federation Ireland (2016) research paper on Assistive Technology for persons with Disabilities and Older Persons. The data confirmed that Ireland used more of the medical -social model OATS that provided more decision-making powers to Health officers and social workers to select AT products and services on behalf of person in need of AT. The 2005 Disability Act recognized AT as a reasonable accommodation and does not provide the right to accessibility and freedom of choice to persons with disabilities in need of AT to select AT product of choice. Ireland ratified the Convention on Rights of Persons with Disabilities and committed to shift from the medical-Social OAT delivery system to the Rights+ Capability OATS delivery system that provides freedom of choice to a Person in need of AT to select AT product of choice. The UNCRPD requires Member States to domesticate the CRPD in the domestic laws.

5 The Recommendations

1. The AT Public funding policies should enable a Person in need of AT to select Public funded AT products and services of choice based on the principle of freedom of choice.
2. The AT Public funding policies and laws should facilitate AT programmes based on the Rights +Capability model OATS delivery system.
3. The Person in need of AT and AT users should be provided with the personalised AT information services that enables them to select AT products and services based on freedom of choice.

References

1. Association of Advancement of Assistive Technology in Europe (AAATE), The Assistive technology Service Delivery Systems in Europe, (2012).
2. Amartya, Sen, "Equality of What?" The Tanner Lectures on Human Values, 1980, Ed. S. McMurrin. I. Salt Lake City: University of Utah Press (1980) Reprinted in Amartya Sen, Choice, Welfare and Measurement, Pages 353-369, Oxford: Blackwell (1982)
3. Bickenbach, Jerome E, Assistive Technology and International Classification of Functioning, Disability, and health, (2008), Engineering Handbook for Smart Technology for Ageing, Disability, and Independence.
4. Retief, M. & Letšosa, R., Models of disability, A brief overview, (2018).
5. Enable Ireland and Disability Federation Ireland, Assistive Technology for Persons with Disabilities and Older Persons, (2016).
6. Higher Education Authority Ireland, 2015-2019, National Plan for Equity of Access to Higher Education, (2015; p38).
7. <https://www.cswe.org/getattachment/Centers-Initiatives/Centers/Center-for-Diversity/Educator-Resource/July-2020/1-Using-the-ICF.pdf.aspx>
8. <https://www.nap.edu/read/2009/chapter/4>
9. Leeds-Hurwitz, W, Social Construction of Reality, (2009), In S. Little john, & K. Foss (Eds.), Encyclopaedia of Communication Theory (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>.
10. Meekosha, Helen and Russell Shuttleworth, "What's so 'Critical' about Critical Disability Studies?", 2009, Australian Journal of Human Rights, 15(1); 47-75
11. Nordic Centre for Rehabilitation Technology, Provision of Assistive Technology in Nordic Countries, (2007).
12. Patricia Welch Saleeby, Using the International Classification of Functioning, Disability and Health (ICF) to Improve Understanding of Disability and Functioning, (2007).
13. Robert K Yin, The Case study Research, 6th edition, (2018).
14. Schalk Sami, "Critical Disability Studies as Methodology", (2017) Lateral, 6 (1). doi:10.25158/L6.1.13 [Schalk 2017 available online].
15. Sebastiaan van der Peijl, Filippo Munisteri, Mar Negreiro, Lionel Kapff, Veronika Jermolina, Clare Folkes, Executive Summary of the Final research report on Internal market for Assistive ICT, 2011.
16. Sophie Mitra, Capability Approach and Disability, (2006)
17. Terje, Sund, Assistive Technology in Norway, a part of the larger system, AT delivery system in Norway, (2017)

18. United Nations, , Convention on Rights of Persons with Disabilities, 2006.
19. WHO, International Classification of Functioning, Disability and Health – ICF, (2001)
20. Fairclough, N, Critical Discourse Analysis, (1995).
21. Fairclough, N, Peripheral Vision. Discourse Analysis in Organization Studies: The Case for Critical Realism. Organization Studies, (2005).

The Validation of the Assistive Technology Capability Approach (ATCA) as a Tool for Assessing the Relationship between AT and Wellbeing

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Abstract. The research studies revealed that Assistive technology(AT) contributes to the compensation of the body's functional loss, participation in the different life environments and wellbeing of the AT user (WHO, 2018). The Sen's Capability Approach (CA) recognised the role of wheelchair as an AT product that facilitated access to work and income and attainment of wellbeing. The Capability Approach recognised the need for contextual and environmental AT products and services to address the environmental barriers that limit the Participation of the person with functional difficulties to do what she or he wants (Sen.M, 1980). Sophie Mitra (2006) noted that the Sen's Capability approach emerged as a frame that responded to the philosophical question of how to achieve justice for human being and how to measure the standard of living and quality of life of the Person. The research paper analysed how the hearing and Ear assistive technology (HEAT) products and services contributed to the wellbeing of University College Dublin (UCD) students and other HEAT users. The research study methodology was composed of multiple research methods. The mixed research methods such as qualitative and quantitative research methods were used to collect and analyse data. The case study research method was used to examine the data from Ireland. The data shows that UCD HEAT users felt freedom and were happy to have AT products of their choice. Over 80% of the survey participants confirmed that AT contributed to their wellbeing and participation in the different life environments and enabled them to perform activities.

Keywords: Assistive technology, Capability Approach, Wellbeing.

1 Introduction

Assistive technology contributes to the compensation of the body's functional loss, independent living and participation in the different life environments and wellbeing of the AT user [1,7]. Nordic centre for rehabilitation Technology [11] and Terje Sund [12] research studies observed that AT contributed to wellbeing, performance of activities and participation in education, health, employment, home and independent living and others. Sen's Capability approach recognised the role of wheelchair in facilitating access to work and income. The Capability approach recognised the need for contextual

and environmental assistive technology solutions to address the environmental barriers that limit the Participation of the person with functional difficulties to do what she or he wants. Amartya, Sen [3] and Mitra [2] noted that the Sen's Capability approach emerged as a frame that responded to the philosophical question of how to achieve justice for human being and Welfare economics' question of how to measure the standard of living and quality of life of each of the Person. The contribution of AT selected based on freedom of choice to the wellbeing of the person as justified by Sen's Capability approach was referred to as the AT Capability approach by this research paper.

2 The AT and Wellbeing Contribution

The World Health Organisation's [4] International Classification of Functioning, Disability and Health (ICF) recognised AT as environment barrier but does not measure the impact of AT on wellbeing and participation of the person in the different life environments. Matching Person to Technology provided a framework for matching the AT needs of the Person to the AT products. However the framework not designed to assess the relationship between wellbeing of the person and AT. The Human Activity Assistive Technology (HAAT) model analysed the relationships among the human, activity, context, and assistive technology. The HAAT does not assess the relationship between AT and wellbeing of the Person [5,8].

The AT Impact model 2 assess the impact of AT on the Person but does not recognise the freedom of choice and Human rights principles' guidance in provision of Assistive technology. The freedom of choice and human diversity is one of the principles of article 3 of the United Nations Convention on Rights of Persons with Disabilities. The AT capability-based approach was developed based on the review of the gaps of limited analysis of the relationship between AT and wellbeing identified in the different AT models analysed above. This research paper validated the AT Capability based approach through the analysis of the impact of hearing and Ear assistive technology solutions on the wellbeing of users of Hearing and Ear assistive technology in University College Dublin Ireland and outside Ireland

3 The Methodology

The multiple research methods composed of case study research method and mixed research methods were used to collect empirical data. The qualitative data was collected through key informant interviews with University College Dublin students using hearing and Ear assistive technology solutions, UCD officials in charge of AT related policies and provision of assistive technology, representatives of government officials in charge of AT related policies and provision and representatives of Non-State Actors providing AT services to students in Higher Education Institutions. The survey data was collected from the audiologists, users of hearing and ear assistive technology and organisations of persons with hearing loss or Hard of Hearing in Ireland and around the world. The research study was approved by the University Ethics committee. The data collection was delayed by COVID-19 pandemic between 2020-2021. The research

paper considered AT Public policies and programmes as socially constructed objects and used the Constructivist Ontology to analyse the data. The Critical discourse analysis was also used to analyse the behaviours of the AT service delivery system as they interacted with the UCD students using Hearing and Ear Assistive Technology (HEAT) and environment [10,13-15].

The semi structured interviews and survey questionnaires were used to help the research participants to respond to the research study. Over 50 users of HEAT solutions from 21 countries around the World responded to the survey of the research study [10]. The survey participants were from Ireland, Austria, Australia, Canada, Czech Republic, Denmark, Germany, Georgia, Italy, Nepal, Norway, Philippines, Poland, Lithuania, Rwanda, Serbia, Uganda, United Kingdom, Vietnam, and Zambia. The 17 qualitative interviews including three key informant interviews with users were used to collect empirical data in Ireland. The data collection was delayed by the COVID-19 pandemic. This research paper used the secondary and empirical data collected from Ireland.

4 Results

One of the UCD student using HEAT and acquired livescribe smart pen and paper book and amplified stethoscope from UCD Access and Lifelong learning centre stated that “The recording of some lectures with the Livescribe smart pen and paper book enables me to listen again in a quiet environment and to write and reflect the notes. However it consumes a lot of time. Sitting in a lecture room of 200-300 people, it is difficult to follow the lecturer..”. The empirical data shows that the livescribe smart pen and books and amplified stethoscope facilitated the participation of the student with hearing loss to participate in the UCD learning activities and environment.

The UCD student further stated that “I do not worry anymore about missing lecturer’s notes and discussion in Lecture room. I use the Livescribe pen and paper book to have a record of the discussions and notes in lecture room”. The empirical data confirms that the use of Livescribe pen and paper book as alternative Hearing and Ear Assistive technology (HEAT) solutions contributed to remove of worries and barriers for HEAT users in higher education learning environment. Emotion stability of the person is one of the indicators for wellbeing of the Person.

The findings show that the Users of hearing and Ear assistive technology felt freedom and were happy to have assistive technology products of their choice. Over 80% of the survey participants using HEAT solutions from different countries confirmed that AT contributed to their wellbeing and participation in the different life environments. It enabled them to perform activities. Approximately 10% of the survey participants reported that AT products did not contribute to their wellbeing. The 5% of the survey participants were undecided. This empirical data confirmed that AT as a capability provider for HEAT users and persons in need of AT. AT facilitated equitable participation in the Higher education learning activities for learners with hearing loss using HEAT products and services.

The 85% of the survey participants viewed Hearing and Ear assistive technology solutions as an equal opportunity to achieve their life goals. 15% of the survey

participants were not sure whether HEAT was an equal opportunity for the users. The data further confirmed AT products and services as equalizer for participation and well-being of the HEAT users and persons in need of AT.

The empirical and secondary data shows that HEAT solutions contributes to the wellbeing of the users. The Assistive technology should be considered as one of the indicators for the quality of life and wellbeing of the person with functional difficulties and users. Lack of assistive technology implies low levels of wellbeing and poor quality of life. The selection of AT of choice by a person in need or AT user was another indicator for measuring freedom of choice and wellbeing of the person.

The AT capability approach was therefore the practice and the view of AT as an equal opportunity, selected based on freedom of choice and contributor to the well-being and participation of the AT user in the different life environments.

5 The Recommendations

The Assistive Technology Capability Approach should be used to assess the impact of the Assistive technology on the wellbeing of the person with functional difficulties in the different environments.

AT should be part of the measurement of the standard of living and wellbeing of persons with functional difficulties.

References

1. World Health Organisation (WHO), Factsheet on Assistive Technology, (2018).
2. Sophie Mitra, Capability Approach and Disability, (2006).
3. Amartya, Sen, "Equality of What?" The Tanner Lectures on Human Values, (1980), Ed. S. McMurrin. I. Salt Lake City: University of Utah Press (1980) Reprinted in Amartya Sen, Choice, Welfare and Measurement, Pages 353-369, Oxford: Blackwell (1982)
4. WHO, International Classification of Functioning, Disability and Health – ICF, (2001)
5. Cook, A. M., & Hussey, S. M, Assistive technology: Principles and practices (2nd ed.), (2002; pp. 34-53). St. Louis, MO: Mosby
6. Smith, R. Integrated Multi-Intervention Paradigm for Assessment and Application of Concurrent Treatments (IMPACT2) Model, (2005), Retrieved May 6, 2016, from: <http://www.r2d2.uwm.edu/archive/impact2model.htm>
7. Bickenbach, Jerome E, Assistive Technology and International Classification of Functioning, Disability and health, (2008), Engineering Handbook for Smart Technology for Ageing, Disability and Independence
8. Scherer, Marcia J. and Dicowden, Marie A, 'Organizing future research and intervention efforts on the impact and effects of gender differences on disability and rehabilitation: The usefulness of the International Classification of Functioning, Disability and Health (ICF)', (2007), Disability & Rehabilitation, 30:3, 161 - 165
9. United Nations, Convention on Rights of Persons with Disabilities, (2006).
10. Robert K Yin, The Case study Research, 6th edition, (2018).
11. Nordic Center for Rehabilitation Technology, Provision of Assistive Technology in Nordic Countries, (2007);

12. Terje, Sund, Assistive Technology in Norway, a part of the larger system, AT delivery system in Norway, (2017).
13. Leeds-Hurwitz, W, Social Construction of Reality, (2009), In S. Littlejohn, & K. Foss (Eds.), *Encyclopedia of Communication Theory* (pp. 892-895). Thousand Oaks, CA: Sage Publications. <https://doi.org/10.4135/9781412959384.n344>.
14. Fairclough, N, *Critical Discourse Analysis*, 1995.
15. Fairclough, N, *Peripheral Vision. Discourse Analysis in Organization Studies: The Case for Critical Realism*, (2005), *Organization Studies*, 26, 915-93.

Population Access to Assistive Technology



Population Access to Assistive Technology

Introduction to the Special Thematic Session

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1 Introduction

Assistive technology enables people in need to participate in important areas of life, to express full citizenship, and to participate in community life and in wider society on an equal footing with others [1]. Without assistive technology, people may suffer exclusion, are at risk of isolation and poverty, and may become a burden to their family and on society. There are also socioeconomic benefits to be gained, by virtue of reduced direct health and welfare costs (such as recurrent hospital admissions or state benefits), and by enabling a more productive labour force, indirectly stimulating economic growth [2]. In 2018, a resolution was adopted at the 71st World Health Assembly (WHA71.8) that urged Member States to take concrete actions to improve access to assistive technology. The same resolution requested the WHO to prepare a Global Report on Assistive Technology based on the best available evidence, and make recommendations to the Member States in developing national assistive technology policies and programs to improve access towards universal health and/or social services coverage [3].

Despite the global imperative on improving access to assistive technology, little data has been systematically collected, analyzed, or published to estimate the use, need, met need, and barriers to accessing assistive technology in the population. The development of the WHO-UNICEF Global Report on Assistive Technology published in May 2022 [1] provided an opportunity to fill this gap through a global collaboration in collecting population data in coordinated and standardized method using the WHO rapid Assistive Technology Assessment (rATA) questionnaire [4]. By December 2021, data collection had been completed in 35 countries across the world, with nearly 330000 individuals interviewed in 28 different languages.

1.1 Measuring Population Access to Assistive Technology

The rATA is an interviewer-administered, population-based survey tool that covers self-reported assistive technology use, need and unmet, source, payer, satisfaction with the products and related services, and barriers to access [5]. Source also includes travel

distance to source, and satisfaction also includes suitability of assistive products for different environments and activities.

The findings from the rATA surveys can support stakeholders to (a) obtain evidence on access to assistive technology in the population; (b) advocate and raise awareness of governments as well as of civil society about the importance of assistive technology; (c) advance research and development in assistive technology; and (d) guide the design, planning or prioritizing assistive technology programmes, or interventions that should be made at global and country levels [4].

1.2 Aim of the Special Thematic Session

This Special Thematic Session included contributions from 11 of the rATA surveys conducted between 2019 and 2021 from four continents: Asia (Myanmar, Mongolia, Indonesia), Africa (Sierra Leone, Malawi, Senegal), Europe (Italy, Sweden, United Kingdom), and South America (Costa Rica, Brazil). The presented findings of the rATA survey sparked discussions on how these findings had been and will be used in different countries and contexts to inform stakeholders and the general public about the need for and importance of assistive technology for both individual and community development, as well as to enable governments to monitor the outcomes of the policy interventions of improving access to assistive technology. The session provided a forum of (1) sharing and comparing the rATA survey findings and impacts; (2) exchanging the experiences in the rATA survey processes; and (3) building collaborations in future implementation of rATA surveys.

References

1. Global Report on Assistive Technology. Geneva: World Health Organization; 2022.
2. Tebbutt, E., Brodmann, R., Borg, J., MacLachlan, M., Khasnabis, C., & Horvath, R. (2016). Assistive products and the sustainable development goals (SDGs). *Globalization and health*, 12(1), 79.
3. Improving Access to Assistive Technology. World Health Organization; 2018. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R8-en.pdf (accessed on 22 April 2022).
4. Zhang, W., Eide, A. H., Pryor, W., Khasnabis, C., & Borg, J.. Measuring Self-Reported Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire: Protocol for a Multi-Country Study. *International journal of environmental research and public health* 18(24), 13336 (2021).
5. World Health Organization [WHO]. rapid Assistive Technology Assessment tool (rATA). World Health Organization; 2021. Available from: <https://www.who.int/publications/i/item/WHO-MHP-HPS-ATM-2021.1>

Rapid Assessment of the Need, Demand, Supply, and User Satisfaction with Assistive Technology among People Attending Rehabilitation Services in Sao Paulo, Brazil

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Abstract. Access to assistive technology (AT) in Brazil is intimately related to rehabilitation services. Studies have shown the complexity of access to AT in the country, with people seeking the care they need according to services availability, accessibility, and affordability. However, they used inconsistent approaches to measuring need for and use of AT and presented a lack of relevant information on demand, supply, and user satisfaction. This study aimed at identifying the prevalence of need, access, and use of assistive products (AP), as well as the barriers to access and users' satisfaction with services and products provided to community dwelling people attending rehabilitation services provided by the public healthcare system in São Paulo, Brazil. Results show a large prevalence of need for and use of AP, although the unmet need is still high. Private and public sectors are the most relevant sources of products, with private funds being most frequently used to acquire them, despite a large financial barrier. It stressed the importance of the public healthcare system and many of its positive impacts on users, but also some of its limitations, such as service-related barriers. Users are mostly satisfied with the products and services they receive, although people with greater functioning difficulties report a moderately different situation. Hence, the study demonstrated that some user groups still face many barriers and obtain worst results of the system in place. Results are internationally comparable to other studies using similar methodology and demonstrate the impact generated by the local AT provision system.

Keywords: Need, Demand, Supply, User Satisfaction.

1 Introduction

Brazil is a vast, mostly urban country characterized by large metropolitan regions [1-3]. Located in the country's southeastern region, the state of São Paulo concentrates almost a fourth of the Brazilian population (circa 46 million inhabitants), with the metropolitan region of the state capital accounting for approximately half of that. As such, the city of São Paulo alone was home to an estimated 12.3 million inhabitants in 2020, densely populated (7.3 thousand people/km²), with a HDI of 0.805 and a GDP/capita level of circa USD 10.3 thousand [4]. However, the city is marked by persistently high social and economic inequalities, with a Gini index of 0.539, only slightly lower than the national index (0.545) in 2019 [5].

As with other Latin American and Caribbean settings, local demographics are transitioning towards a rapidly ageing population [6], which also experiences an incomplete epidemiological transition [7]. As much as ageing and non-communicable diseases relate to functional decline and disability, data compiled from 39 national censuses, household surveys and targeted studies in the region show that 70 million people lived with some kind of disability between 2001 and 2013 [8], who could potentially benefit from assistive products AP and related services [9]. As in other parts of the world [10], disability in the region is more prevalent and more severe among women, the elderly, rural populations, indigenous peoples, black persons, and people living in poorer settings [11]. Recent data from the 2019 National Health Survey (NHS) in Brazil reiterate it, showing people with disability still have poorer educational outcomes, are excluded from the job market, and are overrepresented among the lowest income groups [12].

It also shows that 15.8% of those having at least some functioning difficulty had access to rehabilitation services during the 12 months period before the survey interview, and that 51.4% of them (totaling circa 4.3 million people) accessed it through the public healthcare system. These figures are slightly similar for the Brazilian southeastern region and the State of São Paulo specifically, where approximately 18.4% had access to rehabilitation services, 46.6% of which through the public healthcare system [12].

Access to assistive technology (AT) in Brazil is intimately related to rehabilitation services provision. According to the National Health Policy for Persons with Disability and the organizing principles of the Brazilian public healthcare system, AT service delivery is part of the scope of rehabilitation services provision and is considered an integral part of comprehensive rehabilitation treatment, which is targeted at meeting the needs of individuals with disabling health conditions, irrespective of disability status or certification [13]. Since the creation of this system, it has been responsible for covering most of the Brazilian population, who often relies on it as its sole health services provider. Although private health insurance plans exist in Brazil, they covered only 24.5% of the population in January 2021 [14].

In recent years, different studies explored the prevalence of need and use of AP, as well as their sources [12,15,16], but used inconsistent approaches to measuring them and lacked relevant information on demand for and supply of AP, as well as users' satisfaction. They also show varying research designs and variable levels of studies coverage in terms of geography, population, and products.

This study aimed to identify the prevalence of need, access, and use of AP in the target population, as well as the barriers to access and users' satisfaction with services and products provided. Additionally, by selecting a target population of community dwelling people attending rehabilitation services provided by the local public healthcare system, the study aimed at gaining further insight on the strategies people use to meet their needs for AT and producing evidence on strengths and weaknesses of the system in place.

2 Methods

Answering a World Health Organization's call on access to AT around the world [17], this survey used its rapid Assistive Technology Assessment (rATA) questionnaire and an adapted version of its protocol [18] to meet the needs of a subnational study targeting a specific population carried out remotely to accommodate for social distancing measures in place during the COVID-19 pandemic.

2.1 Study Design

A simple stratified probabilistic sample was drawn using 29 local rehabilitation facilities as its strata. Survey participants were identified and enumerated based on the registries of the facilities covered by the study.

Population subgroups defined by functioning domain (vision, hearing, mobility, cognition, self-care, and communication), age (0 to 18 years, 19 to 59 years, and 60 years or older), and gender were considered the main study domains for sampling purposes.

$$n = \frac{p(1-p)}{(d/z)^2}$$

The sample size was initially estimated by the formula presented above, where P is the proportion to be estimated, d is the maximum tolerated sample error, and $z = 1.96$, for a corresponding parametrical curve with a 95% confidence interval. For purposes of this calculation, the proportion that estimates the widest sample size for a fixed sampling error [19], the study chose $p = 0.50$. Also, it adopted $d = 0.10$, the equivalent of a coefficient of variation estimated as 10.2%. With these figures, $n = 96$ (rounded to 100). Considering that this sample size should be obtained for all domains and that the smallest of them represents 10% of the reference population, the final sample was estimated as 1000 participants ($n/0.1 = 1000$).

2.2 Participants

The reference population was all the community dwelling individuals aged six and older who have attended outpatient rehabilitation services provided by the public healthcare system, in the city of São Paulo, from July 2019 to December 2020. This period was selected to accommodate for variations in the flow of patients seeking care

before and during the COVID-19 pandemic, according to feedback received from the São Paulo Municipal Health Secretariat.

A universe of 85,607 people were eligible to be included in the study, according to the records provided by the São Paulo Municipal Health Secretariat. Anticipating numerous losses due to non-response, the initial sample size was adjusted, and 3,000 individuals were drawn. Sampling was proportional to the number of people registered in each of the 29 rehabilitation facilities considered (which ranged from 738 to 8,354, according to the specific services provided in each facility). Out of the initial sample, 2,256 were enumerated. Enumeration happened progressively, to accommodate for the non-response rate observed.

2.3 Consent

To comply with Brazilian regulations on research involving human participants, the study was appraised and approved by Institutional Review Boards of both the University of São Paulo Medical School General Hospital and the São Paulo Municipal Health Secretariat. Study participants' consent was obtained and registered verbally to accommodate for interviews being conducted remotely, over the phone or through teleconferencing. Whenever possible, study participants received an electronic copy of the consent form for their personal records. For participants under 18 or those unable to provide consent, the latter was obtained from their parents or other legally responsible adults.

2.4 Questionnaire

This study used the rATA questionnaire in Portuguese as originally published by WHO [17] after submitting it to a brief cognitive testing using a convenient, non-probabilistic sample ($n=12$) of AP users attending rehabilitation treatment at the Physical and Rehabilitation Medicine Institute of the University of São Paulo Medical School General Hospital (IMREA), who share the same health conditions and cultural background of this study population and were invited to provide their feedback on rATA's questions and answer options in Portuguese, which were deemed satisfactory.

All interviewers had a background on psychology, occupational therapy, or social work, were trained to use the rATA questionnaire, and to conduct remote interviews using an electronic data collection tool. A sign-language interpreter was also available remotely, enabling video-based interviews with participants with hearing impairments who use Brazilian sign language, as needed.

2.5 Data Collection and Management

A protocol was established to complete and register each attempt to reach out and include potential study participants using purpose-specific running sheets. Interviewers attempted at least five times, in different dates and times of the day, to reach everyone enumerated according to the sampling strategy described before. The result of each attempt was recorded and informed the non-response rate of the study.

Interviewers made every effort to meaningfully include people with difficulties communicating or understanding the interview. Whenever needed, proxy interviews were used to include those who could not communicate or understand the questionnaire as used in this study. It was the same for children and adolescents to assent and participate actively in their interviews.

The study used the electronic tool developed by WHO to support rATA data collection (ArcGIS Survey123 Field App), accounting for the additional changes in the survey form required by the study in São Paulo. It used complementary strategies to improve data quality, which included flagging interviews for discussion with the field supervisor and the study coordinating team; checking data registries and audio records to follow up with any issues identified; and, using reinterviews to check for specific, sensitive aspects of the questionnaire.

Interviews were performed between March 24 and June 24, 2021.

2.6 Outcome Measures and Analyses

In addition to the minimum set of survey indicators identified by WHO (need, use, and unmet need for AT in the target population) [17,18] for each of the six functioning domains covered by the survey tool, these were disaggregated by age group and gender whenever the number of cases recorded for each additional domain offered reliable results (though not presented here). For this, data analyses used a specialized statistical software (IBM SPSS Statistics 27), with descriptive statistics being used to present the results in this article. Sampling weights were used to estimate study results for the entire target population, according to Table 1. For many results, actual counting values are presented unweighted for additional information.

Table 1. Sampling weights used

Age	Male	Female
< 17	0.72886	0.78067
18-39	1.16362	1.04255
40-54	0.90407	1.02532
55-64	0.95480	1.04946
65-74	0.98817	1.04469
75 >	1.22983	1.36825

3 Results

Out of the 2,256 individuals enumerated, 926 consented to participate and answered the survey. Others either did not consent (n=386), were successfully identified but were unavailable (n=294), had inadequate contact information on local registries (e.g., wrong number) (n=538), were excluded for referring not meeting the survey criteria (e.g., not attending or having attended rehabilitation services) (n=45), were dead by the time of the interview (n=55), or were excluded for protocol deviations (n=2) or other reasons (e.g., failed contacts) (n=10).

Table 2 shows the main characteristics of the target population in terms of gender and age groups distributions, as well as functioning levels (maximum level of difficulty reported in any domain). The thresholds adopted reflect the reliability of study estimates considering the number of responses obtained for each group.

Table 2. Gender, age groups and functioning levels of the target population

Variable	Group	Est.	Lower C.I.	Upper C.I.	Coefficient of variation	Count
Gender	Male	42.4%	39.3%	45.6%	0.038	417
	Female	57.6%	54.4%	60.7%	0.028	509
Age group	6 to 17 y.o.	15.6%	13.6%	17.8%	0.068	193
	18 to 64 y.o.	51.9%	48.7%	55.0%	0.031	470
	> 65 y.o.	32.6%	29.6%	35.7%	0.048	263
Functioning level	Some or no difficulty	43.4%	40.2%	46.6%	0.038	410
	A lot of difficulty or cannot do at all	56.6%	53.4%	59.8%	0.029	516

Note: Est. = Estimate; C.I. = 95% Confidence Interval

3.1 Core Indicators

Table 3 shows the core indicators for the entire target population. Disaggregated data shows that core indicators are similar across genders, are high for all functioning domains and higher in the eldest group. Despite AT need and the prevalence of AP use being quite high across groups, the latter is slightly lower among people with difficulties communicating, remembering, and caring for themselves. Moreover, the met need is also lower among people with difficulties hearing, communicating, remembering, and caring for themselves.

Table 3. Core indicators: Use, need and met need

Indicator	Estimate	Lower C.I.	Upper C.I.	Coefficient of variation	Count
Use	72.9%	69.9%	75.6%	0.02	657
Need	82.4%	79.9%	84.7%	0.015	749
Met need	48.5%	46.0%	51.0%	-	-

3.2 Most Used and Demanded Products

It is evident that many of the most used AP are also among the most demanded, showing that some, such as spectacles (used by 42.9% [CI 40.0-45.9]; demanded by 41.6% [CI 37.2-46.1]); hearing aids (used by 12.9% [CI 11.1-14.9]; demanded by 21.8% [CI 18.3-25.7]); shower and toilet chairs (used by 7.5% [CI 5.9-9.1]; demanded by 5.9% [CI 4.1-8.4]); and, manual wheelchairs for active users (used by 5.4% [CI 4.2-6.8]; demanded by 5.8% [CI 4.0-8.2]), are among the most relevant products in this setting.

3.3 AP Sources and Payers

Irrespective of the level of importance attributed by users to each product or any other aspect, data shows that, across domains, the most frequent source for AP is the private sector (54.8% [CI 51.9-57.8]), followed by the public sector (31.2% [CI 28.6-34.0]), friends and family members (9.2% [CI 7.6-11.0]), and NGO (3.7% [CI 2.7-5.0]).

The relevance of the private sector is significant for not only being the most frequent, but also because the study target population is of people serviced by the public healthcare system. Major exceptions to this general picture are people with difficulties communicating and caring for themselves, for whom the public sector is a more frequent source than the private sector, and NGO are more relevant.

This study also indicates that users themselves pay out-of-pocket for most of all AP (40.1% [CI 37.2-43.1]). Additionally, users' friends and family members obtain many of the AP privately sourced (25.1% [22.6-27.8]), with insurance companies (0.1% [0.0-0.5]) and other stakeholders being very rare.

The disaggregation of survey responses show that the public sector, NGO, and friends and family members are more frequent sources and payers of AP used by those who have greater functioning difficulties across domains.

Data on the distance travelled by AP users demonstrate most people in the target population get their AP close to home (52.7% [CI 49.5-55.9] in less than 5km).

3.4 Satisfaction with AP and Related Services

AP users are mostly satisfied with the products, training and follow up and maintenance services they received. For all three different fields, more than 75% of AP users are at least a little satisfied with the products and services received. Nevertheless, according to disaggregated data, satisfaction levels are slightly lower, and dissatisfaction levels higher, among those with greater functioning difficulties, especially with reference to training and follow up services.

Users' reports on the suitability and usability of their AP are largely positive across functioning domains and for people with different levels of functioning difficulties, showing people can use their AP to meet their needs, although those with greater functioning difficulties report a moderately different situation with respect to usability and environmental barriers. The latter still prevent users from making the most of their AP in some cases, which is especially true for people with difficulties moving around, communicating, and caring for themselves, as well as among people with greater functioning difficulties across domains.

3.5 Barriers to Access

Table 4 clearly shows that the major barrier to AP access among the study target population is being able to pay for them. A qualitative analysis of the large number of "other" answers shows that service-related barriers (such as getting an appointment or prescription, as well as service disruptions due to the COVID-19 pandemic) follow

financial barriers closely behind and are largely associated with services provided by the public healthcare system.

Table 4. Barriers to AP access identified by the target population

Barrier	Estimate	Lower C.I.	Upper C.I.	Coefficient of variation	Count
Cannot pay	42.2%	37.7%	46.8%	0.055	197
Other	31.0%	26.9%	35.5%	0.07	143
Lack of support	8.9%	6.6%	11.9%	0.15	43
Unavailability	7.3%	5.2%	10.1%	0.167	34
Inadequacy	4.6%	3.0%	7.0%	0.211	22
Lack of time	4.2%	2.7%	6.4%	0.218	20
Lack of transportation	1.2%	0.5%	2.8%	0.452	5
Stigma / Shyness	0.7%	0.2%	2.1%	0.572	3
Total	100.0%	100.0%	100.0%	-	467

4 Discussion

In 2019, 52.7 million, or 28.5% of the Brazilian population referred having at least some difficulty to see, hear, use their upper and lower limbs, or cope with intellectual and mental impairments when performing activities of daily living [12]. It is understandable that this study identified a higher need for AT, once these are people attending or having recently attended rehabilitation services, hence possibly benefiting from AP temporarily or permanently.

As with other studies, this found that AP use is associated with older age and greater functioning difficulties [20]. Our results on AP use also corroborate previous findings showing that a third to a fourth of people living with some functioning difficulties in the city of São Paulo did not use AP [16]. Interestingly, whilst the prevalence of both AT need and AP use is higher among people with greater functioning difficulties, their met need is lower, showing this group still have needs that haven't been met by the system, services, and products available.

The 2019 Brazilian NHS also showed that while many people used AP (e.g. 40.4% used vision aids, 1.7% used mobility aids, and 0.8% used hearing aids in the general population), only 5.7% of those were sourced from the public healthcare system. Nevertheless, it is largely due to the high prevalence of spectacles use (and other visual aids), which are often (95.5%) privately acquired. On the other hand, the public healthcare system provided for 16.6% of the users with impaired lower limbs functions; 25.3% of those with impaired upper limbs functions; and 44.7% of those with impaired hearing functions [12].

Like others [21,22], our own study showed that the limited use of and demand for AP outside the domains of mobility, hearing and vision might imply the lack of users' awareness of the AP that might benefit people with communication and cognition difficulties.

Furthermore, the short distances travelled by AP users might be answerable by individuals being referred to rehabilitation facilities that are closer to their homes, a general

operating principle of the local healthcare system. The availability of private providers could also be accountable to the city of São Paulo being a well-resourced setting, where suppliers and professionals are concentrated [23]. On the other hand, disaggregated information demonstrates that people living with greater functioning difficulties travel longer distances than others, probably showing a limited number of providers capable of meeting the needs of users with complex health conditions or functioning status.

AT affordability and availability are barriers in other settings [22], but this study's specific design identified many service-related barriers, which could be a target of interventions designed to improve AP access through the local public healthcare system and be incorporated into rATA answer options to clearly identify them in other settings.

5 Conclusion

Using the rATA tool and survey methodology proved itself a successful strategy to identify the prevalence of need, access, and use of AP in the target population, as well as the barriers to access and users' satisfaction with products and services provided. With the upcoming results of similar studies, comparing rATA results will open avenues to better and sounder comparative analyses of assistive technology systems worldwide, and inform monitoring and evaluation at all levels.

With respect to its specific setting, this study shed light on the relevance of the private sector in providing AP, despite the significant financial barrier many AP users still face, what often results in users depending on the support of family members and friends when they cannot afford to pay for them directly. It stressed the importance of the public healthcare system and many of its positive impacts on users, but also some of its limitations, such as service-related barriers. Other actors, such as NGO and insurance companies, have only a marginal participation in the AT sector in this setting.

Importantly, the study showed the positive results obtained by the services and products currently available, which meet many of the needs and satisfaction criteria of users themselves. Nevertheless, it also demonstrated that many AP user groups still face a number of barriers and obtain worst results of the system in place, such as people with greater functioning difficulties across domains and those with difficulties communicating and caring for themselves.

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References

1. População do Brasil [Internet]. Instituto Brasileiro de Geografia e Estatística, IBGE. 2020. Available from: <<https://www.who.int/publications/i/item/978-92-4-000504-4>>. Accessed on Oct 03, 2020.
2. World Bank Open Data [Internet]. The World Bank. The World Bank Group, 2019. Available from: <<https://data.worldbank.org/>>. Accessed on Oct 03, 2020.
3. Instituto Brasileiro de Geografia e Estatística. Sinopse do Censo Demográfico 2010. Rio de Janeiro, IBGE, 2011. Available from: <<https://biblioteca.ibge.gov.br/visualizacao/livros/liv49230.pdf>>. Accessed on Oct 03, 2020.
4. São Paulo [Internet]. Cidades e Estados. Instituto Brasileiro de Geografia e Estatística, IBGE, 2020. Available from: <<https://www.ibge.gov.br/cidades-e-estados/sp/sao-paulo.html>>. Accessed on Oct 03, 2020.
5. São Paulo [Internet]. Síntese de Indicadores Sociais. Instituto Brasileiro de Geografia e Estatística, IBGE, 2020. Available from: <<https://cidades.ibge.gov.br/brasil/sp/pesquisa/45/62585>>. Accessed on Oct 03, 2020.
6. Economic Commission for Latin America and the Caribbean. Tendencias recientes de la población de América Latina y el Caribe. UN: Santiago de Chile, 2019. Available from: <https://www.cepal.org/sites/default/files/static/files/dia_mundial_de_la_poblacion_2019.pdf>. Accessed on Oct 03, 2020.
7. Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2017 (GBD 2017) Results. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2018. Available from: <<http://ghdx.healthdata.org/gbd-results-tool>>. Accessed on Oct 03, 2020.
8. Economic Commission for Latin America and the Caribbean. Informe Regional sobre la Medición de la Discapacidad. Grupo de Tareas sobre Medición de la Discapacidad. Conferencia Estadística de las Américas (CEA), 2014. Available from: <https://repositorio.cepal.org/bitstream/handle/11362/36906/S1420251_es.pdf>. Accessed on Oct 03, 2020.
9. Assistive Technology [Internet] World Health Organization, WHO, 2018. Available from: <<https://www.who.int/news-room/fact-sheets/detail/assistive-technology>>. Accessed on Apr 28, 2022
10. World Health Organization. World Report on Disability. Geneva, WHO: 2011. Available from: <<https://apps.who.int/iris/rest/bitstreams/53067/retrieve>>. Accessed on Oct 03, 2020.
11. Economic Commission for Latin America and the Caribbean. Panorama Social de América Latina 2012. UN: Santiago de Chile, 2012. Available from: <http://repositorio.cepal.org/bitstream/handle/11362/1246/1/S2012895_pt.pdf>. Accessed on Oct 03, 2020.
12. Instituto Brasileiro de Geografia e Estatística. Pesquisa Nacional de Saúde 2019: Ciclos de vida. Rio de Janeiro, IBGE, 2021. Available from: <<https://biblioteca.ibge.gov.br/visualizacao/livros/liv101846.pdf>>. Accessed on Nov 25, 2021.
13. Ministério da Saúde. Portaria 1060/2002, Política Nacional de Saúde da Pessoa com Deficiência. Brasília, 2002. Available from: <http://bvsms.saude.gov.br/bvs/saudelegis/gm/2002/prt1060_05_06_2002.html>. Accessed on Oct 03, 2020.
14. Dados Gerais [Internet] Agência Nacional de Saúde, ANS, 2021. Available from: <<https://www.ans.gov.br/perfil-do-setor/dados-gerais>>. Accessed on Nov 25, 2021.
15. Pesquisa Nacional de Saúde 2013 [Internet] Inquéritos e pesquisas. Ministério da Saúde, 2021. Available from: <<https://datasus.saude.gov.br/pns-pesquisa-nacional-de-saude-2013>>. Accessed on Nov 25, 2021.

16. Secretaria Municipal da Saúde de São Paulo. Deficiência na cidade de São Paulo. Série “Boletim ISA Capital 2015”. Coordenação de Epidemiologia e Informação, CEInfo. Boletim Nº 16. Janeiro 2018. Available from: <http://www.prefeitura.sp.gov.br/cidade/secretarias/upload/saude/arquivos/publicacoes/ISA_2015_PcD.pdf>. Accessed on Oct 03, 2020.
17. Global call for measuring access to assistive technology using the WHO rapid Assistive Technology Assessment (rATA) [Internet] World Health Organization. WHO, 2020. Available from: <[https://www.who.int/news-room/articles-detail/global-call-for-measuring-access-to-assistive-technology-using-the-who-rapid-assistive-technology-assessment-\(rata\)](https://www.who.int/news-room/articles-detail/global-call-for-measuring-access-to-assistive-technology-using-the-who-rapid-assistive-technology-assessment-(rata))>. Accessed on Apr 28, 2022.
18. Zhang, W.; Eide, A.H.; Pryor, W.; Khasnabis, C.; Borg, J. Measuring Self-Reported Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire: Protocol for a Multi-Country Study. *Int. J. Environ. Res. Public Health* 2021, 18, 13336. <https://doi.org/10.3390/ijerph182413336>
19. Silva, N N da. Amostragem probabilística: um curso introdutório. São Paulo: EDUSP, 2004.
20. Pryor W, Nguyen L, Islam QN, Jalal FA, Marella M. Unmet Needs and Use of Assistive Products in Two Districts of Bangladesh: Findings from a Household Survey. *Int J Environ Res Public Health*. 2018;15(12):2901. Published 2018 Dec 18. doi:10.3390/ijerph15122901
21. Baseline Survey in Pakistan. Rapid Assistive Technology Assessment (rATA) [Internet] Health Services Academy, Ministry of National Health Services, Regulations and Coordination, World Health Organization. 2021. Available from: <<https://www.nhsrca.gov.pk/SiteImage/Downloads/Base%20Line%20Survey%20in%20Pakistan.pdf>>. Accessed on Apr 29, 2022.
22. Austin V, Holloway C, Ossul Vermehren I, Dumbuya A, Barbareschi G, Walker J. “Give Us the Chance to Be Part of You, We Want Our Voices to Be Heard”: Assistive Technology as a Mediator of Participation in (Formal and Informal) Citizenship Activities for Persons with Disabilities Who Are Slum Dwellers in Freetown, Sierra Leone. *International Journal of Environmental Research and Public Health* [Internet]. 2021 May 22;18(11):5547. Available from: <http://dx.doi.org/10.3390/ijerph18115547>
23. Battistella LR, Juca SSH, Tateishi M, Oshiro MS, Yamanaka EI et al. Lucy Montoro Rehabilitation Network mobile unit: an alternative public healthcare policy. *Disabil Rehabil Assist Technol*. 2015 Jul;10(4):309-15. doi: 10.3109/17483107.2015.1027294

Measuring Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire in the United Kingdom

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Abstract. This study presents the findings from the WHO UK rapid Assistive Technology Assessment (rATA) questionnaire completed in 2021; using the digital rATA questionnaire with a total of 259 questionnaires completed. 62.9% of respondents used assistive products and the top three selected assistive products were spectacles, hearing aids and grab-bars handrails. 18.5% of respondents had an unmet need for assistive products. Most assistive products were sourced from the private sector. The majority were paid out-of-pocket and approximately one fifth were supplied through government sources. For adults most assistive products were paid out-of-pocket, while for children most were paid for by the government. Most respondents were very satisfied with their assistive products, AT services and with repair, maintenance, and follow-up. ‘Cannot afford’ and ‘Lack of support’ were the most frequently identified barriers to accessing assistive products and many reported that the Covid-19 pandemic was a significant barrier to access. The collected data provides useful information on the use of assistive products in the UK. The collected data dispels the myth that assistive products are only for people with a disability. A large-scale questionnaire at national level would be of significant benefit in raising population awareness in the UK.

Keywords: Assistive technology, Barriers to access; Prevalence of need, United Kingdom.

1 Introduction

According to the Organisation for Economic Co-operation and Development (OECD) report (2016) [1], health systems in the United Kingdom have, for many years, made the quality of care a highly visible priority, internationally pioneering many tools and policies to assure and improve quality of care. Despite being a global leader in quality monitoring and improvement, the United Kingdom does not consistently demonstrate strong performance on international benchmarks of quality. To secure continued quality

gains, the UK health systems will need to publish more quality disaggregated outcomes data and establish a forum where the key officials and clinical leaders from the systems responsible for quality care can meet to learn from each other's innovations [1].

There is currently no central report on the whole UK AT ecosystem. There is a selection of separate reports based on the interests of separate government ministries. There are issues around the correct use of the term AT and the sub-groups within the sector. Issues around quantifying AT need can be seen when you consider specific AT users. Regarding orthotic users, accurate data on the number of users in the UK are not available from the NHS. A report by the Foundation for Assistive Technology stated that there were approximately 1.2 million orthotic users in England in 2007 [2] while a report in 2011 estimated the number of users at 2 million [3].

This paper presents the findings from the WHO UK rapid Assistive Technology Assessment (rATA) questionnaire completed during 2020-2021. This questionnaire is part of the global-scale data collection contributing to the WHO-UNICEF Global Report on Assistive Technology due for publication in 2022. This is the first WHO rATA questionnaire that has been conducted in the United Kingdom.

2 Methods

This was a standalone questionnaire to understand the social and demographic statistics of individuals who need access to some form of assistive technology (available from: <https://www.who.int/publications/i/item/WHO-MHP-HPS-ATM-2021.1>). The tele-rATA was conducted using the digital rATA questionnaire. The study received ethical approval from the Institutional Ethics Committee at Staffordshire University (HEALY_SU-20_076-RN). Our sample size was 1644 individuals or 685 households. The initial target population was a sub-national population-based questionnaire of the general population in the UK midlands region, as it is widely accepted that the midlands region in England is a representative sample of the country [4,5]. During data collection, due to low participation rates, this was widened to all UK residents. A convenience sampling method was employed.

Participants were recruited through advertisements on Staffordshire University's website, social media, local news organisations, direct electronic communication with employees of large organisations along with a healthcare route via Facebook. Participants were directed to view the online information sheet and complete the consent form and pre-questionnaire online via Microsoft Forms, following this, they were called by the enumerators to complete the questionnaire.

Responses were collected using the ArcGIS Survey123® application. Six trained enumerators completed data collection. Most of the conducted calls were by telephone with video calls made available to participants via zoom. The video calls had the option of the addition of subtitles using the Otter.ai software to facilitate access to the deaf, hearing impaired and those requiring access accommodations. Data collection was conducted from 19th March to 3rd June 2021. One-way and two-way chi-squared tests were used for data analysis. Also, descriptive analysis was used to analyse the data.

3 Results

A total of 259 questionnaires were completed, with 192 adults completing the questionnaire themselves, one 15–18-year-old completing the questionnaire with consent from their parent, five completed proxy questionnaires for adults unable to provide consent and sixty-one completed proxy questionnaires for children. There were 161 individual households among the respondents, with an average household size of 2.7 and fifty-six (35%) households with child members.

Of the 259 completed questionnaires, there were 151 (58%) female respondents and 108 (42%) male respondents. Most respondents were adults aged 18–64 years (165; 64%), followed by children (62; 24%) and adults 65+ years (32; 12%). In the pre-questionnaire, via Microsoft Form, the adult respondents (n=197) were asked if they considered themselves to have a disability with forty-six (23%) selecting ‘yes’.

A map displaying the distribution of the respondents by postcode is provided in Fig. 1. In the pre-questionnaire, respondents were asked whether they lived in a city/town/village/the country; with those who selected city or town designated as living in an urban area and those who selected a village/ the country designated as living in a rural area. Most respondents lived in an urban area (62%).

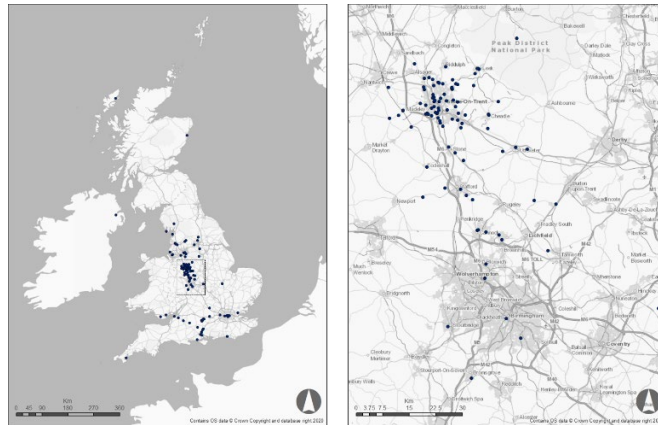


Fig. 1. Geographical distribution of questionnaire respondents.

3.1 Functional Difficulties

Regarding functional difficulties most respondents selected that they had no difficulty (78.4 – 95.1%) with their mobility, hearing, communication, cognition, and self-care; 39.8% of respondents selected having “no difficulty” and 42.9% selecting “some difficulty” with their sight. No functional difficulties were reported for the children <5 years old and higher percentages of functional difficulties were evident for adults.

3.2 Products in Use and Demand

Assistive products were used by 163 (62.9%) respondents and 48 (18.5%) had an unmet need for assistive products. Similar responses for use of assistive products were evident across genders and geography. There was a higher use of assistive products for adults (73.3% for 18-64 years; 87.5% for 65+ years) compared to children (22.6%).

A complete list of the assistive products the respondents selected using is provided in Table 1, with a total of 388 products selected. The top three selected products were Spectacles; Low-Vision, Short/Long Distance/Filters Etc, Hearing Aids (Digital) And Batteries and Grab-Bars Hand Rails. Significantly more people ($p \leq 0.05$) used Seeing AT while significantly less people used Mobility, Hearing, Communication, Cognition and Self-care AT. The top three “Other” assistive products selected were contact lenses (selected by 10 respondents), computer software - speech-to-text (5) and electric can opener and stair lift (3 each).

Comparing across demographics, significantly more ($p \leq 0.05$) adults (18-64 and 65+ years) used mobility, seeing and self-care products than children and significantly more adults 65+ years used hearing AT than children and adults 18-64 years. Significantly more females used Mobility AT than males and more people living in a rural area used Mobility AT than those living in an urban area. Significantly more people with a low household income (<18k) used self-care AT.

As regards to gender, 21.2% of females and 14.8% of males had an unmet assistive product need. Similar responses for the need for assistive products were evident across geography (19.4% urban and 17.2% rural). Adults 65+ years had a greater unmet need (37.5%) than adults 18-64 years (19.4%) and children (6.5%).

3.3 Source of Products and Funding, and Travel Distance

A list of sources for the assistive products is provided in Table 2; the majority of products (73.9%) were sourced from the private sector followed by the public sector (16.5%). Similar responses for the source of assistive products were evident across genders and geography (urban/rural). While the private sector was the lead source for assistive products across all age groups, more children sourced their assistive products from the public sector than adults.

A list of payers for the assistive products is provided in Table 3; the majority of assistive products (57%) were “Paid out-of-pocket (self)”, followed by “Government” (22%). Similar responses for payers of assistive products were evident across genders and geography (urban/rural). For adults most assistive products were “Paid out-of-pocket (self)”, while for children most were paid for by “Government”. For the top three “most important” AT products, significantly more people ($p \leq 0.05$) paid for the products “out of pocket”.

Of the respondents, 117 (72% of respondents who currently use assistive products) identified that they had paid for assistive products in the last 12 months; the average spend was £340 \pm £423 and it ranged from £10 to £3000. The average spend was higher for children (£623 \pm £676 from 9 respondents) than for adults (£314 \pm £415 from 90 18–64-year-old respondents; £326 \pm £242 from 18 65+ year old respondents).

Most respondents (66%) travelled “Less than 5km” to assess their three most important assistive products, this was followed by travelled “6-25km” (27%). More respondents who lived in an urban area reported that they travelled “Less than 5km” to assess their three most important assistive products (73.3% - 89.7%) than those respondents living in a rural area (42.2% - 68.2%).

Table 1. List of used assistive products.

Assistive product	Count	Assistive product	Count
Spectacles; Low-Vision, Short/Long Distance/Filters Etc	148	Wheelchairs, Electrically Powered	4
Hearing Aids (Digital) And Batteries	24	Keyboard And Mouse Emulation Software	3
Grab-Bars Hand Rails	20	Orthoses (Upper Limb)	3
Orthoses (Lower Limb)	19	Recorders	3
Canes/Sticks, Tripod And Quadripod	16	Rollators	3
Smart Phones/Tablets/PDA	15	Standing Frames, Adjustable	3
Chairs For Shower/Bath/Toilet	11	Walking Frames/Walkers	3
Pressure Relief Cushions	10	Alarm Signalers With Light/Sound/Vibration	2
Manual Wheelchairs - Basic Type For Active Users	8	Global Positioning System (GPS)	2
Communication Software	7	Manual Wheelchairs - Push Type	2
Pill Organizers	7	Personal Emergency Alarm Systems	2
Time Management Products	7	Wheelchairs, Manual With Postural Support	2
Incontinence Products, Absorbent	6	Braille Displays (Note Takers)	1
Ramps, Portable	6	Braille Writing Equipment/Braillers	1
Therapeutic Footwear (Diabetic, Neuropathic, Orthopedic)	6	Communication Boards/Books/Cards	1
Closed Captioning Displays	5	Fall Detectors	1
Screen Readers	5	Magnifiers, Optical	1
Smart Phones/Tablets/PDA	5	Orthoses (Spinal)	1
Axillary Elbow Crutches	4	Pressure Relief Mattresses	1
Hearing Loops/FM Systems	4	Prostheses (Lower Limb)	1
Smart Phones/Tablets/PDA	4	Prostheses (Upper Limb)*	1
Smart Phones/Tablets/PDA	4	Travel Aids, Portable	1
Tricycles	4	Video Communication Devices	1

Table 2. List of sources for assistive products.

Sources	Count	%
Public sector: Government facility, public hospital	53	16.5%
NGO sector: Non-profit facility	7	2.2%
Private sector: private facility/hospital/clinic/shop/store	235	73.9%
Friends/family	7	2.5%
Self-made	2	0.6%
Other	19	3.7%
Don't know	2	0.6%

Table 3. List of payers for assistive products.

Payer	Count	%
Government	79	22%
NGO/Charity	6	2%
Employer/School	27	7%
Insurance	1	0%
Paid out-of-pocket (self)	208	57%
Family / friends	25	7%
Other	12	3%
Don't know	4	1%

3.4 Barrier to Access

An unmet need for assistive products was identified by 48 respondents (18.5%) and they reported a range of barriers to access. “Cannot afford” (n=22) and “Lack of support” (n=12) were the most frequently identified barriers to accessing assistive products, with significantly more people ($p \leq 0.05$) reporting “cannot afford” as a barrier to their unmet need. Many of the respondents identified the Covid-19 pandemic as a significant barrier to access (n=12). Responses were similar across gender and geography (urban/rural). “Lack of support” was the most identified barrier for children while “Cannot afford” was the most identified barrier for adults.

3.5 Satisfaction, Suitability, Usability, and Environmental Barriers

Most respondents were “very satisfied” with their assistive products; with dissatisfaction (respondents who selected “dissatisfied” or “very dissatisfied”) for the three most important assistive products ranging from 1-8%. The most frequently identified reasons for assistive product dissatisfaction were fit/size/shape (n=6), followed by replacement needed (n=4) and durability (n=3). Most respondents were “very satisfied” with their AT services; with dissatisfaction for the three most important assistive products ranging from 3-6%. The most frequently identified reasons for dissatisfaction with services was “Quality of care” (n=6), followed by “Waiting time” (n=3). Most respondents were “very satisfied” with repair, maintenance, and follow-up for their assistive products; with dissatisfaction for the three most important assistive products ranging from 5-10%.

When asked about the extent to which the respondents’ assistive products were suitable for their home and surroundings most stated that they were “completely” suitable (66 - 77%). When asked about the extent to which the respondents’ assistive products

helped them to do what they want most stated that their assistive product “mostly” or “completely” helped them to do what they wanted. When asked about environmental barriers to using assistive products most stated that they could “completely” use their assistive products as much as they wanted in the places, they need to visit.

3.6 Respondent Recommendations

The main area that respondents identified as needing improvement was in the ‘provision’ of assistive products, with 42% (n=85) of respondents citing elements of product supply and service provision as areas of concern. Cost (26%; n=23), policy (26%; n=26) and awareness (27%; n=23) were the next areas most identified for improvement. Topics around stigma were the least mentioned at 2%.

4 Discussion

As far the authors know, this is one of the first times that a rATA or a Tele-rATA has been implemented around the world, particularly in a high-income country. We initially planned that the questionnaire would be completed by enumerators in-person but due to the COVID-19 pandemic we implemented the tele-rATA.

Although we achieved a modest number of responses (n=259) in comparison to our stated sample size, the collected data does provide useful information on the use of assistive products in the UK and additionally highlights some of the practical challenges of collecting representative household data via telephone questionnaires and in particular around assistive technology. The collected information provided data to dispel the myth that assistive products are only for people with a disability; while 77% of adult respondents didn’t identify as being disabled 70% of these respondents currently used assistive products and 15% had an unmet assistive product need.

Due to the study design, people using assistive technology were more willing to respond than non-users. Some respondents, who had told enumerators at the start of a call what assistive products they currently use, when describing their functional difficulties in Section C: Need, then went on to initially respond ‘no’ to the question, ‘d.1 Do you currently use any assistive product(s)?’. It was common for respondents to feel embarrassed by this error, however it illustrates the lack of awareness of the term ‘assistive products’ among the general population. In Section f.1 Recommendations, 27% of respondents to this question identified issues concerning awareness as a way to improve access to assistive products. People for example, do not identify spectacles as being an assistive product. We also believe this lack of public awareness contributed to the poor questionnaire participation rate.

It was recorded that one of the most significant barriers to assistive products were around the high price of products, with respondents stating that they ‘cannot afford’ the products they need and citing ‘cost’ issues as a route to improve access to assistive products. The most significant theme in Section F: Recommendations concerned issues around ‘provision’ with 42% of respondents identifying improvements in the supply structure for quality products and allied services, which included concerns around

awareness of where to find and who to contact to find information on appropriate products or funding.

It was found that good access and satisfaction levels were seen for spectacles for children, but there are cost barriers for adults with almost all provision private and at a high cost. While it was identified that the three most important assistive products for child respondents were mostly paid for by “Government”, when respondents were asked about their own spend on assistive products in the last 12 months, the average spend for children was higher than for adults. Eight of the nine responses for children who reported spending on assistive products in the last 12 months reported that the government paid for their three most important assistive products. This suggests that their assistive product needs are not fully met by the government.

In Section F: Recommendations low satisfaction and access to mobility and hearing products were recorded, with a common complaint around hearing aids and wheelchairs that products from the government provision were of low quality and frequently provided low levels of user satisfaction. Respondents also said that the only alternatives available to National Health Service provision were from private companies at a very high cost. Some recommendations were for government vouchers to which they could ‘top-up’ personally to help afford privately supplied high-quality products and services which also avoid long government waiting times. A number of respondents reflected that they had no recommendations to make as they felt that the system worked well and were fortunate to have access to the assistive products.

5 Conclusion

While this questionnaire received a limited response, the collected data provides a valuable insight into the use of assistive products in the UK. Results highlighted high levels of satisfaction with assistive products, assistive technology services and with repair, maintenance, and follow-up among users. As most assistive products were paid out-of-pocket, this means they are not accessible to everyone. 18.5% of respondents had an unmet need for assistive products, and “Cannot afford” was one of the most frequently identified barriers to accessing assistive products. During interviews, it became clear that we were raising awareness of the breadth of products and services that fall under the umbrella term of ‘assistive technology’ according to the WHO definition and that a large-scale questionnaire at national level would be of significant benefit in raising population awareness in the UK.

References

1. OECD Reviews of Health Care Quality: United Kingdom 2016 Raising Standard, <https://www.oecd.org/unitedkingdom/oecd-reviews-of-health-care-quality-united-kingdom-2016-9789264239487-en.htm>, last accessed 2022/04/26.
2. Down, K. and Stead, E.: Assistive technology workforce development. Foundation for Assistive Technology (2006).

3. Global Data: Orthotics and Prosthetics - Global Pipeline Analysis, Competitive Landscape and Market Forecasts to 2017 (2017).
4. University of Essex, Institute for Social and Economic Research: Understanding Society: Waves 1-10, 2009-2019 and Harmonised BHPS: Waves 1-18, 1991-2009: Special Licence Access, Census Area Statistics Wards. [data collection]. 13th Edition. UK Data Service. SN: 6669 (2020).
5. Office for National Statistics: Families and households in the UK: 2019. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2019>, last accessed 2022/04/26.

Access to Assistive Technology: Preliminary Results from the Implementation of the rATA Survey in Italy

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Abstract. The present contribution reports on the preliminary results from the implementation of the rapid Assistive Technology Assessment (rATA) con in Italy. The target population of the survey included residents in Italy aged 0+. The interviews have been conducted through the two mixed interview techniques: CATI (Computer Assisted Telephone Interviewing), and CAWI (Computer Assisted Web Interviewing). In total, 10170 individual responses (52,2% females; 47,8% males) were collected in the period June-September 2021. Prevalence of AT use resulted 58% of the total sample. Only 6,9% of the total population reported an unmet AT need. No differences were observed for what concerns the use of AT according to gender or living conditions (i.e., rural vs. urban). The majority of AT users resulted at least satisfied with their products (83,6%), less so with assessment and training (58,3%) and maintenance (37,8%) services. On the ground of the present results, actions will be undertaken in Italy to promote a continuous collection of data on AT access and quality to ensure that AT systems across the country are capable of maintaining high standards of AT provision over time.

Keywords: Assistive Technology Access, Provision, Procurement, Quality, Rights

1 Introduction

Assistive technology (AT) products, from spectacles to social robots, enable people to live healthy, productive, independent, and dignified lives by facilitating their participation in education, the labor market and civic life [1]. Given the benefits brought about AT for the individual and society, access to AT has been recognized as a fundamental

human right by the Convention on the Rights of Persons with Disabilities (CRPD). Yet only 10% of the people in need of an AT product have access to it [2].

To date, no data have been systematically collected on a global scale about access to AT products. The reason for such lack of data may include the high variability of AT provision practices across systems and countries, which in turn may have prevented the development of tools that could be used to collect comparable information about AT access in different contexts. To overcome this challenge and allow direct comparisons between AT systems across countries and populations, GATE has developed the rapid Assistive Technology Assessment (rATA) questionnaire [3].

On February 2021, a consortium of Italian governmental and non-governmental institutions has partnered with WHO to conduct a nation-wide survey using the rATA with a view to provide governmental authorities (e.g., Ministry of Health) as well as non-governmental organizations (e.g., AT users associations) with a specific tool to collect baseline data and continuously monitor AT access at national as well as regional level.

1.1 The Italian Context

Italy has a population of about 60 million inhabitants, and it is the third-largest national economy in the European Union. The country has a tax-funded universal national health service (Servizio Sanitario Nazionale, SSN) that guarantees the universal provision of comprehensive care throughout the country. Responsibility for the organization and delivery of services, including AT provision, is attributed to its 20 regional authorities. The provision of AT and prostheses is regulated by the ‘Nomenclatore Tariffario’: a law of the Italian state (DPCM 12/01/2017) establishing essential level for assistance (LEA) within the SSN. Roughly described, the decree includes a list of Assistive products (organized by category, code) that can be financed by the SSN. Health professionals in force of the SSN may take advantage of the expertise of independent professionals working in specialized Centres for AT belonging to the GLIC network. These Centres constitute a point of reference for SSN professionals, other stakeholders (e.g. families; school teachers) and for people with disabilities. They offer a variety of AT-related services, in collaboration with professionals from the relative local health authority, social services and, in the case of children, the school system. The Centres for AT are managed at a local and regional level, with the objective of helping the users and the professionals to identify the most suitable AT. Usually, Centres for AT belong to a more complex network of public services, and are part of the rehabilitation, education, and assistance pathways which are addressed to the person with disabilities and which provide the involvement of different, but mutually integrated, professional profiles. Despite the maturity of the AT service delivery system in Italy, no data have been systematically collected on the need and unmet need for AT in the Italian population, as well as on the overall perceived quality of the associated services.

2 Method

2.1 Participants

The target population of the survey included residents in Italy aged 0+. The stratification of the sample (see below) allowed to obtain information on the inhabitants of the 4 subnational areas (North-East, North-west, Center and South) and of different living contexts (urban and rural, small and large cities). People with functional limitations or disabilities were randomly intercepted based on their different prevalence in the population.

2.2 Survey Method

The rATA has been implemented as a stand-alone questionnaire [4]. Before its administration, the rATA has been adapted and translated into Italian [5]. The interviews have been conducted through the two mixed interview techniques: CATI (Computer Assisted Telephone Interviewing), and CAWI (Computer Assisted Web Interviewing). The use of mixed techniques made it possible to limit critical issues by maximizing the potential advantages of each technique. The choice to introduce the CAWI technique in population surveys is based on the need to contain the costs of the survey, but also and above all to exploit the potential offered by technology to intercept segments of the population that are increasingly elusive compared to traditional techniques (telephone interviews), and thus improve the coverage capacity of surveys, while increasing response rates. The combination with the CATI-CAWI technique allows to obtain the responses of those who might have a low propensity to use new technologies, or find themselves unable to fill out an online questionnaire or prefer to carry out the interview with the support of a surveyor. A 2-day training course was organized to train CATI enumerators.

2.3 Sampling Strategy

The sample design has been stratified with numbers proportional to the reference universe, with respect to the variables deemed most suitable for the selection of the sample. In fact, simple random sampling (each unit has the same probability of being included in the sample) is rarely used in sample surveys because it does not use the information known a priori on the population and on the distributive characteristics of the variables. Furthermore, the extraction of the units is completely entrusted to chance, and this can lead to organizational difficulties related to the achievement of the units to be surveyed. If the structure of the universe is such as to allow the identification of homogeneous areas (clusters) with respect to the variables to be detected, it is possible to determine more efficient estimates than those obtainable with a simple random sample through the stratified sample, i.e., the sample obtained from the union of those extracted from the single cluster. The strata into which the universe is divided are determined by the combination of the variables under study (or, in the case of a single variable, by the modalities it assumes): for instance, for a sample of individuals, structural

characteristics can be considered as distinctive variables. Random samples are extracted from individual clusters with autonomous methodologies. The stratification variables that have been considered for the purpose of the current survey are: (a) the geographic area and the demographic size of the municipality of residence of the interviewees, which identifies the geographical coordinates within which the interviewee is located; (b) the gender, which can have an influence in determining opinions and behaviors relating to the issues discussed, and (c) the age, which may have an influence in determining opinions and behaviors relating to the topics covered.

2.4 Sample Size Estimation

The sample size assumed is 10,000 people and ensures, at a 95% confidence level, a sampling error of 1.0%. Furthermore, the stratification carried out guarantees more efficient estimates than simple random sampling of the same number. The sample size is based on global estimates of disability prevalence (i.e. 15%) as reported in the WHO World Report on Disability [6]. The confidence level and the sampling error indicated refers to the estimate of the key indicator represented by the people in need of AT, while the sampling error related to the access rate among the Italian population to the AT is 2,5% at a 95% confidence level.

3 Results

The analyses of the Italian dataset are currently ongoing. For this reason, in the present contribution we report only on the analysis published in the Global Health Observatory developed for the scope of the Global report on Assistive Technology (GReAT) [7]. In total, 10170 individual responses (52,2% females; 47,8% males) were collected in the period June-September 2021. Prevalence of AT use resulted 58% of the total sample (Fig. 1). As shown in Fig. 1, high levels of met needs were reported (51,7%) against an overall need of 58,6%. In other words, only 6,9% of the total population reported an unmet AT need.

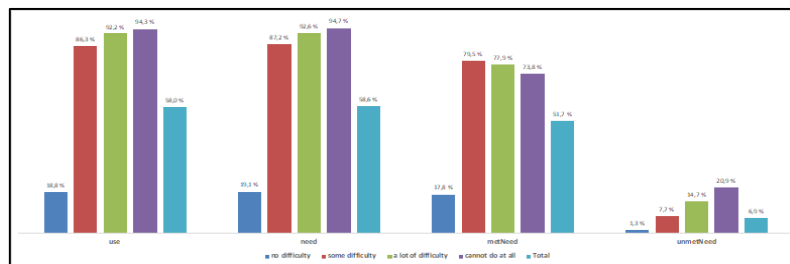


Fig. 1. Prevalence of use, need, met need, and unmet need for assistive products by function limitation with spectacles.

Notably, when excluding the users of spectacles alone from the dataset, the proportion of unmet needs decreases to 4,1%. Visual inspection of the data collected revealed no

noticeable differences for what concerns the use of AT according to gender or living conditions (i.e., rural vs. urban). At a further inspection of the data, the distribution of AT users across the different geographic areas resulted well balanced, without noticeable differences across regions. The three most commonly reported AT products in use included spectacles (44,4%), pill organizers (3,8%), and magnifiers (3,2%). The vast majority of products in use (82%) were purchased out-of-pocket, likely for the high number of products for vision (i.e. spectacles) included. Indeed, when excluding the spectacles from the dataset, the proportion of AT purchased out-of-pocket decreases to 56%.

The majority of AT users resulted at least satisfied with their products (83,6%), less so with assessment and training (58,3%) and maintenance (37,8%) services. Products resulted however overall suitable in different living environments (range of satisfied users 81,3%-78,5%).

4 Conclusions

The steady increase in the number and proportion of older adults in the Italian population, combined with direct and indirect effects of the current pandemic situation on the health and social care systems, are expected to widen the challenges faced by people in need of an AT product. For this reason, strengthening access to AT for disabled persons and those who are frail can be considered a national priority to prevent social inequalities and improve the quality of life of the Italian population. On the ground of the present results, actions will be undertaken to promote a continuous collection of data on AT access and quality to ensure that AT systems across the country are capable of maintaining high standards of AT provision over time.

References

1. Tebbutt, E., Brodmann, R., Borg, J., MacLachlan, M., Khasnabis, C., & Horvath, R. (2016). Assistive products and the sustainable development goals (SDGs). *Globalization and health*, 12(1), 79.
2. Improving Access to Assistive Technology. World Health Organization; 2018. Available from: https://apps.who.int/gb/ebwha/pdf_files/WHA71/A71_R8-en.pdf (accessed on 22 April 2022).
3. Zhang, W., Eide, A. H., Pryor, W., Khasnabis, C., & Borg, J.. Measuring Self-Reported Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire: Protocol for a Multi-Country Study. (2021) *International journal of environmental research and public health* 18(24), 13336.
4. World Health Organization [WHO]. rapid Assistive Technology Assessment tool (rATA). World Health Organization; 2021. Available from: <https://www.who.int/publications/i/item/WHO-MHP-HPS-ATM-2021.1>
5. Desideri, L., Magni, R., Zhang, W., Guerreschi, M., Bitelli, C., et al. (2022). Adapting the World Health Organization rapid Assistive Technology Assessment (rATA) to the Italian context: implementation of a TRAPD-based approach, *Ann Ist Super Sanità*, 58(2): 118-123. <https://doi.org/10.4415/ANN220207>

6. WHO/World Bank (2011). World Report on Disability. Available from:
<https://www.who.int/publications/i/item/9789241564182>
7. Global Report on Assistive Technology. Geneva: World Health Organization; 2022.

Assistive Technology Needs, Use and Experiences among Adults in Sweden Based on a Representative Survey

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Abstract. The objective of the study was to estimate the prevalence of needs for and use of assistive products, and experiences of assistive technology among adults under COVID-19 pandemic circumstances in Sweden. Mainly during June 2021, a nationally representative telephone survey was conducted to collect data through an adapted version of the WHO rapid Assistive Technology Assessment (rATA) questionnaire. Including spectacles, the prevalence of needing at least one assistive product was 68.9% and the prevalence of using at least one assistive product was 68.1%. Excluding spectacles, these prevalence rates were 17.1% and 15.8%, respectively. The access rate was 89.7% including spectacles and 83.2% excluding spectacles. The impact of the pandemic on assistive technology provision appeared to be relatively small.

Keywords: Assistive Technology, COVID-19, Prevalence of Need, Prevalence of Use, Sweden, User Experience.

1 Introduction

In response to the World Health Assembly Resolution 71.8 on improving access to assistive technology [1], the World Health Organization (WHO) has developed the Global Report on Assistive Technology (GReAT) [2] in partnership with UNICEF. GReAT is informed by surveys on current needs for and use of assistive technology undertaken in countries located in each of the six WHO regions of the world. Being one of these surveys, the objective of the Swedish Assistive Technology Survey (SATS) was to estimate the prevalence of needs for and use of assistive products, and experiences of assistive technology, in the population in Sweden aged 18 years and older under pandemic circumstances.

2 Methods

2.1 Study Design

SATS was a representative cross-sectional national telephone survey among the adult population in Sweden. With few exceptions related to the age group of the population, the sample size, the data collection method and the questionnaire, SATS followed the protocol reported in [3].

2.2 Sample and Sampling

The general population in Sweden aged 18 years and older constituted the study population. The sampling frame was a compiled list of all telephone numbers from all operators in Sweden that matched individuals in the concerned age group in the public register of the Swedish Tax Agency.

Calculation of the required sample size was based on an estimation formula for household surveys recommended by UN Department of Social Affairs [4], which is simplified in Formula 1 below:

$$n = (z^2)(r)(1-r)(f)(k) / (p)(e^2) \quad (1)$$

where n is the sample size, z is the statistic that defines the level of confidence desired, r is the prevalence of access to any assistive product in the target population, f is the sample design effect, k is a multiplier that accounts for non-response, p is the proportion of the total population accounted for by the target population, and e is the margin of error to be attained. With $r=4\%$ (assumed prevalence of access), $z=1.96$ (95% confidence that r is between 3% and 5%), $f=1$ (no sample design effect with simple random sampling), $k=1$ (respondents are recruited until the full sample size is achieved), $p=1$ (the target population is the same as the total population), and $e=0.25r$ (with a level of precision at 25%, the margin of error is 1%), the minimum sample size $n=1476$, which was rounded up to 1,500. The prevalence of access (r) was higher in this study than in the protocol [3], which is justified by a relatively high prevalence of use of assistive products in Sweden (for example, in the population 16 years and older, 5.1% used hearing aids and 68.7% used spectacles or contact lenses in 2016 [5]).

The sample was drawn from records comprised of the adult (18 years and above) population matched with a phone number and complemented with extra sampling for under-represented age groups. Two measures were taken to secure representative data: i) quota setup on age and gender; and ii) weighing data on age, gender and NUTS 2 region.

2.3 Data Collection Instrument

The data collection instrument used in SATS included most of the items of the standardized individual-level questionnaire *rapid Assistive Technology Assessment* tool (rATA) developed by WHO [6]. It covers the respondents' characteristics, functioning, and use of, needs for and satisfaction with assistive products and related services, as

well as sources of, costs for and traveling to get assistive products. In addition, the questionnaire collected data on the use of assistive products and related services under pandemic circumstances.

Given that rATA is designed for face-to-face interviewing under non-pandemic conditions, rATA was first adapted to facilitate telephone interviewing. This was followed by the addition of four questions related to the pandemic. The adaptation of the rATA survey for the purpose of SATS was carried out in close collaboration with WHO and SINTEF, Norway.

The SATS questionnaire was translated into Swedish in consultation with six assistive technology experts to ensure correct terminology. The translated questionnaire was then reviewed by two academic researchers and two additional experts on assistive technology. Following a revision to accommodate the feedback of the reviewers, the questionnaire was tested among eight assistive technology users (35-85 years old; 5 women and 3 men) before finalization.

2.4 Data Collection and Analyses

Data were collected between 8 June and 2 July 2021 through computer-assisted telephone interviewing by experienced interviewers at a data collection agency in Sweden. The median interview time was 4:48 minutes.

Using descriptive statistics, weighted data were analyzed according to the protocol reported in [3] with the addition of descriptive statistical analyses of data related to the pandemic. Definitions of key indicators are given below [2].

Prevalence of use. The proportion of a population using assistive products

Prevalence of need. The sum of the prevalence of met need and the prevalence of unmet need, where:

- Prevalence of met need: the proportion of a population using assistive products that do not need new or additional assistive products
- Prevalence of unmet need: the proportion of a population that need new or additional assistive products regardless of whether they are already using assistive products

Access. The ratio of prevalence of met need to prevalence of need.

As spectacles constitute a large proportion of the needed and used assistive products, summarized data are provided with and without spectacles.

2.5 Ethics

The study was approved by the Swedish Ethical Review Authority (Dnr 2021-01453). Only eligible individuals that consented to participation were included. The data collection agency delivered pseudonymized data, which were anonymized after three months.

3 Results

Characteristics of the study participants are given in Table 1.

Table 1. Characteristics of the participants (unweighted).

Characteristic	
Gender (n)	
Female	751
Male	746
Other/No response	3
Age (years)	
Mean	49.5 (SD: 18.9)
Range	18-98
At least some difficulty with... (%)	
Mobility	10.8
Seeing	64.5
Hearing	9.8
Communication	1.9
Remembering	12.5
Self-care	3.2

Data on prevalence of need, access and prevalence of use including and excluding spectacles are summarized in Table 2.

Table 2. Prevalence of need, access and prevalence of use (weighted).

Indicator	Including spectacles	Excluding spectacles
Prevalence of need: ≥ 1 assistive product	68.9%	17.1%
Access	89.7%	83.2%
Prevalence of use: ≥ 1 assistive product	68.1%	15.8%
Prevalence of use: ≥ 2 assistive product	13.2%	3.9%
Prevalence of use: ≥ 3 assistive product	3.3%	1.3%

Proportionally more women than men used assistive products including spectacles (74.1% vs. 61.9%) and excluding spectacles (18.3% vs. 13.1%), as well as expressed a need for assistive products including spectacles (74.6% vs. 63.2%) and excluding spectacles (20.0% vs. 13.9%). Proportionally less women than men reported access to assistive products, both including spectacles (88.7% vs. 90.7%) and excluding spectacles (80.0% vs. 86.5%).

Among 57 specified types of assistive products, the highest prevalence rates of use were found for spectacles (64.6%), hearing aids (5.4%), pill organizers (4.4%),

continence pads (1.7%), self-propelled manual wheelchairs (1.3%), crutches (1.2%), canes (1.1%) and rollators (1.1%).

A large majority of the users were quite or very satisfied with their main assistive product (87.4%), found it mostly or completely suitable for their home and surroundings (95.4%) and in public spaces (94.4%), reported that it mostly or completely helped them to do what they wanted (74.2%), and were satisfied with related assessment and training (91.5%), and repair, maintenance and follow-up (87.7%).

The two commonest sources of a respondent's most important assistive product were the private health sector (83.3%) and public assistive technology sector (13.9%). Most of the users had paid for their most important assistive product out-of-pocket (84.2%); other payers included the public (7.4%) and employers (6.9%).

Among respondents using or needing assistive products, 10.4% needed a new or to replace an assistive product. Reasons for these unmet needs included lack of motivation (18.9%), time (14.2%) and affordability (8.5%), and pandemic circumstances or delays (7.5%).

Compared to before the pandemic, a large majority (85.7%) used their assistive products equally much during the pandemic. Among those that used their assistive products less (5.0%), common reasons were: choosing to stay at home (25.0%), studying or working from home (17.5%), and doing other activities than before (12.2%). And among those that used their assistive products more (7.7%), the most frequent reasons were the same, i.e.: studying or working from home (23.6%), doing other activities than before (11.8%), and choosing to stay at home (11.1%). Other reasons for changes in the use of assistive products were deteriorating health, keeping distance and others.

During the pandemic, 13.1% of those using or needing assistive products had got or were supposed to get at least one assistive product, and 9.9% of them thought that the assistive product was delayed because of the pandemic. Similarly, 8.8% of those using or needing assistive products had got or were supposed to get their assistive product serviced or repaired, and 15.9% of them thought that the service or repair had been delayed because of the pandemic.

4 Discussion

Including spectacles, the prevalence of need for assistive products in Sweden was 68.9%, the access was 89.7%, and the prevalence of use was 68.1%. Excluding spectacles, the corresponding rates were 17.1%, 83.2% and 15.8%, respectively. These rates were among the highest in the WHO multi-country survey, which was completed in 2021 [2]. A larger proportion of women than men reported needing and using assistive products while a larger proportion of men had access to assistive products, which calls for further investigation.

The prevalence of use of spectacles and hearing aids are similar to the rates obtained in a survey in 2016 using a larger sample of the population in Sweden aged 16 years or older ($n=5,778$), which found that 68.7% (margin of error $\pm 1.1\%$) used spectacles or contact lenses, and 5.1% ($\pm 0.5\%$) used hearing aids [5].

Compared to other countries in the WHO survey, the users in Sweden scored among the highest regarding satisfaction with their assistive products and related services, as well as being able to use their assistive products in different settings [5].

In Sweden, most people pay for their spectacles themselves, which partly explains why most people pay out-of-pocket for their assistive products. However, a majority of the other types of assistive products are provided free of cost, while others require a nominal fee [7]. The latter may have been considered by some respondents to be out-of-pocket payment when it in fact was mainly paid for by the public. Reasons for unmet need often relate to personal issues rather than affordability.

Less than 15% of the users changed their use of assistive products during the COVID-19 pandemic. The reasons for changes were largely the same irrespective of whether their use increased or decreased. Less than 1.5% of those using or needing assistive products attributed delay in delivery of products or services to the pandemic. Thus, the impact of the COVID-19 pandemic on assistive technology provision in Sweden was relatively low at group level. This finding contrasts with studies during the pandemic using non-representative samples, which reported that access barriers to assistive products and services, such as training and repair, were exacerbated worldwide due to disruption of supply chains, social distancing requirements, and strains placed on health care, education and other economic and social systems [8-10].

References

1. Resolution WHA 71.8. Improving access to assistive technology. In: Seventy-first World Health Assembly, Geneva, 21-26 May 2018. Resolutions, decisions, and annexes (WHA71/2018/REC/1). World Health Organization, Geneva (2018).
2. Global report on assistive technology. World Health Organization, Geneva (2022).
3. Zhang, W., Eide, A.H., Pryor, W., Khasnabis, C., Borg, J.: Measuring self-reported access to assistive technology using the WHO rapid Assistive Technology Assessment (rATA) questionnaire: protocol for a multi-country study. *International Journal of Environmental Research and Public Health* 18, 13336 (2021). <https://doi.org/10.3390/ijerph182413336>
4. Designing household survey samples: Practical guidelines. Studies in methods, Series F No. 98. Statistics Division, Department of Economic and Social Affairs, United Nations (UNDESA), New York (2005).
5. SCB Statistical Database. Disability by indicator, study domain and sex. www.statistikdatabasen.scb.se, last accessed 2022/04/05.
6. rapid Assistive Technology Assessment tool (rATA). <https://www.who.int/publications/i/item/WHO-MHP-HPS-ATM-2021.1>, last accessed 2022/04/05.
7. Uppdrag statistik på hjälpmedelsområdet. Socialstyrelsen, Stockholm (2021). <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2021-12-7696.pdf>, last accessed 2022/05/06.
8. Smith, E.M., Hernandez, M.L., Ebuonyi, I., Syurina, E.V., Barbareschi, G., Best, K.L., et al.: Assistive technology use and provision during COVID-19: results from a rapid global survey. *International Journal of Health Policy and Management* (2020). https://www.ijhpm.com/article_3954.html, last accessed 2022/04/09.

9. Layton, N., Mont, D., Puli, L., Calvo, I., Shae, K., Tebbutt, E., et al.: Access to assistive technology during the COVID-19 global pandemic: voices of users and families. *International Journal of Environmental Research and Public Health* 18(21), 11273 (2021).
10. Puli, L., Layton, N., Mont, D., Shae, K., Calvo, I., Hill, K.D., et al.: Assistive technology provider experiences during the COVID-19 pandemic. *International Journal of Environmental Research and Public Health* 19, 10477 (2021).

Access to Assistive Technology in Urban Low-Income Communities in Sierra Leone and Indonesia

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Abstract. There is limited data on the prevalence of disability and need for Assistive Technology (AT) in low-income urban communities in the global South. Given the close association between disability and poverty, and that fact that in many contexts AT users need to pay to secure assistive products, it can be anticipated that residents of such settlements are likely to face particular challenges in accessing AT. This underlines the need for data to inform policy development to extend access to life-changing AT to this population. In order to address this knowledge gap, 4,256 individuals in five urban low-income communities in Sierra Leone and Indonesia were surveyed using the Rapid Assistive Technology Assessment (rATA) tool. Given the specific circumstances of our research population, we also adapted the rATA tool to introduce the category of ‘informal sector’ as an AT provider in the rATA questionnaire. This paper presents our findings on patterns of AT need and access amongst the surveyed population, demonstrating a high level of unmet need, and also highlights the importance of distinguishing the informal sector as a key provider of AT to settlements of the urban poor.

Keywords: Assistive Technology, Informality, Low-income communities, Disability

1 Introduction

The WHO defines Assistive Technology (AT) as “the umbrella term covering the systems and services related to the delivery of assistive products and services” [1] and assistive products (AP) as “any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.” [2] Examples of AP are hearing aids, wheelchairs, communication aids, spectacles, prostheses, pill organizers and memory aids. It is estimated that by 2050, two billion people would benefit from AT, yet 90% will not have access [3]. Addressing the large and growing unmet need for AT is central to meeting obligations under the UN Convention on the Rights of Persons with Disabilities (UNCPRD) and in ensuring no one is left behind in achieving the Sustainable Development Goals (SDGs). Given the close association between

disability and poverty [4], it is not surprising that the data available suggests that inadequate access to AT is a particular problem in low resource settings [5] [6]. However, data on AT access and use in low resource contexts in the global South is limited in its scope and coverage, and more research is needed to inform policy interventions to extend access to AT in such settings. Furthermore, given the particular circumstances of many low income AT users in the global South, we argue that data collection tools such as the Rapid Assistive Technology Assessment (rATA) would benefit from being adapted to ensure that the ‘informal sector’ (broadly comprising unregulated providers of AT) is defined as a distinct provider of AT where surveys are conducted in low resource settings. Accordingly, this paper presents both the adaptations we made to the rATA tool to reveal the informal sector as a provider of AT, and the resulting findings of a series rATA surveys. These surveys were undertaken in September 2019 in five low-income communities, three in Freetown, Sierra Leone and two in Banjarmasin, Indonesia, during which a total of 4,256 individuals were surveyed. The surveys were undertaken for the research project “AT2030 Community led solutions”, led by The Bartlett Development Planning Unit, University College London (DPU-UCL) and funded through the wider Global Disability Innovation Hub (GDI Hub) AT2030 Programme. The findings presented in this paper, based on a larger report published earlier this year [7], contribute to addressing the current gap in quantitative data on disability prevalence and access to AT in low-income settlements in the global south, and particularly the role of the informal sector as a provider of AT.

1.1 Informal AT Providers

A substantial literature exists on the *informal economy* and its definition remains a subject of much debate [8] [9]. However, “The prevailing definition accepted across disciplinary and ideological boundaries is that the informal economy refers to income generating activities that operate outside the regulatory framework of the state” [10]. AT providers in the informal economy can imply both problems and opportunities for efforts to ensure access to appropriate AT at scale. On the one hand, defining the informal economy in terms of *lack of regulation* is important when we consider informal enterprises as a source of AT, as it implies (in addition to other forms of regulation around tax, or intellectual property) limited regulatory intervention to ensure the *adequacy and safety of AT for users*. This is a particular concern as inadequate AT can be associated with increased morbidity and mortality for users [11]. On the other hand, informal providers of AT are often more accessible to people on low incomes, providing more affordable products and services. Furthermore, AT enterprises developed by persons with disabilities/ AT users themselves are often positively associated with AT innovation, and may be evaluated more positively by users than formally provided AT – but such enterprise often remain informal due to barriers to formal registration for small, user-led enterprises [12]. The ambiguous value of informal providers for AT users therefore presents a key policy research gap – i.e. the need to better understand “how can the benefits of informal AT providers in providing broader and less expensive access to otherwise unserved populations be promoted whilst protecting AT users from unsafe products and services?” [13] To support such policy research there is a need for more

data on the role of informal enterprises in AT provision and its merits and weaknesses vis a vis other providers.

2 Scope and Methodology

2.1 rATA Survey

Surveys about health or disability rarely include questions about APs, or do not provide enough information to inform decision-making. The rATA aims to address that gap by providing a simple tool to determine answers to the most basic yet important questions about AT [14]. The survey is composed of five parts [15]. The first collects demographic information about the individual and is followed by three core data collection sections: need for AT, demand and supply, and satisfaction. There is a final optional section on recommendations. The survey includes a poster produced by the WHO Global Cooperation on Assistive Technology (GATE) programme, with images of 26 assistive products. The AP depicted relate to the areas of hearing, mobility, seeing, remembering or concentrating, self-caring, and speaking or communicating.

It is important to note that the rATA survey draws on respondents' self-reported perceptions of AT need, and their experiences of AT access and use. This is unlike other population survey tools for AT that are based on clinical assessment. The advantages of a self-reported survey like rATA are that it is quick and low cost, uses consistent and comparable survey elements, and involves AT users' own perspectives and experiences. However, research suggests that self-reported surveys often fail to correspond well to clinical assessments, featuring significant elements of both under- and over-reporting of the need for AT [16]. Despite this caveat, in the absence of clinical assessments of AT need in the two cities, the rATA has an important contribution to make in highlighting locally perceived patterns of AT need and access.

The rATA survey implemented by DPU-UCL is an adaptation of the original WHO survey. Specific changes related to the focus of this paper on informal AT providers were made after piloting the survey in a low-income community in Indonesia, and receiving feedback from data collectors in both countries. These included:

1. *Informal providers*: This survey has added a question on informal providers of AT, based on initial field observations that low-income urban residents in the two cities surveyed access many of their devices from the informal market. Data collectors defined 'informal providers' as second-hand shops, street markets and street hawkers
2. *Evaluation of specific ATs*: This survey has changed the skip logic of the rATA tool to link qualitative evaluations (e.g. users' satisfaction with AP or associated services) to specific AP where respondents use multiple APs. In relation to the theme of this paper this allowed us to compare, for example, user satisfaction with AT from informal sources with AT from formal providers.
3. *AT payment*: The payment for AP question has been rephrased, to focus on what the AT user knows, instead of the sources of funding ("Did you have to

pay for your AP?” instead of “Who paid for your AP?”). Again this was important in relation to our focus on informal providers, as difference in costs between formal and informal providers was revealed to be a key concern for users in our wider qualitative research for the AT2030 project.

Following the rATA survey, further investigation into the role of informal markets as AT providers were explored through qualitative research as detailed in two parallel reports [17].

2.2 Case Studies

The rATA survey was conducted in five low-income urban settlements. The sites were identified by local partners (The Sierra Leone Urban Research Centre (SLURC) and the Federation of the Urban and Rural Poor (FEDURP) in Sierra Leone, and the NGOs Kota Kita and Kaki Kota in Indonesia) as they work with the communities addressing poverty, low-income housing and public spaces, and citizen’s participation among others. In the absence of sound local socio-economic data, that the settlements were identified as low-income communities by partners, and are current targets of interventions for the urban poor by the partners and local government, were taken as a proxy for low-income.

Four of the sites (Dworzark and Thompson Bay in Freetown, and Kelayan Barat and Pelambuan in Banjarmasin) were selected on the basis that they are ‘mainstream’ settlements of urban poor. This means that these settlements have no specific disability-related features, such as disability organizations or facilities, and do not have an unusually high concentration of persons with disabilities as residents. The intention was therefore to understand the need for and access to AT in average settlements occupied largely by low-income people, but without specific provisions for, or visibility of, people with disability.

The fifth community selected, a land occupation by the disabled persons organization (DPO) Help Empower Polio People (HEPPO), in contrast, is an urban low-income community of primarily wheelchair users and people with mobility impairments resulting from polio in Freetown.

It is important to note that the findings do not claim to be representative of each city or country, but in the absence of national data on AT, the findings act as a sample survey which gives insights into patterns of AT access and use in low-income urban communities in the two countries.

2.3 Data Collection

The data was collected and stored using KoBoToolbox¹, a suite of tools for data collection and analysis for use on a smart phone, especially within challenging environments. The aim was to survey 1,000 individuals within a defined area of the settlement using a population survey approach, hence everyone in a specific area. In Dworzark

¹ <https://www.kobotoolbox.org/>

and Thompson Bay (Sierra Leone) 2,076 individuals were surveyed and in Pelambuan and Kelayan (Indonesia), 2,046 were surveyed. In HEPPPO everyone from the community (134 individuals) were surveyed over six days in January 2020 (see Table 1).

The raw data was analysed by AT2030 team members from the NGO Leonard Cheshire and the statistical report was written by DPU-UCL and Leonard Cheshire, with feedback from WHO. Ethical approval for the study was granted by UCL. Consent from participants was sought after a three-minute information video which was shown to everyone on a phone (including subtitles). Each video was prepared considering the cultural differences of each country in terms of language and image type. A sign language interpreter was present in case of respondents that needed this service. Children and young people under age 17 were only interviewed with a carer present, and if not, they were not interviewed. Responses for children between 0-9 years were given by a proxy adult. People with disability who needed a carer to help them communicate were interviewed directly, with a carer present.

Table 1. Sites and population surveyed in Banjarmasin, Indonesia and Freetown, Sierra Leone

Country	Low-income communities	Criteria of selection	Total number of residents	Ain to survey	Total number surveyed	Response rate from individuals approached
Banjarmasin, Indonesia	Kelayan Barat	Mainstream settlement of the urban poor	6,763	1,000	1,020	94%
	Pelambuan	Mainstream settlement of the urban poor	12,854	1,000	1,026	94%
Freetown, Sierra Leone	Thompson Bay	Mainstream settlement of the urban poor	N/A	1,000	1,005	84%
	Dworzark	Mainstream settlement of the urban poor	16,500	1,000	1,071	84%
	Help Empower Polio Persons Organization (HEPPO)	Community of primarily wheelchair users and people with mobility impairments	134	134	134	100%
Total surveyed					4,256	

3 Findings

The findings in the four mainstream communities showed a high self-reported disability prevalence (using the “some difficulty” or above cut-off): 20.6% in Thompson Bay and Dworzark, Sierra Leone; and 30.9% in Kelayan Barat and Pelambuan, Indonesia. Severe disability prevalence (“a lot of difficulty” or above) was 4.3% to 7.0%, respectively. The most common impairments were related to mobility and seeing/vision. The

least common impairments were speaking or communicating, and remembering or concentrating, however their prevalence rose significantly in older people.

More than half of the older population had a disability (62.5% in Thompson Bay and Dworzark, Sierra Leone and 69.4% in Kelayan Barat and Pelambuan, Indonesia) among whom most were severely disabled, indicating that the environment² plays an important role in disability prevalence in these communities. Females tended to have slightly higher disability prevalence than males (21.6% vs 19.5% in Thompson Bay and Dworzark, Sierra Leone; 34.9% vs 27.1% in Kelayan Barat and Pelambuan, Indonesia), had less AP coverage, and more self-reported AP need.

AP coverage was low among the population in need (14.9% in Thompson Bay and Dworzark, Sierra Leone and 47.4% in Kelayan Barat and Pelambuan, Indonesia), and the variety of devices found was extremely limited (see Table 2), with most being spectacles (81.0% in Thompson Bay and Dworzark, Sierra Leone and 93.8% in Kelayan Barat and Pelambuan, Indonesia). Self-caring devices were a priority in all the case studies, and more than half of the respondents that had a difficulty in self-caring said that they did not have the AP they needed (52.9% Thompson Bay and Dworzark, Sierra Leone; 46.7% Kelayan and Pelambuan, Indonesia). Seeing/vision devices were a priority in Thompson Bay and Dworzark, Sierra Leone (56.6%), and speaking or communicating devices (41.9%) were a priority in Kelayan Barat and Pelambuan, Indonesia.

Table 2. Total APs found in the general population in the three case studies

Assistive Product	Domain	Thompson Bay and Dworzark, Sierra Leone	Kelayan Barat and Pelambuan, Indonesia	HEPPO, Sierra Leone
Spectacles	Seeing/vision	52	289	0
Auxiliary/elbow crutches	Mobility	3	0	8
Manual wheelchair (basic type)	Mobility	1	2	0
Manual wheelchair (push type)	Mobility	2	1	13
Rollators and walking frame	Mobility	1	0	6
White cane	Seeing/vision	0	2	0
Tricycle	Mobility	0	0	6
Therapeutic Footwear	Mobility	1	2	0
Orthosis	Mobility	0	2	0

² Acquired vs hereditary health condition.

In relation to the focus of this paper, most AT users got their AP from the informal sector³ (30.8% in Thompson Bay and Dworzark, Sierra Leone; 65.3% Kelayan and Pelambuan, Indonesia) (see Figure 1 and Figure 2). The majority of APs accessed through informal providers were spectacles. One caveat to this finding is that the separation of different AT providers in the rATA survey may oversimplify the complex reality of AT provision and overstate the distinction between AT sources. For example, our wider research into informal AT markets indicated that there is often significant cooperation between AT sources - for example, in both countries, ‘formal’ AT providers, including local government bodies and hospitals, acquired some of the APs that they provide to users from informal sources (secondhand markets in Freetown and informal enterprises in Banjarmasin).

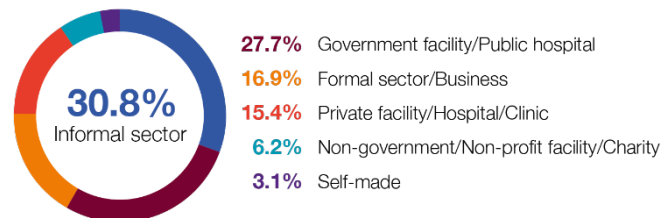


Fig. 1. Sources of AP owned by respondents in Thompson Bay and Dworzark, Sierra Leone.

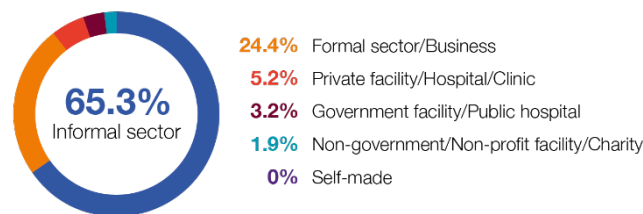


Fig. 2. Sources of AP owned by respondents in Kelayan Barat and Pelambuan.

One explanation for the informal sector being the predominant source of AT in all the settlements surveyed may be the fact that the survey also showed that most AT users had to pay for their AP, and when interviewees were asked why they did not have the AP they need, affordability was the most frequent reason given in all the settlements. This could explain a preference for informal AR providers given that our linked research into informal markets for AT showed that AT from informal providers (particularly second hand goods markets in Freetown and small unregistered providers in Banjarmasin) tend to be significantly cheaper than formal hospital and commercially supplied AT.

³ Data collectors interpreted ‘informal providers’ as shops or enterprises that are not legally registered as AT providers, including local markets and unregistered shops, tradespeople such as mechanics and carpenters, and, in Sierra Leone, the large second-hand goods markets.

However, it is not necessarily always the case that users source AT from the informal sector due to lower costs. Another issue that we were able to highlight in the rATA survey was that the difference in satisfaction with APs and with AP services from formal sources (private formal businesses and government and private hospitals) versus from informal sector providers was very small in both countries, and in some cases informal providers scored more highly. For example in the Lickert scale of 1-5 in the rATA survey focused on ‘Satisfaction with AP by provider type’, respondents in Kelayan Barat and Pelambuan scored Formal Sector Business highly (3.81) but Informal Sector (3.65) scored higher than Private Hospital/ Facility (3.31) or Government Hospital/ Facility (3.30). This throws into question the assumption that the unregulated nature of informal providers necessarily implies lower quality AT.

The rATA findings in HEPPPO, the community organized by wheelchair users, showed that there was extremely high prevalence of severely disabled adults with a mobility impairment (29.9%). There was, however, also very high AP coverage (71.4%) among the population in need. The sources of the APs are different to the ones in the mainstream communities, as most come from non-governmental organizations (45.4%), though despite this almost half had to pay for them (42.9%). A smaller proportion sourced them from the informal sector (16.1%) and these all had to pay (100%). The difference can be explained by the type of APs – mostly wheelchairs and tricycles – and not spectacles as the other case studies. The high visibility that HEPPPO has in the city and their organisation could explain their capacity to access more specialised devices than the mainstream communities as they are frequently targeted by NGO interventions. However, the fact that they have been sourced from NGOs, and not the informal sector, does not guarantee higher satisfaction. Satisfaction with current devices was relatively low (68.6% reported that the device was “moderately” suitable for their environment and 87.1% that it was “moderately” helpful for everyday activities). Self-reported need for AP was extremely high (73.5%). This means that although many people have an assistive device, they reported needing others and/or an improved version of what they have. Most respondents said that they do not have the AP they need because of lack of affordability (91.7%)

4 Conclusion

The paper engages with two main arguments. Firstly, it states the importance of addressing the gap in quantitative data on disability prevalence and the access to AT in urban low-income communities. By conducting the rATA survey in five low-income communities, the study contributes with new data on the access to AT in a population that is under-researched, but it is in pressing need of AT. Secondly, it highlights the importance of acknowledging the informal sector as a key provider of AT to users on very low incomes. Based on our previous research which contributed with new evidence on the role of the informal sector in providing AT in Sierra Leone and Indonesia, the rATA survey was adapted to include the informal sector as a provider of AT. The findings in the five low-income communities showed that most AT users sourced their products from the informal sector, adding to the evidence that this sector is key to

understanding and improving access of AT in low-income settings. Furthermore, given the particular circumstances of many low income AT users in the global South, we argue that data collection tools such as the Rapid Assistive Technology Assessment (rATA) would benefit from being adapted to ensure that the ‘informal sector’ is defined as a distinct provider of AT where surveys are conducted in low resource settings. Given their predominance as a provider of AT in these settings, the ambiguous value of informal providers for AT users therefore presents a key policy research gap and more research needs to be conducted to better understand the benefits of this sector, while also ensuring the provision of safe products and services.

References

1. World Health Organization (2021). Assistive Technology fact sheet. See: <https://www.who.int/news-room/fact-sheets/detail/assistive-technology>
2. World Health Organization and World Bank (2011, p 101). World Report on Disability. World Health Organization. See: <https://www.who.int/publications/i/item/9789241564182>
3. WHO (2021), op. cit
4. Groce, Nora., & Kett, Maria. (2013). The Disability and Development Gap (Working Paper No. 21). London: Leonard Cheshire Disability. Retrieved from: <https://www.ucl.ac.uk/epidemiology-health-care/sites/iehc/files/wp-21.pdf>
5. Eide, A. H., & Øderud, T. (2009). Assistive technology in low-income countries. In Disability & international development (pp. 149-160). Springer, New York, NY.
6. Visagie, Surona, Arne H. Eide, Hasheem Mannan, Marguerite Schneider, Leslie Swartz, Gubela Mji, Alister Munthali, Mustafa Khogali, Gert van Rooy, Karl-Gerhard Hem & Malcolm MacLachlan (2017) A description of assistive technology sources, services and outcomes of use in a number of African settings, Disability and Rehabilitation: Assistive Technology, 12:7, 705-712, DOI: 10.1080/17483107.2016.1244293
7. Ossul-Vermehren, I., Carew, M.T. and Walker, J. (2022). Assistive Technology in urban low-income communities in Sierra Leone and Indonesia: Rapid Assistive Technology Assessment (rATA) survey results. Bartlett Development Planning Unit - Global Disability Innovation Hub, London. See: https://www.ucl.ac.uk/bartlett/development/sites/bartlett_development/files/rata_report_final_20jan22.pdf
8. Boanada-Fuchs, A. and Boanada Fuchs, V. (2018) ‘Towards a taxonomic understanding of informality’, *International Development Planning Review*, 40(4), 397–420.
9. Bunnell, T. and Harris, A. (2012) ‘Re-viewing informality: perspectives from urban Asia’, *International Development Planning Review*, 34(4), 339–348.
10. Meagher, K. (2013, p. 2). WIEGO Working Paper no. 27. Unlocking the Informal Economy: A Literature Review on Linkages Between Formal and Informal Economies in LMICs. Women in Informal Employment Globalizing and Organizing.
11. Øderud, T. (2014). Surviving spinal cord injury in low income countries. *African Journal of Disability*, 3(2)
12. 2020, Walker, Julian, Ahmad Rifai, Fuad Jamil, Vindi Kurniawan, Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Indonesia, Global Disability Innovation Hub Report, AT 2030 Programmer, GDI Hub, London
13. Walker, Julian and Emma Tebbutt, (2022) The informal economy as a provider of assistive technology: lessons from Indonesia and Sierra Leone, Health Promotion International, <https://doi.org/10.1093/heapro/daac005>

14. Nossal Institute for Global Health (2019). A Manual for Implementing the rapid Assistive Technology Assessment
15. WHO (2021). rapid Assistive Technology Assessment tool (rATA). See:
16. <https://www.who.int/publications/i/item/WHO-MHP-HPS-ATM-2021.1>
17. Boggs, D. et al. (2021). Estimating Need for Glasses and Hearing Aids in The Gambia: Results from a National Survey and Comparison of Clinical Impairment and Self-Report Assessment Approaches. *International Journal of Environmental Research and Public Health*, 18 (12).6302.
18. See: Walker, J., Rifai, A., Jamil. A., Kurniawan V. (2020 a). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Indonesia. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub. https://at2030.org/static/at2030_core/outputs/AT2030DPU_Informal_Market_Study_Indonesia_Final.pdf and Walker, J., Sallam, N., Sesay S., and Gandi, I. (2020 b). Country Capacity Assessment for Assistive Technologies: Informal Markets Study, Sierra Leone. Global Disability Innovation Hub Report, AT 2030 Programme, GDI Hub. See: https://at2030.org/static/at2030_core/outputs/AT2030_DPU_Informal_Markets_Study_Sierra_Leone_16_Nov.pdf

Understanding the Demand for and Barriers to Accessing Assistive Technology in Blantyre District, Southern Malawi

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Abstract. Introduction: The need for AT goes beyond persons with disabilities to the chronically ill, elderly and individuals with non-communicable diseases. This paper explores use, met and unmet need for AT and challenges in accessing AT in the general population in Malawi. Methodology: This study was conducted in Blantyre, Malawi and used WHO's Rapid Assistive Technology Assessment methodology. A two-stage sampling design was utilised: 55 and 31 enumeration areas (EAs) in urban and rural Blantyre, respectively, were randomly selected, 25 households were randomly selected per EA. All household members were screened: only those who required or used AT responded to the questionnaire. Cross-tabulations and chi-square test were used to analyse data. Results: In total 2,188 households with 9,485 individuals participated in this survey with 48% males and 63 % urban dwellers. Only 3% of the sampled population used AT while 9% reported needing ATs. The unmet need for AT is highest amongst people with seeing difficulty (65.7%) followed by those with mobility (34.8%) and hearing (23.5%) difficulties. The unmet need for AT increases as the level of functioning difficulty increases. Of the people who reported needing new ATs or their replacements, 61% needed seeing/vision products, 22% needed mobility products while 6.5%, 5.8% and 4.8% needed self-care, cognition and communication products, respectively. The major barrier to accessing ATs is cost (82%), lack of support (19%), unavailability of ATs (10%), ignorance about ATs (4.5%) and lack of transport (3%). Conclusion: While more respondents require AT, only a few use AT. Stakeholders should develop and implement strategies that would improve access to AT not only among persons with disabilities but also in the general population.

Keywords: Assistive Technology; Barriers to Accessing AT; Prevalence of Use of AT, Disability, Malawi

1 Introduction

Assistive Technology (AT) covers systems and services related to the delivery of assistive products (APs) and services. All persons who require AT should have access to it as it enables productive and independent lives including participation in everyday life activities [1]. Every person risk experiencing functional limitations over the course of his or her lifetime due to factors such as age, disease or disability that may adversely affect their daily life participation and access to resources and services. WHO estimates that more than a billion people need one or more APs, and this figure is projected to double by 2050 with an increase in the proportion of the older persons and those suffering from non-communicable diseases [2]. While AT enables people with functional limitations including older adults, people with disabilities or those with chronic conditions to live independent and dignified lives, most people who need ATs are currently unable to access them [3]. The need for AT is very high, demand is generally low, and supply is even lower: for example, at a global level 70 million people need a wheelchair but only between 5% and 15% have access to one [4, 5]. WHO estimates that only 1 in 10 people who need assistive products currently have access [2].

Barriers to accessing AT in low- and medium- income countries (LMIC) include high costs of AT, scarcity of suitably qualified AT personnel, lack of awareness about AT, limited availability, heavy reliance on donations which in most cases are not appropriate, and inadequate financing of the AT sector by government [3, 5, 6]. In most cases, once a person acquires an AT, maintenance and post delivery services are left to the owner and his or her family and follow-up after getting an AT is found lacking [7]. Many countries lack policy frameworks required to effectively govern the AT sector [3]. There is a huge unmet need for AT particularly in developing countries. Countries should, therefore, aim at addressing the growing unmet need for AT as this is central to achieving universal health coverage as envisioned and detailed in the Sustainable Development Goals (SDGs) [8].

In order to address the challenges or barriers to accessing AT, WHO launched the Global Cooperation on Assistive Technology (GATE) programme and the priority Assistive Products List (APL) to improve access to affordable and quality AT [2, 4]. The APL consists of a list of 50 essential assistive products that addresses the unmet need for AT once provided to those in need [2]. A few countries such as Nepal [9], Tajikistan [10] and Malawi [11] have developed their own APLs adapted to country context. WHO argues that the APL promotes access to AT as it creates awareness among the public and is a tool for mobilisation of resources [2]. Through the GATE initiative WHO has also developed the rapid Assistive technology assessment (rATA), a questionnaire that is used to estimate the need and unmet need for AT as well as the barriers to accessing AT among persons who need this [12]. The rATA questionnaire further covers self-reported functional difficulties in six domains namely cognition, communication, hearing, mobility, seeing and self-care. This paper uses data collected in Blantyre district in southern Malawi to estimate the unmet need for AT and barriers in accessing AT in Malawi.

2 Assistive Technology in Malawi

Malawi has a population of just over 18 million people [National Statistical Office, 2020] and it is estimated that 11% of the population are persons with disabilities. Studies have generally shown that access to AT for persons with disabilities who require such products is generally difficult. A 2016/2017 study found that 57% of persons with disabilities in Malawi were aware of APs, 31% needed these products but only 6% received this service. The limited use of ATs has been attributed to high poverty levels prevailing in Malawi to the extent that only 38% of those using ATs procure their own devices while the rest are either bought by the government or non-governmental organizations [13].

The use of ATs among persons with disabilities has been explored in detail in Malawi through the studies on living conditions among persons with disabilities conducted in 2003 [15] and 2016/2017 [13]. However, in addition to persons with disabilities, there are also other persons with functional limitations such as the chronically ill, the elderly and individuals with temporary impairments who use ATs. Zhang et. al. [16] argue that there is very little country level population data on access to AT and this paper, using a WHO commissioned rATA survey data, explores the need and the unmet need for AT in the general population in Malawi and the barriers experienced by individuals in accessing AT. The results will contribute to informing the development of policies as well as the design, planning or prioritization of interventions on AT which will ensure that no-one is left behind.

3 Methodology

This study was conducted in Blantyre which has a population of 1,251,484 of which 64% live in urban and the rest (36%) in rural areas. The household sampling involved a two-stage sampling design: in the first stage 86 enumeration areas (EAs) were randomly selected and 55 of these were from urban Blantyre while the rest (31) were from rural Blantyre. In the second stage, sampling was based on stratified random sampling where research assistants (RAs) went to the centre of the EA, spread themselves outwards in different directions and interviewed every third household until they reached the target number of 25 households in each EA. In cases of non-response from a household, RAs continued to the next third household for replacement.

The sample size for this survey was 2,138, adhering to the sample estimates for population surveys in the rATA manual⁴. This sample size was arrived at based on the following assumptions: an estimated 1% prevalence of AT use in the general population, a desired precision of 0.05, a design effect of 1.3 and a response rate of 0.95. The rATA questionnaire, translated into Chichewa – a local language widely spoken in Blantyre as well as throughout the country, was administered to all the members of the sampled households. A proxy was interviewed in case the individual was unable to

⁴ See the rATA manual on https://cdn.who.int/media/docs/default-source/assistive-technology-2/rata-master-training/20201021-rata-enumerator-manual-final.pdf?sfvrsn=3864b5f8_12

answer as detailed as required in the protocol for conducting rATA surveys [16]. Most interviews at household level were very short as the interview ended if no need for or use of AT was registered. When need for or use of AT was reported, administration of the full questionnaire took around 15 minutes. The rATA questionnaire is found in the manual⁵. The mobile application was used to collect data. The collected data or information was then sent to a secured server at WHO headquarters. Before sending the data to the WHO server, the enumerators shared completed interviews with their field supervisors for quality checks. Data was collected between 19th April 2021 and 10th May 2021. The survey data was analysed in STATA 14 and SPSS 25 using descriptive analysis, chi-square test and logistic regression models. The study was approved by the University of Malawi Research Ethics Committee (UNIMAREC) reference number P.03/21/54.

4 Results

4.1 Background Characteristics

A total of 9,485 individuals from 2,138 households participated in the survey. Forty eight percent (48%) of the respondents were males. Sixty three percent (63%) of the respondents were from urban while 37% were from rural Blantyre. The age of respondents ranged from less than 1 year to 100 years and the mean age was 23.8 years. Table 1 further shows that around three out of four respondents were less 40 years with those aged 5-17 and 18-29 comprising 33% and 25% of the sample, respectively. In terms of functional limitations, most respondents (82%) did not have any difficulties, 13% had some difficulties on at least one of the six functional domains, 4% had a lot of difficulties in at least one domain and 1% reported that they could not do at least one of the domains. This implies that among the individuals enumerated 18% had a functional limitation at the time of the survey (Table 1).

There were no statistically significant differences in the proportion of males and females who had or had no functional limitations. Regarding functioning difficulty, 6.3% (n=600) reported to have at least some difficulty in walking or climbing steps, 9.9% (n=938) had difficulty seeing, 3.6% (n=345) had difficulty hearing, 1.8% (n=151) had difficulty speaking, 3.1% (n=299) had difficulty remembering things and 1.2% (n=98) had difficulty with self-care.

⁵ See https://cdn.who.int/media/docs/default-source/assistive-technology-2/rata-master-training/20201021-rata-enumerator-manual-final.pdf?sfvrsn=3864b5f8_12

Table 1. Demographic characteristics

Characteristics	Gender		Total (9,476)
	Male (4,524)	Female (4,952)	
Severity of disability			
<i>No difficulty (7731)</i>	83.5	79.8	81.6
<i>Some difficulty (1266)</i>	11.2	15.3	13.4
<i>A lot of difficulty (385)</i>	4.0	4.1	4.1
<i>Cannot do it (94)</i>	1.2	0.8	1.0
Age of respondents			
<i>0-4 (1036)</i>	11.5	10.4	10.9
<i>5-17 (3159)</i>	34.1	32.7	33.3
<i>18-29 (2351)</i>	24.0	25.6	24.8
<i>30-39 (1173)</i>	11.8	12.9	12.4
<i>40-49 (837)</i>	9.4	8.3	8.8
<i>50-59 (399)</i>	4.3	4.1	4.2
<i>60-69 (262)</i>	2.4	3.1	2.8
<i>70-80 (176)</i>	1.7	2.0	1.9
<i>80+ (84)</i>	0.9	0.9	0.9
Location			
<i>Urban (5986)</i>	63.2	63.1	100.0
<i>Rural (3491)</i>	36.8	36.9	36.8
Total (9476)	100.0	100.0	100.0

4.2 Use of Assistive Technology

Three percent (3%) of the respondents reported that they use AT regardless of their level of functional difficulty. There was no significant difference in the proportion of males (2.8%) and females (3%) who used AT. Table 2 further shows that the use of AT increased with age with 25% of those aged 80+ reporting that they used AT compared to for example 0.4%, 2.6%, 11.8% and 17.6% among those aged 0-4, 30-39, 50-59 and 60-69 years old, respectively. The use of AT also increased with increased level of functional limitations with 0% of those with no difficulty to about a third of the respondents for those with a lot of difficulty or more (cannot do). The proportion of respondents who used AT in urban areas was higher at 3.4% compared to 2.1% in rural areas but this was not statistically significant.

Table 2. Use of AT among respondents (N=9476)

Characteristics	Gender		Total (9,476)
	Male (4,524)	Female (4,952)	
Severity of disability			

<i>No difficulty (7731)</i>	0.0	0.0	0.0
<i>Some difficulty (1266)</i>	10.4	9.2	9.7
<i>A lot of difficulty (385)</i>	29.7	34.0	31.9
<i>Cannot do it (94)</i>	30.4	26.3	28.7
Age of respondents			
<i>0-4 (1036)</i>	0.8	0.0	0.4
<i>5-17 (3159)</i>	0.6	0.6	0.6
<i>18-29 (2351)</i>	1.2	1.9	1.6
<i>30-39 (1173)</i>	2.6	2.7	2.6
<i>40-49 (837)</i>	4.5	4.8	4.7
<i>50-59 (399)</i>	11.9	11.7	11.8
<i>60-69 (262)</i>	15.5	19.1	17.6
<i>70-80 (176)</i>	19.2	17.3	18.2
<i>80+ (84)</i>	28.2	22.2	25.0
Location			
<i>Urban (5986)</i>	3.3	3.5	3.4
<i>Rural (3491)</i>	1.9	2.2	2.1
Total (9476)	2.8	3.0	2.9

There were 275 respondents who used AT and Figure 1 shows the AT they were using regardless of severity of functional limitations.

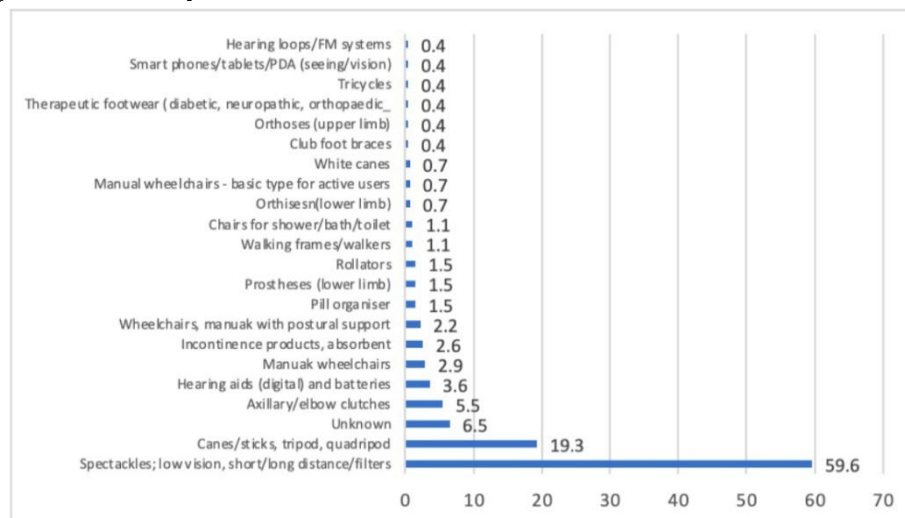


Fig. 1. Types of AT used

Figure 1 shows that the most commonly used AT are spectacles at 60% followed by canes/sticks, tripod and quadripods. Unknown AT in this context are those products where participants did not provide any further details.

4.3 Unmet Need for AT

Nine percent (9%, n=851) of all the individuals who participated in the study reported that they needed AT that they were currently not using or that they were currently using but needed replacement. There was a slightly higher proportion of females at 10% who reported that they needed ATs or their replacement compared to 8% among the males. However, the demand for AT among males and females is not statistically different at the 95% level of significance. There is, however, a significant difference in demand for AT across age groups. For every 10 years in age categories with the exception of the younger age groups (see Table 1), demand for AT increases by 5%. Thus, as the population ages the unmet need for AT also increases as can be seen in Figure 2 below.

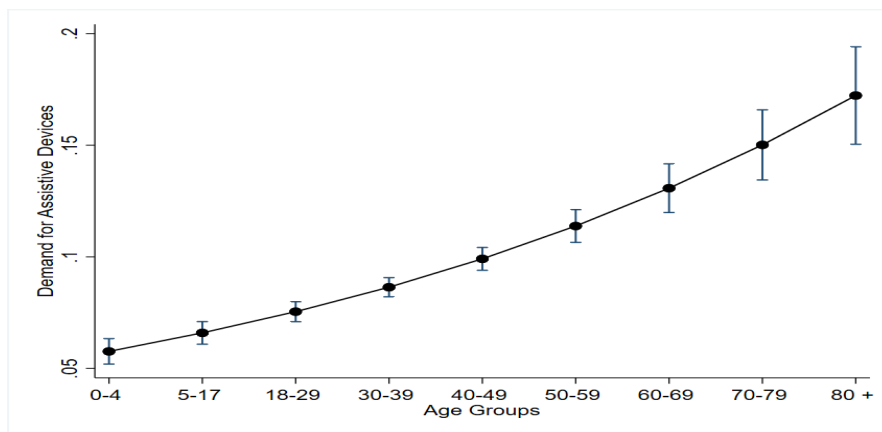


Fig. 2. Demand for Assistive Product by age-group (N=851)

As regards to functional difficulty, the chi-square test indicates that there is an association between demand for AT and level of functioning difficulty. The demand for AT is highest amongst people with seeing difficulty (65.7%), followed by mobility difficulty (34.8%), hearing difficulty (23.5%) and difficulty in self-care (9%). Nevertheless, results demonstrate that as the level of functioning difficulty increases, the demand for AT increases. Thus, people with severe difficulty in functioning have higher unmet need for AT compared to those with some or no difficulty as can be seen in Figure 3 below.

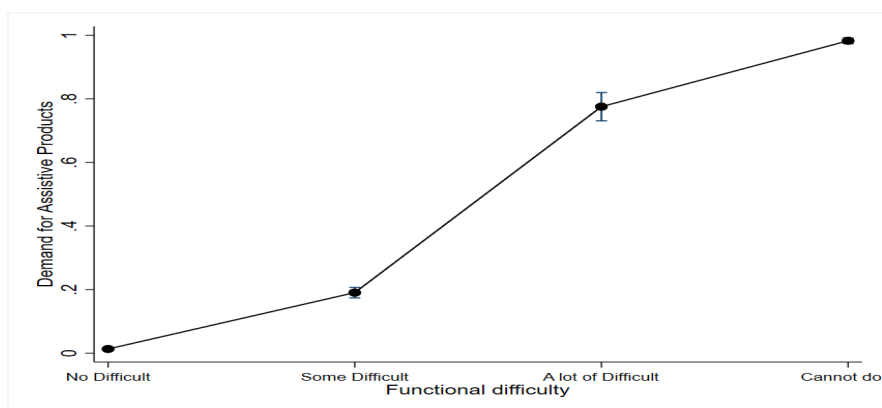


Fig. 3. Unmet need for AT by level of functioning difficulty (N=851)

4.4 Barriers to Accessing Assistive Products

Figure 4 shows that the major reason for not using AT among respondents who reported that they needed an AT, or they needed a replacement of their AT, was that they could not afford the AT (82%), and this was followed by those who reported that they lacked support (18.8%) and then those who said that the AT was not available (10%). Very few respondents mentioned other reasons such as not knowing about the AT (0.5%), the lack of transport (3%) and shyness or stigma (1.5%).

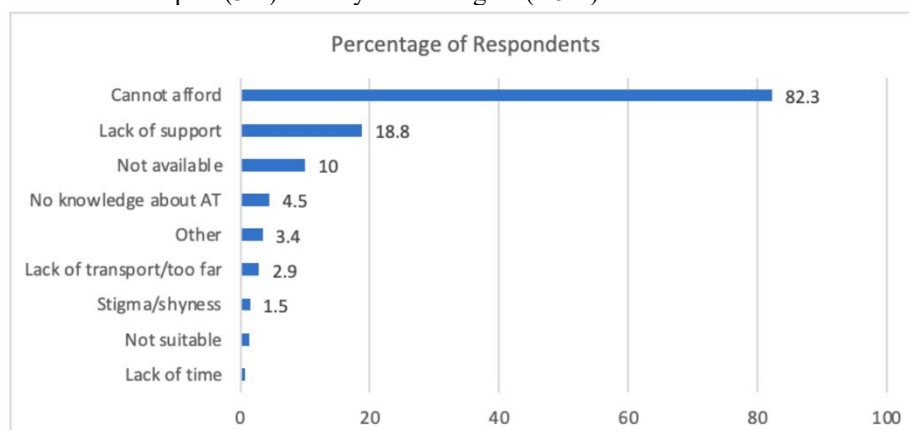


Fig. 4. Why the respondents did not have the AT that they needed (N=851)

5 Discussion

Access to AT is important, not only for persons with disabilities, but to many other persons with functional limitations such as the elderly and those suffering from NCDs. This survey however found that only 3% of the respondents in the general population

were using AT, that the unmet need for AT was 9% and that all in need of AT had at least some difficulty in one domain. A 2016/2017 living condition study found that 5.6% of the Malawi population were persons with disability [14]. These findings from the rATA study generally justify the importance of estimating AT requirements in the general population. This study has also found functional limitation increase with age [14, 17] and that the use of AT and the unmet need for AT increases with age. These findings are similar to other studies [17] which also found that the use of AT and the unmet need for AT increases with age. The high unmet need for AT, as WHO [2] argues, creates missed opportunities for persons who need AT to actively participate in education, work and to live independently. In this study there was no one without functional difficulty reported in need of AT. Malawi is a predominantly young population and that in the general awareness about AT in the general population is low and these factors coupled with high levels of poverty might explain why none of the respondents without functional difficulty reported in need of AT.

This study has found that the reasons for not using AT include the high cost of AT and unavailability. There are other studies which have also found that the high cost of AT [3,5,6,17] and lack of availability [3,5,6] constitute major barriers to accessing AT in LMIC. The lack of availability of AT is mainly due low production of AT in developing countries as most of these are imported [5, 18] and this partly contributes to the high cost of AT. Many countries in the developing world also rely on donations which are not appropriate or replaceable locally and may lead into secondary complications [3]. The lack of support has been mentioned in this study as a barrier to accessing AT. Boisselle & Grajo [18] have explained the lack of support in terms of absence of fitting and training as part of delivery of AT.

The proportion of people using AT was slightly higher in urban than in rural areas. Other studies have also found that access to AT in urban areas is easier as this is where most providers are found compared to rural areas [8]. In addition to this, most people in developing countries, and in Africa in particular, reside in rural areas where physical access to health services is a challenge due to severe rough terrains [6]. Only 1 in 20 respondents in this study reported they did not use AT because they were not aware of AT. Other studies have also found that widespread lack of awareness among potential beneficiaries of AT is a barrier to accessing AT [3, 5].

Malawi is a signatory to the Convention on the Rights of Persons with Disabilities (CRPD) which promotes the provision of AT to persons with disabilities to ensure full and equal enjoyment of all fundamental freedoms. The CRPD also promotes access to high quality and affordable AT for persons with disabilities. However, as is the case with other countries in the developing world, progress in the implementation of the CRPD has been slow and remains far from reality [5, 7]. In order to address the barriers to accessing AT, WHO's GATE initiative is aimed at improving access to affordable and quality AT by focusing on AT policies and programmes, the AT industry, AT service delivery and AT personnel [19]. GATE launched the priority Assistive Product List (APL) and encourages countries to establish their own APL based on need. Malawi has so far developed its own contextually based APL, and this will trigger awareness among service providers especially government and mobilisation of adequate resources for the AT sector. Access to AT is a public health priority and should be included under

universal health coverage and made available in the wider health systems to make them accessible [12]. In Malawi there is a comprehensive section on AT in the National Disability Policy which has been costed and the APL is one of the annexes to the policy [20]. Using the Malawi APL currently the Ministry of Health is in the process of determining the APs that are supposed to be made available at which level of health care. These initiatives in Malawi will contribute towards addressing the barriers to accessing AT and the large unmet need for AT in the country.

6 Conclusion

This study has shown that the unmet need for AT in Malawi as is the case elsewhere in LMIC is high. This deprives many people in need of AT of their fundamental freedoms and basic human rights such as education and employment. The Government of Malawi has made progress in in the development of the APL, costing it and determining the type of AP that should be provided at the different levels of health care. The policy environment in Malawi is therefore conducive for the procurement and distribution of AT. What is largely remaining is that Government and stakeholders with support from development partners should provide adequate funding for the AT sector including the building the capacity of personnel in the AT sector.

References

1. Edyburn, DL. Rapid literature review on assistive technology in education.: research report. London: Department of Education; 2020.
2. WHO. Priority assistive products list (APL). Geneva: WHO; 2018.
3. Rohwelder B. Assistive technology in developing countries. Brighton: Institute of Development Studies; 2018.
4. WHO. Priority assistive products list (APL). Geneva: WHO; 2016.
5. Tangcharoensathien V, Wityhayapipopsakul W, Shaheda S, Patchararumol W. Improving access to assistive technologies: challenges and solutions in low- and middle-income countries. *WHO South East Asia Journal of Public Health*. 2018; 7(2):84-90.
6. Toro-Hernandez M-, Kankipati P, Goldberg M, Contempomi S, Tsukimoto DR, Bray N. Appropriate assistive technology for developing countries. *Physical Medicine and Rehabilitation Clinic of North America*. 2019; 30(4): 847-865.
7. Chakraborty, S. Assistive technology: addressing the divide between the developed and the developing countries. *Journal of Science Policy and Governance*. 2020; 16:2.
8. Matter RA, Eide AE. Access to assistive technology in two southern African counties. *BMC Health Services Research*. 2018; 19: 792. <https://doi.org/10.1186/s121913-018-3605-9>.
9. Government of Nepal. National Assistive List for Nepal. Kathmandu: Government of Nepal; 2020.
10. Mishra S, Pupulin A, Ekman B, Khasnabis C, Allen M, Huber M. National priority assistive product list development in low resource countries: lessons learned from Tajikistan. *Disability and Rehabilitation: Assistive Technology*. 2021; 16:8, 857-864.
11. Munthali A.C., D EI, Jamali MZ, Kafumba J, Chiyamwaka J, Smith EM, et al. Developing a national Assistive Product List: some lessons from Malawi. 2022.

12. Layton N, Bell D, Borg J, Steel E, Maclachlan M, Tebbutt E, Khasnabis C, Swaminathan S. Assistive technology as a pillar of universal health coverage: qualitative analysis of stakeholder responses to the world health assembly resolution on assistive technology. *Disability and Rehabilitation: Assistive Technology*. 2020 Oct 2;15(7):825-31.
13. Eide AH, Munthali AC. Living conditions of persons with disabilities in Malawi. Oslo: SINTEF; 2018.
14. Ebuenyi, I.D., M.Z. Jamali, E.M. Smith, J. Kafumba, P. Chizala, A. Munthali and M. MacLachlan. (2022). age related increase in impairment across the life course: the use of Zomba curves to estimate assistive technology needs in Malawi *Disability and Rehabilitation: Assistive Technology*, DOI: 10.1080/17483107.2022.2060352
15. Loeb M, Eide EH. Living conditions of persons with activity limitation in Malawi. Oslo: SINTEF; 2004.
16. Zhang, Wei, Arne H. Eide, Wesley Pryor, Chapal Khasnabis, and Johan Borg. 2021. "Measuring Self-Reported Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire: Protocol for a Multi-Country Study" *International Journal of Environmental Research and Public Health* 18, no. 24: 13336. <https://doi.org/10.3390/ijerph182413336>.
17. Ministry of National Health Services & WHO. (2019). Rapid assistive technology assessment in Pakistan. Karachi: Pakistan.
18. Boisselle, A. K., & Grajo, L. C. (2018). They Said: A Global Perspective on Access to Assistive Technology. *The Open Journal of Occupational Therapy*, 6(3). <https://doi.org/10.15453/2168-6408.1541>
19. [https://www.who.int/news-room/feature-stories/detail/global-cooperation-on-assistive-technology-\(gate\)](https://www.who.int/news-room/feature-stories/detail/global-cooperation-on-assistive-technology-(gate)).
20. Ministry of Gender, Community Development and Social Services. National Disability Policy. Lilongwe: Ministry of Gender, Community Development and Social Welfare; 2022.

Measuring Access to Assistive Technology in the Public Rehabilitation Outpatient Setting in Costa Rica Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire

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Abstract. Costa Rica is a middle-income Central American country where health care provision works through CCSS, a socialized solidarity-based system where coverage is universalized and incorporates all social strata and geographical areas. We collected responses to the rATA in Costa Rica to determine access to assistive technology. The total sample for this study included 615 individuals, from all ages and geographical areas in Costa Rica, randomly selected among the users of every of the 22-outpatient rehabilitation service of the CCSS. The survey was performed via telephone due to the COVID-19 pandemic. The most important findings include that 68% of individuals reported using AP and 47% of individuals need new or replacement of AP (unmet need). The most used AP were spectacles (34%), therapeutic footwear (10%), and canes/sticks, tripod and quadripod (8%). Most AP (41%) came from the public sector. Out of the total, 39% were paid out-of-pocket 22% were provided by government sources. The main barrier for accessing AP was "Cannot afford" (36%). No association among the setting (urban or rural) with unsatisfied needs was identified, while an increase in the distance travelled to obtain an AP correlated with an increase in unsatisfied needs. An increase in age was associated with an increase in the use of AP. Despite having the possibility to prescribe within the system and provide subsidized products, there is still a high rate of unmet need. Most products need the user to pay for them, with affordability remaining the greatest challenge and distance to travel to obtain an AP remaining as a significant gap in access.

Keywords: Assistive Technology, rehabilitation, low-middle income country

1 Introduction

The WHO Global Disability Action Plan 2014-2021 highlights the lack of data regarding AT around the world and acknowledges significant statistical gaps between countries with higher and middle/low incomes. Data collection of the rATA survey for Costa Rica is relevant due to several factors: (a) The inclusion of Costa Rican data in the rATA offers information about access gaps to AT in a Central American country of

middle-income (b) There is a confluence of interests between the Caja Costarricense de Seguro Social (CCSS-Costa Rica's national healthcare provider) and the GReAT, given that both need data to improve their response to AT needs, and both can provide data to contribute to the global understanding of AT. Finally, (c) the rATA data is extremely useful for our national healthcare provider, given its leading role in providing AT in Costa Rica.

Costa Rica's economy corresponds to a middle-income country, but its epidemiological profile corresponds to a high-income. CCSS is the main healthcare provider in Costa Rica through a socialized system. It has universalized coverage that incorporates all social strata and geographical areas, giving coverage to over 90% of the Costa Rican population and delivering service through a national network divided by regions, allowing access across the whole territory [1]. Care is provided according to the health area of residence, through an increasing complexity system [2].

The CCSS prescribes selected AT through its own budget: Otolaryngology prescribes hearing aids, ophthalmology and optometry visual aids, while physical medicine and rehabilitation (PM&R) provides orthopedics and neurosurgery mobility aids. The widest range of aids is prescribed by PM&R. CCSS has an official "Manual for Technical Aids, Prosthesis, Medical Accessories and Orthopedic Devices" which allows physicians to prescribe different aids and offer different modalities of coverage [3]. However, the last update of this manual, defining which aids would be included and the amount of money allotted to each aid, was written in 2010, so an update to this manual is urgent. At the moment, mobility products are the main aspect of the manual and there are no products for daily life activities, cognition or language. This means the list is significantly behind in the requirements of WHO's Priority Assistive Products List [4].

2 Methodology

The survey was implemented as a stand-alone method with a target population of people with disabilities who are users of the outpatient rehabilitation services of CCSS.

Rehabilitation services in the CCSS medical centers are in charge of covering all types of disabilities, with diagnoses ranging from acquired brain injury to spinal cord injury, neurological, oncologic, cardiac, orthopedic, rheumatologic and post intensive care unit rehabilitation, among many others. From this perspective, all functional domains addressed in the rATA (mobility, vision, hearing, cognition, communication and self-care) are subject to be managed by the CCSS Rehabilitation Services.

Since the CCSS oversees the treatment of up to 90% of the Costa Rican population, all socio-economic strata are represented. The health insurance in the country follows a socialized service, aiming to guarantee the same kind of services and treatment to every patient, regardless of the social stratum or income.

A database of the past 2 years of outpatient physiatrist consultations was obtained for 22 medical centers. It was compiled by the Medical Registry Department of the CCSS, and a subsample of it was selected through a systematic procedure to guarantee randomization.

The sample number was 615, stratified according to 6 geographic planification regions, using data regarding disability distribution from the Costa Rican National Disability Survey from 2018. It includes all ranges of age, socioeconomical groups, urban and rural settings alike. Costa Rica is a small country with varied geographical conditions, which means that small rural areas and urban areas are located very close to one another. Therefore, most hospitals and medical centers serve people from both urban and rural scenarios. As this survey was applied nationally, we have coverage of both areas across the country. The different geographic planification regions have different rates of urban/rural population, which was accounted for in the sampling process.

Data was collected through phone calls using the Spanish version of rATA. The enumerator group consisted of 16 physical medicine and rehabilitation physicians, who work in different hospitals across the CCSS network. All of them have extensive knowledge of the Costa Rican Health System and are prescribers of assistive technology devices themselves.

3 Findings

Important findings include there are as many children and teens that need AP as there are adults between 50-70 needing AP (both groups are 32% of the total).

Despite a very high use of APs (68%) individuals reported many unmet needs (Table 1). Most AP come from public sector providers like CCSS (41%) and from private sector providers, such as private clinics and hospitals (39%).

Table 1. Overall AP Use rATA Study Costa Rica 2021.

	Actually uses AP	Has unmet AP needs
Yes	419 (68%)	291 (47%)
No	196 (32%)	324 (53%)

Spectacles are the most used assistive products (34%), followed by therapeutic footwear (10%) and canes/sticks, tripods and quadripods (8%). Meanwhile, products for selfcare are not used as much as would be expected and products for remembering are barely used at all (Table 2).

Table 2. Overall AP Use rATA Study Costa Rica 2021 - Most used AP for each category, total number, and percent from the 615 people sample.

Mobility	Therapeutic Footwear: Diabetic, Neuropathic, Orthopedic (75; 10%). Canes/Sticks Tripod and Quadripod (59; 8%). Orthoses: Lower limb (57; 8%).
Seeing	Spectacles: Low-Vision Short/Long Distance/Filters (249; 33%)
Hearing	Hearing Aids Digital and Batteries (13; 2%)
Communication	Communication boards, books, cards (3; 0.4%). Smart phones, tablets, PDAs (2; 0.3%)
Remembering	Smart phones, tablets, PDA (3, 0.4%)

Self-care	Chairs for shower, bath, toilet (30; 4%). Grab-bars hand rails (26; 3%). Incontinence products, absorbent (24; 3%)
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Most AP were paid out-of-pocket (39%) and 22% were provided by government sources such as CCSS, followed by family/ friends (21%). Many patients reported needing multiple sources of funding.

The main barrier for accessing assistive products was that users "Cannot afford" them (36%).

There is no statistically significant association between the setting (urban or regional) and unsatisfied needs, while the increase in the distance travelled to obtain an assistive product correlates with an increment in unsatisfied needs.

An increase in age was significantly associated to an increment in the use of assistive products. An increase in the functional difficulty was associated with an increase in unmet needs.

The most common recommendation from users was for the wait time for APs to be reduced, followed by increase in product availability, since CCSS's product list is focused mainly on mobility items, followed by some vision and hearing products with little to no access for communication, cognition and selfcare products. Other important recommendations included the need of more information about the use and availability of AP and the need of guidance services.

An interesting byproduct of this study was the potential to raise awareness about APs on PM&R peers who worked as enumerators, who come from very different regions of Costa Rica and might generate a multiplying effect, allowing for interest to grow in different stakeholders involved.

4 Analysis

There are three major findings in this study: (1) There as many children and teens that need AP as there are adults between 50 and 70 years old (both 32% of the total). (2) Many users get APs from private sources, not from the CCSS, and this might lead to increases in expenses. (3) The CCSS process to provide APs is complex and is mostly available in the urban regions of the Central Valley. This leads to lower use of CCSS resources, but also to longer distances travelled by AP patients.

First, regarding children and teenagers in the rATA, there are many more young people than expected in the sample. Moreover, despite being groups of equal size with adult users, they have very unequal access to AP financing. Adults have limited avenues of financing with the public sector, including only CCSS and CONAPDIS. On the other hand, children have many additional sources of funding, including institutions such as the National Centre for Education Resources (CENAREC), and the Department of Educational Products for Students with Disability within the Ministry of Education, with the caveat that the prescription and provision of the AP might not be well integrated within the health system. This highlights an inequality within the system: funding for adults must be addressed.

Costa Rica's geography allows for urban areas to be also located outside the Central Valley. Nevertheless 15 out of 22 centers with outpatient rehabilitation are located in

the Central Valley region. In this survey, 35.5% of the population came from rural areas, most of them outside the Central Valley. They could have received treatment close to their communities, but instead had to travel to hospitals in the Central Valley for their case to be addressed. This means travelling long distances for their medical care, with all the economic costs this might represent.

Regarding functional difficulties, 47% of the population presented some degree of mobility difficulty. 54% of the population reported vision difficulties, 13% hearing difficulties, 18% communication difficulties, 37% remembering difficulties, and 30% self-care difficulties. This data raises concern regarding the provision of rehabilitation services throughout the country. Physical therapy is widely extended and available in all centers, but occupational therapy, which is important for selfcare activities, is only available in 5 centers. This also occurs with speech therapy, which is pivotal for communication disorders, but which is only available in 6 of the surveyed centers. Moreover, even though 37% of the patients reported remembering difficulties, only 2 centers have psychology and cognitive support services.

Since the main area that showed functional difficulties was sight, it is to be expected that spectacles are the most used assistive products (34%). This is followed by mobility, the second most common functional difficulty, where items such as therapeutic footwear (10%) and canes/sticks, tripod and quadripod (8%) are the second and third most used APs. Meanwhile, products for selfcare are not used as much as expected and products for remembering are barely used at all.

Despite a very high use of AP (68%) individuals reported very high unmet needs as well, which could not only mean the need for replacements but also the need for new or different APs. This might be related to the long wait times for medical appointments, which would force users to use a product that is damaged or worn off. There is also a lack of information on how to get new prescriptions within CCSS. Moreover, the product list approved for funding in the CCSS is centered on vision, hearing, and mobility and therefore many other needs are left out.

Most AP come from public sector providers like CCSS (41%) and from private sector providers, such as private clinics and hospitals (39%). The partial dependence on the private sector might be explained by the lack of availability and long wait times for some AP in the public sector. There is also a lack of knowledge from physicians and users about the AP that can be prescribed in CCSS or the mechanisms to do it, giving the common misconception that products must be obtained through private payment.

Most AP were paid out-of-pocket (39%) and 22% were provided by government sources such as CCSS, followed by family and friends (21%). Many patients reported needing multiple sources of funding. Long waiting times might be forcing users into buying the products themselves. The patients might also need to acquire products outside the CCSS's list of subsidized products. One remarkable finding is the underuse of NGO resources; only 4% of the sample reported them as sources of AP.

Most of the population spent less than 50,000 Costa Rican colones (approx. \$78) from their pocket money or family core on APs in the last 12 months. This amount is relatively small, mainly because many products have subsidies from CCSS. Costa Rica's minimum wage per month is around 326,000 Costa Rican colones (approx. \$515 USD).

32% of the population travelled less than 5km for their AP, but 14% travelled more than a 100 kms. In both cases, the main product they travelled for were spectacles. Sometimes the approval for the AP might need to be in the same center where it was prescribed, which means someone might have to travel several times to health centers far from their home.

73% of the population was either very or quite satisfied with their AP and 71% of the population was either very or quite satisfied with the assessment and/or training for the AP. In addition to this, 69% of people were very or quite satisfied with the repair, maintenance and follow-up services of their AP. Spectacles, therapeutic footwear and canes were cited both as the devices that people are most satisfied with, and as the devices that people were most dissatisfied with. One explanation for this pattern is that there is a large group of the population who get their spectacles and footwear from the private sector, which allows for a larger variety in the offer, for more frequent changes in the AP, and for differences in the amount of use given to the AP. On the other hand, some users obtained the same product from the public sector, and the lack of variety there may also raise dissatisfaction. Finally, the limited number of AP mentioned, also shows the small variety of APs prescribed throughout the country.

77% of the population considered their AP to be either completely or mostly usable and 78% of the population was able to use their AP either completely or a lot despite environmental barriers. Almost the same products share reports of being highly usable and being unusable, such as spectacles and therapeutic footwear, which could be explained for the same reason mentioned above (i.e. products from both public and private providers). There could also be a lack of updates in the items, which would not allow the users to properly benefit from them and might create barriers to their use.

The main barrier for accessing assistive products was that users "Cannot afford" them (36%). However, many APs are provided by CCSS, so this might be related to people acquiring their products in the private sector because of CCSS appointment delays, and because of misinformation regarding products, including which products are available with a subsidy from CCSS or not.

There was no statistically significant association between the setting (urban or rural) and unsatisfied need, which might be a reflection of equity in access and opportunities regarding AP in both settings, despite the differences in distance. This might be due to the universal geographic coverage of the CCSS system.

The increase in the distance travelled to obtain an AP correlated with an increase in unsatisfied need. This entails fewer possibilities of follow up and maintenance of the AP. Transportation costs might also generate an inability to travel the long distances that some rural inhabitants need to cover to get an AP.

An increase in age are significantly associated to an increase in the use of AP. This is to be expected, as life expectancy in Costa Rica surpasses 80 years and functional decline can be observed more frequently in aging populations.

An increase in functional difficulties was associated with an increase in unmet need. This is associated with a lower availability of more complex APs and increased difficulties in providing more complex products in contexts where there are no occupational or speech therapists to aid the prescription and training.

The most common recommendation from users was for the wait time for APs to be reduced. The situation deteriorated due to the COVID-19 pandemic, which made waiting times even longer. This is a justified concern, given that the CCSS AP prescription process is very complex.

There is an uneven presence of providers across the national territory, and each provider offers different products. Most of the providers are in the Central Valley, so there are fewer APs in the periphery, which explains the recommendation given by users of reducing travel distance. Currently, users have to travel long distances, with the sacrifice of time and money that this entails. This also explains why there is an increment in unmet needs as people have to travel longer distances to obtain the AP.

Product availability was also suggested as a potential improvement. CCSS's product list is focused mainly on mobility items, followed by some vision and hearing products with little to no access for communication, cognition and selfcare products. These products are usually paid out-of-pocket or provided through NGOs. This could be a reason for why users are requesting financial assistance to pay for their APs.

Further recommendations include the need of more information about the use and availability of APs and the need of guidance services regarding APs, where the user could be introduced to different products.

5 Conclusions

Rehabilitation services in Costa Rica cover multiple types of disability, therefore a high prevalence of usage is expected. Despite having the possibility to prescribe within the system and provide subsidized products, there is still a high rate of unmet need, with most products needing the user to pay for them and affordability remaining the greatest challenge.

Barriers concerning travel distances to obtain an assistive product, regardless of an urban or rural setting, also represent a gap in access to assistive products.

References

1. Arturo C, Ramírez A. Financiamiento y cobertura del Seguro de Salud en Costa Rica : desafíos de un modelo exitoso. *Gestión en Salud y Segur Soc.* 2020;1:12–20.
2. Caja Costarricense de Seguro Social (Gerencia Médica). *Establecimientos de salud 2012-2019*. San José, Costa Rica; 2022.
3. Caja Costarricense de Seguro Social (Equipamiento Institucional). *Instructivo de Prótesis y Aparatos Ortopédicos*. 1997. p. 5.
4. World Health Organization. Priority Assistive Products List [Internet]. The GATE Initiative. 2016. Available from: http://apps.who.int/iris/bitstream/10665/207694/1/WHO_EMP_PHI_2016.01_eng.pdf?ua=1

Situation of Assistive Technology Provision in Indonesia A Rapid Assessment Survey Based on National Household Population

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Abstract. Background: In Indonesia, slightly more than 9 percent (around 23.3 million individuals) of the Indonesian population experience disabilities and may require at least one form of Assistive Technology (AT). There is limited data on access to AT in Indonesia. The rapid Assistive Technology Assessment (rATA) Survey supported by WHO is a strategic contribution capturing the recent situation of AT provision in Indonesia. Method: A cross-sectional household population-based survey. Cluster sampling was carried out in two stages. First is the random selection of geographic units and the second is a random selection of households within each selected geographic unit. Two provinces, eight districts/cities, 32 sub-districts, 96 villages and 288 RW (block/cluster) were selected. A simple random sample was used for each RW to select 14 households based on the list of households. No specific criteria and characteristics required to become a respondent. Survey data collection carried out using the Survey123 rATA 2020 application. Data collection was conducted in August to December 2021. Results: Total of 11.300 respondents as valid cases consisted of 46.7 % male and 53.3 % female from 72.7% urban and 27.4% rural areas. There are 32.1 % participants have “any difficulties” and 12.7% participants have ‘a lot of difficulty’ or ‘cannot do at all’. Prevalence of unmet need per level of functional difficulties and for the whole population were quite high. Proportions of different sources for assistive products highlights 74,5 % from private while 6.5 % from public, and 3.8 % from self-made. Proportions of different funding for assistive products explain 64.7 % from out of pocket, 28.2 % from friends/family compare with 3.8 % from government, 1.3 % from NGO, and 1.9 % from insurance. The highest proportions of different barriers to access for assistive products has capture that 51.3 % participants can’t afford assistive products in Indonesia while

12.4 % has no support. Conclusion: Need of AT is increase with the increase of age. Contribution of government for AT is limited, which made people have to raised self-fund. Affordability of AT is remain a barrier for most people. The research has shown numbers of self-made AT, using local resource material with modest technology. Recommendation: All relevant stakeholder should develop new strategies to improve access to AT, advocate to governments and civil society the unmet needs for AT, provide data to help plan or prioritize AT provision, design and deliver interventions to improve access to AT, evaluate the effectiveness of efforts to strengthen access to AT, and measure progress towards AT targets.

Keywords: Assistive Technology (AT), People with disabilities (PWDs), rATA Survey, unmet need, WHO.

1 Background

On 13 December 2006, the United Nations General Assembly passed Resolution A/61/106 on the Convention on the Rights of Persons with Disabilities. The Government of Indonesia signed the Convention on the Rights of Persons with Disabilities on March 30, 2007 in New York.

Indonesia is an archipelago country, covering 34 provinces, 514 districts/Cities, 7.246 Subdistricts, and 83.931 villages. Population in 2021 was 273,879,750. According to National Socio-Economic Survey (Susenas) March 2019, slightly more than 9 percent (around 23.3 million individuals) of the Indonesian population experience disabilities, with 2.2 percent (approximately 5.7 million) experiencing severe disability. [1]. The proportion of children (5-17y) with disabilities 3,3%, and adult (18-59y) 22,0% [2]

As the implementation of the UN Convention on the Rights of Persons with Disabilities (UN-CRPD), the government has established Law number 19 of 2011 on Ratification of Convention on the Right of Persons with Disabilities, Law number 8 of 2016 on Persons with Disabilities, Government Regulation number 70 of 2019 on Planning, Organizing, and Evaluating of Respect, Protection, and Fulfillment the Rights of Persons with Disability, Government Regulation Number 52 of 2019 on The Implementation of Social Welfare for Persons with Disabilities, and Regulation of The Minister of National Development Planning number 3 of 2021 on the Implementation of Government Regulation number 70 of 2019.

Based on Law No. 8 of 2016, persons with disabilities have the right to live independently and be involved in society, among others in the form of personal mobility with the provision of assistive product and ease of access. People with disabilities also have health rights including obtaining assistive product based on their needs.

To be able to carry out the Mandate, the Government must have clear data on the needs of the population for assistive products and types. Unfortunately, the data is not yet available in detail. Data systems to track disability prevalence and AT need in Indonesia are fragmented. Intercensal Population Survey (SUPAS) and National Socio-

Economic Survey (SUSENAS) estimates of various functional impairments and disability prevalence nationally but cannot provide estimates of the need for specific AT.

Management Information System for People with Disabilities (SIM-PD), which launched by Ministry of Social Affair (MoSA) in 2018, utilizes real-time data entry by social workers spread across sub-districts in Indonesia, still experiencing problems in terms of slow data input and the need to improve on data quality. Based on these considerations, Indonesia's participation in the Rapid Assistive Technology Assessment (rATA) survey with WHO support is very important.

2 Method

A cross-sectional national household population-based survey. Cluster sampling was carried out in two stages. First is the random selection of geographic units and the second is a random selection of households within each selected geographic unit. At first stage, 2 provinces representing the low-medium Human Development Index - HDI (NTT Province) and medium-high HDI (East Java Province) were selected by systematic random sampling. The second stage selected 4 districts/cities from each selected province, i.e. District of Alor, North Central Timor, Sikka, Kupang City in NTT Province, and District of Situbondo, Banyuwangi, Pasuruan City, and Surabaya City in East Java Province. From each selected District/City, 4 sub-districts were selected using simple random sampling. In each selected sub-district, 3 villages and 3 RW (block/cluster) were selected, and a simple random sample was used for each RW to select 14 households based on the list of households. No specific criteria for each respondent and no special characteristics required to become a respondent. Survey data collection was carried out using the Survey123 rATA 2020 application with a PC, mobile phone or tablet that has been translated into Bahasa. Data collection was conducted in August to December 2021. Process involved 16 enumerators from each province, which recruited based on local Disabled People's Organizations (DPOs) consideration, 11 of them are People with Disabilities. Expedited Ethical approval for this survey obtained from the Health Research Ethics Commission, National Institute of Health Research and Development, Republic of Indonesia number LB.02.01/2/KE.471/2021

3 Result

There were 11,300 respondents in this survey. Respondents in East Nusa Tenggara Province (55.7%) were more than respondents in East Java Province (44.3%). Among all districts / cities, respondents from Sikka Regency were the most (15.2%). Based on characteristics, the largest proportion of respondents were women (53.3%), living in urban (72.7%), and aged 5-17 years (20.1%). (table 1).

Table 1. number of samples based on survey location and characteristics of respondents

No.	Variable	n	%	No	Variable	N	%
1.	Sample Location			3.	Living		

1.1.	East Nusa Tenggara (NTT)	6298	55,7	3.1	Urban	8218	72,7
1.1.1.	Kupang City	1403	12,4	3.2.	Rural	3082	27,4
1.1.2.	Timor Tengah Utara	1557	13,8	4.	Age		
1.1.3.	Sikka	1714	15,2		- 0-4y	606	5,4
1.1.4.	Alor	1624	14,1		- 5-17y	2273	20,1
1.2.	East Java Province	5002	44,3		- 18-29y	1888	16,7
1.2.1.	Situbondo	1017	9,0		- 30-39y	1528	13,5
1.2.2.	Pasuruan	1299	11,5		- 40-49y	1623	14,4
1.2.3.	Surabaya City	1239	11,0		- 50-59y	1529	13,5
1.2.4.	Banyuwangi	1447	12,8		- 60-69y	1090	9,7
2.	Sex				- 70-79y	533	4,7
2.1.	Male	5275	46,7		- 80+y	230	2,0
2.2.	Female	6025	53,3				

A total of 67.9% of respondents did not have difficulty in doing certain activities because of a health condition. About 32.1% had difficulty at least one of mobility, seeing, hearing, speaking, remembering or concentrating, and selfcare. The largest proportion of respondents experienced in 1 type of difficulty (20.8%), then 2 difficulty (6.7%), 3 difficulty (2.7%), 4 difficulty (1.2%), 5 difficulty (0.4%), and 6 difficulties (0.3%).

Among the types of difficulties experienced by respondents, the largest proportion were those who experienced some difficulties (19.3%), although there were also 1.5% of respondents classified as "can't do at all". (1,5%). The most difficulty was in seeing, but the largest proportion in "can't do at all" classification was experienced by respondents who had difficulty in mobility. (table 2)

Table 2. Difficulty of respondents in doing certain activities

No	Difficulty	No	Some	A lot of	Can't do at all
1.	Difficulty level	67,9	19,3	11,2	1,5
2.	Type of difficulty				
2.1.	Mobility	88.6	7.1	3.6	0.7
2.2.	Seeing	75.3	17.1	7.1	0.4
2.3.	Hearing	94.6	3.1	1.9	0.4
2.4.	Speaking	98.2	0.8	0.7	0.3
2.5.	Remembering or concentrating	94.7	3.8	1.3	0.1
2.6.	Difficulty selfcare	97.2	1.4	1.0	0.3

Overall, both in terms of with spectacles and without spectacles, "Need" for assistive products is greater than "Use". Similarly, "Unmet Need" is much larger than "Met Need". Ironically, the heavier the level of difficulty the greater the proportion of Need and Unmet Need to assistive products. The same phenomenon also occurs in the age group, where the higher the age, the greater the proportion of Need and Unmet Need.

Table 3 also shows the proportion of Met Need without spectacles in respondents who experience some difficulty and a lot of difficulty is much smaller than that with spectacles. This condition illustrates that the gap in meeting the needs of other assistive products is also still large.

In terms of gender, the use of assistive product in female is greater than that of male, both in groups with spectacles and without spectacles. However, female also showed a greater proportion of Unmet Need than male. Need and Met Need for female were smaller than male in the group without spectacles, contrast to the group with spectacles.

Respondents living in urban areas had a greater proportion of assistive product use than rural areas. Respondents living in rural areas had a greater proportion of Unmet Need assistive products than urban in the group without spectacles.

Table 3. Comparison of the use of assistive products between spectacles and without spectacles

No	Variable	With spectacles (%)				Without spectacles (%)			
		Use	Need	Met Need	Unmet Need	Use	Need	Met Need	Unmet Need
1.	Difficulty Level								
1.1.	No difficulty	0,2	0,5	0,2	0,3	0,0	0,1	0,0	0,1
1.2.	Some difficulty	41,3	76,0	24,8	51,3	4,7	16,2	2,3	13,9
1.3.	A lot of difficulty	63,4	93,4	38,1	55,3	21,3	49,0	9,5	39,5
1.4.	Cannot do at all	43,8	87,5	15,1	71,9	41,8	86,3	15,1	71,2
	Total	15,6	26,1	9,2	16,9	3,9	9,8	1,7	8,1
2.	Age								
2.1.	0-4y	0,9	1,7	0,2	1,7	0,6	1,7	0,0	1,7
2.2.	5-17y	4,0	6,4	2,0	4,3	1,3	3,0	0,4	2,6
2.3.	18-29y	9,5	12,7	6,0	6,7	1,7	3,7	0,7	3,0
2.4.	30-39y	7,6	14,3	4,4	9,9	1,8	5,1	0,8	4,4
2.5.	40-49y	15,6	27,4	9,4	18,0	1,9	5,1	0,8	4,3
2.6.	50-59y	29,5	46,5	20,0	26,6	3,3	10,9	1,4	9,5
2.7.	60-69y	32,9	56,9	18,6	38,3	10,8	26,2	6,4	19,9
2.8.	70-79y	30,0	59,3	13,9	45,5	15,1	38,5	5,0	33,5
2.9.	80+y	35,2	64,3	16,4	47,5	26,6	54,9	11,5	43,3
	Total	15,6	26,1	9,2	16,9	3,9	9,8	1,7	8,1
3.	Sex								
3.1.	Male	13,6	23,2	8,4	14,8	3,6	9,9	1,9	8,0
3.2.	Female	17,4	28,8	10,0	18,8	4,1	9,8	1,6	8,2
	Total	15,6	26,2	9,2	16,9	3,9	9,8	1,7	8,1
4.	Location of living								
4.1.	Urban	16,6	26,9	9,7	17,2	4,2	9,9	1,8	8,0
4.2.	Rural	9,7	21,8	6,5	15,4	2,2	9,7	1,0	8,7
	Total	15,6	26,1	9,2	16,9	3,9	9,8	1,7	8,1

The largest proportion of assistive products came from private for both those with spectacles and those without spectacles (74.5%; 53.6%). Out of pocket also become the biggest proportion in financing (64.7%; 44.6%), comparing with government's financing which only 3,8%. In fact, the largest proportion of barriers to accessing the assistive products is "Can't afford", both for spectacles and those without spectacles (51.3%; 67.7%). In terms of distance to obtain assistive products are generally within < 25 km from where the respondent lives (>90%).

Satisfaction to product; assessment and training; maintenance and repair, is quite high, not much different between with spectacles (78.1% - 82.2%) and without spectacles (74.9% - 86.7%). It is more or less the same in Suitability of Use in term of Home

and environment; Participation in activities; public environment, between 62.0% – 68.6% in with spectacles and 66.1% - 67.3% for without spectacles.

Table 4. Source, barrier, satisfaction and suitable of assistive product

No	Variable	With Spectacles (%)	Without spectacles (%)
1.	Source of assistive product		
1.1.	Public	6,5	9,0
1.2.	NGO	1,9	3,6
1.3.	Private	74,5	53,6
1.4.	Friends and family	12,5	18,7
1.5.	Self-made	3,8	16,9
1.6.	Other	2,4	1,3
1.7.	Do not know	1,1	1,7
2.	Funding		
2.1.	Government	3,8	3,8
2.2.	NGO	1,3	3,3
2.3.	Employer/school	0,7	0,0
2.4.	Insurance	1,9	1,8
2.5.	Out-of-pocket	64,7	44,6
2.6.	Friends or family	28,2	44,2
2.7.	Other	0,6	2,0
2.8.	Do not know	0,4	0,9
3.	Barrier to accessing assistive product		
3.1.	Not available	3,9	8,3
3.2.	Not suitable	4,0	4,5
3.3.	Too far	3,6	4,5
3.4.	No time	8,1	9,5
3.5.	No support	12,4	21,0
3.6.	Can't afford	51,3	67,7
3.7.	Stigma	2,6	2,8
3.8.	Other	0,5	0,7
3.9.	Do not know	0,3	0,5
4.	Travel		
4.1.	<5km	51,8	52,4
4.2.	6-25km	42,4	40,9
4.3.	26-50km	1,9	2,0
4.4.	51-100km	0,5	0,8
4.5.	100+km	1,0	1,3
4.6.	Don't know	2,3	8,5
5.	Satisfaction		
5.1.	Products	82,2	86,7
5.2.	Assessment and training	78,9	79,0
5.3.	Maintenance and repair	78,1	74,9
6.	Suitability of use		
6.1.	Home and environment	65,0	67,3
6.2.	Participation in activities	68,6	66,3
6.3.	Public environment	62,0	66,1

Spectacles have the largest proportion of assistive use (81%), far more than the use of others. This is in line with its prevalence. Spectacles also ranked first in the Assistive Product Unmet Need Rank and Assistive Product Need Rank. (Table 5).

Table 5. Prevalence of Use Assistive Products, Unmet Rank, and Need Rank

No	Type of assistive product	Proportion (%)	Prevalence (%)
1.	The use of assistive product		
1.1.	Spectacles; low-vision, short/long distance/filters etc	81.0	12.62
1.2.	Canes/sticks, tripod and quadripod	6.0	0.93
1.3.	Manual wheelchairs - push type	4.0	0.63
1.4.	Magnifiers, optical	3.0	0.47
1.5.	Axillary / Elbow crutches	2.2	0.34
1.6.	Incontinence products, absorbent	1.9	0.30
1.7.	Manual wheelchairs - basic type for active users	1.8	0.28
2.	Assistive product unmet Need Rank		
2.1.	Spectacles; low-vision, short/long distance/filters etc	59.9 %	4.1 %
2.2.	Hearing aids (digital) and batteries	11.3 %	0.8 %
2.3.	Smart phones/tablets/PDA (for communication)	4.8 %	0.3 %
2.4.	Chairs for shower/bath/toilet	2.6 %	0.2 %
2.5.	Grab-bars / Hand rails	2.6 %	0.2 %
2.6.	Wheelchairs, electrically powered	2.0 %	0.1 %
2.7.	Therapeutic footwear (diabetic, neuropathic, orthopedic)	2.0 %	0.1 %
3.	Assistive Product Need Rank		
3.1.	Spectacles; low-vision, short/long distance/filters etc	76.7 %	19.93 %
3.2.	Canes/sticks, tripod and quadripod	9.2 %	2.39 %
3.3.	Hearing aids (digital) and batteries	6.4 %	1.66 %
3.4.	Magnifiers, optical	3.7 %	0.97 %
3.5.	Manual wheelchairs - push type	3.5 %	0.92 %
3.6.	Chairs for shower/bath/toilet	2.3 %	0.59 %
3.7.	Time management products	2.2 %	0.58 %

4 Discussion

The World Report on Disability states that about 15% of the world's population lives with some form of disability whereas 2–4% of the world's population have severe difficulties in functioning without use of Assistive Technology. Findings from this study showed 32% of respondents have difficulty (some, a lot of, can't do at all) in doing certain activities because of a health condition, some respondents even experienced overall mobility difficulties, seeing, hearing, speaking, remembering or concentrating, and selfcare. Assistive Technology maintains or improves an individual's functioning and independence to facilitate participation and to enhance overall well-being [3]

This study found high proportion unmet need levels of "some difficulty", "a lot of difficulty" and "can't do at all" on with spectacles (>60%). Unmet need (population with no coverage) interpreted as the proportion of a population who need and do not use any Assistive Product (AP). Danemayer, J., et al., 2021, who conducted a systematic review of the need and coverage for five priority assistive products (hearing aids, limb prosthesis, wheelchairs, glasses and personal digital assistants), found a high unmet need (>60%) for each of the five AP [4].

In fact, from this Survey, the largest proportion of barriers to accessing the assistive products is "Can't afford", both for spectacles and those without spectacles (51.3%; 67.7%). This situation lead to phenomena of improving creation of AT. The research has shown numbers of self-made AT, using local resource material with modest technology.

The most common cases of difficulty found from this survey are difficulty in seeing (24.6%), mobility (11.4%), and hearing (5.4%). Berardi, A., et al, 2021, shows the most common unmet need in Canada was for hearing AT, followed by bathroom aids [5].

Related to blindness and impairment, WHO data shows, globally at least 2.2 billion people have a near or distance vision impairment. In at least 1 billion (or almost half) of these cases, vision impairment could have been prevented or has yet to be addressed. The leading causes of vision impairment and blindness are uncorrected refractive errors and cataracts. The majority of people with vision impairment and blindness are over the age of 50 years; however, vision loss can affect people of all ages [6].

In addition to vision, another problem related to health problems that require this AT is impaired mobility. Over one billion people with disabilities (PWDs) and older adults with mobility impairment are currently in need of assistive technology devices (ATDs) and only 10% of those population have ordinarily access to them [7].

WHO also estimates that by 2050 nearly 2.5 billion people are projected to have some degree of hearing loss and at least 700 million will require hearing rehabilitation. Over 1 billion young adults are at risk of permanent, avoidable hearing loss due to unsafe listening practices. Over 5% of the world's population, or 430 million people, require rehabilitation to address their 'disabling' hearing loss (432 million adults and 34 million children). It is estimated that by 2050 over 700 million people, or one in every ten people, will have disabling hearing loss [8].

This study also shows that respondents who living in urban areas had a greater proportion of assistive product use than rural areas. Respondents living in rural areas had a greater proportion of Unmet Need assistive products than urban in the group without spectacles. Karki, J., et al, 2021, from the study at Nepal, India, and Bangladesh found that there are significant discrepancies in available AT service provisions for people living in the urban and rural areas of each country [3]. AT service provisions are poorly developed in all three countries. Even there has been some increase in financial resources through the local Government in India and Nepal, but this is still insufficient. Therefore, the Governments should significantly increase their budgets for PWDs related activities and AT services. AT services are still treated as charities in all three countries rather than as a fulfilment of PWDs' rights [3].

The small role of government-sourced financing is also experienced in Indonesia where only 3.8% of financing for AT, compared to out of pocket which reached 64.7%

(with spectacles) and 44.6% (without spectacles). Different government funding schemes exist for AT provision in Indonesia. However, these schemes do not interact, are not fully utilized, and are operationalized through different procedures. These schemes include: government managed insurance including the National Health Insurance (known as JKN) and the Occupational Injury Benefit (known as JKK); Indonesia's central budgets such as the Ministry of Social Affairs' (MoSA) budget for AT; local government budgets; and village budgets such as Village Funds for PWDs. The allocation and utilization of available funding were still fragmented with no available national system to integrate the procurement and provision procedures within each scheme.

Lack of accessibility, eligibility, reachability and affordability are the main barriers to access AT services for PWD in Nepal, India and Bangladesh. This is not much different from in Indonesia, where affordability to Assistive Product is the most important, both for spectacles and those without spectacles. Furthermore, Tangcharoen-sathien, V., et al, explained four key gaps contribute to limited access on AT. First, although need is high, demand is low. Second, product designs are insufficiently informed. Third, barriers to supply. Fourth, there is a dearth of high-quality evidence on the effectiveness of different types of technology [9].

For the context of Indonesia, despite the existence of policies and implementation framework for disability rights including access to AT as well as clear functions and responsibilities between these ministries, there is a lack of a coordinated effort across ministries in Indonesia for increasing access to AT. With the recent shift to a decentralized system from central government to local, a large number of local governments and several additional ministries will be involved in the provision of AT. Procurement of AT is fragmented across numerous government and non-government actors, which leads to low volume, limited supply and high prices. Very few assistive products are included in the e-catalog limiting the visibility of available products, price points, and quality suppliers to the procurers, such as government units, health facilities. Significant gaps in the quantity and distribution of AT-related health workforce are also occurring. Meanwhile, AT access is higher in Java Island due to the availability of suppliers and service providers compared to other islands in Indonesia.

The Government had published national guidelines, standardizing some assistive products, and procurement standards. Meanwhile, those policies need to cover more assistive products, based on functionality and should be used as a reference by local government. National Standardization Body (BSN) established a new Assistive Technology Committee in 2020 to accelerate its Indonesia's National Standard.

5 Conclusion

The prevalence of people with significant difficulties is directly proportional to unmet need of AT. Result shown that the need of AT is increase with the increase of age. Due to gender aspect, the unmet need of AT for female is higher than male. In demographic aspect, the need of AT among urban community is remaining higher than rural. Contribution of government and insurance coverage for AT is limited, which made people have to raised self-fund. Affordability of AT is remain a barrier for most people. This

situation lead to phenomena of improving creation of AT. The research has shown numbers of self-made AT, using local resource material with modest technology.

6 Recommendation

Results are very beneficial and would be as main reference to further improving access to AT in Indonesia systematically, define priority of intervention, and remove the barriers. Recommendations for all relevant stakeholder are develop new strategies to improve access to AT, advocate to governments and civil society the unmet needs for AT, provide data to help plan or prioritize AT provision, design and deliver interventions to improve access to AT, evaluate the effectiveness of efforts to strengthen access to AT, measure progress towards AT targets; increase number of product and AT coverage through JKN, innovation of available local AT, strengthen appropriate intervention of primary health service.

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References

1. The National Team for The Acceleration of Poverty Reduction (TNP2K), 2020, Disability Situation Analysis, Challenges and Barriers for People with Disability in Indonesia
2. Ministry of Health, 2018, National Report of Basic Health Research 2018.
3. Karki, J., Rushton, S., Bhattarai, S., and Witte, L.D., 2021, Access to assistive technology for persons with disabilities: a critical review from Nepal, India and Bangladesh, Disability and Rehabilitation; Assistive Technology. <https://doi.org/10.1080/17483107.2021.1892843>
4. Danemayer, J., Boggs, D., Ramos, V.D., Smith, E., Kular, A., Bhot, W., Ramos-Barajas, F., Polack, S., Holloway, C., 2022, Estimating need and coverage for five priority assistive products: a systematic review of global population-based research. *BMJ Global Health* 2022;7: e007662. doi:10.1136/bmjgh-2021-007662
5. Berardi, A., Smith E.M., Miller, C.M., 2021, Assistive technology use and unmet Need in Canada, Nov;16(8):851-856. doi: 10.1080/17483107.2020.1741703. Epub 2020 Mar 24.
6. WHO, 2021, Blindness and vision impairment, <https://www.WHO.int/news-room/fact-sheets/detail/blindness-visual-impairment>
7. Alqahtani, S., Joseph, J., Dicianno, B., Layton, N.A., Toro, M.L., Ferretti, E., Tuakli-Wosornu, Y.A., Chhabra, H., Neyedli, H., Lopes, C.R., Alqahtani, M.M., de Vliet, P.V.,

- Kumagaya, S.I., Kim, J.B., McKinney, V., Yang, Y.S., Goldberg, M., Cooper, R., (2021) Stakeholder perspectives on research and development priorities for mobility assistive-technology: a literature review, *Disability and Rehabilitation: Assistive Technology*, 16:4, 362-376, DOI: 10.1080/17483107.2019.1650300
8. WHO, 2021, Deafness and hearing loss, <http://www.who.int/mediacentre/factsheets/fs300/en/>
 9. Tangcharoensathien, V., Witthayapipopsakul, W., Viriyathorn, S., Patcharanarumol, W., 2018, Improving access to assistive technologies: challenges and solutions in low- and middle-income countries, *WHO South East Asia J Public Health*. 2018 Sep;7(2):84-89. doi: 10.4103/2224-3151.239419.

Measuring Access to Assistive Technology using the Rapid Assistive Technology Assessment (rATA) Survey in Myanmar

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Abstract. Access to assistive technology (AT) is essential for many people to maintain and improve function, health and wellbeing, and quality of life. Although the need for Assistive Products (AP) is continue rising, only one in 10 people globally have access the AP they need¹. Furthermore, there is not sufficient data for AT in many countries around the world yet. We aimed to estimate the prevalence of assessing to AT, need and unmet need of AT, barriers, satisfaction and quality of AT services in Myanmar. Method: A nationwide cross-sectional household survey was conducted from June to August 2021 among 8,209 participants using two-staged cluster sampling methods. Results: In our study 29.4% of the study population needed any type of AP, among which seeing was 26.1% mobility 16.2%, cognition 15%, self-care 13.3%, hearing 9.1%, and 6.4% for communication. The private sector currently used AP accounted for 52.8%, while the public sector contributed only 6.6%. The prevalence of unmet need was 21.5%. It was highest among the elderly. Out-of-pocket payment (67.5%) was the main funding source of AP in Myanmar. Unaffordability was the major barrier to access to AP (38.4%). Majority of the people (66.1%) were satisfied with the assistive products they use. Conclusion: Outcomes of the rATA survey provided key information related to AP in the Myanmar population. Our findings pointed out the importance of formulating and implementing strategies to improve the accessibility of AP and enhance the fair financial opportunity for everyone who needs AP.

Keywords: Assistive Technology, Rapid Assistive Technology Assessment (rATA), Assistive Product, Need, Unmet Need, Barriers, satisfaction

1 Introduction

Assistive technology (AT) is essential for assisting the people with disabilities and those who need rehabilitation to manage personal activities of daily living without the assistance of another person. By using adaptive techniques and equipment, AT also minimize the need for external assistance for people who needs rehabilitation. It can also improve the social, economic, vocational, educational aspects of an individual's life and reduce the burden of disease.

Because of the rising trends of the ageing population, higher prevalence of injury and accidents, and non-communicable diseases, the need of AT will continue rising. Despite its benefits to help people promote independence and improve function, only one in 10 people globally have to access the AP they need [1]. Possible reasons for that are weak services of the assistive products in many parts of the world, people with more complex problems, people who are not aware of what they need, and poor socioeconomic status [2]. Furthermore, there is not sufficient data for AT in many countries around the world yet.

To solve this problem, according to the mandate of the resolution on “improving access to assistive technology (WHA71.8)”, WHO has developed the Rapid Assistive technology Assessment (rATA) survey to develop a global report on assistive technology (GReAT) in the context of an integrated approach, based on the best available scientific evidence and international experience [1]. Being the first-ever country to launch National Rehabilitation Strategic Plan under Global Rehabilitation 2030 [3], Myanmar has been one of the member countries to participate in developing the first global report on effective access to assistive technology by using rATAsurvey. With approval and guidance from Ministry of Health (MOH) Myanmar, technical support from WHO it was a great opportunity to generate evidence for improving access to AT, as increasing access and provision of assistive products is one of the strategic areas to be implemented in Myanmar National Rehabilitation Strategic Plan [3].

1.1 Aim

To obtain National data on access to assistive technology (AT), need and unmet need of AT, barriers, satisfaction, and quality of AT services in the population of Myanmar

2 Methodology

We conducted a cross-sectional, nationally representative population-based household study and collected the data from June to August 2021 in all 17 States and Regions except Kayah. A two-stage cluster sampling method supported by Department of Population was used. First, 268 clusters was selected from the whole country using probability proportion to size. Then, we randomly chose ten households from each cluster. We used the sampling weight to get a nationally representative estimate for all indicators. All household members from the selected households were eligible for this study. We did a proxy interview for the household members who could not provide

information regarding AT. We used a household survey tool– a rapid Assistive Technology Assessment (rATA), developed by the WHO. Data were collected using the mobile data collection tool to support countries in collecting such data in a systematic and rapid approach [1]. The detailed stepwise procedure of the study followed the Global Deployment Plan (GDP) developed by WHO as guidance for member states to obtain integrated evidence-based scientific data. The rATA is an interviewer-administered household survey either used stand-alone or to be incorporated into the broader population or household surveys or national census. The survey was simple to administer and non-technical so that enumerators selected by Myanmar Red Cross Society (MRCS) were able to use it from varied backgrounds and experiences and across cultures and contexts. We provided the online enumerators training before the data collection. Pilot training and field testing of data flow practice with WHO technical team and enumerators from Yangon Division were carried out before the enumerator training. A total of 8,209 participants (Male = 3886, female = 4323) were included in this study. Data collection was done online using ArcGIS survey 123 application. STATA version 15.1 was used for data analysis.

3 Result

Table 1 shows the background characteristics of the study population. In our study, 29.4% of the study population needed any type of AP. Among them, seeing was 26.1%, mobility 16.2%, cognition 15%, self-care 13.3%, hearing 9.1%, and 6.4% for communication (Table 2).

The national prevalence of at least one AP currently used was 17.8%. The prevalence among males was not significantly different from that of females (18% vs. 17.6%, $P=0.594$). The urban prevalence was significantly higher than the rural prevalence (24.1% vs. 15.9%, $P<0.001$). The prevalence was highest in Nay Pyi Taw, a capital of Myanmar, (38.7%) and lowest in the Bago region (10.3%). The prevalence of unmet needs was 21.6%. It was statistically different by age group ($P<0.001$) and region ($P<0.001$). It was highest among the elderly. Regional variation also existed, i.e., highest in Kachin state and lowest in Tanintharyi region (36.1% vs. 6.7%). See details in Table 3.

The private sector was the major source of currently used AP, accounting for 52.8%, while the public sector contributed only 6.6% of AP. Out-of-pocket payment (67.5%) was the primary funding source of AP in Myanmar. Unaffordability was the major barrier to access to AP (38.4%). The majority (66.1%) were satisfied with their assistive products (Table 4). Only 6 % of participants responded that their products were not suitable for them.

Table 1. Background characteristics of the study population (N=8209)

Variables	N	%	Variables	N	%
Region			Age group (Yr)		
Kachin	360	4.4	0-4	311	3.8

Kayin	308	3.8	5-17	1468	17.9
Chin	256	3.1	18-29	1509	18.4
Sagaing	1148	14.0	30-39	1180	14.4
Tanintharyi	252	3.1	40-49	1261	15.4
Bago	712	8.7	50-59	1117	13.6
Magway	679	8.3	60-69	780	9.5
Mandalay	779	9.5	70-79	411	5.0
Mon	413	5.0	80+	171	2.1
Rakhine	553	6.7			
Yangon	705	8.6	Settlement		
Shan (South)	334	4.1	Urban	1889	23.0
Shan (North)	231	2.8	Rural	6320	77.0
Shan (East)	255	3.1	Total	8209	100
Ayeyarwady	979	11.9			
Nay Pyi Taw	245	3.0			
Sex					
Male	3886	47.3			
Female	4323	52.7			
Total	8209	100			

Table 2. Types of needs for AP, the association of any type of AP by sex and settlement

Variables	%	95% CI	N
Any type	29.4	[28.4, 30.4]	2,503
Seeing	26.1	[25.2, 27.1]	2,270
Mobility	16.2	[15.4, 17.0]	1,403
Cognition	15	[14.2, 15.8]	1,261
Self-care	13.3	[12.6, 14.0]	1,160
Hearing	9.1	[8.5, 9.8]	765
Communication	6.4	[5.9, 7.0]	553
	Proportion	95% CI	P value
Any type by sex			0.023
Male	28.2	[26.8, 29.6]	
Female	30.5	[29.1, 31.9]	
Any type by settlement			<0.001
Urban	34.3	[32.2, 36.5]	
Rural	27.9	[26.8, 29.1]	

Table 3. Current use of AP, unmet need of AP, and their association with sex, settlement, age group and region.

	Current use of AP			Unmet need		
	%	95% CI	P-value	%	95% CI	P-value
All	17.8	[16.9, 18.6]		21.6	[20.6, 22.4]	
By Sex			0.593			0.078
Male	18.0	[16.8, 19.3]		20.7	[19.4, 22.0]	
Female	17.6	[16.5, 18.7]		22.3	[21.1, 23.6]	
By Settlement			<0.001			0.563
Urban	24.1	[22.2, 26.1]		21.0	[19.2, 22.9]	
Rural	15.9	[15.0, 16.8]		21.6	[20.6, 22.7]	
By age group			<0.001			<0.001
0-4	3.0	[1.6, 5.7]		12.7	[9.3, 17.1]	
5-17	3.2	[2.4, 4.2]		8.2	[6.9, 9.8]	
18-29	9.0	[7.6, 10.6]		9.2	[7.8, 10.9]	
30-39	7.9	[6.5, 9.6]		14.6	[12.7, 16.9]	
40-49	20.3	[18.2, 22.6]		25.6	[23.3, 28.1]	
50-59	30.3	[27.7, 33.1]		33.3	[30.6, 36.1]	
60-69	39.1	[35.8, 42.5]		38.2	[34.9, 41.6]	
70-79	44.1	[39.4, 48.9]		50.8	[46.0, 55.6]	
80+	54.1	[46.8, 61.4]		53.5	[46.1, 60.8]	
By region			<0.001			<0.001
Kachin	19.1	[14.7, 24.5]		36.1	[30.4, 42.1]	
Kayin	25.2	[20.1, 31.2]		26.9	[21.6, 32.9]	
Chin	20.1	[14.8, 26.6]		34.7	[28.1, 42.1]	
Sagaing	17.1	[14.8, 19.4]		31.1	[28.4, 34.0]	
Tanintharyi	10.8	[7.2, 15.8]		6.7	[4.1, 11.1]	
Bago	10.3	[8.5, 12.4]		12.7	[10.7, 15.0]	
Magway	12.2	[10.1, 14.8]		18.7	[16.1, 21.6]	
Mandalay	21.9	[19.2, 24.9]		25.9	[23.0, 28.9]	
Mon	16.5	[13.6, 20.0]		17.3	[14.3, 20.8]	
Rakhine	13.1	[10.4, 16.2]		16.6	[13.6, 20.1]	
Yangon	26.8	[24.2, 29.6]		20.6	[18.3, 23.2]	
Shan (South)	16.5	[12.7, 21.2]		27.4	[22.6, 32.8]	
Shan (North)	11.2	[7.5, 16.3]		16.1	[11.6, 21.8]	
Shan (East)	17.7	[13.3, 23.2]		20.0	[15.3, 25.6]	

Ayeyarwady	16.2	[14.2, 18.5]	14.6	[12.7, 16.7]
Nay Pyi Taw	38.7	[32.4, 45.4]	16.4	[11.9, 22.1]

Table 4. Frequency distribution of source and funding of main AP and barriers and reasons for not having AP in need.

Variables	N	%
Source of main AP (N=1214)		
Private sector	641	52.8
Self-made	334	27.5
Friends/family	181	14.9
NGO sector	95	7.8
Public sector	80	6.6
Other	19	1.6
Don't know	6	0.5
Funding of main AP (N=1214)		
OOP	819	67.5
Family/friend	356	29.3
NGO/charity	89	7.3
Government	46	3.8
Employer/school	10	0.8
Insurance	6	0.5
Other	6	0.5
Don't know	13	1.1
Barriers and reasons for not having AP (N=1811)		
Not available	206	11.4
Not suitable	134	7.4
Lack of transport	149	8.2
Lack of time	33	1.8
Lack of support/too far	264	14.6
Cannot afford	695	38.4
Stigma/shyness	13	0.7
Other	80	4.4
Don't know	125	6.9

4 Discussion

Out of 8209 participants, 77% of respondents were from rural and 23% were from urban area. Myanmar's population is 54.1 million, and according to the inter-censal survey

2019-2000, the Disability prevalence rate has been revised to 12.8% (5,968,986) while the WHO South-East Asia estimates 16% [5].

As Myanmar has variable geographical regions with 7 major ethnic groups, majority of enumerators are able to speak local language, and only a few interpreters were needed during the interview of household survey in some remote areas. The survey underwent cultural adaptation through coordination meetings with MRCS supervisory committees from all regions, AP users, leaders of Disabled People's Organizations, NGOs, INGOs, and development partners, community leaders. Most importantly, safety precautions for COVID-19 pandemic have been strictly carried out for all enumerators and participants during the data collection in the field.

In our study, 29.4% of the study population needed any type of AP. Women had more functional difficulty than men and it was more prevalent in urban areas. Among the study population who needed assistive products, seeing was the most prevalent 26.1%, mobility (16.2%), and self care (13.3%). The national prevalence of at least one AP currently used was 17.8%. The prevalence was highest in Nay Pyi Taw, a capital of Myanmar, (38.7%) which indicates people from rural areas have less awareness about use of AP. The prevalence of unmet needs was 21.6%. People living in the urban area need more AP than those living in the rural area. Regarding the age, the older the age group, the more they need assistive products.

In the study of Wesley Pryor et al. from household survey from two districts of Bangladesh by using Assistive Technology Assessment- Needs (ATA-N) survey, 7.1% of studied population used any AP and it's positively associated with age and self-reported functional difficulty. Of all the people with any functional difficulty 71% self-reported an unmet need for AP [7].

In a study of perceived unmet needs, during home visit in Southern Sweden, out of 371 individuals, the most common types of AP used were for furnishing/ Adaptation (35%). The highest perceived unmet need concerned for communication in total 8% as the study population is 3rd age people [8].

Private sector was the main source of AP which has been followed by self-made especially in rural areas. Main funding source for AP was Out Of Pocket payment. Our findings clearly pointed out Availability and accessibility of AP should be expanded in the public sector through the implementation of National Rehabilitation Strategic Action Plan.

Unaffordability was the major barrier to access to AP (38.4%). The majority (66.1%) were satisfied with their assistive products. Only 6 % of participants responded that their products were not suitable for them.

Outcomes of rATA survey provide many essential information to improve accessibility, and provision of quality assistive products for those who need AT in Myanmar. Having the concrete information of rATA survey outcomes, we have an opportunity to study more about the quality service provision for AT at all levels of health care, training of workforce, increase financing for AT, development of priority AP list, advocacy and development of Policy and guidelines for AT.

5 Conclusion

Outcomes of the rATA survey provided key information related to AP in the Myanmar population. About one-third of Myanmar's population needs AP for their daily activities, and one-fifth of the population encounters an unmet need for AP. Our findings pointed out the importance of formulating and implementing strategies to improve the accessibility of AP and enhance the fair financial opportunity for everyone who needs AP.

Policymakers and program managers should be used the study's findings to understand the need, demand, and barriers to access AT in the population. Moreover, it is also valuable to advocate and raise awareness to conduct policy dialogues and formulate policy guidelines for Assistive Products according to the National Rehabilitation strategy.

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References

1. World Health Organization (2018) Assistive technology factsheet. <https://www.who.int/en/news-room/factsheets/detail/assistive-technology>
2. World Health Organization (WHO): A Rapid Assistive Technology Assessment (rATA) Concept note for the global data collection in measuring access to AT.
3. Myanmar National Rehabilitation Strategic Plan (2019-2023): The Republic of the Union of Myanmar
4. World Health Organization (2016). Priority Assistive Products List (<http://www.who.int>)
5. A Situation Assessment of Rehabilitation in the Republic of the Union of Myanmar (2019), Ministry of Health and Sports, the Republic of the Union of Myanmar
6. World Health Organization (2020). Measuring Access to Assistive Technology using the Rapid Assistive Technology Assessment (rATA) Global Deployment Plan v.2020.08
7. Pryor, W. Nguyen, L., I, Naher Islam. Q (2018) Unmet Needs and Use of Assistive Products in Two Districts of Bangladesh: Findings from a Household Survey Int. J. Environ. Res. Public Health 15, 2901;doi:10.3390/ijerph15122901
8. Lofqvist Charlotte et.al (2014). Use, non-use and perceived unmet needs of assistive technology among Swedish people in the third age. (<https://doi.org/10.3109/17483107.2014.961180>)

Understanding the Needs of Assistive Products in Mongolia through WHO's rATA Survey

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Abstract. Mongolia conducted a rapid Assistive Technology Assessment (rATA) survey in 2021 using an assessment tool developed by the World Health Organisation (WHO). The survey involved different Government and non-governmental stakeholders. The country was divided into 4 regions and using a 2-step random sampling method, 137 clusters were identified for the survey, including 2 provinces in each region. A total of 2,868 households and more than 10,000 persons were interviewed. The data was analysed by a team from WHO. This paper explains the challenges linked to conducting such a large survey in Mongolia due to its geographical and demographic characteristics. It also presents the main findings from the rATA survey and how these findings can be used for strengthening the access to assistive technology services in the country.

Keywords: Mongolia, rATA survey, Assistive Technology.

1 Background

1.1 Introduction

Mongolia had signed and ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2009. In 2016 the Government of Mongolia passed the National Disability Law in line with the provisions of CRPD (1). For example, art. 11 of the law asks for ensuring that all information and communication services are accessible to persons with disabilities, while art. 21 ensures the provision of assistive products through different insurance and welfare funds.

Ministry of Labor and Social Protection (MLSP) is responsible for the provision of assistive products to persons with disabilities and elderly persons with functional

limitations. MLSP has conducted surveys to understand the gaps in the AP provision services. For example, a survey (2) conducted in 2019 had shown that around 81% of the beneficiaries of assistive products were elderly persons. It also showed that persons in rural areas had limited understanding about the usefulness of assistive products, they face many difficulties in receiving the necessary products and in getting them repaired.

In 2019, the Government of Mongolia signed an agreement with Asian Development Bank (ADB) for ensuring inclusiveness and service delivery for persons with disabilities. Output 2 of this collaboration focused on strengthening of different services for persons with disabilities including the services for provision of assistive products and the establishment of 6 model development and rehabilitation centers. (3) A review of the existing assistive technology (AT) services and a strategy for strengthening it has been proposed, which needs to be formalized by the Government. Ministry of Health is developing National Rehabilitation Action Plan (2021-2026) including the assistive products with the technical support of WHO. (4)

The proposal from WHO to conduct a rapid Assistive Technology Assessment (rATA) in Mongolia arrived when all the different initiatives to strengthen the national AT services were being planned and implemented.

1.2 Planning rATA Survey

WHO provided the technical and financial support for conducting the rATA survey. Ministry of Health (MOH) acted a leading organization to conduct the rATA at national level (August 2020). National Disability Coordinator (NDC) is appointed from MOH. When NDC is appointed from MOH, National Statistics Office (NSO), Ministry of Labor and Social Protection (MLSP) and Italian association “Amici di Raoul Follereau” (AIFO), working in Mongolia since 1991 in disability field were invited for a meeting (October 2020). 4 persons from above-mentioned organizations (MLSP, NSO, AIFO and WHO/CO) attended in 3 days long online master training conducted by WHO in November 17-19, 2020. After the master training, MOH decided to appoint National Development Center, the agency of MOH to conduct the rATA survey at national level (Order No. A/246, Minister of Health, April 22, 2021). WHO employed national consultant to support to the organization to conduct the rATA survey. The national consultant is from AIFO, who worked in Mongolia since 1991 implementing Community based rehabilitation program for the persons with disabilities (CBR) in collaboration with MOH. NSO played a role of calculating sample size and approving the methodology to be used for data collection of national representative household survey.

1.3 Objectives

To conduct a sample survey in different provinces of Mongolia to understand the coverage and uncovered needs of different kinds of assistive products among different age groups through the Rapid Assistive Technology Assessment (rATA) survey methodology developed by the World Health Organization.

2 Methodology

The standard methodology developed by WHO was used for conducting rATA survey in Mongolia. 4 persons (MOH, NSO, WHO/CO and AIFO, INGO) from Mongolia took part in the training of the trainers' workshop organized by WHO. This was followed by the development of action plan for conducting rATA survey and an agreement was signed between the Government (Ministry of Health) and WHO.

Different Government organizations (Ministry of Health, Health Development Center and National Statistics Office) as well as some non-governmental organizations (Tegsh Niigem NGO and "Universal Progress" Independent Living Center) were involved in the data collection exercise. This posed additional challenges in conducting and coordinating the data collection.

National Statistics Office (NSO) in Mongolia calculated the sample size using two-step, random sampling method. Total of 137 clusters were selected using proportional method taking into consideration of WHO suggestion, which is 10% of non-responsive rate and 30% of relative error and 95% of confidence level.

According to the Statistics of Mongolia by the end of 2020 there are 3.25 million people living in 908.7 thousand households. The average household size is 3.58.

Since Mongolia has huge territory and scares living, NSO selected 2 aimags (provinces) from 4 (western, khangai, eastern and central) regions and Ulaanbaatar, the capital city. A random sample of 2740 households were identified from 8 aimags (provinces) and Ulaanbaatar 6 districts representing all the different regions of the country using proportional method.

A total of 70 enumerators (5 enumerators from each 14 enumeration areas) and 14 supervisors (1 from each 14 enumeration areas) were trained and data collection was carried out between October 30 and 25 November 2021. The duration of data collection was varied from 9 to 23 days on the basis of the destination of the territory and size of the population. Average number of households to be visited per day was calculated that 2 enumerators visit to 5 households on average and at least 15 households will be visited by a team of 6 enumerators and supervisors.

Enumerators from above-mentioned two non-governmental organizations collected data from selected enumeration areas. The selection of supervisors relied on the experience of working with persons with disabilities in Mongolia CBR program between 1991-2015. Supervisors from enumeration areas supervised the data collection in the field.

2.1 Process of Conducting rATA Survey and Specific Challenges Faced during the Survey

Mongolia has a large geographical area with a small population and a very low population density. In winters, the country experiences very low sub-zero temperatures and field visits are difficult. rATA survey in Mongolia was conducted in these specific conditions, which posed specific challenges to data collection: (1) Climate: rATA survey in Mongolia was conducted in November, which became low sub-zero condition. Convenient condition to conduct survey in Mongolia is March to June and September to

October. But the rATA survey couldn't be carried out in convenient condition owing to different bureaucratic steps. (2) Geographical distance: Households, especially those who live in nomadic area (village) live far from each other. In some area there are around 20 km between two households. The road is unpaved. Survey time is spent for travelling to the selected households. The farthest sum (village) was 520 km in one way from aimag (province) center. One of the enumeration areas was "Tsaatan" /Reindeer herders/ minority, who lives in snowy mountain "Taiga". Reindeer herders were living 452 km in one way from aimag center. The enumerators needed to rent reindeers to reach to the Reindeer herders. Enumerators were also needed to go on ice to reach to "Hanh" sum, at the Russian border. (3) Due to COVID-19 pandemic, the majority of the households, especially in Ulaanbaatar, the capital city and aimag (province) centers, were not allowed to enter their homes. So the enumerators needed to collect data while standing outside. (4) Address of Ulaanbaatar was not well structured. District and sub-district personnel were helping to the enumerators to find the selected households, it was challenging to find the households, especially in Ger district.

3 Results

A total of 2868 households were visited during the survey covering a total sample of 10,739 persons, including 9,687 persons (90.2%) of less than 59 years and 1,052 persons (9.8%) above 60 years. The data entry forms were checked by the supervisors and national data coordinator, corrected and cleaned. The data was sent to WHO for analysis.

Total of 9960 persons' responses were collected, including 531 responses from minors who were not accompanied by a family adult during the interview. All the responses have been included in the analysis presented here.

Among the APs, spectacles were the most commonly used AP, needed by more than 71.8% AP users. Other most frequently used products included canes/sticks 11.5%, crutches 6%, magnifier 5.8%, hearing aids 5.6%, spinal orthosis 4.8%, bath/toilet chair 4.1%, manual wheelchairs 2.7%, pill-organizers 2.3% and manual wheel-chairs 1.6%.

To improve a better the understanding of remaining data, information about spectacles-users has been excluded for this analysis.

3.1 Coverage of Assistive Products Excluding Spectacles in Mongolia

Globally 8.1% of persons in Mongolia needed APs excluding spectacles and 2.3% had received them and 5.8% of individuals had unmet needs. In terms of gender, 7.4% of the men needed APs, 1.1% had them and 5.3% had unmet needs; among women, 8.7% needed, 2.5% had them and 6.2% had unmet needs.

In terms of age, in the below 59 years, total need was 4.4%, among whom 1.3% had received APs while 3.1% had unmet needs. In the above 60 years, the total need was 37.6%, among whom 10% had received the APs while 27.6% had unmet needs.

In urban areas, the need for APs was among 7.8% of the population and 2.7% had received them, while 5.1% had unmet needs; while in the rural areas, the need was 8.2% and 2% had received them and 6.3% had unmet needs.

In terms of source of AP provision, the Government covered 24.6% of the need, about 48.2% was covered by private sector and the remaining 27.2% of the APs were covered by different sources such as NGOs, self-made, and friends and families.

In terms of funding for APs, the three biggest sources were - Government which covered 23.1%, out of pocket by individuals covered 53.5%, and family-friends who covered 20.3%. The remaining 3.1% costs were covered by other sources including NGOs.

50.5% of persons identified lack of support and funds as the principal barrier for not having an AP. Other barriers were 8.8% non-availability, 7.4% non-suitability, 3.9% distance, and 5.1% lack of time. Only 2.8% identified stigma as a barrier.

Around two-thirds of the respondents had found the APs at less than 50 km including 35.7% who had found it at less than 5 km, while one-third of the respondents had to travel to more than 50 km to receive them including 20.7% who had to travel for more than 100 km.

The level of satisfaction among persons who have already received the assistive products was good in 63.7%, about 30.7% of users were neutral and about 4.5% were unsatisfied with the APs. The level of satisfaction with the after-delivery services such as follow-up, repair and maintenance, was much lower.

93.5% of the users felt that the APs were moderately to highly suitable for them, while 6.5% felt that the APs were unsuitable.

4 Discussion

The analysis of the rATA shows the gaps between males and females, where females have greater uncovered needs (6.2% compared to 5.3%); and, between rural areas and urban areas, where rural areas have greater unmet needs (6.3% compared to 5.1%). However, the biggest challenge seems to be among elderly persons compared to younger persons (27.6% compared to 3.1%).

Another issue for the decision-makers would be regarding the high percentage of costs (around 74%) for the APs covered by the individuals and their families, while the Government contribution covers only 23%.

While the user satisfaction and suitability of the APs for the users show higher prevalence of positive comments, this is probably also influenced by the products acquisition from personal funds.

As the rATA survey implementation coincided with the plans for the review and strengthening of the national assistive technology services in Mongolia, these findings will provide a necessary background to identifying strategies to answer these challenges.

5 Conclusions

Conducting rATA data collection exercise in Mongolia had posed some specific challenges linked to its geography and climatic conditions, as it was conducted in winter when temperatures reach below zero temperatures and reaching the rural areas becomes problematic. Another challenge was to bring together the different stakeholders in completing this exercise.

At the same time, the survey has provided some very important information about specific assistive products and their unmet needs among the different age groups, which will help Mongolia to strengthen and improve its assistive technology services and set-up a disability and assistive technology related database.

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References

1. National Law on the Rights of Persons with Disabilities, Government of Mongolia, Ulaanbataar, Mongolia, 05 February 2016
2. Assessment of implementation of social welfare programmes: Assistive products for elderly persons, adults with disabilities and children with disabilities, Labour & Social Protection Research Institute, Ministry of Labour and Social Protection, Ulaanbataar, Mongolia, 2019
3. Project “Ensuring Inclusiveness and Service Delivery for Persons with Disabilities Project” (Proj. n. 48076-002), Asian Development Bank, Manila, Philippines, 2019
4. Mongolian National Rehabilitation Strategic Plan 2021–2026, Ministry of Health, Ulaanbataar, Mongolia, 2021

Closing the Digital Divide: Competence Development in AT and Accessibility



Addressing Assistive Technology Training Needs in Education

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Abstract. Enable Ireland's Assistive Technology Training Service has a long history in providing training to stakeholders in the assistive technology ecosystem, and anecdotal evidence showed the need specifically for training for primary school educators and those who support students at primary level, including class and support teachers, school principals, Special Needs Assistants, and family. In 2021 a short taster eLearning course, focusing on primary school assistive technology resources, approximately one hour in duration, was made available free of charge. The course received a positive response, with over 850 enrollees in 8 months, with a completion rate of approximately 20% (average completion rate of self-enrolled courses is 5-15%). This demonstrated that there was a strong appetite for more training and information provision around assistive technology for education. This paper will summarise the development of resources in response to the above need. Central to Enable Ireland's conceptualisation of this eLearning resource was the goal of providing content equally to teachers, special needs assistants and parents. Modules included a focus on mainstream accessibility options; specialised hardware; software; and apps that targeted the principal areas of the primary school curriculum in Ireland. Central to this was inclusion of information on Universal Design for Learning, to ensure that classroom interaction could be adapted for the use of assistive technology by students. The SETT (Student, Environment, Task and Tools) assessment model by Joy Zabala, was described in detail. Content also addressed the areas of Language, Maths, Arts and Physical Education. Uniquely to this assistive technology course was the area of technology for the Irish language. This paper will discuss the design of the course, reviewing content in many different formats, including written, auditory, visual as well as practical tasks to reinforce the knowledge and skills discussed. Accessibility of the course to participants was of a high priority, and efforts were made to ensure that all content was presented in a manner compliant with Universal Design for Learning. Feedback received from participants will also be present and planned changes to the content and format are discussed. The eLearning course can be accessed through the Enable Ireland Moodle website at Learning with Assistive Technology - Primary Level (enableirelandat.ie) (<https://enableirelandat.ie/course/view.php?id=48>)

Keywords: Education, eLearning, Universal Design for Learning,

1 Background

1.1 Identifying the Need for Assistive Technology Training in the Education Sector

Enable Ireland's Assistive Technology Training Service has a long history in providing training since its establishment in 2001. The primary focus of the service was to provide information and upskill those working in front line positions with current and potential Assistive Technology users.

In the first instance, anecdotal evidence showed the need for training in assistive technology, through regular contacts with school staff and family members while supporting learners with additional needs.

In 2021, a short taster eLearning course, focusing on primary school assistive technology resources, was made available free of charge, through Enable Ireland's Moodle site. This course was approximately 1 hour in duration and provided a high-level overview of the areas of assistive technology applicable to the primary school setting, including information on access, language and numeracy supports.

This taster course received a very positive response. Over 850 participants enrolled in the course over an 8-month period. Completion rates were approximately 20%, which compared to an average completion rate in self enrolled MOOC courses is between 2.5 and 19% [1], was extremely positive. Feedback from the course indicated that there was a strong appetite for more training and information regarding assistive technology for education.

1.2 Identifying the Audience

Considering the differing profiles and needs of learners across the preschool, primary, secondary, and tertiary levels of education, it was decided to focus on one level at a time. As most learners are introduced to technology to assist with access to the curriculum in primary school (usually aged 5-12 years in Ireland), this was decided upon as the focal point of the first course, with plans to create training resources focusing on secondary, preschool and the special school settings in the future.

The audience targeted included class and support teachers, school principals, Special Needs Assistants (SNAs) and family. Given the rise in homeschooling during the pandemic, reaching parents/guardians and homeschooling communities were also considered.

Research into teachers' eagerness to be involved in further training was investigated and published as part of a report by the Economic and Social Research Institute in 2011 [2]. It was noted that up to 70% of teachers were keen to update their skills and knowledge.

1.3 Identifying the Scope of the Content

In planning the content to be included in the course, a review of the prescribed primary school curriculum, designated by the National Council for Curriculum and Assessment

[3] was conducted to see the areas covered and the individual strands within those subject areas. There are no state examinations carried out at primary level, but guidance is given to schools around assessment of the various subject areas. As such, rather than focusing on passing standards for exams, emphasis was placed on being able to interact with and produce work according to the curriculum strands. This is in line with the principles of Universal Design for Learning.

Within the primary curriculum, seven areas are explicitly identified, and further subdivided into subject areas. It was decided to focus on four areas of the curriculum, and these will be further discussed below.

1.4 Identifying the Delivery Method of the Content

A number of factors influenced the decision to create the resource as an online entity, including the global pandemic, which prevent the delivery of training sessions in real time, face to face settings. Also, given the difficulty in educators accessing cover and other resources to attend live training events, an online, self-paced course allowed the training to be completed in their own time, without an extended absence from working with learners. As an online resource, educators also could revisit and reference content on an as needed basis, rather than the once off nature of a live event.

2 Course Design

2.1 Universal Design for Learning (UDL)

Universal Design for Learning focuses on a set of principles for curriculum development that gives all individuals equal opportunities to learn, including Students with Disabilities [1]. UDL was central to the design of the course, from two key perspectives.

2.2 UDL in Course Design

This course was designed with UDL principles in mind for the individuals undertaking it. In short, the three main principles of Multiple Methods of Engagement; Multiple Methods of Representation; and Multiple Methods of Expression/Action [5] were applied to the development of the course content.

Multiple Means of Representation. Content was made available in multiple formats, including text, audio, and imagery (photographs and video), and content was checked for accessibility, so that it would be capable of converting to other formats if required by those undertaking the course. Videos were subtitled and images described in Alternative Text. Summaries of key point were provided at the end of sections.

Multiple Means of Action and Expression. As the content was presented in a time free manner, participants could elect when to engage with the content. Additionally, options were provided around showing comprehension of the materials, including quizzes and multiple-choice questions, engagement in forums, completion of set tasks,

engagement with social media etc. Participants were guided to complete a reflective journal as part of the course content, which could be collated at the end for their own reference.

Multiple Means of Engagement. To maintain engagement with the course materials, efforts were made to include motivators for the participants to personalize the knowledge and skills gained. This included trying out assistive technology options for themselves, proving case studies and anecdotes on how various solutions could be used in the classroom setting etc.

2.3 Universal Design for Learning in Course Content

As part of this course, rather than simply providing content on various assistive technology options available, a strong emphasis was placed on how these solutions could be integrated into the classroom to achieve learning goals for the individual learner. As mentioned above, UDL was embedded into the course design, but a module was also included on explaining UDL to the educators undertaking the course. This was a high priority of the course developers, to ensure that the technology introduced would be used to achieve these goals appropriately, rather than creating another barrier.

This content was outsourced to another agency [4], specializing in creating inclusive environments for people with disabilities in education. These modules looked at explaining UDL and how its principles could be applied to the classroom, and adaptations made for those following a reduced or adapted curriculum.

2.4 Content Platform

Moodle was used as the platform for hosting and presenting the course. As well as having a strong track record of being an accessible platform, proving multiple ways of presenting and interacting with content, it was also an established platform in use by Enable Ireland's Assistive Technology Training Service. Outside expertise was sourced to help ensure that all content provided reached the desired level of accessibility.

Moodle badges were also utilized to encourage engagement and completion. The length of time required for completing each section was outlined on the initial screens, so that participants could self-pace their timing.

2.5 Emphasis on Free/Inbuilt Tools

Given the audience of the course, an emphasis was placed on presenting free and inbuilt tools across platforms as part of the course design. There were multiple reasons for this. Having access to easily access solutions meant that educators could try out options without the need for expensive technology and resources. It also made these solutions more readily available for use with learners. Inbuilt tools were designed to work consistently with main office applications such as word processors, spreadsheets etc.

3 Course Content

3.1 Overview

The course was subdivided into a welcome and summary section, as well as six content areas.

3.2 Welcome and UDL Sections

The initial section of the course provided an overview of the entire course, including the learning objectives. A pre-course survey was also administered. Content presented here included definitions of assistive technology, as well as assessment models. Emphasis was placed on the SETT (Student Environment Tasks and Tools) model, by Joy Zabala [6], as it was designed for use in educational setting, and was most appropriate to this course.

Following on from the above, the concept of Universal Design for Learning is introduced, as mentioned above.

Resources, both general to the area of Assistive Technology and specific to UDL were provided following the content presentation.

Both sections included interactive, reflective exercises for participants to apply learning.

3.3 Access

One of the larger sections of the course focused on access. This included content on ergonomic issues for those learners who did not require specialised Assistive Technology, along with information on alternative keyboards and mice; mouse alternatives, such as eyegaze and head pointing; switches; and speech recognition. Access concerns stemming from sensory issues were also addressed. An emphasis was placed on inbuilt accessibility features across all operating systems.

Resources such as web links to free trials and demonstration software were provided, so the participants could trial solutions themselves.

3.4 Language

Content in the language section followed the outline for the curriculum, as provided by the National Council for Curriculum and Assessment. As such, it was subdivided into Oral Language, Writing and Reading. In addition, under Oral language, Alternative and Augmentative Communication (AAC) was explored. Unique to this course was the exploration of supports for learners regarding the Irish language curriculum.

Tools and strategies to support language under each of these headings were explored, again placing emphasis on how UDL could be applied to their inclusion in the classroom.

3.5 Maths

Options regarding numeracy skills were explored. These focused on the strands of the curriculum, but also covered how premade classroom materials such as workbooks could be adapted.

3.6 Arts

The three strands of the Arts curriculum were examined – Visual Arts, Drama, and Music. In particular, resources mentioned in the Drama section could be adapted to assist in other areas of the curriculum, including interaction in the classroom, and managing behaviour.

3.7 Physical Education

Some resources specific to physical education are discussed in this section, but it also allows for the use of tools that while may not directly involve the curriculum targets, help learners remain on task, interact with peers etc.

3.8 Summary Section

A summary section sought to review key point in relation to UDL and the Assistive Technology presented throughout the course. A feedback survey was included, and links provide to other sources of information and suppliers.

4 Pilot Study

Prior to the launch of the course, a pilot study was conducted in March 2022. Participants were selected from a list of those who had engaged with Enable Ireland's Assistive Technology Training Service in the past and offered free enrollment.

4.1 Feedback

Feedback was received from six of the twenty people who piloted the course. Of these six people, four were teachers, and one was a Special Needs Assistant. All engaged in supporting current and potential AT users.

When asked to select from a list of words to describe the course, options elected included "Essential," "Interesting" and "Relevant".

All would recommend the course to colleagues.

When asked to rate how useful individual modules were to their individual set of circumstances, all the content modules were considered "very useful". The welcome section was considered useful by two participants, and neutral by one. The summary section was considered useful by one, and all other considered it very useful. In all this was a positive response to the content of the course.

When asked to rate how usable the participants found Moodle, most rated activities such as creating an account, enrolling, editing profiles, navigating, interacting with

quizzes, and continuing from where they left off as either easy or very easy. One person noted downloading a file as difficult.

When asked to rate statements about the course structure, positive responses were received regarding vocabulary used, reflective exercises, learning goals, and the level of content presented. One person disagreed that the structure was clear and easy to follow. When asked about having an opportunity to interact and learn from other participants, two participants were neutral, while four expressed an interest in this.

4.2 Changes to the Course

From the feedback received, there were overwhelming positive opinions of the course.

One of the areas highlighted was the opportunity to interact with other course participants. As the course is not presented in real time, but as self-directed learning, one way we are looking to address this is through the use of social media. A hashtag was developed (#LearningWithAT) for use across multiple platforms, including Facebook, Twitter, and Instagram. We are actively encouraging participants to use this to post, find related content and interact with peers who have partaken in the course.

5 Conclusion

The development of this course sought to fulfill an identified need for more training in the Ireland regarding Assistive Technology usage and integration in primary education.

Positive feedback from the pilot stage, with minimal editing to the course, means that it can be launched to educators and others involved or interested in supporting learners in the primary education sector in Ireland in May 2022.

References

1. Khalil, H. & Ebner, M. (2014). MOOCs Completion Rates and Possible Methods to Improve Retention - A Literature Review. In J. Viteli & M. Leikomaa (Eds.), *Proceedings of EdMedia 2014--World Conference on Educational Media and Technology* (pp. 1305-1313). Tampere, Finland: Association for the Advancement of Computing in Education (AACE).
2. Banks, Joanne & Smyth, Emer, 2011. "Continuous Professional Development among Primary Teachers in Ireland," Research Series, Economic and Social Research Institute (ESRI).
3. National Council for Curriculum and Assessment, <https://www.curriculumonline.ie/Primary>, Last accessed 2022/2/7.
4. Universal Design for Learning – AHEAD, <https://www.ahead.ie/udl>, last accessed 2022/5/1
5. CAST, 2022, About Universal design for Learning, <https://www.cast.org/impact/universal-design-for-learning-udl>, last accessed 2022/2/7.
6. Zabala, J.S. (2020), "The SETT Framework: A Model for Selection and Use of Assistive Technology Tools and More", Chambers, D. (Ed.) *Assistive Technology to Support Inclusive Education (International Perspectives on Inclusive Education, Vol. 14)*, Emerald Publishing Limited, Bingley, pp. 17-36.

Primary School Educators' Involvement in Assistive Technology Assessment and Support

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Abstract. During the global pandemic, innovative techniques were required to assess the assistive technology needs of primary school learners. Prior to the pandemic, most students attended a health care setting to be assessed for their educational technology needs, as funding applications required the recommendations of a therapist or similar professional. Learners with sensory difficulties are able to access recommendations for assistive technology through the Visiting Teacher service, but for those students with physical, intellectual, or neurodevelopmental conditions, healthcare professionals are usually involved in the process of assessment, trialing of solutions and making recommendations [1]. Historically, as part of Enable Ireland's Assistive Technology Assessment Support service, learners attended for assessment with parents/guardians, and their primary therapists (Occupational/Speech and Language Therapists mainly) and while information was requested from educational staff, in the majority of cases, they were unable to attend appointments, due to the logistics of cover for their positions, time and travel. With the widespread use of teleconferencing facilities to reduce contacts, and educational staff upskilling in their use of digital technology, an innovative way of including teachers and SNAs in assessments, training, and trialing of assistive technology solutions was conceived. Educational staff found it easier to attend assessment appointments using remote platforms such as Microsoft Teams, as cover for their positions was required for a minimal amount of time (45 minutes – 1.5 hours), that could be sourced within the schools' own resources. In some cases, the student was present with the teacher while the assessment was conducted, and both the educator and student took a more active part in the assessment process, through the use of discussions, screen sharing to demonstrate apps and software, adjusting inbuilt accessibility options in existing technology etc. If hardware was recommended for trialing, this was provided after the remote session on loan, and reviewed as to its suitability. This paper examines the feedback received from teachers involved in this approach to assistive technology assessment, in particular to see if their participation at this initial stage had implications for the integration of the technology recommended into the student's educational experience. It will also look at the training they received in relation to software and apps, and their confidence in applying skills into their work with the students.

Keywords: Education, Assessment, Universal Design for Learning

1 Background

During the global pandemic, innovative techniques were required to assess the assistive technology needs of primary school learners, as face to face appointments and training sessions were no longer possible on a regular basis.

1.1 Prior to Pandemic

Historically, learners attended for appointments to look at Assistive Technology solutions in a health care setting. This was due to the fact that in Ireland, most occupational Therapists and Speech and Language Therapists are employed in the health care sector, with few being employed directly in the educational sector. As funding applications for the Assistive Technology Grant [2] require recommendations from a therapist or psychologist, most learners accessed assessment through therapists working in the health care sector or in the private sector. This applies to learners who require technology supports due to physical or cognitive impairments or through neurodiversity. Learners with sensory issues can access recommendations for technology through the Visiting Teacher services, which serves learners with visual or hearing difficulties.

1.2 Engagement with Educators in the Past

Prior to the pandemic, when a learner was referred to Enable Ireland's National Assistive Technology Training Service for assessment for technology to support access to the curriculum, their primary therapist contacted the school and invited teachers and other staff supporting the learner to attend for the appointment. If they were in a position, the primary therapist could conduct a school visit to collate concerns in person. In most cases, it was not possible for school staff to attend due to issues concerning class cover, time, and travel. However, most teachers were open to sharing information about progress, areas of difficulty and any other concerns. These were discussed with the learner (if appropriate), parents/guardians and the health care team as part of the assessment process, in selecting options for trial, feedback and making recommendations.

Due to a lack of resources and coordination, it was not possible in all cases for staff from the National Assistive Technology Service to attend the school in most cases, unless considered a high priority/complex case.

1.3 Motivation

With the widespread use of teleconferencing facilities to reduce contacts, and educational staff upskilling in their usage during the pandemic, an innovative way of including teachers, other educational staff and Special needs Assistants (SNAs) in assessments, training, and trialling of assistive technology solutions was conceived.

1.4 Use of Teleconferencing Facilities

Educational staff found it easier to attend assessment appointments using remote platforms such as Microsoft Teams. Cover for their positions was required for a minimal amount of time (45 minutes – 1 hour) and could be sourced within the schools' own resources.

Parents could also attend using teleconferencing facilities.

In some cases, the student was present with the teacher while the assessment was conducted, rather than at home or in the clinic. This allowed for the more immediate feedback on the solutions presented, and both the educator and student took a more active part in the assessment process, through the use of discussions, screen sharing to demonstrate apps and software, adjusting inbuilt accessibility options in existing technology etc.

If hardware was recommended for trialling, this was provided after the remote session for loan for a period of up to 4 weeks and reviewed as to its suitability. Free versions of software and apps could be downloaded to the school's own devices, if available, or if commercially available options were considered as part of the solution, these could be loaned on a device.

1.5 SETT Framework

The SETT (Student, Environment, Task and Tools) model for assessment was employed for assessments, both directly and through teleconferencing options [4].

1.6 Current Study

As services are now at a point where face to face sessions are possible, a survey was undertaken to see if this temporary change in service delivery could have an impact in the longer term.

Separate to their involvement in individualised assessment, we also sought to explore teachers' knowledge of Universal Design for Learning, and how using this approach may have benefits for all students, including those using assistive technology [2]. We also enquired regarding further assistive technology training needs. Sullivan et al [3] showed the need for teachers to have access to a person knowledgeable in assistive technology, and we wished to explore if the teachers involved here feel they may become that key resource person for their colleagues.

2 Study Design

A survey was circulated to a select range of teachers and other support staff who have taken part in a remote assessment or episode of support, during the period March 2020 to January 2022.

2.1 Survey Distribution

The survey was distributed via email and remained anonymous. An online survey creator, Microsoft Forms, was used, and responses were accepted via the online portal and post (where preferred by respondents).

2.2 Participants

A random group of 20 educators/school staff was selected for the purposes of this survey. They were all involved in mainstream education settings. Of these 20, the survey was rejected by 4 email accounts, possibly due to the recipient having changed jobs/on long term leave. Of the remaining 16 participants identified, responses were received from 9 recipients.

2.3 Key Areas of Survey

As introductory questions, respondents were asked about their role in the education setting and their general experience of Assistive Technology.

Following on from that, specific questions regarding the episode of assessment/support were posed, including satisfaction with involvement in the process, comparison to previous experiences if relevant, peer support, confidence in supporting the learner, application of skills gained to other learners, and knowledge of Universal Design for Learning [5].

One key question was regarding their preference for involvement in the assessment process in the future.

The results of these questions will be considered below.

3 Results

3.1 Role and Experience of Assistive Technology

Of the nine respondents, three were class teachers, and five had a role as either a Resource or Learning Support teachers. One school principal also responded to the survey.

Only one respondent had no prior experience of supporting a learner with assistive technology needs. Two respondents rated themselves as having extensive experience, four with some experience and 2 with little experience. These were self-reported observations.

When asked if having another staff member attend the appointment was of benefit, 4 responded that the question was not applicable in their case i.e. they attended alone from the educational setting. However, of the five respondents who did have a peer attend, all found it to be to of benefit.

3.2 Satisfaction with Involvement in Remote Assessment/Support Sessions.

Interestingly, all nine respondents indicated that they were satisfied with the remote assessment/support process, with 7 rating themselves as very satisfied. This however needs to be considered with reference to the following question. When asked if the respondents felt if they had adequate opportunity to state concerns around the learner's educational progress, and if these were addressed as part of the assessment process, all nine respondents reported that they did.

3.3 Involvement in Face-to-Face Assistive Technology Assessment in the Past

When asked if they had been involved in a direct assessment in the past, as opposed to a remote assessment, none of the respondents had the experience. Given that they could not compare the experiences may have implications for the interpretations of their responses.

3.4 Confidence in Using the Assistive Technology Recommended.

When asked about their confidence in using the technology recommended for the learner, four reported to be very confident in assisting the learner in applying their skills, while 5 reported that while they were confident, they would benefit from more training/support.

A question on whether the skills and knowledge gained in support the subject of this specific assessment may be of benefit to other learners, six respondents replied in the positive, while three were unsure.

3.5 Experience of Supporting Trials of Equipment

In six cases, equipment was loaned to the learner for trial in school before making the final recommendations. When asked their option of this, six responded that it was beneficial and that they had adequate training to support the learner. In two cases, the recommendations were changed after the trial period. Five of the six felt they had adequate opportunity to feedback on how the trials went.

3.6 Future Assessment

Regarding preference in the future of assessment, the majority (5) reported a preference for on-site in school assessment. Three expressed a preference for remote sessions, similar to what they experienced, while one reported that a clinic session would be their preference.

3.7 Understanding of Universal Design for Learning and Further Training.

When asked about universal design for learning, one respondent reported they were very familiar with the approach and knew how to implement it. 3 felt they had some knowledge and skills, while the majority (5) reported having no knowledge of UDL.

Six respondents reported that they were open to further training in the area of assistive technology, while 3 were unsure.

4 Interpretation

Although only a small survey size, some conclusions can be tentatively drawn from the information gathered through this survey.

4.1 Staff Training

Resource/Learning Support teachers were mainly involved in the response to the survey, with the majority rating themselves as having some experience in the area of assistive technology. Combined with the question on whether more training in assistive technology would be of benefit, we can see a need and interest in developing more resources for school staff involved in supporting learners who require technology in accessing the curriculum.

The lack of awareness of the approach of Universal Design for Learning and how this can be of benefit to Assistive Technology users, also shows a need for a more informed educational staff. This in turn would ensure that the learner is best supported in using their technology to access the curriculum.

4.2 Training and Transfer of Skills

Some training was provided as part of the assessment and trial process. It was interesting to note that most respondents felt confident in using the technology recommended for the learner, although some noted the need for more in-depth training.

Six respondents noted that skills and knowledge gained could be used with other learners, showing a secondary benefit to those not directly involved. This shows that the reach of assistive technology assessment may extend beyond just the learner directly involved in the assessment.

4.3 Satisfaction with Remote Support

Although all respondents reported positive experiences with remote support, none had experience of a face-to-face assessment, so a direct comparison was not possible. However, five respondents later in the survey expressed a preference for a school site assessment in the future, showing that the issue is not clear cut. While this may not be

possible in all cases, due to resources and logistics, some thought should be given to how this can be balanced.

4.4 Experiences of Trialling Equipment.

In six cases, technology was loaned directly to the learner to trial before a final recommendation was made. In two cases, this resulted in a change to the initial recommendations. This shows the importance of trialling equipment to ensure that the best solution is put in place and to avoid abandonment of technology and wasted resources.

4.5 Peer Support

Although not all the respondents had the experience of having a colleague present for the assessment, those that did found it useful. This is one suggestion that could be given to school staff ahead of appointments to see if another staff member would be able to attend also, to give support to both the learner and their peer.

5 Conclusions

Although only a small sample size, information on training needs, on both assistive technology and Universal Design for Learning are key to the future planning of remote assessment and support. Giving educators the knowledge on how to integrate technology into the classroom and to best support its usage will ensure that the technology does not create an additional barrier for the learner.

Having access to peer support, from within the educational setting, appears to be of assistance to those who have experience of it. Requesting all staff supporting a learner attend the assessment may help achieve the best possible outcome but may not be realistic. Having at least two staff members may be possible and should be requested when planning appointments.

Acknowledging educators' preferences for onsite assessments may need to be addressed, while working within limited resources. None of the respondents had experience of direct assessment; however, it was interesting to note that they felt remote assessment adequately met the learner's and their needs in a different question. More in-depth questioning may be required to determine the issues that they feel may influence their desire to have more face-to-face interactions.

From an AT service point of view, remote assessments have resulted in more prompt appointments, as less time and resources need to be reserved to conduct the session. Without travel time on the part of assessors and teaching staff, and extended class coverage for educators, a more effective system was established. This resulted in time efficiencies and a greater reach of the service.

Loaning equipment for trial has been shown to be of utmost importance to avoid recommendation of Assistive Technology solutions that may not meet the learners needs, and possibly resulting in abandonment. Allowing educators, along with families and the learners, to provide feedback and adapting recommendations, resulted in

technology tools that will meet the learner's needs. Having access to equipment establishes an evidence base that can be used for funding applications and ensuring that the best fit for the learner's needs has been put in place.

Although direct appointments with learners are now possible, with safeguarding conditions, the positive outcomes from having conducted remote assessments during the pandemic will influence on future service delivery. It has shown to be an efficient and effective way of engaging educators in the assessment process, delivering training and providing support, in a way that may not have been possible in the past.

References

1. National Council for Special Education, 2013. Circular No 0010/2013. Viewed 7/2/2022. https://www.sess.ie/sites/default/files/cl0010_2013.pdf
2. Alkahtani, K. D. (2013). Teachers' knowledge and use of assistive technology for students with special educational needs. *Journal of Studies in Education*, 3(2), 65-86.
3. O'Sullivan, K.; McGrane, A.; Long, S.; Marshall K.; Maclachlan M. (2021) Using a systems thinking approach to understand teachers perceptions and use of assistive technology in the Republic of Ireland, *Disability and Rehabilitation: Assistive Technology*, DOI: 10.1080/17483107.2021.1878297
4. Zabala, J.S. (2020), "The SETT Framework: A Model for Selection and Use of Assistive Technology Tools and More", Chambers, D. (Ed.) *Assistive Technology to Support Inclusive Education (International Perspectives on Inclusive Education, Vol. 14)*, Emerald Publishing Limited, Bingley, pp. 17-36.
5. CAST, 2022, About Universal design for Learning, <https://www.cast.org/impact/universal-design-for-learning-udl>, last accessed 2022/2/7.

Bridging the Digital Divide

A review of the ENTELIS+ project on the development of Digital Accessibility Training addressing the EU and Global disability policy agendas

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Abstract. This paper presents the work performed in the framework of the European co-funded Project ENTELIS+, which aims at developing and implementing innovative methods and practices to foster inclusive education and enhancing the digital skills and competences of digitally excluded groups, particularly persons with disabilities of all ages. The project outputs have been produced in three phases. Phase one involved a desk study and consultation process that informed the State-of-the art of the project and the baseline knowledge. Phase two involved the development of the conceptual framework and a common terminology based on which the ENTELIS+ training curriculum was designed. In phase three, localised training modules were developed, implemented and revised. The project also established a design-thinking methodology and digital literacy competence framework towards capacity building of those supporting people with disabilities in developing digital competencies, including end-users both as trainers and as trainees.

Keywords: Digital Accessibility, Inclusion, Digital Skills, Training.

1 Introduction and State of the Art

Numerous policies and legislations – including the UN Convention on the Rights of Persons with Disabilities, the European Social Charter, and the Council of Europe Disability Strategy 2017-2023 – request for persons with disabilities of all ages to receive education in an inclusive environment, and to have access to high-quality services enabling them to live independently and realise self-determination and citizenship.

Internationally, there is consensus that accessibility and assistive technologies (AT) are beneficial for the individual, for service providers and for society as a whole. The research literature supports the belief that use of assistive technology plays a vital role in enabling people with disabilities to complete daily activities and more fully participate in society (e.g. [1-3]). Furthermore, in order to effectively use and fully exploit the benefits of assistive technology for inclusion it is essential to foster the development of the pertinent competences. Currently, competence development for the use of assistive technology is intertwined with the discussions on digital competence development and endeavors for the empowerment of various groups of citizens in accessing and using technology and digital applications.

Arguably, digital competences became a fundamental factor for the effective participation of every citizen in Europe and globally, especially under the rapid shift to digitalisation and digital transformation in the last five years. The rapid rate of innovation in technology brings both opportunities and risks to people with disabilities. While a number of tools and applications are now available to support access and accessibility, findings from many studies indicate that people with disabilities of all ages face difficulties in their effective use, due to accessibility challenges and lack of sufficient digital competencies [4-7]. The result of these challenges, among other factors, leads to a digital divide and the digital exclusion of many people with disabilities, with a negative impact on their participation in education, their employability and career prospects, and their participation in social, cultural and political life [5].

Accessibility has been on the political agenda for more than four decades, however, digital assistive technology (ICT-AT) is not properly integrated into the education of service providers, caregivers, managers, administrators, educators and policymakers. In this framework, the ENTELIS+ project [9], co-funded by the European Commission under the Erasmus+ Key Action 3, worked to reduce the digital divide by strengthening organisations to collaborate in the development of strategies and policies for digital skills development of persons with disabilities of all ages. To this end, the project aimed to raise awareness about the importance of accessibility as an enabler for inclusive learning and teaching; developing the digital skills of persons with disabilities and older persons so that they can participate in the digital society; and enhancing the capacity of the key actors in charge of the design and implementation of facilitating frameworks (public authorities and service providers). This paper aims to present an overview of the key phases of the project development, its main activities and how these have been exploited to the project aims.

2 Methodology

In order to achieve its objectives and to generate impact not only on partner organisations, but also at both local and systemic level, the ENTELIS+ project adopted an innovative methodological approach that built on methodologies that had proven effective and impactful in previous projects. Specifically, ENTELIS+ built on the outcomes of the European Network for Technology Enhanced Learning in an Inclusive Society (ENTELIS) Project (Network) [10], and on the methodological approach of the

European Innovation Partnership on Active and Healthy Ageing (EIP on AHA). All partners in the consortium utilised their strong links with local ecosystems around inclusive education to support more inclusive educational frameworks, encouraging co-operation between education institutions, local administrations and civil society organisations. The constant promotion of the values and benefits of inclusive education at the local/regional level served as a source of inspiration to further enhance effective collaboration with all players of local ecosystems to have policy impact.

More specifically, the methodological approach of the project included the following phases. All three phases involved users and representatives of the various project target groups in different ways.

2.1 Phase 1: Building the Case

Through desk and field research, baseline knowledge was produced to build a case that highlights the importance of providing accessibility digital skills for persons with disabilities and older persons. Three main methods were employed in this phase: resource collection tool, consultation questionnaire and training needs survey. The three tools were disseminated within the project partners' organisations and input was received not only from the core team of each partner, but also from other members and beneficiaries of the organisations. Hence, especially the consultation questionnaire, which was also publicly disseminated to other pertinent stakeholders, aimed at gaining insights on individuals' experience in accessibility, opinions on accessibility education and digital skills in society, training needs and desires, and identification of potential gaps and barriers. The process was not launched as a research survey, but rather as a consultation, since the aim was to obtain people's views as collaborators in the design process of the training, which followed, based on the outcomes of Phase 1.

2.2 Phase 2: Knowledge Brokering & Training

During this phase, the project conceptual framework was defined, the overall methodological approach was agreed and core content for training in different pilots was developed. To do so, in terms of conceptual framework, the consortium built upon existing knowledge and concepts defined in previous projects' experiences, in order to establish common language and understanding among project partners as well as involved stakeholders as users of the project outcomes.

Additionally, the strategic conceptualisation of the training and training material development followed the principle of 'interconnected development and tailored adoption'. It was based on the assumption that professional standards in local settings can be developed in a framework with a universal relevance for European countries, but that concrete adoption of the training development can only be successful if the concepts of the programme are open for adaptation in a specific country/region involved. A training workshop for expert trainers of pilot partners took place, during which the materials in English were discussed and shared, and a focus group with country experts took place in order to fine-tune the methodology and facilitate localisation, in the next phase.

2.3 Phase 3: Localisation of Training & Pilot Testing

Following design-thinking methodology and using the training modules developed in Phase 2, specific local plans were next developed for each pilot, developing an ecosystem of local key players following the EIP on AHA methodological approach based on local commitments. During the localisation process on national level, users, as target groups of the project outcomes (i.e. persons with disabilities, professionals in service provision, educators) were involved either as potential trainers or as part of a second round of consultation for providing feedback on the modules content and structure. Once the different language versions of the training manual and the 5 training modules were ready, they were pilot tested by the consortium and revised accordingly.

Users were also involved in this stage as piloting consisted of the implementation and trial of the training within the partners' organisations. Persons with disabilities were also involved as trainers in some sections of the training. The experiences of trainers as well as trainees were captured through the project outcomes evaluation stages, towards the end of the project. The tools used for the pilot evaluation and feedback included trainer focus groups discussions, trainer log/diary and participant/trainee focus groups. The tools were designed in accessible formats and were also available in alternative modes, including easy-to-read and symbol supported form. All tools have been localised and adapted to national languages and context.

3 Results

The project was designed in such a way that the outcomes of each of the three phases built on each other and created a stakeholder cooperation model based on commitments. By doing this, the project aimed to empower people with disabilities of all ages through accessibility digital skills as a way to overcome the digital divide and open a wide range of social, career development and job market opportunities. In brief, outcomes of each phase included:

3.1 Phase 1: Building the Case

The collection of information for building the case and the State-of-the art of the project focused on examining existing resources, publications, practices and key perspectives on existing gaps and needs in relation to digital literacy and competence development in accessibility. The combination of the three methods provided a comprehensive view on opinions, aspects, gaps, barriers and suggestions on key issues related to accessibility and digital skills for inclusion. The analysis of the resources collected provided a basis for the mapping of best practices, which have been analysed in terms of barriers and content and structural elements for developing the training curricula and modules. The consortium identified as good practices "individual training courses or elements of training curricula that, through experience and research have proven reliably to lead to the desired result of reaching the target group and improving digital skills and teaching, in relation to assistive technology (AT), Accessibility and ICT" (p. 8) [11]. The identified good practices served as inspiration for the development of the training materials

in Phase 2 of the project. Furthermore, the curricula used in other initiatives provided a basic structure on which the ENTELIS+ project could be adapted and personalised. In addition to this, the resources were used to complement the training materials that were subsequently developed.

The consultation questionnaire provided an insight of the experiences of various stakeholders in accessibility and identified the gaps and the additional needs of increasing awareness and improving the level of knowledge and skills. Particularly, responses to the consultation tool informed the consortium that individual experience was not significantly represented among stakeholders. The concept and the role of accessibility was not clear within organisations, while implementation of digital accessibility is far from practice. Respondents expressed their concerns on the need to improve awareness and knowledge for all target groups, especially for understanding legal frameworks and obligations, as well as obtaining funding. Particular topics for training were also suggested, and blended forms of learning seemed to be preferred.

Finally, the training needs survey that was conducted among the project partners identified the main target groups (i.e. service providers, people with disabilities, disabled persons organisations, technology designers and local and regional authorities), as well as particular training needs in terms of knowledge and digital (accessibility) skills and assistive technology in two progression levels (i.e. basic and advanced). The final outputs of this phase concluded with guidelines, fact sheets and success factors published on the project website.

3.2 Phase 2: Knowledge Brokering & Training

The outputs of the work in phase 2 included the definition of the project conceptual framework and the training modules. The conceptual framework of the project was defined upon a common vocabulary and glossary, which was built on the basis of the existing ENTELIS Glossary and Taxonomy, enriched and revised based on the new knowledge and outcomes of the first phase. The first ENTELIS project taxonomy and Glossary focused largely on Information and Communication Technology (ICT), learning events and processes in various educational settings. The ENTELIS+ Glossary has built on this approach, providing a stronger focus on accessibility-related terms and covering topics such as practices and procedures, tools, design methodologies, policies and frameworks and assistive technology (AT). It includes definitions identified during the state-of-the-art research carried out in Phase 1, as well as the consortium's own definitions on specific topics. It also provides additional reference material to accompany the other training materials that were produced. The Glossary was updated during the project whenever new terms or concepts arose in the execution of Phases 2 and 3. Its finalised version is available in the Project results page of the ENTELIS+ Website [12].

Furthermore, the core of the project, the five modules and training curriculum, were developed following the principle of 'interconnected development and tailored adoption'. Hence, course curricula and material were developed and made available translated and localised in national languages. Localisation was conducted according to the needs of partners' countries (see Phase 3).

Particularly, the ENTELIS+ training package [13] includes five training modules, two (2) of which are at a basic level and three (3) at a more advanced level:

- Basic Level: An introduction to accessibility
- Basic level: Empowerment of People with Disabilities through human rights
- Advanced level: Assistive Technology (AT)
- Advanced level: Creation of accessible resources to support teaching and learning
- Advanced level: Roadmap for professional development in ICT accessibility.

The training curricula include clearly defined learning outcomes in both basic and advanced level, suggested activities and learning material. They are designed to be flexible and easy to adapt, including additional resources and practical examples of accessibility as well as tips for trainers. Table 2 includes the learning objectives of each module.

Table 1. Learning Objectives of ENTELIS+ Training Modules

Training module	Learning Objectives
Basic Level: Introduction to accessibility	<ul style="list-style-type: none"> • Gain basic understanding of accessibility as a concept • Gain knowledge on the diverse groups whom accessibility can affect on a daily basis • Be able to identify basic accessibility issues • Identify accessibility tools on devices and software • Understand the benefits of accessibility for an organisation • Understand the benefits of accessibility for individuals and society • Understand what inclusive design is
Basic level: Empowerment of People with Disabilities through human rights	<ul style="list-style-type: none"> • Understand the difference between legislation and standards • Be able to differentiate between the different types of legislation • Be aware of the rights of People with Disabilities offered through legislation • Be aware of the obligations of the public sector authorities and how one can get involved
Advanced level: Assistive Technology (AT)	<ul style="list-style-type: none"> • Gain an overview of the different types of assistive technologies (AT) available and how they are used • Gain insights into the existing built-in support for accessibility • Increase knowledge of where to obtain assistive technology and the different systems that operate in Europe • Gain awareness regarding the affordability of AT and the ability to select the appropriate

	technology according to the user needs
	<ul style="list-style-type: none"> • Identify AT for the different target groups
Advanced level: Creation of accessible re-sources to support teaching and learning	<ul style="list-style-type: none"> • Gain an overview of how to produce accessible digital content • Discover how to create specific accessible content in different formats (text, images, video, audio, PowerPoint, pdf) • Learn how to carry out a quick and easy accessibility check of a website • Understand the difference between plain language and easy to read • Highlight the importance of multimodal communication and “less is more” concepts • Be familiarised with co-creation as a tool for working with target audiences
Advanced level: Roadmap for professional development in ICT accessibility	<ul style="list-style-type: none"> • Learn how to build a plan for professional development in ICT accessibility • Be able to adapt the training methods and tools and make them accessible to target audience • Be acquainted with, and adhere to, the principles of Universal Design and Universal Design for Learning

In addition to the main content and learning objectives of the training curricula, and upon feedback from users and potential trainers, additional sections were added in the curricula corpus. These involve additional reading lists and resources, accessibility in action feature which included accessibility examples, and trainer tip including guidance, highlights and additional information for trainers. In the localisation phase these features were also localised and contextualised in each partner's language, culture and background.

Furthermore, to support the development of the training curricula and modules, the consortium identified the need to support the learning programmes development with a competence framework for trainers that support people with disabilities in digital competence development. The ENTELIS+ Trainers Competence Framework (ETCF) was developed to contextualise the ENTELIS+ training. The methodology and process of the development of the ETCF are presented in a different contribution in the ICCHP-AAATE 2022 conference.

3.3 Phase 3: Localisation of Training & Pilot Testing

Following a design-thinking methodology, the core curricula and learning modules of the project were further localised and made available in the different language versions. The localised versions were pilot tested by the consortium involving different target groups as identified in the first phase, in four (4) of the project partners. It is noted that trainers across pilot partners varied in terms of background and expertise, and in some persons with disabilities were also involved as trainers and facilitators in the training. As mentioned above, experiences and feedback from the pilots were collected by both

trainers and participants, again in the form of consultation through personal reflections (i.e. trainers' logs) and discussions in focus groups.

Based on the feedback and experiences of both the trainers and the trainees involved in the pilots, as well as the stakeholders involved in the development and localisation process, the curricula and learning modules were revised accordingly. Across all four national reports, participant feedback regarding the training was overwhelmingly positive. Participants noted the relevance, appropriateness and usefulness of the training content, as well as declared their intent to use the training and content in their work. Some national differences in terms of the suggestions and the feedback provided that were related to the particular ways the training was offered locally, as well as in relation to more localised elements of the trainings were also identified. In terms of the trainers' feedback, this was also generally positive, with trainers expressing some hesitation initially regarding the content but eventually feeling confident in its delivery. Trainers also made some remarks regarding the difficulty level of certain modules and the need to provide material in an easy-to-read mode.

In addition, as mentioned above, the training curriculum was developed in two levels: basic and advanced. Upon receiving trainer and trainee feedback, the feeling is that an intermediate level of competence development may also be preferable. A broader differentiation range could also be beneficial, where content, learning objectives and learning outcomes could vary for different individuals, different groups as well as different organisations, with adaptations being made either prior the training or during its progress based on flexibility provided. Hence, the variation into three progression levels was reflected in the ENTELIS+ Trainers Competence Framework (ETCF), which identified three progression levels, useful for both trainers' competence development as well as those of potential trainees.

Finally, it is worth mentioning that some external informal piloting also took place outside the pilot partners, through dissemination activities and involvement of the general public in different settings and languages. Some informal feedback was also collected through this approach, with most important element the need for raising accessibility awareness to the general public and to make a connection with everyone's everyday life and activities. The general understanding was mainly that accessibility deems essential for all.

4 Conclusion

The relevance of the ENTELIS+ project is rooted in policies and legislations requesting for persons with disabilities of all ages to be part of an inclusive education system, to have equal opportunities and access to high-quality services enabling them to live independently and contribute to society. Results and benefits of the project address important policy agendas of the European Union, including the Strategy for the rights of person with Disabilities 2021-2030, the Web Accessibility Directive and the European Accessibility Act, and of course the UNCRPD. In particular, Member States should promote and facilitate training programmes, relating to the accessibility of websites and mobile applications for relevant stakeholders and staff of public sector bodies. They

should also take the necessary measures to raise awareness of the accessibility requirements, of their benefits to users and to owners of websites and mobile applications. The elaboration by the ENTELIS+ consortium of a set of globally validated training materials on the nature of innovation in service provision, on new trends in the digital skills of workers, and on contextual shifts in working with people with support needs, and the localisation of the developed material in several member states, will raise the number of professionals who can receive training and will also foster the provision of cross-border services and make a more dynamic internal market of inclusive digital services.

The main outcomes of the project are directly applicable and implementable for service providers and other target groups across Europe and internationally. Service providers can be supported in understanding and defending the importance of strategic investments in inclusive measures developing accessibility digital skills for people with disabilities and older adults. For educational staff, the project promotes the adoption of more positive attitudes towards the inclusion of learners with disabilities of all ages, thus stimulating the overall learning environment. For disabled persons organisations and organisations in the accessibility and active ageing sector, the project provides valid knowledge and strategies to foster inclusive education in local ecosystems and to develop accessibility digital skills of people at risk of digital exclusion, empowering them and contributing to the minimisation of the digital divide. Moreover, thanks to the co-creation approach adopted in the project, learners with disabilities can be constantly involved, thus enhancing their inclusion and full participation in society. Finally, public government and policy makers, can increase their awareness of the socio-economic benefits of the implementation of inclusive policies, and of the importance of adopting inclusive approaches to education. The European networks have and will continue to distribute the project results via their membership and extensive networks, thus facilitating the transferability and scaling up of the inclusive education innovations resulting from ENTELIS+ across the EU educative and research community.

References

1. Scherer, M. J., & Glueckauf, R. (2005). Assessing the Benefits of Assistive Technologies for Activities and Participation. *Rehabilitation Psychology*, 50(2), 132–141.
2. Bühler, C. & Pelka, B. (2014). Empowerment by Digital Media of People with Disabilities: Three dimensions of support. In K. Miesenberger, D. Fels, D. Archambault, P. Peñáz, & W. Zagler (Eds.) *Computers Helping People with Special Needs. 14th International Conference, ICCHP 2014, Proceedings, Part I*, pp.17-24
3. Gilligan J. (2020) Competencies for Educators in Delivering Digital Accessibility in Higher Education. In M. Antona & C. Stephanidis (eds) *Universal Access in Human-Computer Interaction. Applications and Practice. HCII 2020. Lecture Notes in Computer Science, 12189*. Springer.
4. Van, Isacker, K. et al. (2009). D2.2b User needs and System Requirements Specification, ACCESSIBLE FP7 project. Available online at http://www.accessible-eu.org/documents/ACCESSIBLE_D2.2b.pdf.
5. Van, Isacker, K. (2010). Status of AT/ICT Usage in Europe, 1st AEGIS International Conference, Seville, Spain, 7-8 October 2010. Available online at: <https://www.yumpu.com/en/document/view/49623352/download-conference-proceedings>

6. ViPi Project. Virtual Portal for Interaction and ICT Training for People with Disabilities. Available at <http://www.vipi-project.eu/>
7. ATLEC Project (2014). Job profile(s) of an ICT-AT trainer, available at: <http://atlec-project.eu/download/>
8. Polovko, S., Shatrevichs, V. & Grinberga-Zalite, G. (2021). Analysis of Practical Implementation of Social Innovation in European Union. In Proceedings of the 2021 International Conference “Economic Science for Rural Development” Jelgava, LLU ESAF, 11-14 May 2021, pp. 171-180
9. Entelis+, Accessibility skills for a technology enhanced learning in an inclusive society, available at: <https://entelisplus.entelis.net/>
10. European Network for Technology Enhanced Learning in and Inclusive Society (ENTELIS), available at: <https://www.entelis.net/>
11. Entelis+ Consortium (2021). D1.4. Mapping of identified good practices with knowledge and training needs. Project Internal Document
12. Entelis+ Consortium (2021). ENTELIS+ Glossary of terms, available at: https://entelisplus.entelis.net/wp-content/uploads/2021/11/D2.1-ENTELIS-Glossary-of-Terms_November-2021.pdf
13. Entelis+ Training Materials, available at: <https://entelisplus.entelis.net/training-materials/>

ENTELIS+ Competence framework

Empowering Educators and Trainers to Bridge the Digital Divide

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Abstract. The paper presents the rationale, methodology and process for the development of the ENTELIS+ Trainers Competence Framework. The framework is an output of the ENTELIS+ project and provides a set of competencies for educators, trainers and other stakeholders involved in the education and training for the digital literacy of persons with disabilities and older adults. The framework has been developed after the examination and analysis of existing frameworks and examples of good practices, and it is built in a way anticipated to fill in the gap for trainers' capacity to support digital competencies for persons with disabilities. Competencies have been developed in three progression levels, across five domains, and they represent indicators for self-evaluation or setting learning outcomes in relevant educational/training programmes.

Keywords: digital competencies, digital literacy, digital divide, (e)accessibility, ICT-AT

1 Introduction

The discussions around the digital divide for persons with disabilities and older adults has been around for more than a decade, and recently became more central, in view of digitalization and digital transformation, which is not only a result of the recent pandemic situation. A number of studies on the digital divide concentrate on its different dimensions [1], including access to technology and the internet [2], technical and content accessibility [3], digital literacy and digital competence development [4], socio-economic, policy and cultural factors [5]. While research interest on disability and digital inclusion is growing and accessibility and non-discrimination legislation and regulations are becoming stronger, there is not much evidence on the decrease of the digital divide for persons with disabilities. The variety of studies and hence the diversity of

dimensions reveals the complexity of the conceptualization, but also of the efforts to address the digital divide.

Additionally, digital transformation and the introduction of technology for the digitalization of a variety of human activities extends essential potentials for the participation of persons with disabilities, but also poses new barriers that need to be addressed through accessible technologies [6]. European and global policies and initiatives seem to establish a framework for action [7] by turning the attention of the various stakeholders to investigate possibilities and develop practices towards the use of technology and accessibility for inclusion. Digital empowerment of persons with disabilities is part of this wider framework for educational and societal changes [8], while the development of competences in assistive technology and accessibility and the call for more training becomes an imperative factor for successfully addressing the challenges of the digital divide and giving voice to persons with disabilities [9] [10]. Acknowledgement of the barriers in relation to digital literacy and digital competence development has led assistive technology and accessibility researchers and professionals to design and develop competence frameworks mostly specific to particular groups of users, groups of professionals or other target population, or even to particular context of implementation, types of technology or set of competences. Nevertheless, and through the methodology described in the next section of this paper, it has been identified that addressing the competence development needs of a variety of stakeholders in the broader field of education at different levels and services is a challenge. The ENTELIS+ project aimed at developing a flexible training curriculum and suggested modules responding as much as possible to these variety. Thus, it deemed necessary to also provide a systematic description of competencies related to digital education for those working in formal and informal education supporting learners with disabilities developing digital skills and fill in this gap in the existing frameworks. This paper describes the development of a competence framework, namely ENTELIS+ Trainers Competence Framework (ETCF) for those supporting the digital inclusion of persons with disabilities and older citizens, through the activities of the ENTELIS+ project.

2 Methodology

For the development of the ETCF a structured workplan was followed, which constituted the following methodological approach: (a) review and analysis of existing frameworks, in order to identify components, structure, aims, formats and possible gaps; (b) identify and define the aims of the ETCF based on the analysis of existing frameworks as well as on the needs assessment of the ENTELIS+ project and training participants; (c) identify and define the structural elements of the ETCF in terms of Levels, Domains (Areas) and Types of Competencies. An interdisciplinary approach was implemented to this methodology, by the involvement of a broader team of stakeholders each representing a different discipline in the field of disability and assistive technology services, coming from policy, education, rehabilitation, academia, accessibility research and design, vocational training and supported employment. The broader team provided input in the collection and analysis of the existing frameworks, and then a core team worked

more closely to the identification and definition of the ETCF components, structure and content. The broader team then functioned as an Advisory Board to the finalization of the framework.

3 State of the Art

The output of the examination and the analysis of the various existing competence frameworks proved twofold: (a) identification and definition of the ETCF goals and structure, and (b) identification of two basic existing frameworks that seemed more relevant and closer to the needs of the project and the goals of the development of a new framework.

A total of eighteen (18) have been identified, each one which was presented and analyzed on the ways they address the use of elements providing the structure of a competence framework, including level of competence (e.g. novice, expert, etc), areas (domains) of competence (e.g. assessment of training needs, accessibility, assistive technology (AT), different disabilities, etc.), types of competence (e.g. knowledge, skills, attitudes), areas of application (e.g. formal or non-formal education, including adult education and target group). The tables of analysis of each one of the 18 frameworks are available in the relevant ENTELIS+ project deliverable [11]. In terms of levels, it was identified that most frameworks distinguish between levels with different terminology (e.g. Basic – Average – Advanced, Novice – Intermediate – Expert), they vary in numbers of levels adopted (e.g. three, four, eight). Some frameworks such as the DigComp2.1 and the KPT are inspired by the European Qualifications Framework (EQF). Progression in levels is often defined and described based on Bloom's taxonomy.

In terms of types of competences, the analysis indicated that frameworks aim at developing knowledge (i.e. acquisition of information), skills (referring mostly to development of practical competence) and sometimes attitudes (i.e. a more personal outcome of deeper understanding, appreciation and towards the more affective perspective of competencies). These types of competences have been identified across various areas (domains) which shift interest among pedagogy and teaching, knowledge and understanding of disability in general or particular groups of people with disabilities, technical and hands-on skills for mastering assistive technology and accessibility accommodations and context of application (e.g. education, employment, leisure, communication etc).

The analysis of the existing frameworks provided the state-of-the art of competence development through current similar to ETCF efforts and facilitated the final decisions for the structure of the ETCF. In addition, through the analysis two of the existing competencies framework identified as the most relevant to the aims of the ENTELIS+ project and the scope of the ETCF. These are the European DigCompEdu framework [12] and the ATLEC competence framework for ICT-AT trainers, previously developed in the ATLEC Project [13]. The DigCompEdu was chosen because of its specific focus on the digital competencies that educators and teachers need to have to support the development of their students' digital skills. The ATLEC framework was chosen

because it specifically focuses on the competencies needed for a professional to support and train persons with disabilities to become effective AT users. Both frameworks were used to provide ideas and re-conceptualization of the Domains (Areas) of Competencies relevant for ETCF, as well as the types of competencies to be included, in a way that would help the development team to explore and exploit existing knowledge and good practices, while also avoid repetitions.

Adopting the rationale of the DigCompEdu structure, while been informed by the analysis of other competencies frameworks, domains of competencies have been defined and re-defined for the purposes of the ETCF. At the same time, the ETCF elements have been aligned with DigCompEdu in order enable stakeholders involved in curriculum development based on DigCompEdu to consider and integrate ETCF competences in relevant activities.

Building on the current stages in the development of digital competencies frameworks as well as pertinent previous activities, the ETCF is considered an endeavor that specifically brings accessibility and disability issues into the attention of any European (and maybe global) efforts for digital education, digital literacy and digital competence development. The aspect of digital inclusion and empowerment of persons with disabilities and older adults it is often superficially touched upon, but not truly mainstreamed in most regional and national policies and practices [14].

4 Results: The ENTELIS+ Trainers Competence Framework

Based on the assessment of the frameworks, the input received from ENTELIS+ project partners and the experience of the task force members representing different learning environments, the final ETCF resulted in a framework including five (5) domains (areas) of competencies, for each of which three progression levels have also been defined. A long list of competence descriptors was drafted by the team members and mapped into the framework, across domains and levels, under different types of competencies. Domains of competencies of the ETCF have been defined as following:

- **Assessment of Needs:** referring to competences of trainers to identify both barriers and opportunities to accessibility and AT use
- **Resource Selection:** including selecting, creating, modifying and sharing accessibility and AT resources
- **Inclusive Teaching and Learning:** referring to competences in designing learning activities by implementing differentiation and UDL to promote participation
- **Creating Inclusive Learning Environments:** referring to the process of co-design, in organizing and managing the learning environment through the development of positive attitudes
- **Promoting Learners' digital competencies:** This domain actually reflects the corresponding area of the DigCompEdu that connects the educators' and trainers' frameworks to the digital competences of the end-users

As mentioned above, domains of the ETCF have been inspired, re-defined and aligned to the European DigCompEdu framework. A summary of the competencies domains re-definition and alignment is presented in Table 1.

Table 1. DigCompEdu and ETCF elements alignment

DigEduComp framework elements		ENTELIS+ framework elements
Educator's pedagogic competencies. Together these areas explain educators' digital pedagogic competence, i.e. the digital competencies educators need to foster efficient, inclusive and innovative teaching and learning strategies.	4. Assessment <ul style="list-style-type: none"> Assessment strategies Analysing evidence Feedback and planning 	Assessment of Needs and Barriers <ul style="list-style-type: none"> Identify accessibility and AT use barriers Identify opportunities for AT use and accessibility
	2. Resources <ul style="list-style-type: none"> Selecting Creating and modifying Managing, protecting and sharing 	Resource selection and use <ul style="list-style-type: none"> Select Create & Modify Share
	3. Teaching and learning <ul style="list-style-type: none"> Teaching Guidance Collaborative learning Self-regulated learning 	Inclusive teaching and learning <ul style="list-style-type: none"> Learning Design Differentiation & Flexibility Participation
	5. Empowering learners <ul style="list-style-type: none"> Accessibility and inclusion Differentiation and personalization Actively engaging learners 	Creating inclusive environments <ul style="list-style-type: none"> Co-design Organisation and Management Attitudes and Emotions
Learners' competencies This area details the specific pedagogic competencies required to facilitate students' digital competence.	6. Facilitating learners' digital competence <ul style="list-style-type: none"> Information & media literacy Communication Content creation Safety (responsible use) Problem-solving 	Promoting learner's digital competencies <ul style="list-style-type: none"> Information & media literacy Communication Content creation Safety (responsible use) Problem-solving

The three progression Levels defined across domains have been identified as Core, Intermediate and Advanced, to reflect the wide variety of roles and responsibilities involved in supporting learners with disabilities. Each Level of progression is described

through proficiency statements, for each one of the Domains. The proficiency statements aim at providing the general concept of the individual competencies that are anticipated within each Domain, at each Level, as presented in Table 2.

Table 2. Proficiency Statements Overview per Level of Competencies

Areas of competencies	Core level	Intermediate level	Advanced level
Assessment of Needs and Barriers <ul style="list-style-type: none"> Identify accessibility and AT use barriers Identify opportunities for AT use and accessibility 	<p>I understand the importance of digital participation for all, and I am aware of the physical, digital, societal and other barriers to digital participation for persons with disabilities</p>	<p>I can identify accessibility challenges for barriers to access and accessibility for the use of technology by persons with disabilities, and I can identify possible solutions</p> <p>I can identify the current level of competencies of the learners in the use of assistive technology and accessibility adaptations they may need for the use of digital technologies.</p>	<p>I can perform a gap analysis of the learners' competencies for the use of assistive technology and implementation of accessibility for digital inclusion</p> <p>I can assess training options and recommend specific training plans for the use of assistive technology and implementation of accessibility for digital inclusion</p>
Resource selection and use <ul style="list-style-type: none"> Select Create & Modify Share 	<p>I am aware of common/mostly used assistive technology and accessibility resources</p>	<p>I can search and identify/select assistive technology and accessibility resources for the particular needs of individual learners.</p> <p>I can set up and configure common/mostly known assistive technology and accessibility resources</p>	<p>I can compare, evaluate and critically select assistive technology and accessibility resources by filtering according to various criteria to respond to variations of possible users' needs.</p> <p>I can implement assistive technology and accessibility resources with a broad range of users and contextualise, individualise and customise them for users. If necessary, I can make some alterations (modify) and new developments (create) with existing resources.</p>
Inclusive teaching and learning <ul style="list-style-type: none"> Learning Design Differentiation & Flexibility Participation 	<p>I am aware of the basic principles of differentiation and universal design for learning with the use of technology</p>	<p>I integrate assistive technology and accessibility requirements in learning activities for different users' needs and disabilities.</p>	<p>I design the whole learning process based on the principles and guidelines of universal design for learning with the integration of</p>

		I put each learner's active use of assistive technology and implementation of accessibility adaptations at the centre of the instructional process to develop their digital competencies.	<p>assistive technology and accessibility.</p> <p>I reflect and re-design learning for actively engaging learners in using their assistive technologies and accessibility requirements.</p>
<p>Creating inclusive environments</p> <ul style="list-style-type: none"> • Co-design • Organisation and Management • Attitudes and Emotions 	<p>I am mindful of the social and emotional dynamics in a learning environment and their impact on learning.</p> <p>I use inclusive language and diverse examples across disabilities, cultures, gender.</p>	I organise the learning environment (activities, resources, opportunities for participation, collaboration, etc.) to promote interaction and respect learners' individual needs and characteristics.	I design in collaboration with learners and other stakeholders (parents/carers/professionals) learning experiences for developing digital competencies with the use of personal assistive technologies and implementation of accessibility requirements
<p>Promoting learner's digital competencies</p> <ul style="list-style-type: none"> • Information & media literacy • Communication • Content creation • Safety (responsible use) • Problem-solving 	<p>I encourage learners to use assistive technologies and look for accessibility requirements when accessing information and communication in digital environments.</p> <p>I encourage learners to look for solutions for technical problems and safety issues in the use of technology</p>	<p>I teach learners how to use their assistive technology and make accessibility adaptations, including basic technical problems solutions.</p> <p>I implement learning activities in which learners use assistive technology and implement accessibility requirements accessing information and for communication/interaction in well defined digital environments.</p>	<p>I enable learners to understand their needs for assistive technology and accessibility requirements and request relevant adaptations when selecting or creating content and resources using different media.</p> <p>I enable learners to understand risks and threats in digital environments (e.g. identity theft, fraud, stalking, phishing) and appropriately react.</p> <p>I enable learners to participate actively and contribute positively to digital media and media discourse, using multimedia channels for communication and identifying discriminatory language, practices and policies in digital and media environments.</p>

Finally, types of competencies identified for ETCF are: Knowledge, which includes familiarity with and understanding of information and facts in various levels; Skills, which includes more practical application of the knowledge and implementation in different contexts, with different groups of people and across domains; and Attitudes

representing a more personal perspective of competence involving acknowledgment, emotions and motivation. Individual competencies of the ETCF mapped across domains levels, under the three types of competences are articulated in the form of self-evaluation statements, under three different types of competencies. These can serve either as self-evaluation indicators for identifying the current situation of own/organizational/institutional capacity in relation to building accessibility and assistive technology competences for persons with disabilities, or as indicators for setting learning outcomes while developing a relevant training program. The aim of this paper is not to reproduce the full ETCF but to present the rationale and methodology of its development, suggesting how European and other projects can establish strategic partnerships and networks which build a capacity for exploiting past and current project outcomes for contributing to the European and global efforts towards the digital empowerment of persons with disabilities. The full version of the ETCF can be retrieved directly from the ENTELIS+ website, as part of the pertinent deliverable [11].

Validation and further exploitation activities of the ETCF are currently designed through Erasmus+ Right to Connect project (started January 2022), as well as through its very recent adoption by part of the ENTELIS+ partner countries educational policy system (Digital Education Transformation, Ministry of Education, Culture, Sports and Youth, Cyprus) [15]. Both these activities have very recently been launched and hence there is no evidence of further impact. Nevertheless, the core team of the ETCF as well as the Entelis network are following these activities and will be able to report impact and exploitation at a later stage.

References

1. Sachedeva, N., Tuikka, A.M., Kimppa, K.K., & Suomi, R. (2015). Digital disability divide in information society A framework based on a structured literature review. *Journal of Information, Communication and Ethics in Society*, 13(3/4), 283-298.
2. Scholz, F., Yalcin, B., & Priestley, M. (2017). Internet access for disabled people: Understanding socio-relational factors in Europe. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1), article 4. doi: 10.5817/CP2017-1-4
3. Soon G. Hong, Silvana Trimi, Dong W. Kim & Joon H. Hyun (2015) A Delphi Study of Factors Hindering Web Accessibility for Persons with Disabilities, *Journal of Computer Information Systems*, 55:4, 28-34.
4. Jaeger, P., Bertort, J.C., Thomposon, K., Katz, S., DeCoster, E.K. (2014). The Intersection of Public Policy and Public Access: Digital Divides, Digital Literacy, Digital Inclusion, and Public Libraries. *Public Library Quarterly*, 31:1, 1-20
5. Hilbert, M. (2015). Digital Divide(s). In *The International Encyclopedia of Digital Communication and Society* (eds P.H. Ang and R. Mansell). <https://doi.org/10.1002/9781118767771.wbiedcs012> U
6. Lord, J.E. (2017). Accessible ICTS and the Opening of Political Space for Persons with Disabilities. In J. Lazar & M.A. Stein (Eds). *Disability, Human Rights and Information Technology*, Pennsylvania: University of Pennsylvania Press (pp. 24-40).
7. Broderic, A., Ferri, D. & Boot F.H. (2021). A framework for action. In E.J. Hoogerwerf, K. Mavrou & I. Traina (Eds). *The Role of Assistive Technology in Fostering Inclusive Education: Strategies and tools to support change*. London & New York: Routledge (pp. 7-44)

8. Hoogerwerf, E.J. & Mavrou, K. (2021). Inclusive education and digital empowerment as part of wider societal challenges. In E.J. Hoogerwerf, Mavrou, K. and Traina, I. (Eds.). *The Role of Assistive Technology in Fostering Inclusive Education. Strategies and Tools to Support Change*. London & New York: Routledge (pp. 131-144)
9. Hoogerwerf, E.J. (2021). The development of competences in assistive technology. In E.J. Hoogerwerf, Mavrou, K. and Traina, I. (Eds.). *The Role of Assistive Technology in Fostering Inclusive Education. Strategies and Tools to Support Change*. London & New York: Routledge (pp. 131-144)
10. Seale, J.K. (2014). *E-Learning and Disability in Higher Education: Accessibility Research and Practice*. New York & London: Routledge.
11. Entelis+ Consortium (2022). D3.17. Development of a competence framework for competence related to digital accessibility, available at <https://entelisplus.entelis.net/wp-content/uploads/2022/01/D3.17-ENTELIS-Competency-framework.pdf>
12. Digital Competence Framework for Educators (DigCompEdu), available at https://joint-research-centre.ec.europa.eu/digcompedu_en
13. ATLEC Project (2014). Job profile(s) of an ICT-AT trainer, available at: <http://atlec-project.eu/download/>
14. European Disability Expertise Country Reports on Exploring the action of EU countries to harness the potential and address challenges of digitalisation and digital transformation to advance the rights of persons with disabilities. Soon available at <https://ec.europa.eu/social/main.jsp?catId=1532&langId=en>
15. Advisory Committee for the use of Digital Technology in Education (2022). In-Service Professional Development for Curriculum Development Working Groups. Digital Competences in the Cyprus National Curriculum. Cyprus Pedagogical Institute, 9 & 16 February, 2022, online.

Voice Cloning and the Socio-Cultural Challenges of Assistive Technologies

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Abstract. This paper aims to raise attention on the socio-material aspects of assistive technologies, wishing to foster collaboration and dialogue among engineering and social science as a way to better design and present assistive tools. It uses as an illustrative case the voice technologies for speech-impaired people, with particular focus on Google's project to reunite speech-impaired users with their voices using voice cloning technology, an evolution of speech synthesis which allows for the reconstruction of the sonic and timbric characteristics of an individual person's voice. The paper argues that assistive technologies in general, and voice technologies in the specific, are not only prosthesis, but also sites as sites of knowledge production about disability, that is sites where disability is defined in the first place. In this perspective the paper invites to consider how, in assistive technologies, cultural and social factors are as crucial as material operations.

Keywords: Speech Synthesis, Voice Cloning, Socio-material perspective.

1 Introduction

Speech synthesis is a key technology in contemporary media landscape, as it is employed in navigators, Interactive Voice Responses (IVRs) in customer service hotlines, and more recently in virtual assistants such as Siri or Alexa. This technology has also an enormous potential in disability assistance: already in the '80s scientist Stephen Hawking showed how it could be used to 'give voice' to people who lost the ability to speak because of ALS (Amyotrophic lateral sclerosis), a disease in which the neurons that control a person's voluntary muscles die, eventually leading to a total loss of control over one's body. Nowadays a new technique of speech synthesis known as voice cloning (Jemine, 2017; Marr, 2019), which allows for the reconstruction of the sonic and timbric characteristics of an individual person's voice, allows to increase the realism of artificial voices and to improve the user experience of speech-impaired people who rely on this technology to have their voices back. As highlighted by Alper (2017), classic synthetic voices as the one employed in most of the commercial assistive technologies (such as Proloquo2Go), present three main critical problems: although they sound human and gendered, they are very generic as they don't represent a person's

age, ethnicity and relation with family members. In this way they reduce the possibility for a person to feel comfortable with a synthetic voice.

Voice cloning technology has to potential to overcome those limits. Its peculiarity is that it doesn't sound 'generic' as it did with Hawking's synthetic voice, aiming instead to reproduce the features of an embodied and personal voice, the voice of a specific person. In short, it uses machine learning to 'learn' the profile of a person's voice and then allows to employ that profile in a text-to-speech, in this way customizing a speech synthesizer. This means that a speech-impaired person can use a synthetic voice which has the sound of his own voice before he lost it.

Nevertheless, 'giving back' to someone his voice is not just a technological operation, but entails important cultural and social questions. In particular: Can a voice that sounds like mine be considered really mine? How does a voice which comes out from loudspeakers affects the relation between body and personal identity? And, more in general, what does it mean to 'own' a voice?

In this paper I argue that those kind of questions are not simply theoretical concerns, but are of primary importance for the design and engineering of voice technologies. In order to that I present the illustrative case of Google's project to reunite speech-impaired users with their voices using voice cloning technology. Through this case I show how social and cultural aspects are embedded both in material operations of assistive technology and in presentations and discourses about it. Accordingly, I propose a socio-material approach that considers assistive technologies in general, and voice technologies in the specific, not only as prosthesis, but also as sites of knowledge production about disability, that is sites where disability is defined in the first place. I argue that this approach can foster collaboration and dialogue among engineering and social science as a way to better design and present assistive tools.

2 Theoretical Framework and Methodology

In this work I propose a socio-material investigation of assistive technology, focusing on voice cloning as exploratory case (Yin, 2005). Following Sterne (2021) and Ernst (2018), this approach is based on the analysis of discursive and non-discursive aspects of voice cloning technology. Discursive aspects are retrievable in presentations of technological devices such as advertising, journal articles, movies, press releases and public debates. Non-discursive aspects instead regard the set of meanings expressed by the non-human agencies of technological devices, such as the way the process voice signal, the affordances of their interfaces, the bodily postures they enact.

This kind of approach is becoming established in media studies (Ellcessor et al., 2017), and has been influenced by Science and Technology Studies (Bijker et al., 1992) and Actor-Network Theory (Latour, 2005). Since the '80s, those perspectives have highlighted the social dimension of technology not only for what concerns the cultural ways human users appropriate and give meaning to artifacts, but also for the agency embedded in the artifacts themselves. Adopting and expanding on this assumption, studies focused on disability technologies (Ellcessor et al., 2017) have developed a techno-social approach addressed to both the evaluation of the assistive potential of

such technologies and to the consideration of the technological artifacts as sites where knowledge about disability is produced, represented and enacted.

The validity of such approach has been already suggested by disability studies. In this framework, a 'social model' of disability has been recognized as alternative or complementary to the 'medical model' (Siebers, 2008). Unlike the medical approach, which seeks to explain, diagnose, treat, and 'cure' disability as a pathology, the emerging field of disability studies considers disability as a social construct, in this way denaturalizing it (Williams & Mavin, 2012). The social model of disability aims rather to study the social meanings, symbols, and stigmas attached to the concept of disability as a component of identity, and how it relates to enforced systems of exclusion and oppression. As noted by Mills and Sterne (2017, p. 365), 'not only do media produce disability through their textual representations of disability, they produce disability through their very operations, their institutional existences, and their policy and juridical dimensions'.

Placing artifacts and technologies at the center of issues of disability, this approach to the study of disability has interested scholars in media studies as well (Goggin and Newell, 2003; Ellis and Kent, 2011; Elccessor et al., 2017). Disability, in fact, is all too often reconstituted and reconfigured in and through new technologies, both at the narrative and at the operational level. As Ellis and Kent argue (2011), new technology can broaden accessibility and inclusion for impaired people through their affordances, but those same affordances can also produce new forms of exclusion and disability. In this regard, Elccessor et al. (2017, p. 16) argue that: 'we need to understand the ways that media and information technologies are intertwined with the standardization and regulation of the human body' and how those processes shape the meaning of ability and disability. In their view, this investigation must consider both meaning and materiality, since ideas are embodied in and shaped by material conditions and human practice, and made endowed with meaning by the discourses that inform them and that they in turn inform. Innovations in media technologies thus raise issues of materiality and embodiment which affect also cultural ideas and meanings: how we interact with buttons, dials, or gaming consoles; how we plug in earbuds or position ourselves toward screens, listening devices or speaking devices; how manufacturers imagine the bodies that will engage with their creations, and so on.

Maryil Alper's (2017) work is probably the first study addressed to speech synthesis and communication aids from an interdisciplinary perspective, uniting social, cultural, material and organizational issues. Through ethnographic engagement in the life of speech-impaired children in American public schools, she explores the links between the assistive potential of new communication technologies and the normative and 'ableist' (Siebers, 2010) assumptions embedded in the behaviors promoted by the institutions through representations, economic policies and organizational models. From a perspective inspired by media archeology, Mara Mills (2011) shows how the modern concepts of 'impairment' and 'hearing loss' – as well as the contributions of deaf and hard-of-hearing people – were central to the development of telecommunications technologies and signal processing in the twentieth century. Similarly, Jonathan Sterne's first book (2003) locates the origins of sound reproduction in nineteenth-century sound culture, with its peculiar conceptions of hearing, speech, and deafness.

Imagines of disability, in fact, are not only represented by media, but are also embedded in technology affordances and operations (Mills & Sterne, 2017). Thus, assistive technologies design could benefit from a media-archeological analysis (Ernst, 2018) which is addressed to unearth latent ideas and social prejudices about a specific disability reproduced at both discursive and non-discursive level and to deconstruct them.

In the next section I will use Google's project to reunite speech-impaired users with their voices using voice cloning technology⁶ as an illustrative case of a socio-material approach to assistive technology. In this direction, I will analyze both the discursive level of representations of disability which emerge from the narrations built around voice technology (such as the documentary *The Age of AI*⁷ where Google's project is presented) and the non-discursive level of material aspects regarding the technological operations and affordances (such as the data-driven practices and operations employed in voice cloning for speech-impaired people).

3 Findings

3.1 Discursive Level

At the discursive level, speech synthesis is usually presented as 'giving voice' to those who can't physically speak. Voice cloning in particular is presented as a technology which can give speech-impaired people 'their own' voice back. The documentary about Google's project of reuniting speech-impaired people with their voices through voice technology goes in this direction. Tim Shaw, a former NFL player who has lost his ability to speak after being affected by ALS (Amyotrophic lateral sclerosis), is 'healed through AI' by Google: collecting voice recordings from Shaw's interviews on national television, Google employed Artificial Intelligence (specifically machine learning) to create a synthetic voice profile that imitates Shaw's way of speaking in a realistic and natural-sounding way (Chen et al., 2019). The project's aim, as underlined by the documentary commenter, was 'to get his voice back', reconstructing his 'original' voice.

In this representation, the meaning of 'owning' a voice and the relation between voice and identity is assumed as given and unproblematic. Nevertheless, artificial voice calls into question cultural categories about voice as a 'natural' attribute of human being. In this case, role of the discourse analysis (Fairclough, 2010) is to unearth the hidden cultural assumptions present in the technology presentations and to show how those assumptions work as 'tacit knowledge' (Polanyi, 1966). Through such analysis it's possible to unearth hidden connections between social constructions and cultural-epistemological attitudes which drive modern science and technology, of which AI is perhaps one of the most prominent outcomes.

⁶ <https://deepmind.com/blog/article/Using-WaveNet-technology-to-reunite-speech-impaired-users-with-their-original-voices> (visited on 30/01/2022)

⁷ The documentary is available online at the link: https://www.youtube.com/watch?v=V5aZjsWM2wo&ab_channel=YouTubeOriginals (visited on 30/01/2022)

The first assumption can be related to what Jacques Derrida (1967/2010) famously named the ‘phonocentrism’ dominant in western philosophy. According to Derrida, voice has been considered as the immediate expression of the inner self. This view relies on a metaphysical understanding of the world and the human subjectivity, according to which the true self is not in the body but in the disembodied soul and voice would be the sensory expression of the soul. This kind of thought seems assumed also in Google’s presentation of its voice cloning technology for disabled people, and accordingly affects also the resulting definition of disability.

Google’s narration seems in fact consistent with a certain sort of AI ideology: that human beings might be uploaded into new hardware whenever their old hardware wears out (Natale and Pasulka, 2019). This misleading claim is grounded on a metaphysical understanding of reality, insofar as it assumes the duality of mind and body and the superiority of the first over the second. This attitude denies both the social construction of disability and the embodied condition of subjectivity and identity, locating subjectivity rather in an abstract and supernatural soul. Being disembodied, this kind of subjectivity is by definition ‘able’, can’t be affected or defined by any impairment, which remains by definition an external, bodily flaw. Voice, with its traditional relation to metaphysical subjectivity (Derrida, 1967/2010), is the perfect representation of this condition. In this perspective, the loss of the voice would be the worst tragedy imaginable, a direct attack to the core of what makes us human. But voice is also considered as a bodily thing, a mere interface with the purity of the inner self, which is in fact disembodied. As such, the loss of voice doesn’t compromise the supposed ability of the inner self. It’s in this perspective that a compensation for the loss of the voice can be in the first place imagined and then pursued by medical or technological means.

Google’s narrative can be ascribed to what Rosemarie Garland Thomson (2001) defines a ‘sentimental rhetoric’, addressing what Oliver (1996) sees as ‘the tragedy model’ of disability, which positions disability as a terrible issue for the afflicted individual. ‘Every single day is a struggle for me’, Tim Shaw says through his synthetic cloned voice, but, using voice cloning technology, he can now ‘get his voice back’. The emphasis emerging is that of an individualized medical interpretation of disability as biological or functional limitation; the narration leads to an attempt to compensate people with impairments, rather than enabling their full inclusion in social life. Technology, in particular AI, is seen here as a tool to achieve this compensation and reduce the tragic nature of the disability, a tool to ‘fix’ the impaired person, overlooking the social conditions in which disability is constructed as such.

3.2 Non-Discursive Level

As highlighted by media studies scholars, material operations of technological devices are not neutral but embed precise cultural meanings. At this level, voice cloning way to treat and process voice signal, as well as the embodiment it enacts for the users, is expressive of conceptions of voice and disability.

Voice cloning employs machine learning algorithms to determine the features of a person’s voice profile – those characteristics which differentiate it from that of another person – starting from the data of that voice (Marr, 2018). The collection of such voice

data becomes crucial to the successful operation of the technology. This entails that voice cloning relies on a sort of essentialist epistemology based on the assumption that voice is something that can be owned. It assumes that each person owns a voice, her own voice, and this voice can be translated into data with little or no loss from the “original”, embodied one. This means affirming a quantitative correspondence between voice and sound data and between sound data and identity, all of which has practical and political consequences such as the possibility to profile people from the measurement of their voice features, ever more included in forensic practices of automatic speaker identification (Singh, 2021).

At the same time, and in contrast with this assumption, voice cloning technology seems to take a step beyond the normative and essentialist perspective: as vocal features are made to emerge directly from the data, which is a prerogative of machine learning algorithms, this technology is not attempting to synthesize a ‘pre-defined’ standard voice, but rather to get to the singularity of each voice, in its peculiarities and without reference to standards, capturing also the ‘imperfections’ and deviations from the norm that make each voice unique. This makes AI look like a promising technology when discussing disability, because instead of looking for norms among the variations, it opens the technology to the differences which characterize disability as itself ‘a form of human variation’ (Siebers, 2008, p. 25) – a material practice that collides with the mainstream deceptive narration about AI described in the previous section.

One consequence of this can be observed in the fact that voice cloning, bypassing classic issues with synthetic voice, sidesteps the problem of avoiding gender, race and class stereotypes culturally coded into pre-defined voice characters. The fact that features of a person’s body can be built into a synthetic voice (indeed, it is these very factors which make that voice personal) represents more than mere engineering of the human body with rehabilitative aims (Hamraie, 2017, p. 15): it can also be seen as another form of technological embodiment.

4 Discussion

This paper argues that assistive technology design has to face cultural and philosophical issues at both the material level of artifacts operations and at the discursive level of presentations and sense-making. As Graham Pullin (2009, p. 158) has argued, ‘not just meaning but also identity are conveyed through tone of voice’. This entails that voice communicates not only through words but also through its very sound. Voice technologies, in fact, both when addressed to disabled people and when addressed to generic audience, enact specific forms of embodiment. The assumption that a voice which doesn’t come from someone’s mouth but from a loudspeaker can still be considered as someone’s own voice is something that destabilizes naturalizing ideologies of ‘presence’ (Derrida, 1967/2010) and universalist conceptions of the body, of the voice and of the identity (Sterne, 2021). In this regard, voice cloning seems deconstructing the very idea of ‘owing’ a voice in the same moment it pursues it at the narrative level. Moreover, in engineering voice, technology not only assumes but defines what a normal voice is (Mills, 2020), in so doing re-enacting a normative attitude which is in

contrast with the aim of customization and personalization proper of assistive technology. Even if voice cloning employs machine learning algorithms to determine the features of a person's voice profile that differentiate it from that of another person, it risks reproducing a kind of forensic attitude which is inherent speaker identification functions necessary to its functioning (Napolitano, 2020; Singh, 2021).

Moreover, the collection of such voice data leads to the articulation of socio-material practices of voice data collection, such as 'voice banking', which must be pre-emptive. That is, they must happen before someone experiences significant speech impairment (or as soon as one is diagnosed with a degenerative disease). This has implications which reach beyond the simple act of speaking, associating voice banking with cultural practices related to saving, preventing, leaving traces, making a will (not so far from having to decide in advance whether to be an organ donor).

Based on all of these elements, technologies for disability seem characterized by a certain tension: while enhancing agency and access for impaired people, such technologies often reproduce an 'ableist' paradigm (Siebers, 2008) which assumes an original, untouched condition of ability and perfection, subsequently corrupted by disability, which must be restored through medical intervention and technology. According to this interpretation, Google and other tech companies seem to affirm a medical model through their representations, producing narratives of personal liberation via technology which overlook the social construction of disability. These stories portray technology as allowing individuals to 'overcome' their disability as an individual limitation, and at the same time are intended to be uplifting and inspirational for able-bodied audiences, assuming ability as an unquestioned and neutral condition in the first place. For this reason these narrations appear implicitly and essentially ableist. One consequence of this understanding of disability as an essentialized individual problem is that the (marginalized) subject position of disabled people is not problematized. As Ingunn Moser (2006, p. 373) puts it: 'the mobilization of new technologies works to build an order of the normal and turn disabled people into competent normal subjects. However, this strategy based on compensation achieves its goals only at a very high price: by continuing to reproduce boundaries between abled and disabled, and normal and deviant, which constitute some people as disabled in the first place.'

As a consequence, it is of main importance for assistive technology designers, engineers and other professional figures involved to take care of the social meanings embedded into artifacts at both narrative and material level. As Pullin (2009, p. 178) underlines, 'the design is done together: not by the designer for the individual, but neither by the individual using the designer just as a facilitator. It emerges from a dialogue and a relationship.' My proposal is that this dialogue involves also social scientists, in order to critically interrogate the cultural assumptions so often reproduced and embedded into artifacts, and to frame design into wider social issues. This is a way to avoid that inclusive technologies turn into means of new exclusions and marginalizations.

References

1. Alper, M. (2017), *Giving Voice: Mobile Communication, Disability, and Inequality*. Cambridge, MA, MIT Press.

2. Bijker, W., T. Hughes, T. Pinch (eds) (1992), *The Social Construction of Technical Systems*, Cambridge, MA: MIT Press.
3. Chen, Y., Casagrande, N., Zhang, Y., Brenner, M., (2019), Using WaveNet technology to reunite speech-impaired users with their original voices, Google DeepMind blog, <https://deepmind.com/blog/article/Using-WaveNet-technology-to-reunite-speech-impaired-users-with-their-original-voices> (visited 30/06/2021).
4. Derrida, J. (1967/2010), *Voice and phenomenon: Introduction to the problem of the sign in Husserl's phenomenology*, trans. L. Lawlor, Evanston, IL, Northwestern University Press.
5. Ellcessor, E., Hagood, M., Kirkpatrick, B. (2017), Introduction: Toward a Disability Media Studies, in Ellcessor, E., Kirkpatrick, B. (eds.), *Disability Media Studies*, New York, New York University Press.
6. Ellis, K., Kent, M. (2011), *Disability and New Media*, New York, Routledge.
7. Ernst, W. (2018), *Radical Media Archaeology: Its Epistemology, Aesthetics and Case Studies*, *Artnodes*, 21, pp. 35-43.
8. Fairclough, N. (2010), *Critical Discourse Analysis*, 2nd ed., New York, Routledge.
9. Garland Thomson, R. (2001), Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography, in P.K. Longmore and L. Umansky (eds.), *The New Disability History: American Perspectives*, New York, New York University Press, 355-74.
10. Goggin, G., Newell, C. (2003), *Digital Disability: The Social Construction of Disability in New Media*, Lanham, MD, Rowman & Littlefield.
11. Hamraie, A. (2017), *Building Access. Universal Design and the Politics of Disability*, Minneapolis, University of Minnesota Press.
12. Jemine, C. (2019), *Real-time Voice Cloning*, Master Dissertation, Université Liège.
13. Latour, B. (2005), *Reassembling the social. An introduction to actor-network theory*, Cambridge, Oxford University Press.
14. Marr, B. (2019), Artificial Intelligence Can Now Copy Your Voice: What Does That Mean For Humans?, *Forbes*, 6 May, <https://www.forbes.com/sites/bernardmarr/2019/05/06/artificial-intelligence-can-now-copy-your-voice-what-does-that-mean-for-humans/> (accessed 20/07/2021).
15. Mills, M. (2020), Testing Hearing with Speech, in V. Tkaczyk, M. Mills, A. Hui (eds.), *Testing Hearing: The Making of Modern Aurality*, New York, Oxford University Press, 23-48.
16. Mills, M., Sterne, J. (2017), Afterword II: Dismediation – Three Proposals, Six Tactics, in Ellcessor, E., Kirkpatrick, B. (eds.), *Disability Media Studies*, New York, New York University Press, pp. 365-378.
17. Moser, I. (2006), Disability and the Promises of Technology: Technology, Subjectivity and Embodiment within an Order of the Normal. *Information, Communication & Society*, vol. 9, no. 3: 373-95.
18. Napolitano, D. (2020), The cultural origins of voice cloning, in M. Verdicchio, M. Carvalho, L. Ribas, A. Rangel (eds.), *xCoAx 2020 Proceedings of the Eighth Conference on Computation, Communication, Aesthetics & X*, available at the website: <http://2020.xcoax.org/xcoax2020.pdf>.
19. Natale, S., Pasulka, D. (2019), *Believing in Bits: Digital Media and the Supernatural*, New York, Oxford University Press.
20. Oliver, M. (1996), *Understanding Disability: From Theory to Practice*, Basingstoke, Macmillan.
21. Singh, R. (2019), *Profiling Humans from their Voice*, Singapore, Springer.
22. Polanyi, M. (1966), *The Tacit Dimension*, New York, Anchor Books.
23. Pullin, G. (2009), *Design Meets Disability*, Cambridge (MA), MIT Press.
24. Siebers, T. (2008), *Disability Theory*, University of Michigan Press.

24. Singh, R. (2019), *Profiling Humans from their Voice*, Singapore, Springer.
25. Sterne, J. (2003), *The Audible Past. Origins of Sound Reproduction*, Durham and London, Duke University Press.
26. Sterne, J. (2021), *Diminished Faculties: A Political Phenomenology of Impairment*, Durham and London, Duke University Press.
27. Williams, J., Mavin, S. (2012), Disability as Constructed Difference: A Literature Review and Research Agenda for Management and Organization Studies, *International Journal of Management Reviews*, vol. 14, 159-179.
28. Yin, R. K. (2015). *Qualitative research from start to finish*. New York N.Y.: Guilford publications.

Perspective of Educators and Parents of Four European Countries on Integrating (Assistive) Technology in Inclusive Early Childhood Education and Care Settings

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Abstract. Nowadays, it is key to explore the opportunities of integrating Digital Mainstream Technologies (DMT) and Assistive Technologies (AT) into Early Childhood Education and Care (ECEC), especially for children with disabilities. In order to achieve a successful implementation into practice two main stakeholders, educators and parents, have to be actively involved in this process. Literature about the insights of parents on implementing technology for their children in ECEC is limited. Therefore, the aim of this study is to identify the conceptions and beliefs of educators and parents in inclusive ECEC in four European countries (Belgium, Cyprus, Italy, Republic of North Macedonia) in relation to the current practice, barriers and opportunities for integrating DMT and AT in inclusive ECEC. A total of 76 educators working with children 0-6 years of age in inclusive ECEC and 71 parents of children, with and without disabilities, 0-6 years of age in inclusive ECEC, participated in focus group interviews across the four countries. According to them, important barriers to integrate DMT and AT in ECEC are the lack of resources such as knowledge, expertise and budget. However, using DMT and AT as a tool for differentiation or as a support for communication are one of the many opportunities for using technologies for educational purposes and for the inclusion of children with disabilities.

Keywords: Inclusion, Early Childhood Education and Care, Assistive technology, Digital Mainstream Technology, Parents, Educators

1 Introduction

1.1 Inclusion and Technology in Early Childhood Education and Care

Infants, toddlers and pre-schoolers, with and without disabilities, nowadays grow up in an environment where technology is everywhere and use technology on a daily basis [1-2]. Although the educational potential of technology, there are also related developmental and health concerns due to excessive technology use, e.g. increased risk for obesity and shorter night time sleep duration [1]. However, embedding technology in teaching to complement and improve traditional teaching methods can help develop certain skills such as collaborative problem solving, cultural awareness and sensitivity, critical thinking, and creativity [3].

According to the UN Convention on the Rights of Persons with Disabilities [4], all children with disabilities have the right to education, more specific to an inclusive education system at all levels. Hence, in recent years more children with disabilities are included in mainstream education settings, which causes an increased demand for Assistive Technologies (AT) to meet their special needs in inclusive education [5]. Inclusive education is frequently not possible without access to fit-for-purpose AT. If AT is an enabler for learning, actions for identifying and addressing the unique AT needs of each individual child must take place as early as possible. This is to ensure that young children interact as much as possible with the world around them and that by the time the child goes to school, the use of AT is already an acquired habit and does not create an additional barrier. [6] The Convention on the Rights of Persons with Disabilities states also that the availability and use of new technologies, including information and communication technologies and assistive technologies, should be promoted [4].

The literature describes various opportunities or benefits (e.g. development of problem-solving and computational thinking, support collaborative learning and social interaction, enabling participation of children with disabilities) of incorporating Digital Mainstream Technologies (DMT) and AT into Early Childhood Education and Care (ECEC), but also several barriers (e.g. access to technology, attitudes towards technology, concerns about negative impact of technology, digital competences of educators, lack of awareness of existing technologies, financial barriers, absence of policies, legislations and/or national programmes) [6-9]. Notwithstanding the barriers, educators in ECEC explore the opportunities to integrate DMT and AT into their curriculum [2]. Therefore, they need adequate digital competence. For educators, adequate digital competence means knowing when, how and why digital tools should be used. A first important step is to examine their understandings and experiences of digital tools, but also why they are not always capable to use digital tools [10]. Parents are another important stakeholder in ECEC but literature on their conceptions and beliefs on integrating technology in ECEC is limited.

1.2 Aim

The aim of this study is to identify the conceptions and beliefs of educators and parents in inclusive ECEC in four European countries (Belgium, Cyprus, Italy, Republic of

North Macedonia) in relation to the current practice, barriers and opportunities for integrating DMT and AT in inclusive ECEC. The outcome of this study will also contribute to the development of the guidelines and the educator training for integrating DMT and AT in ECEC, as envisioned in the Erasmus+ SKATE project (<https://skateerasmus.be/>, Project N°2020-1-BE02-KA201-074810).

2 Method

This study draws on data from multiple focus group interviews in the four European countries with (1) educators (childcare workers, classroom teachers, teacher assistants, special educators and paramedics that supports teaching activities) working with children 0-6 years of age in inclusive ECEC; and (2) parents of children, with and without disabilities, 0-6 years of age in inclusive ECEC. A well-conceived script, including an interview guide, was provided for conducting the focus group interviews. In each country, local standards on ethical approval were respected and informed consents were obtained from all individual participants.

The first country analysed their own organised focus group interviews in the local language by using intelligent verbatim transcription and thematic analysis in 6 steps: (1) familiarizing with the data, (2) generating initial codes, using a code list, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report, using a self-developed template [11].

The other countries analysed their focus group interviews following the same themes of this thematic analysis by using the summaries of their interviews. The findings were translated in English, structured and then merged into an overall report with conclusions and discussion based on the results of the four countries.

3 Results

3.1 Participants

A total of 76 educators participated in the focus group interviews across the four European countries. The educators involved had experience with children with different disabilities (e.g. attention-deficit/hyperactivity disorder, speech or language impairment, visual impairment, motor disability, intellectual disability, autism spectrum disorder, multiple disabilities) in their ECEC setting. Altogether in the four European countries 71 parents of children without ($n = 45$) and with all kinds of disabilities, such as motor disability, intellectual disability, autism spectrum disorder ($n = 26$) participated. An overview of the participants per country is presented in Table 1.

Table 1. Overview participants per country

Role	Number of participants per country				Total participants
	Belgium	Cyprus	Italy	Republic of North Macedonia	
Educators	21	20	14	21	76
Parents of children without disabilities	16	11	8	10	45
Parents of children with disabilities	4	5	6	11	26

3.2 Perspective of Educators and Parents of Four European Countries on Integrating (Assistive) Technology in Inclusive Early Childhood Education and Care Settings

Participants' views were grouped for both DMT and AT into four main themes: (1) conceptions and beliefs, (2) experiences, (3) opportunities, and (4) barriers.

Digital Mainstream Technology. In relation to DMT, in all four countries DMT are used in ECEC for education and/or play or leisure. Most commonly used DMT are interactive boards, interactive walls, (smart) TVs, smartphones and (giant) tablets. In some countries also computers, laptops, projectors, programmable robots and sound systems are used.

According to educators, DMT can create opportunities if it is used in an appropriate way for (1) supporting and encouraging language and speech development, communication and social relations, (2) learning, for example through educational games, educational software or multimedia, (3) creating quiet moments or relaxing children, (4) stimulating motor skills and exercising pre-reading/writing skills, (5) collaborative (movement) learning, (6) children to get familiar with technology, and (7) inclusion as a common language for all children, a tool for differentiation and substitute exercises, a support or stimulant for communication, a motivation for children, and a facilitator of group activities and collaborative learning. In the opinion of parents, DMT can create opportunities for (1) learning, e.g. learning and stimulating (foreign) languages, self-image, (2) exercising motor skills, (3) children to get familiar and learn to work with DMT, (4) stimulating children's curiosity and motivation, (5) children to socialise, to experiment and to become creative, (6) relaxing children, (7) remote learning and communication, and (8) inclusion through differentiation, substitute exercises, a common language for all children and supported communication.

A barrier to the use of DMT in inclusive ECEC, according to both educators and parents across the four countries is lack of digital knowledge, competences, skills and/or training on technology-use. Both educators and parents mention the following barriers: (1) lack of digital equipment and/or budget for the acquisition of DMT in ECEC, (2) concerns about possible negative impact of digital technologies for young children e.g. social interaction, (3) lack of appropriate applications, software and other

resources in the local language(s), (4) the vision and values of the school and/or educator about technology, (5) insufficient (technical) support, (6) lack of collaboration with experts and other educators to use technology with children (with disabilities) in ECEC, and (7) lack of time on the part of educators to search and implement technology. Parents highlighted also one additional barrier: lack of guidelines for both educators and parents.

Assistive Technology. In relation to AT, in all four countries the general conceptions and beliefs of educators and parents about the use of AT in ECEC are positive. Educators believe that the use of AT helps to achieve inclusive education by promoting interaction and making activities more accessible. AT can also be used to create interesting activities for all children and specific AT could be used to potentiate children's abilities and autonomy. Parents mentioned that it is important that AT are used in a reasoned and inclusive way to train or support specific deficits or in specific classroom activities to enhance inclusion of children with disability by a trained educator. AT provide a real tool to capture children's attention, increase their motivation during activities, expand their communication skills and prepare them for adulthood. Nevertheless, according to both educators and parents, there is limited use of AT in ECEC.

AT that are mentioned by both educators and parents are: (1) low- and high-tech augmentative and alternative communication systems, (2) (educational) software or applications for children with disabilities, (3) listening picture books, (4) adapted toys, and (5) alternative input devices, e.g. joysticks, access switches, trackballs, touch screen devices. Educators also highlighted following AT: (1) Vibrating Platform to stimulate attention to the presence or absence of sounds, (2) changing colour panels to give children feedback about the intensity of sounds in the room, (3) cinema with amplified sounds to stimulate inclusive group activities with deaf children, (4) multi-sensory stimulation room, and (5) Cause and Effect Sensory Lightbox and similar – cause-effect software and hardware.

According to both educators and parents, AT can create opportunities for (1) all children, e.g. practice motor skills with all children, (2) inclusion by supporting children with disabilities in all educational activities, supporting and stimulating language and speech development of children with communication disabilities, substitute exercises and making learning and play activities more accessible so that children with disabilities can interact, do activities with other children and grow along with their peers. In addition, educators highlighted following opportunities: AT can (1) support and stimulate language and speech development, (2) capture the attention, (3) be adapted to the needs of the child, and (4) strengthen the abilities of children with disabilities to help them to be more autonomous. Parents additionally mentioned that AT: (1) can provide additional structure for all children using pictures and pictograms, (2) can motivate children, and (3) offers various means and modes of developing children's different competences, directly or indirectly, such as specific skills, attitudes, knowledge, and enhance their learning process.

The barriers to the use of AT in ECEC for both educators and parents are (1) limited or absence of available AT and/or budget for the acquisition of AT, (2) lack of awareness, knowledge and training of educators and parents on AT, (3) lack of collaboration between educators and AT experts, (4) lack of technical and/or pedagogical support of

AT experts in ECEC, (5) lack of time of the educators, e.g. to adapt learning activities and materials to individual needs, to learn to use AT, to prepare AT, (6) reluctance to use AT, (7) vision of the school or educators on AT, (8) limited portability of AT, and (9) lack of an implementation plan and follow-up procedures after the assignment of (individual or not) AT to a child or a classroom. Additional barriers mentioned by educators are: (1) lack of affordable, appropriate, adaptable software, applications and other AT resources in the local language(s), (2) fear of damaging AT, (3) the use of AT demands a lot from the educator because pre-schoolers cannot yet work with them independently, (4) sometimes there is a long wait before AT are used in ECEC, the focus is often still on stimulating and practising skills and the demand for AT for skills that are not successful is not made, and (5) children evaluation in the preschool years is of no importance for the Ministry of Education and it is also time consuming. Parents also highlighted some additional barriers to the use of AT in ECEC: (1) educators are not familiar with or afraid to introduce AT, (2) parents prefer that preschools provide tangible experience and interaction with other children, and (3) absence of appropriate legislation (and policy gaps), especially in relation to inclusive education as well as a clear legal framework for AT provision.

4 Conclusion and Discussion

This study provides a view on the conceptions and beliefs, current practices, barriers and opportunities for integrating Digital Mainstream Technologies and Assistive Technologies in inclusive ECEC from the perspective of educators and parents across four European countries. Based on the focus group interviews, AT is used less than DMT in inclusive ECEC. Important barriers to integrate DMT and AT are the lack of resources such as knowledge, expertise and budget. However, the educators and parents see many opportunities for using DMT and AT for educational purposes and for the inclusion of children with disabilities. The use of DMT and AT offers opportunities to enhance the communicational, motor and educational skills of all children, with and without disabilities, can strengthen the abilities of children with disabilities and give them the chance to grow along with their peers. It is recommended to use DMT and AT in a well-considered pedagogical way.

Due to the exploratory nature of the focus group interviews the results may not be considered fully representative for the entire population of stakeholders targeted. But the fact that similar findings could be noted in the four European countries indicates that the same beliefs and concerns are prevalent in different areas of Europe in the same way. Furthermore, the inclusion of both educators and parents of children with and without disabilities of different ages (0-6 years) in the study in all four countries is a strength and certainly because parents, an important stakeholder for successful integration of technology in ECEC, are often not involved in current literature.

Despite many opportunities for integrating DMT and AT in inclusive ECEC, we must not lose sight on the fact that every situation is different and the centre of the process for applying DMT and AT must always be the child. Therefore it is also

recommended to investigate and reflect on the children's experiences and behaviour during the use of DMT and AT in inclusive ECEC in further research.

References

1. American Academy of Pediatrics: Media and young minds (policy statement). *Pediatrics* 138(5), 1–8 (2016). doi: 10.1542/peds.2016-2591
2. Lyons, C.D., & Tredwell, C.T.: Steps to Implementing Technology in Inclusive Early Childhood Programs. *Computers in the Schools* 32(2), 152-166 (2015). doi: 10.1080/07380569.2015.1038976
3. Sepúlveda, A.: The digital transformation of education: Connecting schools, empowering learners. 2020 ICT in Education, 249-260 (2021). www.cetic.br
4. UN: Convention on the Rights of Persons with Disabilities. Article 24 (2007). <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>
5. Zilz, W., & Pang, Y.: Application of assistive technology in inclusive classrooms. *Disability and Rehabilitation: Assistive Technology* 16(7), 684-686 (2021). doi: 10.1080/17483107.2019.1695963
6. Hunt, P.F.: Inclusive education: The case for early identification and early intervention in assistive technology. *Assistive Technology* 33(s1), S94-S101 (2021). doi: 10.1080/10400435.2021.1974122
7. Botelho, F.H.F.: (2021). Childhood and Assistive Technology: Growing with opportunity, developing with technology. *Assistive Technology* 33(sup1), 87-93 (2021). doi: 10.1080/10400435.2021.1971330
8. Blackwell, C.K., Lauricella, A.R., & Wartella, E.: Factors influencing digital technology use in early childhood education. *Computers & Education* 77, 82-90 (2014). doi.org/10.1016/j.compedu.2014.04.013
9. Murcia, K., Campbell, C., & Aranda, G.: Trends in Early Childhood Education Practice and Professional Learning with Digital Technologies. *Pedagogika* 68(3), 249–264 (2018). <http://pages.pedf.cuni.cz/pedagogika/>
10. Lindeman, S., Svensson, M., & Enochsson, A.-B.: Digitalisation in early childhood education: a domestication theoretical perspective on teachers' experiences. *Education and Information Technologies* 26, 4879–4903 (2021). doi.org/10.1007/s10639-021-10501-7
11. Braun, V., & Clarke, V.: Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77-101 (2006). doi: 10.1191/1478088706qp063oa

Digital Assistive Solutions in Person-Centred Integrated Care for Older People



A Pragmatic Participatory Design Approach of an Implementation Readiness Tool ProTransfer

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Abstract. The SEURO Horizon 2020 project is developing ProTransfer, a self-assessment tool aimed at evaluating the readiness of organizations to transfer (or adopt) a digital health solution in their specific context. However, organizations vary greatly in structure, culture and stakeholder make-up, a factor to be considered when designing innovations intended for real-world application. Findings are presented from a synchronous collaborative online workshop conducted with Living Lab practitioners (n=10), using a Miro virtual whiteboard (VW) to test and evaluate elements of the ProTransfer tool. With this workshop format we created a pragmatic approach to evaluate initial conceptual ideas of the self-assessment tool with different stakeholders in an interesting and time efficient way for all parties. Findings suggest that effective completion of the ProTransfer tool requires input from a wide range of stakeholders. This presents a challenge in designing the questions and/or statements within the tool to be both sufficiently clear and unambiguous for both ease of consideration and to generate comprehensive responses. Implications for the design of transferability self-assessment tools include consideration of the manner in which end-users of the tool should be guided to ensure completing the tool in a collaborative multi-stakeholder process.

Keywords: Digital Health, Participatory design, User centred design, self-assessment tool, transferability model.

1 Introduction

1.1 Digital Health Technology Innovations

Every day, innovative digital health technology innovations (DHTIs) are developed across Europe, responding to cross-border needs. Many, though beneficial and measurable, may never be incorporated into the mainstream. A range of factors influence the likelihood that DHTIs will be effectively implemented into organizational systems [1]. The ProACT proof of concept trial [2-4] aimed to develop a web-based digital

intervention to support older adults in the self-management of multiple chronic health conditions. Part of the ProACT project included an extensive study on the key factors necessary to evaluate if an organization or region is prepared to successfully implement and scale an innovative, people-centric digital integrated health and social care solution. The transferability model presents a first step to systematize existing knowledge and experience on transferability of digital tools in the field of ICT (Information Communication Technology). See Figure 1.

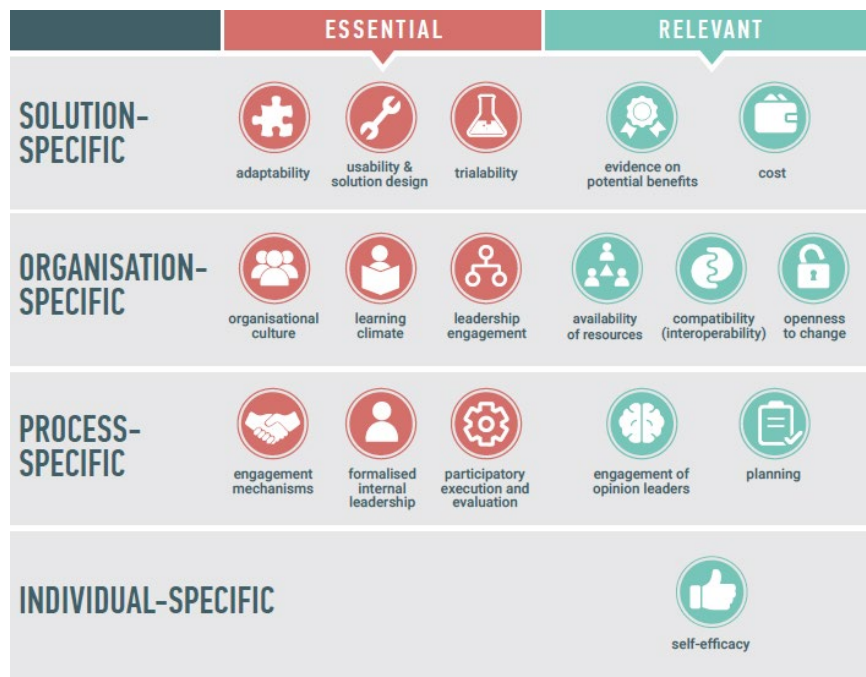


Fig. 1. The Transferability Model

The ProACT Transferability Model, including the factors categorised as I) Essential and II) Relevant, is informing the development of the ProTransfer tool, aimed at helping organisations to assess their readiness in implementing, transferring and scaling digital health solutions. Outcomes from the use of the tool will generate transferability scores, assessing the readiness for a solution transfer under the 4 model headings (see Figure 1):

- **Solution Specific** (characteristics of the digital solution).
- **Organization Specific** (organizational settings required to facilitate solution transfer).
- **Process Specific** (processes within organizations required to facilitate solution transfer).
- **Individual Specific** (characteristics of the workers).

ProTransfer will also offer recommendations on how to strengthen organizational ability to address transferability of a digital health solution, based on scores for each of the factors. The provided recommendations aim to support the sustainability and scalability of existing and/or new solutions across different regions and countries, leveraging the potential of digital innovations for more efficient and person-centred care in Europe.

1.2 ProTransfer Tool and the ENoLLworkshop

The term digital health solution (or intervention) is broad in scope: it includes mobile health (mHealth), health information technology (HIT), wearable devices, telehealth and telemedicine, and personalized medicine. Digital health technologies can use computing platforms, connectivity, software and sensors for health care and related uses. Structured partnerships have been shown to have value, for the effective implementation of innovations aimed at improving personalized and timely health care [6]. Living labs, having evolved from user innovation and open innovation paradigms for new product development, emphasize the essential value of including the views and experiences of all stakeholders when designing, developing and implementing innovations in services and technologies [7]. This paper presents learnings from a workshop conducted at Digital Living Lab Days 21 (DLLD21) (<https://openlivinglabdays.com/program-2021/>), the annual conference of the European Network of Living Labs (ENoLL). Living Lab practitioners, experienced in multi-stakeholder orchestration across a range of health and wellbeing living lab and open innovation projects, tested a sample of elements/statements from the proposed ProTransfer tool. This work has informed the development of a transferability self-assessment tool (ProTransfer) to assess organizational preparedness for digital solution transfer, within the SEURO project (<https://seuro2020.eu/>).

2 Methods

The pragmatic workshop design approach aimed to enable evaluation of the initial conceptual design of the implementation tool, with different stakeholders in an interesting and time efficient way. The DLLD21 conference presented a suitable opportunity where diverse groups of experts on implementation of innovation meet. The workshop format was developed with the specific requirements of this conference, which was being delivered online due to the COVID-19 pandemic, using a dedicated Miro board.

2.1 Arrival and Introduction

Prior to registering for the workshop participants had access to a short video and text explaining the workshop goal to present the ProTransfer transferability self-assessment tool and stimulate discussion on how to improve the tool. Participants self-selected to attend the workshop, experience the tool and provide feedback. At the beginning of the workshop participants were invited to write down what they expected to learn in the workshop – also providing an opportunity to test how to contribute on a Miro board.

Subsequently the facilitators and workshop goal were introduced along with the high-level concept of the tool: a digital questionnaire with a scoring system to be used iteratively before and during DHTI implementation.

2.2 Preparing- Priming the Experience with the Tool

Before interacting with the ProTransfer tool, participants were primed with a sample DHTI, the ProACT CareApp, and provided some unfinished personas representing the expected target users of the tool. Selection and completion of personas occurred within three separate facilitated breakout groups labelled: Decision Maker, Technical Implementer, and Front-end Implementer. Participants chose one of three possible roles based on the responsibilities outlined for each job title. Once the persona was selected, a name and photo image were provided for the persona and participants in the breakout room were asked to consider what the chosen persona might think about proposed DHTIs and their implementation into the organization. Following the selection of personas, participants returned to the plenary session and a short overview of the ProACT CareApp and ProTransfer tools was provided. The ProACT CareApp was provided as an example of a digital health technology innovation (DHTI), for evaluation with ProTransfer, though participants could opt to choose another or their own DHTI. Information about the ProACT CareApp sample was provided on the Miro board.

2.3 Experience and Discussing the Tool

Returning to breakout rooms, each group then had an opportunity to review up to three statements from the ProTransfer tool that would be relevant to their persona categorization. The Decision Maker and Technical Implementer groups were provided solution specific, organization specific and process specific statements to consider. The Front-End Implementer group was provided process, individual, and organization specific statements. For all statements, each group was asked to consider (1) the ease of understanding of the statement and (2) the appropriateness of the statement for the persona represented by the breakout group. After some discussion, the explanatory text for the statement was then revealed and further discussion ensued to consider further the response to the statement and if the explanatory text provided clarity to the response being discussed. Participants were invited to add post-it notes with thoughts or comments to the Miro board. The facilitators also added notes to the board reflecting the discussion. Following the breakout sessions, a plenary session was conducted where facilitators provided feedback from the breakout rooms and the whole group engaged in discussion of issues identified.

3 Results

Findings are presented from the persona selection process, followed by themes identified during the tool evaluation breakout sessions and final plenary session. Ten participants attended the workshop representing nine living labs across Europe. Attendees

overwhelmingly identified they would like to learn if and how the tool would be useful to their organization or members ‘to improve our support activities’. Further, attendees wished to understand how the tool might be implemented. In particular to ‘scale up innovations’ and implement them.

3.1 Personas

The persona chosen by the Decision Maker group was an Innovation Manager from a Regional Public Health System, with responsibilities including the selection of tools and resources to enhance care across care delivery and design implementation processes. Participants expected this persona would be concerned about the cost, potential reimbursement and the potential risks associated with the DHTI implementation. The Innovation Manager was also expected to recognize the value of taking the needs of the different stakeholders into account, highlighting the digital literacy of patients and caregivers as a likely hesitation about the potential for successful implementation of the intervention. Nonetheless, the Innovation Manager was expected to recognize the potential of the DHTI to empower patients and to support them in being more active with their treatment. Greater condition self-management, through use of the DHTI, was further expected to be valued as having potential to contribute to increased efficiency and faster implementation of health and wellness processes.

The Technical Implementer group selected the persona of the Chief Technological Officer (CTO) at a private Diabetes Clinic with responsibilities including leading implementation of technical innovations in the organization. Participants in this group were emphatic that the person(s) responsible for technical implementation must be involved in all discussions, from the first consideration of the DHTI to active implementation within the system or organization. It was expressed that no DHTI could be successfully transferred without the inclusion of the Technical Implementer. A primary reason given for the inclusion of the Technical Implementer was that new DHTIs are regularly brought into organizations but are often not successfully adopted. Poor adoption results in unmet objectives and often leads to the attempted implementation of another new DHTI. The Technical Implementer was considered likely to be cautious about the introduction of new DHTIs because considerable work is required to integrate new apps and tools, particularly where the function of different tools may overlap with each other. Training is also required for each new tool, however, participants noted from their experience that there is often reluctance to engage in training for new digital tools that might be soon replaced.

The Front-End Implementer group selected the personal of a Home Care Organization manager with responsibilities including supervising the home care nursing team and oversight of client/patient care planning and implementation. Participants highlighted the importance of the organization manager having good understanding about the type of patients and operators who belong to the structure. Operators are essential to be able to transfer a technology within the facility and its various departments. The importance of training, understanding the improvement of the service, and above all, the timing of implementation of the insertion of technology was noted.

3.2 Sample Statements

Solution specific statements focus on the characteristics of the proposed DHTI in terms of the degree to which it can be adapted, tailored, refined or reinvented to meet local or regional needs (Adaptability); the ease of use or user satisfaction with DHTIs (Usability and Design); the ability to test the solution on a small scale in the organization (Trialability). Three solution-specific, Essential Factor statements were considered during breakout sessions.

The Decision Maker group examined an Adaptability statement: ‘The digital health solution can be adapted by my organisation, for meeting the local and regional needs’. The Technical Implementer group examined a Usability and Design statement: The design of the digital health solution is particularly interesting and attractive for our organization: a) Due to its usability; b) Due to its ability to be tailored to end-user requirements; c) Due to other reasons’. From the perspective of a CTO, the Technical Implementer group also considered a statement relating to the Essential Factor of Trialability: ‘The digital health solution can be tested prior to its definitive implementation’. Process specific statements focus on the processes required to facilitate the transfer of DHTIs. The Front-End Implementer group, using the persona of a Home Care Organization manager, considered a statement relating to Engagement Mechanisms: ‘There are engagement mechanisms already defined’.

3.3 Ease of Understanding

Participants noted that some statements were not sufficiently intuitive for clear understanding. This was due to questions arising about who would be using the tool and how terminology would be interpreted: the ‘definition of usability may be different to different people e.g., health administrator versus technical administrator’ and this difference in interpretation may be pertinent to how the statement would be addressed. The nature of the organization or system, where implementation of the proposed DHTI was being considered, was also deemed to impact effective understanding of the statement as well as its appropriateness: participants observed that Decision Makers might struggle to evaluate the DHTI effectively using the transferability tool.

Addition of the explanatory text improved understanding of most statements: ‘explanatory text helps to clarify the purpose of [the] statement’. However, in the case of the other statements, participants suggested that the explanatory assertion was unnecessary, as it did not provide any additional depth of understanding or guidance for consideration of the main statement. Feedback on the statements noted that it was not always clear how to ameliorate ideas, although, questions with a greater orientation to/about the individual were deemed more easily understood.

3.4 Appropriateness

Participants confirmed the appropriateness of all statements, in terms of their relevance for inclusion in considering transferability. However, questions arose about how statements might be interpreted, as well as by whom. Participants suggested that the nature

of the context might affect the perceived appropriateness of the statement. They questioned how effectively some Decision Makers would be able to address the first statement, for example where the selected persona was from a regional public health system rather than from an ‘organization’. The influence of organizational context was also raised where, for example, an organization may not already have all the necessary capabilities to adapt technologies. On the other hand, it was noted that digital solutions being considered, when using the transferability tool, would most likely already be adaptation ready. Therefore, it was proposed the statement might more accurately address what ‘specificities of an organization could prevent a good fit with the solution’.

As with ease of understanding of the statements, appropriateness was also linked to the role of the person who would be using the tool. The Technical Implementer group agreed that the chosen persona (CTO) ‘may have an idea of how staff adopt and adapt to new digital technologies - they may be the interface with staff when new technologies [were] introduced’. Furthermore, this person ‘would also have their own experience of being a patient to bring to bear on their view of the tool’. However, participants did not consider having these experiences as sufficient. Instead, it was agreed that the CTO would not be able to answer these questions alone but would need input from other stakeholders. Participants also noted how essential it would be for Front-End Implementers to be involved in completion of the ProTransfer tool. It was suggested that some consideration should be given to who would be deemed a Front-End Implementer, for this purpose. For example, pharmacists might not be considered relevant Front-End Implementers, but the group asserted that pharmacists would provide an important perspective on potential transferability of the ProACT CareApp example.

During discussion of part b) of the second statement (tailoring to end-user requirements), it was observed that the CTO persona ‘may be more concerned with [technical] system integration’ and, therefore, ‘may not have the skills to answer this question’. It was viewed that the ‘technical implementer may have a more technical viewpoint on this than any other stakeholder’. However, in addition to context and role, participants noted the importance of relevant experience to inform responses to statements presented in the ProTransfer tool. Competing concerns worthy of consideration included: ‘the cost of devices and app may be an issue for end-users’ or ‘the number of devices and app the end-users and nurse need may be an issue’. Participants concurred that reflecting such real-world experiences in transferability evaluations was also essential, by testing proposed DHTIs.

It was expected that the Technical Implementer ‘would be best able to respond to this statement if [they] have access to testers’, in particular it was suggested that end-users should be involved in such testing and that ‘small-scale pilots are important before implementing digital solutions’. Indeed, it was the position of the living lab practitioners in the group that ‘it would be important for [Technical Implementer] to do this testing (or be involved with it) to inform their decision about how to evaluate this statement’. Notwithstanding the necessity of pilot testing the DHTI, it was recognized that conducting such testing is fraught with challenges such as the possibility of needing ‘a safety server, outside the system, to test the solution?’ or potentially requiring ‘a confidential contract with the stakeholders. Discussion by participants in the Front-End

Implementer group, also raised the question: *‘is the organization already experienced with testing or implementing new technical products?’*

4 Discussion and Conclusions

Major stakeholders of health systems will continue to demand greater value and this demand requires continuous improvements in access and in both the objective quality of care as well as of patient experiences of that care [8]. The drive to improve care and increase value, while maintaining or reducing costs, requires health systems and organizations to remain open to adopting evidence-based innovations. However, healthcare organizations and systems risk missing out on effective innovative solutions if they maintain a position that the ‘uniqueness’ and complexity of health care provision, organizations, and systems makes it too difficult to adopt solutions developed outside healthcare settings [8]. The ProTransfer tool offers a sequential and comprehensive method for evaluating the potential for successful adoption of a digital innovation to enhance performance and care delivery that is sensitive to the variable ‘unique’ and complex contexts of different health organizations.

An innovation is defined as ‘an idea, practice, or object that is perceived as new by an individual or other unit of adoption’ (p11) [9]. For scholars of innovation diffusion, the perceived ‘newness’ of an innovation is a key factor in receptiveness to adopt the innovation. As such, the adoption of innovations, including DHTIs, is more than simply a technical or logistical matter but it is also a social process. The ProTransfer tool workshop reflected this complexity, with participants identifying technical, logistic, linguistic, social structural and systemic factors of relevance to how the transferability evaluation tool might be used.

Transferability of DHTIs into health systems, whether regional, national or global, requires considering who will adopt the intervention, how much they are willing to pay and what forces in the marketplace are necessary to sustain the adoption [10]. However, these questions are often not asked when innovation implementation is being considered. The ProTransfer tool includes opportunities for consideration of these questions and more. However, as workshop participants highlighted, a challenge when presenting the tool to organizations may be in preparing them to include a range of stakeholders in completing the tool. What emerged during the workshop helped researchers to better formulate some questions and explanatory texts, and also helped to spark a discussion on how to compile the self-assessment tool and its length. It also opened a discussion on which platform is easier to use, how to structure the questions and the possibility of answering the questionnaire by several people at the same time.

The group discussions on the importance of capturing the varied experiences, of relevant stakeholders affected by the implementation of a new DHTI, highlighted the role living labs could play in exploring implementation, due to their expertise in multi-stakeholder engagement in design, as well as development and testing of innovations and solutions. Likewise, in recognition of the potential challenges inherent in small scale pilot testing for implementation, which also require multi-stakeholder participation, it was noted that living labs are well placed to assist organizations with this process as

they are generally experienced in the orchestration of multi-stakeholder projects as well as ensuring the perspectives and experiences of all stakeholders are represented. Workshop findings should inform the design of transferability self-assessment tools to include consideration of the way end-users of the tool are guided to ensure completing the tool in a collaborative multi-stakeholder process.

References

1. Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(1), 50. <https://doi.org/10.1186/1748-5908-4-50>
2. Ross, J., Stevenson, F., Lau, R., & Murray, E. (2016). Factors that influence the implementation of e-health: A systematic review of systematic reviews (an update). *Implementation Science*, 11(1), 146. <https://doi.org/10.1186/s13012-016-0510-7>
3. Doyle, J., Murphy, E., Gavin, S., Pascale, A., Deparis, S., Tommasi, P., Smith, S., Hannigan, C., Sillevs Smitt, M., van Leeuwen, C., Lastra, J., Galvin, M., McAleer, P., Tompkins, L., Jacobs, A., Marques, M.M., Medina, J., Boyle, G., Dinsmore, J., (2021) ProACT – A digital platform to support self-management of multiple chronic conditions: findings in relation to engagement during a one-year Proof-of-concept trial. In *Journal of Medical Internet Research (JMIR)*.
4. Valentijn, P. P., Schepman, S. M., Opheij, W., & Bruijnzeels, M. A. (2013). Understanding integrated care: A comprehensive conceptual framework based on the integrative functions of primary care. *International Journal of Integrated Care*, 13(1). <https://doi.org/10.5334/ijic.886>
5. Ferrando M, Hoogerwerf E-J, Kadyrbaeva A. Qualitative research on the factors affecting transferability of digital solutions for integrated care. *International Journal of Integrated Care*. 2019;19(4):236. DOI: <http://doi.org/10.5334/ijic.s3236>
6. Proctor, E., McKay, V., Toker, E., Maddox, T., Hooley, C., Lengnick-Hall, R., . . . Evanoff, B. (2021). Partnered innovation to implement timely and personalized care: A case study. *Journal of Clinical and Translational Science*, 5(1), E121. doi:10.1017/cts.2021.778
7. Schuurman, D., De Marez, L., & Ballon, P. 2016. The Impact of Living Lab Methodology on Open Innovation Contributions and Outcomes. *Technology Innovation Management Review*, 6(1): 7-16. <http://doi.org/10.22215/timreview/956>
8. O'Connor, S.J. Enhancing the depth and breadth of healthcare services in communities: insights, innovations, and applications. *BMC Health Serv Res* 17, 404 (2017). <https://doi.org/10.1186/s12913-017-2338-5>
9. Rogers, EM (1995) *Diffusion of Innovations*, 4th edition. The Free Press: New York.
10. Proctor, E.K., Toker, E., Tabak, R. et al. Market viability: a neglected concept in implementation science. *Implementation Sci* 16, 98 (2021). <https://doi.org/10.1186/s13012-021-01168-2>

Benefits and Challenges of Evaluating an Existing, Commercially Available Digital Health Intervention A Self-Management Application for Asthma

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Abstract. Adherence to inhaled corticosteroids (ICS) is an integral component of effective asthma self-management. However, suboptimal adherence is common and is particularly low for young adults as they become responsible for their health amidst an already challenging developmental stage of the lifespan. Digital health interventions (DHIs) have shown potential to improve adherence to ICS. However, their potential to support adherence behavior within this specific population remains under investigated. Accordingly, the current research aims to investigate the potential for a commercially available application (app) to support medication adherence in young adults living with asthma. Through this process, novel insights were gained into the benefits and challenges of conducting research with an existing, commercially available asthma self-management app.

Keywords: Digital Health, Commercially Available Application, Medication Adherence, Self-management.

1 Background

Asthma is the most prevalent chronic respiratory condition affecting over 330 million people globally [1]. Inhaled corticosteroids (ICS) can effectively control the condition, increase lung function, and decrease exacerbations and related healthcare use [2]. However, despite their established efficacy adherence to ICS remains low. Adhering to this medication may be especially challenging for young adults as they become responsible for their self-management amidst a dynamic period of psychological development, defined as Emerging Adulthood [3, 4]. Emerging Adulthood occurs from approximately age 18-29 years and typically involves greater autonomy, exploration in life directions and engagement in health risk behaviors. Simultaneously balancing these developmental demands impacts young adults' self-management of asthma including adherence to ICS [5, 6], thus warranting appropriate intervention.

Smartphones are almost universally owned and highly used among young adult populations in several contexts. For example, young adults are the most likely cohort to own a smartphone across high and low-middle income countries [7]. As a result, interventions based around this technology may offer a suitable solution that is accessible and scalable with high reach. Recent years have seen an exponential growth in commercially available asthma self-management applications (apps). Apps are constantly evolving with a range of increasingly sophisticated technological abilities, and so may be the most appropriate to capture the interest and engagement of young adults over earlier types of mobile interventions such as text messaging. Recent reviews of available asthma self-management apps have demonstrated their positive effect on medication adherence and asthma control in adolescents [8] and adults [9]. However, their use and potential to support adherence in the young adult population specifically has been largely under studied to date [9-11]. This research aims to investigate the potential for a commercially available app to support medication adherence in young adults living with asthma.

2 Methods

Two studies were conducted to identify a potentially suitable, commercially available asthma app. Firstly, in line with the UK Medical Research Council (MRC) Framework for developing and evaluating complex interventions [12-14], a systematic review and meta-analysis were conducted to quantify the prevalence of adherence to ICS in young adults, and to synthesize the evidence related to the predictors of this behavior [15]. This is a fundamental step to identify potential intervention components.

Secondly, a qualitative interview study was conducted with young adults [16]. The predictors of adherence identified in the systematic review and meta-analysis informed the interview guide, to explore whether young adults considered these predictors as relevant adherence supports, and if so, what are their preferences for DHI features to deliver these supports. The preferred type of DHI appeared to be a smartphone app. Preferences for adherence supports and features included supporting young adults to take responsibility for adherence through a reminder to refill and take their medication, along with being provided with three types of information: (1) asthma and ICS education through images/videos from healthcare providers, (2) self-monitoring information through an adherence chart, symptom and trigger monitoring, and goal setting and rewards, and (3) feedback on outcomes of adherence to ICS through visuals of lungs before and after a period of adherence and lung function monitoring.

These preferences were compiled and used to identify the most suitable, commercially available app to support adherence in young adults. Systematic searches using search terms 'asthma' and 'inhaler' were conducted on the Apple App Store and Google Play Store in August 2020. All apps retrieved were downloaded and checked for the presence of young adults' preferences by the first author (JM). An asthma app developed by a research team based in Australia was initially identified as the most suitable app on the market. However, a license agreement was required to use this app for

research purposes. Due to the challenges encountered with progressing this agreement, it was no longer deemed feasible to pursue the use of this app in the current research. As a result, the next most suitable app on the market was identified. This was the AsthmaMD app. Finally, a multi-methods study was conducted to assess the usability, acceptability and feasibility of AsthmaMD to support adherence in young adults, and to determine the feasibility of recruiting and retaining this population to future app trials [17].

3 Findings

Through this process, novel insights were gained into the benefits and challenges of conducting research with an existing, commercially available asthma self-management app. These benefits and challenges are discussed below.

3.1 Benefits

Efficient method of developing evidence-based DHIs. Recent years has seen an exponential growth in commercially available asthma self-management apps. While some of these apps include evidence-based, behaviour change techniques (BCTs; 18), their quantity of BCTs in addition to overall app quality and maintenance varies markedly (19, 20). Therefore, despite their rapid proliferation much work remains to maximise the potential success of these DHIs and for them to fully benefit from recent developments in behavioural science. However, applying behavioural science approaches to develop and evaluate DHIs is a lengthy and resource-intensive process. Leveraging existing apps by applying behavioral science to evaluate and refine them may be most efficient and timely to establish evidence-based, relevant digital supports for young adults, particularly given the rapid pace of advancements in technology.

Evaluates a DHI that entered a largely unregulated market. Consideration of the quality of certain commercially available self-management DHIs is now particularly pertinent as the European Union Medical Device Regulation (EU MDR) 2017/745 became fully applicable in May 2021 (21). According to this, software is considered Medical Device Software (MDSW) if it is intended to be used alone or in combination for “diagnosis, prevention, monitoring, prediction, prognosis, treatment, or alleviation of disease and which does not achieve its main intended purpose by pharmacological, immunological or metabolic means but may be assisted in its function by such means” (21). While uncertainty remains around which exact commercially available DHIs this regulation applies to, it may include asthma and other chronic disease self-management apps, meaning they would now be considered a MDSW and therefore would have to comply with the relevant regulations to be commercialized and placed on the European market. The MDR requires the manufacturer to demonstrate that general MDR safety and performance requirements are met, and that consideration has been given to software design and maintenance, risk management, a clinical evaluation plan, data protection and cybersecurity. As a result, this may lead to the availability of higher-quality self-management apps for chronic disease.

However, prior to the implementation of the MDR, the mHealth app market was largely unregulated amidst a rapid growth in size. A total of 318,000 mHealth apps were available in March 2020, with an additional 200 being added every day (22, 23). This has led to a myriad of commercially available mHealth apps that are often of uncertain quality and not evidence based, including asthma apps (24, 25). Furthermore, there appears to be a significant grey area around the future of apps that were placed on the market before the MDR came into effect, that may not comply with the current MDR. Transitional exceptions appear to be granted on a case-by-case basis, depending on previous quality approvals attained by the device or software. As a result, it is possible that currently available apps which should but do not comply with the MDR or general quality and evidence-based standards, will remain available for some time. Therefore, it is critical to evaluate existing commercially available apps.

Responds to policy and legislation for DHI integration into healthcare. In Europe, policymakers are increasingly recognizing the importance of evaluating DHIs. This is now an essential prerequisite to their formal integration into healthcare systems. For instance, the UK NHSX have developed the Digital Technology Assessment Criteria (DTAC) (26) that DHIs must satisfy in order to enter the UK national health and social care service. The DTAC aims to build on the Evidence Standards Framework for DHTs previously developed by the UK National Institute for Health and Care Excellence (27). This framework outlines the evidence standards required for digital health technologies to demonstrate effectiveness and value in the UK health and social care system. Moreover, recent digital healthcare legislation in Germany and Belgium (28, 29) outline the evidence that must be provided for these technologies to qualify for HCP prescription. In sum, these stipulate that digital health technologies must demonstrate patient safety, data accuracy and security, usability and acceptability among users and evidence of effectiveness through appropriate evaluation.

3.2 Challenges

Compliance with Complex Legal Requirements. For potential individual users, commercial apps are freely available to download and use from the app stores. However, certain requirements may need to be fulfilled to use these apps for research purposes and to comply with relevant intellectual property and copyright law. For example, the app developers may require a license agreement to be in place for its use in research which often requires a fee. Seeking approval for such license agreements may be a lengthy process. For example, if the researchers seeking its use are affiliated with an educational institution, review and approval may be needed by the respective institution's 'Technology Transfer Office' or equivalent. Typically, a number of personnel within this office will be required to review such license agreements (e.g. commercial executives, business specialists) and subsequently determine if a legal review is also required. If so, this legal review can take several months to complete. Following this, further iterations of the proposed agreement may be needed to obtain approval and sign-off from all relevant parties. Moreover, several parties may own/have the rights to the app in question, which can further add to the duration of the license agreement process.

As a result, this can significantly impact research timelines and resources and thus compromise the feasibility of pursuing the use of such apps in research.

Access to Objective User Engagement Data. Accessing users' back-end app usage data may constitute a significant challenge for researchers who are not affiliated with the app developers. These researchers would represent an external, third-party seeking access to app user data, which would likely raise ethical and data protection concerns with the relevant committees and data protection officers that may be difficult or time consuming to address. Accessing this data is critical to objectively measure user engagement with DHIs, a prerequisite to their success (30). Without this, researchers may need to rely on self-report methods of app use alone. While these measures can generate meaningful context to DHI use (31), evidence has shown that smartphone users can under or overreport their use of this device (32-34) and their engagement with mHealth interventions specifically (35). Therefore, using a combination of objective and subjective measures may be most appropriate to gain a more complete understanding of user engagement.

Compromise between End Users 'Wish List' and Features in Existing DHIs. It may not be possible to identify an existing DHI that satisfies all end user preferences for behavioral supports and features. As a result, certain preferences may need to be compromised and the most suitable app selected (e.g. the app with the highest number of or most salient preferences). For example, in this research young adults discussed their preference for a goal setting and rewards feature to increase and maintain their adherence behavior. However, AsthmaMD did not include this feature. Perhaps compromised features represent potential additions that can be made to refine the app. This may be investigated as part of the evaluation process by asking users if they would make any changes/additions to the app following their real-world use of it.

4 Conclusion

The benefit of evaluating commercially available self-management apps for asthma and other chronic conditions is clear, particularly for those that entered the market before regulations governing their quality came into effect. However, this may involve significant challenges that warrant consideration. These potential benefits and challenges highlight the need for increased collaboration between research, industry and policy to ensure the highest-quality, evidence-based DHIs become available to support self-management and adherence in chronic disease populations.

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References

1. Vos T, Abajobir AA, Abate KH, Abbafati C, Abbas KM, Abd-Allah F, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet*. 2017;390(10100):1211-59.
2. GINA. Global Strategy for Asthma Management and Prevention. 2021.

3. Arnett JJ. Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*. 2000;55(5):469-80.
4. Arnett JJ. Adolescence and emerging adulthood. Fifth edition, Pearson new international edition. ed. Harlow , England: Harlow , England : Pearson Education Ltd.; 2014.
5. Withers AL, Green R. Transition for adolescents and young adults with asthma. *Frontiers in Pediatrics*. 2019;7.
6. Zaeh SE, Lu MA, Blake KV, Ruvalcaba E, Ayensu-Asiedu C, Wise RA, et al. "It is kind of like a responsibility thing": transitional challenges in asthma medication adherence among adolescents and young adults. *Journal of Asthma*. 2021:1-11.
7. Taylor K, Silver, L. Smartphone ownership is growing rapidly around the world, but not always equally. Pew Research Center; 2019 5 February.
8. Alquran A, Lambert KA, Farouque A, Holland A, Davies J, Lampugnani ER, et al. Smartphone applications for encouraging asthma self-management in adolescents: a systematic review. *International journal of environmental research and public health*. 2018;15(11):2403.
9. Unni E, Gabriel S, Ariely R. A review of the use and effectiveness of digital health technologies in patients with asthma. *Annals of Allergy, Asthma & Immunology*. 2018;121(6):680-91. e1.
10. Miller L, Schüz B, Walters J, Walters EH. Mobile technology interventions for asthma self-management: systematic review and meta-analysis. *JMIR mHealth and uHealth*. 2017;5(5):e57.
11. Jeminiwa R, Hohmann L, Qian J, Garza K, Hansen R, Fox BI. Impact of eHealth on medication adherence among patients with asthma: A systematic review and meta-analysis. *Respiratory medicine*. 2019;149:59-68.
12. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337.
13. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *International Journal of Nursing Studies*. 2013;50:587-92.
14. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby J, et al. A new framework for developing and evaluating complex interventions: Update of Medical Research Council guidance. *BMJ*. 2021;374.
15. Murphy J, McSharry J, Hynes L, Matthews S, Van Rhoon L, Molloy GJ. Prevalence and predictors of adherence to inhaled corticosteroids in young adults (15–30 years) with asthma: a systematic review and meta-analysis. *Journal of Asthma*. 2020;58:683-705
16. Murphy J, McSharry J., Hynes L., & Molloy G.J. Young adult preferences for digital health interventions to support adherence to inhaled corticosteroids in asthma: A qualitative study. *In press Health Psychology & Behavioral Medicine*. 2022.
17. Murphy J, McSharry J, Hynes L, Molloy GJ. A Smartphone App to Support Adherence to Inhaled Corticosteroids in Young Adults With Asthma: Multi-Methods Feasibility Study. *JMIR Formative Research*. 2021;5(9):e28784.
18. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. *Annals of Behavioral Medicine*. 2013;46(1):81-95.
19. Ramsey RR, Caromody JK, Voorhees SE, Warning A, Cushing CC, Guilbert TW, et al. A systematic evaluation of asthma management apps examining behavior change techniques. *The Journal of Allergy and Clinical Immunology: In Practice*. 2019;7(8):2583-91.

20. Camacho-Rivera M, Vo H, Huang X, Lau J, Lawal A, Kawaguchi A. Evaluating Asthma Mobile Apps to Improve Asthma Self-Management: User Ratings and Sentiment Analysis of Publicly Available Apps. *JMIR mHealth and uHealth*. 2020;8(10):e15076.
21. European Union. Regulation (EU) 2017/745 of the European Parliament and of the Council of 5 April 2017 on medical devices, amending Directive 2001/83/EC, Regulation (EC) No 178/2002 and Regulation (EC) No 1223/2009 and repealing Council Directives 90/385/EEC and 93/42/EEC. *Official Journal of the European Union*. 2017.
22. IQVIA. The Growing Value of Digital Health: Evidence and Impact on Human Health and the Healthcare System Institute Report. IQVIA; 2017.
23. Roberts AE, Davenport TA, Wong T, Moon H-W, Hickie IB, LaMonica HM. Evaluating the quality and safety of health-related apps and e-tools: Adapting the Mobile App Rating Scale and developing a quality assurance protocol. *Internet Interventions*. 2021;24:100379.
24. Huckvale K, Car M, Morrison C, Car J. Apps for asthma self-management: a systematic assessment of content and tools. *BMC Medicine*. 2012;10(1):144.
25. Huckvale K, Morrison C, Ouyang J, Ghaghda A, Car J. The evolution of mobile apps for asthma: an updated systematic assessment of content and tools. *BMC Medicine*. 2015;13(1):58.
26. NHSX. Digital Technology Assessment Criteria (DTAC) 2021 [Available from: <https://www.nhs.uk/key-tools-and-info/digital-technology-assessment-criteria-dtac/>].
27. NICE. NICE Evidence Standards for Framework for Digital Health Technologies. 2019.
28. Federal Institute for Drugs and Medical Devices. The Fast-Track Process for Digital Health Applications (DiGA) according to Section 139e SGB V: A Guide for Manufacturers, Service Providers and Users. 2019 [Available from: https://www.bfarm.de/EN/Medical-devices/Tasks/Digital-Health-Applications/_node.html].
29. mHealthBELGIUM. mHealthBelgium: Validation pyramid 2021 [Available from: <https://mhealthbelgium.be/>].
30. Perski O, Blandford A, West R, Michie S. Conceptualising engagement with digital behaviour change interventions: a systematic review using principles from critical interpretive synthesis. *Translational Behavioral Medicine*. 2017;7(2):254-67.
31. Yardley L, Spring BJ, Riper H, Morrison LG, Crane DH, Curtis K, et al. Understanding and promoting effective engagement with digital behavior change interventions. *American Journal of Preventive Medicine*. 2016;51(5):833-42.
32. Lee H, Ahn H, Nguyen TG, Choi S-W, Kim DJ. Comparing the self-report and measured smartphone usage of college students: a pilot study. *Psychiatry Investigation*. 2017;14(2):198.
33. Andrews S, Ellis DA, Shaw H, Piwek L. Beyond self-report: tools to compare estimated and real-world smartphone use. *PloS One*. 2015;10(10):e0139004.
34. Ellis DA, Davidson BI, Shaw H, Geyer K. Do smartphone usage scales predict behavior? *International Journal of Human-Computer Studies*. 2019;130:86-92.
35. Short CE, DeSmet A, Woods C, Williams SL, Maher C, Middelweerd A, et al. Measuring engagement in eHealth and mHealth behavior change interventions: viewpoint of methodologies. *Journal of Medical Internet research*. 2018;20(11):e9397.

Transferability of an Integrated Care Platform

Use Case

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Abstract. The transfer and implementation of digital health solutions from one setting to another can be challenging. This study functioned as a use case to examine the transferability of a digital integrated care platform from research to practice. In 2019, a healthcare facility in Belgium aimed to advance supported self-management and integrated care for patients with Type II diabetes, aged between 18 and 75 years old. Methodology: The ProACT integrated care platform was implemented in a healthcare facility that consisted of a multidisciplinary team, monitoring a total of 12 participants with Diabetes Type II for a duration of six months. By using a qualitative method, we conducted interviews with diabetes educators, held focus groups with healthcare providers and used ethnographic documentation. Findings: The choice of using the ProACT platform was a top-down decision made by management and the qualitative data showed that the readiness and willingness of the employees to incorporate the platform hindered the implementation. They welcomed the technology, however all employees noted the additional workload they experienced on top of an already full work schedule. As a result, organisation-specific, solution-specific, process-specific and individual-specific barriers were identified. Conclusion: The use case on implementing an integrated care platform outside of a research setting, corroborated barriers identified in the ProACT transferability framework. This paper will reflect on the ProACT transferability framework and highlight the practical challenges healthcare facilities could face.

Keywords: Transferability, integrated care platform, digital health.

1 Introduction

Technological advancements have led to the development of digital health solutions (DHS) for health and well-being management to help patients in monitoring their health and wellbeing, supported by healthcare providers (HCP). In 2018, a digital integrated

care platform called ProACT was developed through a user-centric approach, with the aim to integrate the needs, context and requirements of its users [1]. ProACT was tested in a Proof of Concept trial for people with multimorbidity (covering diabetes, chronic heart disease, chronic heart failure and chronic obstructive pulmonary disease (COPD)) over a 12-month period as part of a Horizon 2020 project [2]. Outcomes of the trial showed the platform to be valuable for home-based self-management. Currently, in the SEURO⁸ project the platform development is continued and research is done to further assess transferability and effectiveness in different healthcare settings. Earlier, in 2019, a healthcare facility in Belgium aimed to advance supported self-management and integrated care for patients with Type II diabetes, aged between 18 and 75 years old, using the digital platform ProACT. With this case study we review the relevance of the factors in the Proact transferability framework from research to practice.

1.1 Implementation frameworks

Several studies have documented the challenges which can arise when DHS are implemented outside of a research setting [3-6]. With a move towards integrating health and wellness technology into a patient's home, a shift will also be required in the day to day work of HCPs using the technology to monitor patients' health. To get the maximum benefit from a DHS, healthcare organisations are required to change or innovate their care service toward patients. For this reason, practice and research communities have been advocating for more awareness of the implementation challenges that come with DHS, particularly those advancing integrated care.

One of the complexities of implementing an integrated care platform lies in the coordination of multidisciplinary and interdisciplinary collaboration between HCPs and patients. Frameworks have been developed, for instance HSPA⁹, Scirocco Maturity model¹⁰, The integrated Project Framework¹¹ to address their implementation challenges. However, they are primarily from a descriptive and theoretical perspective and their applicability requires more insight. Due to limited knowledge on the barriers to transfer a DHS from one healthcare setting to another, a transferability framework was developed as part of the ProACT H2020 project. This framework outlines the factors necessary for successful transferability of digital integrated care platforms (such as ProACT) across health services. Within the framework, key enablers and barriers to implementing digital integrated care solutions are identified. The transferability framework (Fig. 1) consists of four main themes: solution, organisation, process and individual factors that contribute to understanding the implementation challenges in a new setting. A full description of the framework is available elsewhere [7].

⁸ <https://seuro2020.eu/>

⁹ https://ec.europa.eu/health/health-systems-performance-assessment/priority-areas-hspa_en

¹⁰ <https://www.scirocco-project.eu/maturitymodel/>

¹¹ <https://www.projectintegrate.eu.com/>

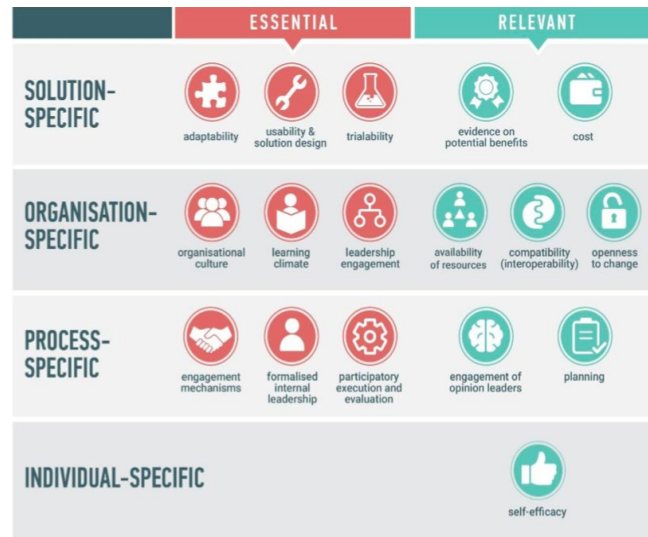


Fig.1. ProACT transferability framework

2 Methodology

2.1 Implementation Setting and Set-Up

The healthcare facility multidisciplinary team included a health coordinator (nurse), podologist, physiotherapist and dietician, who monitored 12 Participants with Diabetes Type II (PwD) over six months. A researcher from the Belgian Proact team coordinated the implementation including, providing training and trial support to the HCPs in using the ProACT platform. The health coordinator was appointed as the main study coordinator in the facility. Four diabetes educators (DEs) were recruited to visit the PwD to enrol them in the study, train them in using the technology and to be the first point of contact for (technical) help and questions. The DE would follow-up by using the DHS to look at the PwD self-monitored data and contacting them to provide diabetes related education and self-management support. When PwD self-monitored data exceeded thresholds, alerts were generated and processed by triage nurses in a separate call centre, who would then contact the PwD by phone. PwDs were expected by the healthcare organisation to perform weekly self-monitoring of their glucose values, blood pressure, weight, activity and sleep and to engage in one or more types of care provided by the healthcare organisation, such as physiotherapy or nutritional advice.

2.2 Data Collection and Analysis

To evaluate the transferability of the ProACT platform into the healthcare facility, we used a qualitative approach. We conducted semi-structured interviews with DEs, focus groups with HCP before and after ProACT implementation, and used ethnographic

documentation of the experiences of the researcher supporting the platform implementation. The ethnographic documentation was captured in emails, notes and observations derived from close collaboration with the health coordinator who was responsible for implementing the ProACT platform in the healthcare facility. The (focus group) interviews covered topics such as usability, adoption and evaluation of the ProACT platform and were audio-recorded, transcribed and coded through an inductive thematic analysis by use of MAXQDA software [8]. Subsequently, the qualitative themes derived from the analysis were arranged within the categories of the ProACT transferability framework.

3 Findings

The ProACT transferability framework aims to delineate the conditions that influence a successful implementation of a DHS. Comparing the qualitative data with the ProACT transferability framework, demonstrated several factors that explain the implementation challenges experienced during the study. Findings aligned with a number of factors are outlined below in the context of the framework.

3.1 Solution Specific - Level

We saw Evidence of Potential Benefits. HCPs expressed interest in the DHS and saw the value of telemonitoring but there was variation in how HCPs viewed the necessity of adopting the ProACT DHS into their work practice. For some, the usefulness of ProACT was apparent, 'instead of seeing patients frequently, I could follow-up on their activity patterns and discuss the data with them during a consult' (Physiotherapist), so that the consultation was better adjusted to the patient's current needs. However, others felt that the data was not applicable enough for their work or customizable enough to make them use the DHS on a regular basis. As a consequence, the adaptability and the usability and solution design- essential factors were not addressed sufficiently.

3.2 Organisation Specific - Level

Although not an essential factor in the framework, the Available Resources factor appeared as the theme 'care-cost trade-off' across all HCPs. The DEs (n=4) expressed interest in the study, however all employees noted the burden of the additional workload they experienced on top of an already full work schedule. The additional time required to become acquainted with the technology and learn the protocols did not fall under the regular DE activities and they were not compensated. Although willing to put voluntary effort for the project, they concluded it was too time consuming to be trained and support the PwD in using the devices. The perceived extra effort required to implement the technology was considered to have diminished the time for interacting with their patients and providing diabetes related education.

Within healthcare organisations all actors are ascribed roles to play, with interdependent patient and HCP roles defined by the organisational culture. This is an essential

factor in the framework and is shown to us via the theme ‘user profile’. Concerns were expressed about long term engagement of the PwDs. HCPs suggested that a PwD with a particular profile would be the ideal candidate for the use of the ProACT system / telemonitoring. An ideal user was defined as a PwD who is motivated, has sufficient digital literacy to use the technology or is willing to learn, and has (high) disease complexity. HCPs suggested that PwDs with this profile would be best able to provide data through self-monitoring and that the HCPs can utilise the data for better care provision.

3.3 Process Specific – Level

As expected, several PwDs required additional training and support to enable them to use the self-monitoring technology [9]. There were engagement mechanisms (an essential factor in the framework) within the project to cope with this. Examples of recurring problems included data transfer issues, not knowing how to use the devices, and how to do problem-solving if a device was not working properly (such as replacing the batteries or reconnecting with Bluetooth). This resulted in additional help desk related visits from the health coordinator visiting the PwD and the introduction of weekly check-up calls. The health coordinator took initiative and was dedicated to implementing the DHS in the organisation. However, the additional tasks required to maintain the engagement of the PwD were not in line with the expected time investment. In addition, some technical issues hindered access to the platform, e.g. a firewall that was installed at the healthcare organisation.

3.4 Individual Specific – Level

Self-efficacy is the only relevant factor in this dimension of the framework. Some DEs reported stress related to having the responsibility for the technology. For example, during the set-up of the technology at a PwD’s home, the DE felt insecure when there was an unexpected iPad installation question ‘I am already quite happy when a few installation steps work well, but then I get a follow-up question and I have to make a lot of choices, and that type of hindrance I have all the time’ (DE_04). The DE described a training situation of a technology set-up at a PwD’s home. ‘I saw how there was suddenly an update [ipad or application] and you [referring to researcher] had to find a way to sort this out, if I was in that situation I would have panicked and I would not have found a solution’ (DE_04).

4 Discussion

Following the implementation of the ProACT platform to support PwDs by a multidisciplinary team of HCPs, themes were identified aligning with five factors from across the transferability framework. While not all 17 factors were represented in the themes, all four transferability levels were represented in the data; solution-specific, organisation-specific, process-specific and individual-specific factors.

The current study analysed the framework and the qualitative data in retrospect. The findings indicated value in considering the transferability framework factors prospective. Therefore, future DHS implementation cases should include specific protocol elements aimed at determining both the benefits of adopting the DHS and which barriers need to be identified at what stage of the implementation. For example, in line with the trialability suggestions from the framework, the healthcare organisation may have benefited from a longer and slower introduction to the DHS. In such an exploratory phase, HCPs could gradually adapt their personal workflow with the implementation of the DHS, providing time to experience the benefits of adapting work practices to include the DHS.

The choice of using the ProACT platform was a top-down decision made by management, both the readiness and willingness of employees to adopt the platform may have been presumed. While welcoming the technology, all employees noted the burden of the additional workload they experienced. The most significant challenges reported were time resources. As a consequence of this deficit, there was limited capacity to adapt the technology to the local setting of the healthcare organisation. This may have acted as a bottleneck, preventing the ability to overcome the barriers related to adaptability and usability and solution design.

For HCPs and PwDs alike, adopting a new DHS required developing mastery of multiple domains (such as health interpretation and digital technology) as well as new ways of negotiating healthcare relationships [10]. The implementation of a DHS could change or disrupt existing workflows with PwDs and between other HCPs. In particular in the start-up phase, time needs to be allocated to obtain confidence in using the technology, and explore new workflows. The use of the technology for PwDs was set-up by the HCP. This required a level of confidence in using the technology by both the PwD and HCP, and was underestimated at the time of deployment. Additional time and training may have supported HCPs and PwDs alike in transitioning to use of ProACT.

The complex ecosystem of a digital integrated care platform requires in-depth understanding and mapping of the different PwD-HCP and HCP-HCP relationships [11], [12]. In the current study the high variety in HCP specialisms resulted in adaptability requests of the DHS that could not be foreseen with the technical, time and budget constraints. Participatory and collaborative approaches should be deployed to ensure adequate adaptability of the DHS and to manage users' expectations. Furthermore, the inclusion of multiple stakeholders in the analysis of a DHS implementation pilot may offer alternative perspectives on the benefits and barriers experienced. For the framing of DHS pilot studies, using an objective tool such as the transferability framework reduces the potential for decisions to be based on subjective experiences or preconceptions.

To conclude, only the main identified factors derived from the data are discussed. Other factors may have been present in the use case but were not identified. Given their potential importance, and the inter-relationship between factors, further research should endeavour to examine all factors as part of the implementation evaluation.

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References

1. J. Dinsmore *et al.*, 'A Digital Health Platform for Integrated and Proactive Patient-Centered Multimorbidity Self-management and Care (ProACT): Protocol for an Action Research Proof-of-Concept Trial', *JMIR Res. Protoc.*, vol. 10, no. 12, p. e22125, Dec. 2021, doi: 10.2196/22125.
2. J. Doyle *et al.*, 'A Digital Platform to Support Self-management of Multiple Chronic Conditions (ProACT): Findings in Relation to Engagement During a One-Year Proof-of-Concept Trial', *J. Med. Internet Res.*, vol. 23, no. 12, p. e22672, Dec. 2021, doi: 10.2196/22672.
3. J. Shaw *et al.*, 'Beyond "implementation": digital health innovation and service design', *Npj Digit. Med.*, vol. 1, no. 1, p. 48, Dec. 2018, doi: 10.1038/s41746-018-0059-8.
4. L. Wolfenden, A. Ziersch, P. Robinson, J. Lowe, and J. Wiggers, 'Reducing research waste and improving research impact', *Aust. N. Z. J. Public Health*, vol. 39, no. 4, pp. 303–304, Aug. 2015, doi: 10.1111/1753-6405.12467.
5. L. Wolfenden *et al.*, 'Designing and undertaking randomised implementation trials: guide for researchers', *BMJ*, p. m3721, Jan. 2021, doi: 10.1136/bmj.m3721.
6. L. M. Ross *et al.*, 'Effects of a single-task versus a dual-task paradigm on cognition and balance in healthy subjects', *J. Sport Rehabil.*, vol. 20, no. 3, pp. 296–310, Aug. 2011.
7. M. Ferrando, A. Kadyrbaeva, and E.-J. Hoogerwerf, 'Transferability of Digital Solutions Enhancing Integrated Care Across Europe: Identifying and Prioritising Barriers and Enablers'. 2019. [Online]. Available: <http://aaate2019.eu/wp-content/uploads/sites/24/2019/09/ProAct-digital-final-8.14.pdf>
8. V. Braun and V. Clarke, 'Using thematic analysis in psychology', *Qual. Res. Psychol.*, vol. 3, no. 2, pp. 77–101, Jan. 2006, doi: 10.1191/1478088706qp063oa.
9. S. Smith, P. McAleer, J. Doyle, S. Gavin, and J. Dinsmore, 'Technical support needs of older users of digital health technologies to support self-management of multimorbidity', p. 9., *Proceedings ICCHP-AATE conference*, Jul. 2022.
10. N. Oudshoorn, 'Diagnosis at a distance: the invisible work of patients and healthcare professionals in cardiac telemonitoring technology', *Sociol. Health Illn.*, vol. 30, no. 2, pp. 272–288, 2008, doi: 10.1111/j.1467-9566.2007.01032.x.
11. S. Ziebland, E. Hyde, and J. Powell, 'Power, paradox and pessimism: On the unintended consequences of digital health technologies in primary care', *Soc. Sci. Med.*, vol. 289, p. 114419, Nov. 2021, doi: 10.1016/j.socscimed.2021.114419.
12. A. Fiske, A. Buyx, and B. Prainsack, 'The double-edged sword of digital self-care: Physician perspectives from Northern Germany', *Soc. Sci. Med.*, vol. 260, p. 113174, Sep. 2020, doi: 10.1016/j.socscimed.2020.113174.

Older Adults' Experiences of Using Digital Health Technology for Multimorbidity Self-Management

Findings from a Longitudinal Study

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Abstract. It is widely accepted that digital health technologies can support the self-management of chronic disease, aiding in symptom and lifestyle monitoring and management, encouraging behaviour change, and sharing data amongst a care network. However, little is understood about how older adults with multiple chronic conditions might digitally self-manage. In this paper, we present findings from a longitudinal 12-month trial whereby older adults with multimorbidity used the ProACT digital health platform to self-manage their conditions. Interviews were conducted with participants at four time-points during the trial and data were thematically analysed. Findings presented in this article relate to three themes, the learning journey of participants, routines and strategies of using the technology, and facilitators and barriers to use. This paper demonstrates that older adults with multiple chronic conditions are willing and capable of engaging in digital self-management, and that this cohort can develop and master the technical skills necessary for self-management.

Keywords: Older adults, Digital health, Multimorbidity, Longitudinal study

1 Introduction

There is much to celebrate about living longer, including the potential for older people to continue contributing to their families, communities and broader society. However, ageing also presents challenges, such as higher prevalence rates of chronic disease and in particular multimorbidity, the presence of two or more chronic diseases [1]. Prevalence rates of multimorbidity are estimated as affecting one in three people globally [2]. Self-management is a necessary part of living with any chronic condition. However, self-management is demanding, requiring engagement in multiple tasks such as symptom monitoring, adhering to lifestyle recommendations, medication management as well as navigating healthcare systems. To ensure older people with multimorbidity can maintain active and healthy lives, it is necessary to support them to successfully self-manage.

Digital health technologies hold great promise to support health self-management at home, either independently or with support from family or those who care for them [3]. In particular, such technologies have the potential to help reduce the burden of self-management for people managing multimorbidity and to support integration of care amongst a person's care network, including family and health and social care professionals [4-5]. However, if older adults are to engage with such technologies, they need to be designed to be useful and usable. While there are some studies exploring older adults' use of digital health technologies, there are few evaluations that explore longitudinal use, and we are not aware of any that focus on older adults with multimorbidity.

2 Methodology

In this paper, we report on findings in relation to use and perceptions of technology from older adults with multimorbidity who used the ProACT digital health platform for approximately one year. Participants were aged 65 and over and had two or more of the conditions diabetes, chronic obstructive pulmonary disorder (COPD), chronic heart disease (CHD) and chronic heart failure (CHF). A total of 120 participants were recruited across Ireland and Belgium, 93 of whom completed the study. Participants were provided with a suite of digital devices for monitoring symptoms (e.g., blood glucometer, pulse oximeter, blood pressure monitor), dependent on their conditions, as well as a weight scales and an activity watch measuring steps and sleep. Participants were also provided with an iPad with the ProACT CareApp through which they could view their data over time, self-report on health and wellbeing (e.g. breathlessness, mood), view personalised education, set activity goals, and share their data with a care network.

The full trial protocol can be found in [6], while further detail on the platform, including its co-design with older adults with multimorbidity and their care networks can be found in [4]. Training on the devices and CareApp was split across two home visits at the start of the trial, to avoid overloading participants with information. During the first visit, training was provided on using the devices, while the second visit focused on the CareApp. A paper-based training manual was provided to all participants, containing detailed instructions for each device, troubleshooting instructions and detail on each CareApp feature. Online training materials and videos on how to use the devices and CareApp were also available within the CareApp education section.

Interviews were conducted at four timepoints throughout the trial, T1 (technology deployment) to T4 (trial end). The same interview protocols were used in both Ireland and Belgium. All interview data was transcribed verbatim and a qualitative thematic analysis was conducted, with multiple meetings between the teams in Ireland and Belgium to reach consensus on the themes and sub-themes. While a number of themes emerged relating to various aspects of the users' experiences during the trial, this paper focuses on findings in relation to their experiences with the ProACT technology, namely the CareApp and devices.

3 Findings

In total, 120 PwMs consented to take part, 60 in Ireland and 60 in Belgium. In Ireland, the average age of PwMs was 74.23 years (range 65-92 years) and 60% were male. In Belgium, the average age of PwMs was 73.61 years (range 60-91 years) and the participants were predominantly male (72%). In Ireland, eight participants withdrew, primarily due to ill health, while three passed away and in Belgium, 16 participants withdrew, with difficulties with the technology being cited as the main reason for withdrawal [4]. Three main themes emerged in relation to participant experiences of using the technology. Each of these themes, and related sub-themes, are presented below.

3.1 The Learning Journey

Training Requirements. At T2, three or four months into the trial, there were some participants in Ireland who were still struggling to understand particular aspects of the technology and a need for further training was identified as an important issue. It was apparent that many participants were not using all parts of the ProACT CareApp, or even aware of particular features. Researcher: “[demonstrating health tips section] So these are all videos and information about diabetes.” Participant: “Oh yes! That’s very good now I never saw that before!” (P058, M, 71, Diabetes+CHD, IE, T2). With another participant, the researcher was demonstrating how to see the answers to daily questions: “Oh, that’s good, that is very good now, yes... I’m glad you brought that to my attention because I don’t know why I closed my eyes to that, I don’t know why” (P003, M, 72, COPD+CHD, IE, T2).

Many participants discussed how they used the paper-based training manual created by the ProACT team, to learn how to use the platform: “I kept referring to my manual until I got the hang of [the ProACT platform]” (P045, F, 74, F, Diabetes+COPD, IE, T2). Other participants reported using trial and error to learn how to use the platform rather than the ProACT manual: “For training, I found trial and error was the best way” (P015, M, 82, Diabetes+CHD, IE, T2).

The Belgian participants did mention at T2 that they did not use all the parts of the CareApp. P65 said that he had used some parts a couple of times: “Uh the tips yes, I have watched them but I am not going to watch these every week” (P65, M, 70, Diabetes+CVD+COPD, BE, T2). However, during the interviews no additional training was given or requested. Overall, the participants seemed to be comfortable with the technology. The majority of participants in Belgium had some prior experience with using health monitoring devices, whilst only a small number of Irish participants mentioned prior experience, and this was mostly with blood glucometers.

Mastering the Technology. At T2, participants were keen to discuss their experiences learning the system. For novice technology users, there was a steep learning curve. Learning how to interact with the iPad, for example, was challenging for users who had never used a touchscreen device before, and users discussed how core simple gestures such as how to tap was challenging: “Absolute novice...And as I said, initially, I could not get any of them. Couldn’t get them, no matter what I did. And I’d tap it and she’d

[researcher] say tap it again, I'd tap it again. That's my problem with it... The first day, I got my son to come down to help me to get the tapping right, and then all of a sudden it came right and that was it, yes" (P011, M, 81, Diabetes+COPD, IE, T2); "I didn't even know how to turn it on" (P018, F, 73, Diabetes+CHD, IE, T2).

While a need for training was identified for certain aspects of the technology, some participants also demonstrated familiarity and understanding of the devices and applications and were more confident to troubleshoot themselves when things went wrong. For example, P009 had the following strategy to cope with Siri voice assistant automatically opening: "I find the only way of getting rid of [Siri opening unprompted] is to actually turn off the iPad altogether and then wait a few minutes and turn it on again" (P009, M, 71, COPD+CHD+Diabetes, IE, T2). Another participant expressed how she had become much faster at using the technology as she became more familiar with it: "I have it down to a fine point whereas before it could take me nearly twenty minutes to get around everything. I can do it in under five!" (P045, F, 74, Diabetes+COPD, IE, T2).

By T3, participants had been using the devices for an average of 10 months and described a growing mastery and confidence with the system: "Well I thought in the beginning that it might be too much, I was trying to take on too much technically. But then I conquered it... So I just stuck at it, no, I don't find it difficult at all now" (P034, M, 67, COPD+CHF, IE, T3); "It's, I'd say a comfort feeling now using it. The surprise was the beginning. Getting to know and understand the different bits and what was expected of me. And once I got to terms with that, I had no problems with it, as time went on" (P045, F, 74, Diabetes+COPD, IE, T3).

Few Belgian participants reflected on learning or adjusting to using the CareApp or the associated devices. For many, the devices did not offer a new experience, as they had their own devices already. Nevertheless, some of the participants did talk about how they were surprised by their learning curve. P93 for example, said that using the platform at the start of the trial was challenging, but now he was surprised that he "was relatively good at handling the devices, at least that is what I think" (P93, M, 65, Diabetes+CHD, BE, T2); P95 said that the blood pressure monitor was the hardest to learn but "I practiced it until I got it. That is the way you learn best" (P95, F, 85, COPD+CHF+CHD, BE, T2).

Overcoming Fear. At T1, a small number of participants in Ireland expressed a fear of the technology. There were worries about potentially damaging the technology, about making a mistake (such as wiping data from the iPad) and general anxiety about using the technology correctly. A very small number of participants expressed a concern that they would worry over their readings, both symptoms and wellbeing data, whilst three participants were concerned about where their data would be stored and who it would be shared with. By T2, participants spoke about overcoming a fear of technology in order to be able to use the system: "In the beginning, I'd be a little bit apprehensive about going through it because if I lose the screen, I'd be afraid I couldn't get it back again and that, and I've overcome that a little bit. [Researcher] would have said to me it's alright to play around with it a little bit, and I suppose you do gain a little bit of confidence" (P041, M, 69, Diabetes+CHD, IE, T2).

3.2 Routines and Strategies of Use

At T2, it was clear that the majority of participants had adopted the ProACT platform to measure their health and wellbeing parameters. Participants shared their experiences noting how using ProACT became part of their self-management routine, with many using the platform in the morning: “First thing in the morning, I do the weight and then it depends on how quickly it responds... So I would say about a quarter of an hour I spend” (P002, F, 85, CHF+CHD, IE, T2); “It is becoming a habit; I wake up and the first thing I do is blood pressure and all the rest. Then I can put it all in the cupboard, then my coffee, yeah it is a habit” (P115, F, 73, CHF+CHD, BE, T3).

T2 interviews highlighted varying levels of engagement with the platform. For some it was a daily discipline: “It’s the first thing I do every morning, more or less” (P040, M, 67, Diabetes+CHD, IE, T2); “Well in the mornings I weigh myself... as soon as I wake... Then before breakfast I take my blood pressure. I regularly check the steps, it is important to get enough activity. And during the day not all the time, but sometimes when I think about it, I will go to the ProACT (app) and complete the (self-report) questions” (P81, M, 68, CHD+CHF, BE, T2). Other participants interacted less often for different reasons, including not wanting to focus on self-management tasks too much, or only feeling it was necessary to monitor if feeling unwell: “I said I would do this, the system because I can keep an eye on important things to do with my heart and my blood pressure and my activity. All those things are important, but only the way I’m doing it. You know I wouldn’t want to spend a half an hour a day pouring over and saying ‘how many steps more did I walk today than yesterday?’” (P001, F, 76, COPD+CHD, IE, T2); “If I feel unwell. Then I will check my blood pressure [researcher: and what happens then?] Then I would know... if it is too high and I would lay down a bit” (P61, M, 70, Diabetes+COPD+CHD+CHF, BE, T2).

While talking about routines, it became evident that several of the participants used additional means of recording the results of their monitoring besides the ProACT platform. For example, P117 (F, 79, CHD+COPD, BE, T2) stated that she also writes all the measurements down and P61 (M, 70, Diabetes+COPD+CHD+CHF, BE, T2) and P103 (F, 79, CHF+Diabetes+CHD, BE, T2) added the numbers into an excel file. The participants did not explain why they did this even after additional prompting. Due to our holistic knowledge of our participants, it is possible to hypothesise about the reasons that these additional means are used. In some cases, it may have been out of a previous habit (as participants were often previously instructed to do this by their GP or specialist), to make the readings more tangible, or also it may be that they did not trust the digital means.

3.3 Facilitators and Barriers to Use

Support. In relation to using the technology, participants had two forms of support that acted as a facilitator to use – those in their care network and the research teams. While most participants were capable of using the devices and CareApp independently, a small number relied on support from their care network (usually an informal or formal carer). For example, some participants found the devices physically difficult to use by

themselves; P105 (F, 76, CHD + Diabetes+ COPD, BE, T1) mentioned she was not able to move the blood pressure monitor easily over her own arm. Some participants waited until their carer was present to help them to take measurements and view readings: “[formal carer] and [informal carer] showed me, but I couldn't use anything else. She told me to use ProACT and to get different things up, but I couldn't do that... Yes, [formal carer] comes from 10 to 11...It only takes her a couple of minutes [to use ProACT], she's really quick, she's great” (P018, 73, F, Diabetes+CHD, IE, T2).

Technical support was provided for the duration of the trial through a helpdesk in each country, staffed by the research team. Details of the types of issues experienced by participants included devices not working as expected, hardware and software updates and participants forgetting how to use devices. More detail on the issues experienced in Ireland have been published elsewhere [7]. During interviews, participants expressed their appreciation of this service: “If you wanted anything you just had to ring them. And they were there straight away, you know, leave a message and they'd get back on to us” (P018, 73, F, Diabetes+CHD, IE, T3); “I pressed something that knocked everything off or something and she was able to talk me through...Oh god yeah and she was very patient with me, she must have spent nearly an hour with me trying to talk me through it” (P043, 77, F, COPD+CHD, IE, T4).

Usability. Usability was both a facilitator and a barrier to engaging with ProACT during the trial. Most usability issues related to use of the hardware, including the monitoring devices and the iPad. Throughout the trial, participants experienced specific technological issues with devices, which were a source of frustration, in particular the blood pressure monitor and the glucometer: “I just stopped taking the blood pressure measurements at all. Because all the equipment wasn't working properly. In that it wasn't connecting to the iPad. And just to check it out, there was one morning I timed it and it was only after spending half an hour connecting the thing on the screen” (P009, M, 71, COPD+CHD+Diabetes, IE, T3). The persistent issues experienced by some users with the blood pressure monitor may be attributed to the device owner change (from Withings to NokiaHealth at the beginning of the trial), which caused calibration issues for larger or smaller arm sizes.

While the blood pressure monitor was the device that caused the most frustration for participants, they reported that other devices were also challenging to use. For example, participants reported challenges using the iPad: “[The technology is] manageable but still the tablet is a bit much for me” (P058, M, 71, Diabetes+CHD, IE, T2); “Except my ineptness with the iPad. I'm just not very good with it. That's the only challenge” (P001, F, 76, COPD + CHD, IE, T2). “My frustration with some of those is that, and this happens me frequently, I get into something and I can't get it off the screen. I don't know how to do it and then of course I press buttons and everything and it still comes back up on the screen, but I'm getting a little bit better at that” (P041, M, 69, Diabetes+CHD, IE, T2).

There were also many users who did not report experiencing any issues with the devices: “Everything links in quickly enough... And I don't have a problem, there's no delay or whatever in it. The watch is linking all the time so it's not a problem. It's

straightforward. I think the equipment is excellent” (P012, M, 67, Diabetes+CHD, IE, T3); “The scales I find really good” (P63, M, 76, Diabetes+CHD, BE, T2).

In relation to the ProACT CareApp, few usability issues were mentioned by participants. Feedback tended to focus on the features, including which ones were used, when and for what purpose: “The app itself I think is very good. And I think it’s helpful to get people to focus on a small number of things. That are key to their, you know their health. To also have a system that was easy to use, it is easy to use” (P015, M, 82, M, Diabetes+CHD, IE, T3).

Reliability of Monitoring Devices. Several participants had comments about the outcome of the measured values from the devices. Participants seemed to have concerns and questions about the reliability of the data. For instance, some participants commented that the watch didn’t detect sleep correctly “At times, it [tablet] showed that I had an afternoon nap, while I did not have an afternoon nap” (P111, M, 76, Diabetes+CHD+COPD, BE, T3). Another concern was that some participants noticed a difference between the devices used by the ProACT system in comparison to the devices used at home or by their healthcare professionals. For instance, P65 stated: “When I was there [GP], then I did a measure, and that gave a difference, the blood pressure device of the system [ProACT] gave 170 and I think at the GP had 130” (P65, M, 70, Diabetes+CHD, BE, T3). P103 (F, 79, Diabetes+CHD+CHF, T2) who had mobility issues stated that her limited steps did not always register. The perceived reliability concerns resulted in some using ProACT less: “Because of the fact that it does not show correct values, then I say I do not see the use of using it [blood pressure device and iGluko devices] anymore” (P91, M, 80, CVD+CHF+Diabetes, BE, T3). Over time, participants adapted to the use of the devices and adopted them into their daily lives: “If you have been working with it for a while, then everything will happen by itself” (P81, M, 68, CHD+CHF, BE, T3).

Perceived Benefits. Throughout the interviews, participants discussed the various benefits of using the ProACT platform, which may have acted as a facilitator or motivation to continue using the technology. Perceived benefits included improved self-management and control of symptoms: “If I see that there are moments that my blood pressure is higher, then I try to adjust my diet and my activity” (P62, M, 75, CVD+COPD, BE, T4); “I certainly am getting better readings than the first weeks that we took here. Because I’m doing the activity.” (P004, M, 84, CHF+CHD, IE, T3); improved health and wellbeing outcomes: “No, [my health is] better I think. Well I’m not in any pain and I want to go out more often. And I feel much better” (P016, F, 73, Diabetes+CHD, IE, T3); increased confidence and reassurance: “You can follow-up better, you will get the feeling, okay, if there is something wrong, then I will notice it on time” (P101, M, 72, CHF+CHD, BE, T4); “ProACT... helps you to focus and having been in the hospital it gave me the confidence to talk to the consultant and say look I think this machine is pumping too much oxygen into me” (P043, 77, F, COPD+CHD, IE, T4).

In addition to using the iPad to engage with the ProACT devices and CareApp, many participants also spoke of how they saw the trial as an opportunity to learn how to use other applications on the iPad: “I hope to use an iPad and communicate with people. I

would love to use Skype, I would love to use Facebook” (P011, M, 81, Diabetes+COPD, T1). P011 later reported that he set up email and Facebook accounts, while P027 reported using YouTube to find exercises she could do to improve her strength and flexibility: “Yeah and then of course the exercise. Since somebody said I can put YouTube on [the iPad], I think it was my granddaughter. You know so I try you know they say this is for seniors. I tried and like a duck to water, just love it... I go to YouTube and do the sitting exercise for seniors, like I manage to do them all you know” (P027, F, 79, Diabetes+CHD, IE, T3). Participants also reported setting up Skype and using many other apps, including radio apps, weather apps and news apps.

4 Discussion

While there have been some studies on the attitudes of older adults and those with multiple conditions to digital self-management [5], [8], actual evaluations of usage and experience with such technologies are limited. The study presented in this paper addresses this gap, highlighting that older adults with multiple chronic conditions are willing and capable of engaging in digital self-management, and that this cohort can develop and master the technical skills necessary for self-management. This paper also provides insights into the experiences and attitudes towards digital health technology use, patterns of usage and the supports required to assist usage.

Digital health technologies are widely heralded as the solution to address the challenges anticipated as a result of ageing populations, to support the shift from clinician-centric to patient-centric care, and to improve health and wellbeing outcomes [3]. Yet, societal adoption of such technologies, particularly by older adults, has been low and a number of barriers to uptake still exist [9]. There are several barriers, including a lack of focus on user-centred design, which can result in technology that is neither useful nor usable. The findings in this paper indicate that the vast majority of technology issues experienced by participants related to the hardware devices used in the trial, including the health and wellbeing monitoring devices and the iPad. The CareApp, which was co-designed with older adults with multimorbidity, appeared to cause fewer issues, though repeated training was necessary for many participants. Despite the technical issues with devices, including concerns about the reliability of data, the majority of participants (77.5%; n=93 of 120) persevered with using them, remaining engaged with the trial for the full period. Findings in relation to engagement and possible reasons for engagement have been published elsewhere [4]. However, significant support was required from the research teams to achieve this continued engagement [7], while some relied on their care network for help with the technology. If digital health technologies are to be more easily and widely adopted by older adults, issues around their usability, reliability and robustness need to be addressed.

Considerations are also required about how best to provide training and technical support, particularly at early stages of deployment. Even though some participants demonstrated confidence with the technology at T2, this was far more widespread at T3 with learning developing into mastery and confidence for more participants as they developed clear strategies and individual patterns of use, which was maintained at T4.

Participants in Ireland spoke about putting effort into learning the platform. This supports other research indicating that older adults are willing to put time and effort into learning how to use technology, if they perceive value [10]. Designers of technology for older adults should also consider different strategies to support engagement. While initial training was spread over two sessions, and training materials provided covered all features, some participants were not aware of certain features within the CareApp at T2. This may have been as a result of not exploring or being afraid to explore. Prompts and nudges could be delivered through the CareApp as reminders or encouragement.

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References

1. The Academy of Medical Sciences. Multimorbidity: a priority for global health research (2018). Available at <https://acmedsci.ac.uk/file-download/82222577> (last accessed March 2021).
2. Marengoni A, Angelman S, Melis R, et al. Aging with multimorbidity: a systematic review of the literature. *Ageing Research Reviews* 2011;10(4):430-9. [doi: 10.1016/j.arr.2011.03.003] [PMID: 21402176].
3. World Health Organisation. Global strategy on digital health 2020-2025 (2021). Available at https://www.who.int/health-topics/digital-health#tab=tab_3 (last accessed April 2022).
4. Doyle, J., Murphy, E., Gavin, S., et al. ProACT – A digital platform to support self-management of multiple chronic conditions: findings in relation to engagement during a one-year Proof-of-concept trial. *Journal of Medical Internet Research (JMIR)*, 2021;23(12).
5. Caldeira, C., Gui, X., Reynolds, et al. Managing healthcare conflicts when living with multiple chronic conditions. *International Journal of Human-Computer Studies*, 2021;145.
6. Dinsmore, J., Hannigan, C., Smith, S., et al. Digital health platform for integrated and ProACTIVE patient centred care (ProACT): protocol for an action-research proof of concept trial. In *JMIR Research Protocols*, 2021;10(12).
7. Smith, S., McAleer, P., Doyle, J., Gavin, S., Dinsmore, J. Technical support needs of older users of digital health technologies to support self-management of multimorbidity. AAATE conference, 2022.
8. Ienca, M., Schneble, C., Kressig, R.W., Wangmo, T. Digital health interventions for healthy ageing: a qualitative user evaluation and ethical assessment. *BMC Geriatr*, 2021;21(412).
9. Wilson, J., Heinsch, M., Betts, D., et al. Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health*, 2021;21(1556).
10. Sharit, J., Moxley, J.H., Czaja, S.J. Investigating older adults' willingness to invest time to acquire technology skills using a discounting approach. *Innovation in Aging*, 2021;5(2).

Digital Health and Social Care Technology Acceptance and its Conceptualization and Measurement in Older Adults

Protocol for an Umbrella Review

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Abstract. Digital technologies for health and social care have potential to support older adults' activities, quality of life, and autonomy. Technology acceptance is a commonly identified outcome in studies, but is conceptualized in numerous ways, which may influence measurement and conclusions. We wish to understand how technology acceptance is conceptualized and measured in older adults' health and social care. We will undertake an umbrella review to generate a relevant overview, by systematically searching databases (e.g., PubMed, Embase, PsycINFO, CINAHL, Cochrane, IEEE Xplore, Social Sciences Full Text, EconLit, Global Index Medicus) for systematic reviews and meta-analyses published since 2016. Inclusion criteria are: Population—older adults (aged 65+, or 40+ for adults with intellectual disability); Intervention—digital health and social care technology; Comparison—all comparators; Outcomes—technology acceptance; Study type—systematic reviews or meta-analyses. Independently, two reviewers will screen titles and abstracts, included full-texts, extract data, and appraise study methodological quality/risk of bias. We will present a narrative overview summarizing included reviews' characteristics, findings, limitations, and quality. This umbrella review will support a renewed understanding of technology acceptance as a concept and its measurement in this area, highlighting areas for future research and synthesis.

Keywords: older adults, digital health, technology acceptance.

1 Introduction

Global population growth and ageing[1], concomitant increases in chronic illness and disability, rising dependency ratios[2], and trends toward community-based and integrated care have contributed to demand for health and social care technologies. Such technologies have the potential to support older adults to maintain (or improve) mobility, communication, medical self-management, activity levels, community

participation, quality of life, autonomy, ageing-in-place, and overall capabilities, thereby preventing/delaying institutionalization[3]. Such technologies may also help states and providers to provide cost-effective care. Accordingly, there has been a recent, rapid proliferation of health and social care technologies, with myriad technologies—from wearables to social robots—deployed in countless populations, settings, and health or social care use cases.

Technology acceptance has been identified as a key outcome across studies of digital health and social care technologies and has been understood and conceptualized in a variety of ways[4], including, for example, the technology acceptance model[5], diffusion of innovations[6], unified theory of acceptance and use (UTAUT)[7–9], among others. Despite the concentration of research, development, and investment, there is evidence of continued non-use and abandonment of care technologies[10].

The diversity of older adults deserves considerable emphasis[11]. They range widely in age itself[12]. They may or may not experience substantial declines in physical or cognitive health or incident disability. They may be of any gender or ethnic background and may experience intersectional inequalities and exclusion[13]. They may have different levels of comfort with technology, and different social supports or financial means to afford technology.

We wish to understand, in the context of the rapid proliferation of technologies, how technology acceptance has been conceptualized in the domain of older adults' health and social care and how it is being measured. Considering diversity, we wish to understand what relationships sub-groups of older adults have to technologies vis-à-vis acceptance. We view an umbrella review[14]—a systematic review and overview of existing systematic reviews—as the appropriate method to summarize information in this complex and rapidly evolving area.

2 Method

2.1 Review Questions

A protocol for this review was registered on the PROSPERO register[15]. Our review questions are as follows:

1. How has health and social care technology acceptance been conceptualized and measured in digital health for older adults? a) What models of technology acceptance are used in digital health and social care for older adults? b) How has technology acceptance been measured among older adults?
2. What relationship does digital health and social care technology acceptance for older adults have with: a) specific models or model components of acceptance, b) different models of measurement of acceptance, c) specific sub-populations or demographics of older adults, and d) specific digital technologies?

2.2 Search Strategy

To prevent redundant efforts, we will search for relevant ongoing or completed umbrella reviews, in databases dedicated to protocol registrations, systematic reviews, and umbrella reviews (e.g., Prospero, JBI, Cochrane, Campbell).

PubMed, Embase, PsycINFO, CINAHL, Cochrane Library, IEEE Xplore, Social Sciences Full Text, EconLit, and Global Index Medicus will be searched. We will search reference lists of included studies, and for relevant grey literature using online databases (e.g., Google Scholar). We will first implement the search in PubMed, and then replicate it as closely as possible across the other databases. Search terms will be identified in extant literature, database subject headings, and pilot searches.

Using PICOS (Population, Intervention, Comparison, Outcome, Study Type) to search databases, we will search for titles and/or abstracts containing keyword combinations aligned with PICOS categories: 1) population: older adults; 2) intervention: digital health/digital technologies for health and social care; 3) outcome: technology acceptance, and; 4) study type: systematic reviews/evidence syntheses. Terms from each category must be present in the title and/or abstract, i.e., 1 AND 2 AND 3 AND 4. (We will not specify anything in a comparison category as it does not pertain to our review questions.) We will also search subject headings (e.g., PubMed's medical subject headings (MeSH)) to capture studies with differing terminology and in diverse research fields. See Table 1 for detailed search strategy.

Table 1. Original, PubMed Search Strategy

Field	PICOS	Domain	Search Terms (all [Title/Abstract], except where stated)
1	Population	Older adults	(Older adults OR Older adult OR older people OR older peoples OR older population OR older person OR older persons OR elder* OR geriatric* OR aging OR ageing OR senior* OR aged 65 OR 65+ OR over 65 OR age related OR old age OR mature adult OR oldest old OR aged adult OR Late Life OR Retire* OR "End of life" OR OAP OR OAPs OR Pensioner* OR geront* OR "Aged"[Mesh] OR "Aged, 80 and over"[MeSH] OR "Frail Elderly"[MeSH])
2	Intervention	Digital health (or digital social care) / connected health	(digital health OR digital medicine OR digital care OR health technol* OR medical technol* OR care technol* OR welfare technol* OR wellbeing technol* OR telemedicine OR telehealth OR telecare OR telemonitoring OR telerehab* OR eHealth OR e-Health OR eMedicine OR mHealth OR mHealth OR mobile health OR "technology enabled care" OR connected health OR connected medicine OR connected care OR device* OR install* OR innovation* OR gerotech* OR gerontech* OR electronic health OR tele-cure OR tele-conf* OR cyber* OR robot* OR online therapy OR e-learning OR smart home OR wearable* OR sensor* OR sensing

			OR assistive technol* OR games OR gaming OR IoT OR "Telemedicine"[Mesh] OR "Digital technology"[Mesh] OR "Self-Help Devices"[Mesh] OR "virtual reality" OR "augmented reality" OR "artificial intelligence" OR "virtual reality"[Mesh] OR "augmented reality"[Mesh] OR "artificial intelligence"[Mesh])
3	Outcome	Technology acceptance	ac- (accept* OR approv* OR reject* OR usage OR "use" OR nonuse OR utilization OR utilisation OR underutilization OR underutilisation OR attitude* OR adopt* OR abandon* OR diffusion OR adhere* OR compliance OR comply OR assimil* OR "TAM" OR UTAUT OR "Patient Acceptance of Health Care"[MeSH] OR "Diffusion of Innovation"[Mesh])
4	Study design	Systematic reviews	("systematic review" OR "systematic literature review" OR "meta-analy*" OR "meta analy*" OR "evidence synthesis" OR "umbrella review" OR overview OR "meta-review" OR "meta review" OR overview OR "Systematic Review" [Publication Type] OR "Meta-Analysis" [Publication Type])
5	Final search strategy: 1 AND 2 AND 3 AND 4		

We will use an English-language search protocol, but no language restrictions will be applied. Screening and data extraction will be limited to studies in English. We will provide a reference list of studies that we exclude at full-text screening for not having an English-language full text. We judge a five-year search window to be appropriate, considering the recency of interest in digital health, swift evolution of digital health technologies, and high likelihood that extant reviews capture studies from well beyond our five-year window. We will search for studies published between 2016-01-01 and 2021-07-22. We will conduct quality appraisal of included studies.

2.3 Participants

We define older adults as people aged 65 or older, with the exception of those with intellectual disability (ID). Given that this group often experience lower life expectancy, a lower threshold of age 40 or older will be applied to this sub-population, to broaden inclusivity. We will not exclude participants based on their living setting or where they might use health and social care technologies. Included: Adults aged 65+, or adults with ID aged 40+. Excluded: Children and adults aged 64 and younger, or adults with ID aged 39 or younger.

2.4 Intervention

Digital health or social care technologies include information and communication technologies used to support health or social care, including (but not limited to) technologies in the areas of eHealth, mobile health (mHealth), wearable devices, telehealth or telemedicine, and health information technology, where older adults themselves use,

wear, or interface with those technologies. We will not restrict the deployment settings, as technologies may be deployed in a wide range of settings and in the community and everyday living. We will exclude technologies that 1) do not have a digital component, and/or 2) are not applied in a health and social care context, and/or 3) are not used, worn, or interacted with by the older adults themselves.

2.5 Study Type

In an umbrella review, only systematic reviews and/or meta-analyses are included. We will include reviews that systematically review technology acceptance in relation to digital health or social care technology for older adults, where older adults are the population of the systematic review. Technology acceptance in such reviews may be explicitly considered as an outcome or as a predictor or moderator of other outcomes. Quantitative and qualitative conceptualizations and measures of technology acceptance are included. We will exclude studies in which older adults cannot be separated from other age groups for analyses. We will exclude studies that do not employ digital health or social care technologies.

2.6 Outcomes

Technology acceptance is the primary outcome. We use a broad definition encompassing older adults' adoption of, actual use of, intention to use, approval of, rejection or abandonment of, or satisfaction with technology, or the diffusion of technology among older adults. We will include adherence where adherence refers acceptance or use of specific technologies themselves and not to the non-technological medical, health, or psychosocial active components of an intervention. We will include studies of older adults' experience of, or attitudes toward, technologies where these relate to the dimensions of acceptance outlined above. Acceptance may be measured quantitatively or described in qualitative terms.

2.7 Study Selection Method

Title and abstract screening will be conducted with Rayyan reviewing software[16]. Study titles and abstracts will be independently reviewed for eligibility and inclusion by two reviewers. Reviewers will not have access to each other's decisions. Where reviewers disagree, decisions will be discussed, and where consensus is not reached, disagreement will be resolved by a third reviewer. Full-text screening will be recorded with spreadsheet software (Excel). Two, independent reviewers, unaware of each other's decisions will review full texts, with disagreements resolved by a third party.

2.8 Data Extraction Method

Using JBI umbrella review guidelines[17] data extraction will include: author/year; objective(s); participants (characteristics/total number); setting/context;

interventions/phenomena of interest; number of databases/sources searched; date range of included studies; number of studies; type of studies; study country of origin ; appraisal instrument and rating; type of review/method of analysis; outcomes (including definition and measurement of technology acceptance); results/findings (including any relationship of acceptance with specific models or model components of acceptance, or different modes of measurement of acceptance, or specific sub-populations or demographics of older adults, or specific digital technologies); and comments. We will contact authors for evidently unreported data. Two researchers will independently extract data from included studies and extracted data will be compared for completeness and agreement. A third researcher will resolve disagreements.

Quality Appraisal Method. We will appraise study quality with the AMSTAR 2 quality appraisal tool[18], supplemented with the following items from Aromataris and colleagues' checklist: 'Were recommendations for policy and/or practice supported by the reported data?', and 'Were the specific directives for new research appropriate?' [14].

Analytic Method. We will generate summary overviews of how technology acceptance has been conceptualized and measured in older adults for digital health and social care technologies. We will generate an overview of levels of acceptance, and the relationship between acceptance and conceptualization and measurement, different technologies, and sub-populations. In line with JBI guidelines[17], we will summarize, but refrain from re-synthesizing, results of included reviews. Wherever possible, we will summarize findings by demographic characteristics, including gender, age (older adults and oldest old, for example), and impairment status (e.g., cognitive impairment; physical impairment; multimorbidity). We will also summarize results by health and social care technology type (e.g., wearables, social robots, telehealth, etc.), by conceptualization of technology acceptance, and by measurement method.

3 Discussion

This protocol sets out the design and methods a priori for the conduct of our umbrella review. We anticipate that this approach will support meaningful summary and comparison of existing systematic reviews of older adults' technology acceptance as it relates to health and social care technologies.

This umbrella review will permit a broad-based understanding of acceptance across a wide range of technologies for health and social care. It will generate knowledge of the conceptualizations of technology acceptance that are prevalent in this space, as well as how technology acceptance is measured. Older adults are diverse, and this method will provide an overview of any difference in levels of technology acceptance, not merely across the wide landscape of different technologies, but also across different subgroups of older adults, who may have divergent needs or experiences of technology.

These elements of our design and method are key strengths in the context of the rapid evolution of technology in health and social care, the oft-experienced problems with or barriers to the adoption, sustained use, sustainability, scale-up, reach and spread of

digital health[10], the ageing populations wherein the majority of technologies are or will soon be employed, and the cost of technology development and implementation.

4 Ethics

As this is secondary research, reviewing existing research material, we did not require institutional review board approval. This research is funded by the European Union's Horizon 2020 research and innovation program under grant agreement No 857159. The authors declare that they have no known conflicts of interest.

References

1. European Commission. Statistical Office of the European Union.: Ageing Europe: looking at the lives of older people in the EU : 2020 edition. Publications Office, Luxembourg (2020).
2. European Union, Eurostat: Eurostat regional yearbook 2021. Publications Office of the European Union, Luxembourg (2021).
3. Rogers, W.A., Mitzner, T.L.: Envisioning the future for older adults: Autonomy, health, well-being, and social connectedness with technology support. *Futures*. 87, 133–139 (2017). <https://doi.org/10.1016/j.futures.2016.07.002>.
4. Or, C.K.L., Karsh, B.-T.: A Systematic Review of Patient Acceptance of Consumer Health Information Technology. *Journal of the American Medical Informatics Association*. 16, 550–560 (2009). <https://doi.org/10.1197/jamia.M2888>.
5. Davis, F.D., Bagozzi, R.P., Warshaw, P.R.: User Acceptance of Computer Technology: A Comparison of Two Theoretical Models. *Management Science*. 35, 982–1003 (1989). <https://doi.org/10.1287/mnsc.35.8.982>.
6. Rogers, E.M.: Diffusion of innovations. (2003).
7. Venkatesh, Morris, Davis, Davis: User Acceptance of Information Technology: Toward a Unified View. *MIS Quarterly*. 27, 425 (2003). <https://doi.org/10.2307/30036540>.
8. Dwivedi, Y.K., Rana, N.P., Jeyaraj, A., Clement, M., Williams, M.D.: Re-examining the Unified Theory of Acceptance and Use of Technology (UTAUT): Towards a Revised Theoretical Model. *Information Systems Frontiers*. 21, 719–734 (2019). <https://doi.org/10.1007/s10796-017-9774-y>.
9. Tamilmani, K., Rana, N.P., Wamba, S.F., Dwivedi, R.: The extended Unified Theory of Acceptance and Use of Technology (UTAUT2): A systematic literature review and theory evaluation. *International Journal of Information Management*. 57, 102269 (2021). <https://doi.org/10.1016/j.ijinfomgt.2020.102269>.
10. Greenhalgh, T., Wherton, J., Papoutsis, C., Lynch, J., Hughes, G., A'Court, C., Hinder, S., Fahy, N., Procter, R., Shaw, S.: Beyond Adoption: A New Framework for Theorizing and Evaluating Nonadoption, Abandonment, and Challenges to the Scale-Up, Spread, and Sustainability of Health and Care Technologies. *J Med Internet Res*. 19, e367 (2017). <https://doi.org/10.2196/jmir.8775>.
11. Enßle, F., Helbrecht, I.: Understanding diversity in later life through images of old age. *Ageing and Society*. 41, 2396–2415 (2021). <https://doi.org/10.1017/S0144686X20000379>.
12. Schoenhofen, E.A., Wyszynski, D.F., Andersen, S., Pennington, J., Young, R., Terry, D.F., Perls, T.T.: Characteristics of 32 Supercentenarians. *Journal of the American Geriatrics Society*. 54, 1237–1240 (2006). <https://doi.org/10.1111/j.1532-5415.2006.00826.x>.

13. Lu, P., Kong, D., Shelley, M., Davitt, J.K.: Intersectional Discrimination Attributions and Health Outcomes Among American Older Adults: A Latent Class Analysis. *The International Journal of Aging and Human Development*. 009141502110665 (2021). <https://doi.org/10.1177/00914150211066560>.
14. Aromataris, E., Fernandez, R., Godfrey, C.M., Holly, C., Khalil, H., Tungpunkom, P.: Summarizing systematic reviews: methodological development, conduct and reporting of an umbrella review approach. *International Journal of Evidence-Based Healthcare*. 13, 132–140 (2015). <https://doi.org/10.1097/XEB.000000000000055>.
15. Lombard-Vance, R., Joksimovic, N., Maguire, R., Desmond, D.: Digital health and social care technology acceptance and its conceptualisation and measurement in older adults: Protocol for an umbrella review. *PROSPERO* 2022 CRD42022308419, www.crd.york.ac.uk/prospere/display_record.php?ID=CRD42022308419.
16. Ouzzani, M., Hammady, H., Fedorowicz, Z., Elmagarmid, A.: Rayyan—a web and mobile app for systematic reviews. *Systematic Reviews*. 5, 210 (2016). <https://doi.org/10.1186/s13643-016-0384-4>.
17. Aromataris, E., Fernandez, R., Godfrey, C., Holly, C., Khalil, H., Tungpunkom, P.: Chapter 10: Umbrella Reviews. In: Aromataris, E. and Munn, Z. (eds.) *JBIM Manual for Evidence Synthesis*. JBI (2020). <https://doi.org/10.46658/JBIMES-20-11>.
18. Shea, B.J., Reeves, B.C., Wells, G., Thuku, M., Hamel, C., Moran, J., Moher, D., Tugwell, P., Welch, V., Kristjansson, E., Henry, D.A.: AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. *BMJ*. j4008 (2017). <https://doi.org/10.1136/bmj.j4008>.

Towards a Model for the Adoption of Person-Centred Technology in Integrated Care

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Abstract. In the SHAPES project, which is funded by the European Commission under the Horizon 2020 Programme (GA 857159), research was developed aiming at understanding the factors that impact on the adoption, upscaling and transfer of person-centred technology in integrated care programmes across Europe. Seventeen experiences of technology adoption in care providing organisations were analysed, which resulted in a list of over 150 factors that have impacted on the success or failure of the technology uptake process. The factors were grouped in domains which, in turn, were clustered based on their importance in different phases of the technology adoption process. The resulting framework model, the 4-Wheel Framework Model, together with a self-assessment tool to identify critical factors can provide guidance to organisations that plan to make a step towards the digitalisation of their person-centred services. The factors were further prioritised by a mixed panel of different stakeholders which led to a core list of four factors and sets of recommendations for their consideration in the deployment of person-centred digital solutions in care environments.

Keywords: Person-centred Technology, Integrated Care, Digital health

1 Introduction

1.1 Towards New Models of Integrated Care

Health and care systems require reforms and innovative solutions to become more resilient, accessible, and effective in providing quality care to European citizens. Due to

ageing populations, economic pressures, and the recent global pandemic, the need to improve and adapt the health and care systems to new contexts, operational needs and contingent situations has significantly increased.

Both, the development of people-centred integrated care programmes [1] and the use of new technologies [2], are identified by the global community as key strategies to cope with the challenges faced by health and care systems to meet current and future demands for quality care in a flexible and economically sustainable way. Healthcare organisations thus need to be transformed to absorb innovative technologies and deliver more flexible and personalised services to citizens [3].

The widespread expectation is that digital solutions can radically change the way health and care services are delivered to patients. If designed purposefully and implemented in a cost-effective though not cost-cutting way they might increase the well-being of millions of citizens, some of whom, without those solutions, risk to remain without services for geographical or social-economic reasons.

According to the European Commission [4], digitalisation in health and care can achieve the following:

- support the reform of health systems and their transition to new care models, centred on people's needs and enable a shift from hospital-centred systems to more community-based and integrated care structures;
- help to promote health and prevent disease, including in the workplace;
- support the continuity of care across borders, an important aspect for those who spend time abroad for business or leisure purposes.

1.2 Challenges

Despite substantial experience with integrated care models and digital solutions for healthcare systems at different levels of implementation, that aim to go beyond the traditional delivery systems and to cope with the challenges listed above, tangible results are still scarce. In particular, technology implementation projects are at high risk of failure, not only in their implementation phase [5], but also in their scaling-up and transfer.

A study concluded in 2018 by AAATE, EASPD and AIAS Bologna could not find examples of the transfer of digital platforms supporting integrated care from one region to another in Europe. [6]

1.3 The SHAPES Project

The Smart & Healthy Ageing through People Engaging in Supportive Systems (SHAPES) Innovation Action is funded by the European Commission under the Horizon 2020 Programme (GA 857159). SHAPES intends to build, pilot and deploy a large-scale, EU-standardised open platform. The integration of a broad range of technological, organisational, clinical, educational and societal solutions seeks to facilitate long-term healthy and active ageing and the maintenance of a high-quality standard of life. Mediated by technology, in-home and local community environments interact with

health and care (H&C) networks contributing to the reduction of overall H&C costs, as well as hospitalisation and institutional care rates.

Technological innovation is a fundamental drive for the evolution of integrated care. This is because it lays the basis for a communication infrastructure enabling end users (patients, informal as well as professional carers) and others involved in the care ecosystem to collect and share data in an autonomous way and to manage decision making processes differently.

Work undertaken in the framework of the SHAPES project aimed at gaining the knowledge necessary to identify factors of potential success and failure in the deployment, scaling-up and transfer of digital solutions supporting integrated care programmes.

2 The Complex Process of Person-Centred Technology Adoption in Integrated Care

2.1 Existing Models

The implementation, scaling-up and transfer of solutions supporting integrated care is a complex process. Different models and frameworks have tried to bring together factors that have to be considered, or that describe complexity in technology uptake in integrated care, such as the NASSS framework [5], the ProACT transferability model [6], the Momentum Blueprint [7].

2.2 Tracing Impacting Factors in Technology Adoption

Original field research was conducted by a group of researchers within SHAPES to identify the factors that will facilitate or hinder the successful deployment of technology in integrated care programmes. The scope of this work was to learn from existing experiences, especially those of care organisations that are using on a daily basis digital person-centred technology in the way they deliver their services. They have gone through a process of technology adoption in their care models and much can be learned from their experience.

The following 5 criteria were identified to selected cases.

- Person-centred solutions
- Part of operational service delivery models
- Connecting different actors in a care ecosystem
- Non-exclusively focussed on short term medical treatment
- Evaluated from the perspective of different stakeholders

It was extremely difficult to find cases responding to all 5 criteria. For that reason some experiences were included that had gone through a pilot phase but that were not yet fully deployed in an existing care service. In the end, 17 suitable organisations were identified and their managers were interviewed with a semi-structured interview schedule.

As a result:

- More than 163 enabling factors or barriers were identified;
- More than 45 reported lessons were collected;
- More than 45 recommendations were collected.

Some enabling factors were quite similar one to another, which is not surprising. Others were contradictory, for example those mentioning the importance of mixed public/private funding compared to those mentioning the importance of public funding only, thus highlighting the impact of the health context where the experience was developed. This led to the conclusion that context awareness is important and that it is more appropriate to consider them just impacting factors that have to be considered in person-centred technology adoption in integrated care. Not doing so might increase the risk of failure of the adoption process.

By focussing on the technology adoption process, it was possible to group all retrieved factors in either one of the domains listed in Table 1.

The thus obtained domains of factors have a different impact according to the stages of development, implementation, and consolidation of the solution, or, using more appropriate terms, the conceptualisation, contextualisation, implementation, and evaluation stage.

Table 1. Overview of domains and stages in technology adoption

Stage	Domains of impacting factors
Conceptualisation <i>In this “imaginary” stage a possible solution to existing needs is imagined and theorised.</i>	Target groups and needs
	Policy
	Values, vision, and goals
Contextualisation <i>In this “feasibility” stage a possible solution is assessed according to its compatibility with existing local health and care systems, cultures and practices and its financial sustainability.</i>	Service context
	Health and social care systems
	Economic
Implementation <i>In this “realisation” stage a feasible solution is made into reality and technology is embedded in a service flow.</i>	Human factors
	Technology
	Solution design
	Information and communication
	Process management
Evaluation <i>In this “evaluative” stage the solution outcomes are measured, and plans are made for adaptation, scaling-up or transfer of the solution and its results.</i>	Outcomes
	Impact

2.3 The 4-Wheel Framework Model

A consideration can be made regarding the relationship between stages in the technology adoption process and the domains of impacting factors. Solution design processes,

and even more person-centred design processes, are cyclical in nature. This means the assessment of the impact of the factors in each domain will have to be repeated. This is made visual in the 4-Wheel Framework model (Figure 1). Based on the outcomes of the technology adoption process, adaptations of further development can be expected (e.g., new deployments, scaling-up and/or transfer). In both cases, new adoption or adaptation, the four wheels will start a new cycle, as evidenced in Figure 1.

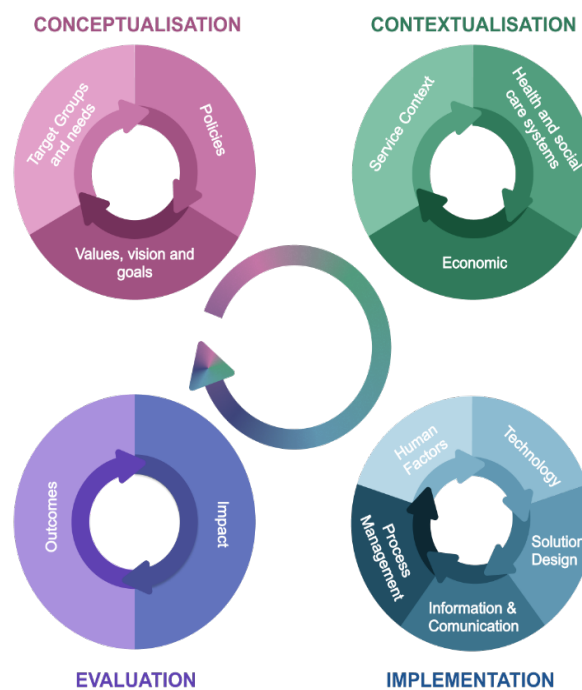


Fig. 1. The 4-Wheel Framework Model

2.4 Prioritising Core Factors

As a next step a survey asking a community of experts (19 participants) to evaluate the importance of each factor was developed. An overall score was generated for each factor and the three highest scoring factors were presented to a consensus building seminar to be further reduced to a core factor for each stage.

The following factors were considered the most important ones:

- The solution should match the needs and interests of the beneficiary group across all care domains.
- The solution design should be functional from the perspective of the end-user.
- The solution should promote healthier lifestyles.
- The solution should increase the efficiency in care.

Building upon input from the participants in the consensus building process, recommendations were developed for each of the core factors.

2.5 Next steps: Towards the Development of Tools

At the end of the consensus building process, the full list of factors was reviewed and finalized. The list of relevant factors to consider in the different stages of adopting, up-scaling or transferring technology-based persons-centred solutions in integrated care can be used as a basis for the development of a useful tool providing guidance to *care managers and innovators* in the process from conceptualization to evaluation of technology-based solutions in care pathways. For the different stages the assessment criteria to be applied to the factors would be slightly different as indicated in Table 2.

Table 2. Assessment criteria to be applied to impacting factors for the different stages.

Stage	Assessment criteria		Scale		
Conceptualisation	Factors are considered	Not considered	Partially considered	Fully considered	Not relevant
Contextualisation	Factors are analysed	Not analysed	Partially analysed	Fully analysed	Not relevant
Implementation	Factors are managed	Not managed	Partially managed	Fully managed	Not relevant
Evaluation	Factors are assessed	Not assessed	Partially assessed	Fully assessed	Not relevant

A second tool could be made for developers seeking to enhance the transferability of the solutions that they are developing. There are factors that have core relevance for those aiming at transferring a solution that is developed elsewhere in a different political and social environment with a different culture and organisation of care. The problems and the needs might be the same, but the answers to those needs might not be. For developers of person-centred technology-based solutions it is important to consider right from the start of their development work which factors are particularly relevant to consider in such a transfer process. Addressing them appropriately will turn these factors into facilitators for transfer instead of barriers. An example is the early consideration of language as well as accessibility options for the solutions at stake (e.g. different alphabets, font size options, etc.).i. Such critical factors might inform the development of a specific checklist for developers to enhance wider uptake of their solutions across Europe and worldwide.

References

1. WHO: WHO global strategy on people-centred and integrated health services: Interim Report. WHO Publications. Geneva (2015) (WHO/HIS/SDS/2015.6).
2. WHO. Global strategy on digital health 2020–2025. (2020).

3. D'Erico, G., Duda-Sicula, M., Zwiefka, A., Krzyzanowski, D., Kurpas, D.: Health technologies and smart & integrated care – key action 2 stage of the Regions 4Per Med (H2020) Project. *Medial Science Pulse* (13) 4 (2019)
4. European Commission: Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society (2018).
5. Greenhalgh T., Maylor H., Shaw S., Wherton J., Papoutsis C., Betton V., Nelissen N., Gremyr A., Rushforth A., Koshkouei M., Taylor J.: The NASSS-CAT Tools for Understanding, Guiding, Monitoring, and Researching Technology Implementation Projects in Health and Social Care: Protocol for an Evaluation Study in Real-World Settings. *JMIR Res Protoc* 9 (5) (2020). DOI: 10.2196/16861
6. Ferrando M., Hoogerwerf E.-J., Kadyrbaeva A.: Qualitative research on the factors affecting transferability of digital solutions for integrated care. *International Journal of Integrated Care* 19(4): 236. (2019). DOI: <http://doi.org/10.5334/ijic.s3236>
7. Momentum Consortium: Personalised Blueprint for telemedicine deployment: validated and tested version. Deliverable 3.4. (2015). http://www.telemedicine-momentum.eu/wp-content/uploads/2015/02/D3.4_v1.0_ValidatedBlueprint.pdf. Retrieved: 27.04.2022 (last assessed 28/04/2022).

Information Obligation as a Balancing Tool in the Context of Active and Assisted Living

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Abstract. This contribution aims to present information obligation as an important balancing tool in the context of Active and Assisted Living (AAL). The importance of being informed is emphasised in economics, social life, and law. In the context of AAL, there is a potential informational imbalance, which has three aspects: 1. The market position of the consumer. 2. Processing of personal data. 3. Understanding of technologies. Those imbalances may influence the perception of AAL and its acceptance by people. An information obligation may be a proper tool to solve the problem of informational imbalance. Therefore, two key European legal acts, the General Data Protection Regulation and the AI Act, proposed in 2021, establish various information obligations. Those obligations must be carried out effectively. The three most crucial consequences of the acts are as follows: 1. In case of a legal dispute concerning the information obligation, the burden of proof is on the provider of the product. 2. Providers of the AAL systems should deliver information in an intelligible way. 3. The form in which information is given shall be harmonised to enhance the comparability of products. This does not have to be done by legal regulation, but can be implemented by the industry itself (in a form of technical standards or a code of best practices). Experiences from the field of European banking and investment law may be used to effectively fulfil information obligation in the context of AAL. In the conclusions, practical consequences of the role of information obligation will be discussed. The reflection takes stock of three aspects of information obligation as a balancing tool: 1. Its importance. 2. Its sufficiency. 3. The most needed improvements.

Keywords: Active and Assisted Living, information obligation, data protection, EU law

1 Introduction

Access to the proper information in the context of Active and Assisted Living (AAL) is not only a matter of ethics and values, but also a crucial requirement of users, guaranteed by law. Potential users of AAL need to have access to information allowing them to understand the system, and how it can impact them. Lack of such information

may make them feel vulnerable in relation to providers of AAL. One of the possible tools to answer that problem is information obligation.

The current contribution aims, firstly, to highlight the importance of information obligation in the fields of law, society, and economics. Secondly, potential informational imbalances in the context of AAL will be identified. In the third step, information obligation in General Data Protection Regulation (GDPR) [1] and the Artificial Intelligence Act (AI Act), [2] two European legal acts crucial for the AAL, will be described. Special attention will be given to the requirement of effectiveness and its consequences. In the following step, possible inspirations from European banking law will be presented.

While it is widely recognised that information obligation is an essential facet of consumer protection, information obligation has not been analysed as a balancing tool. The proposed perspective aims to present providers and users of AAL as partners whose relationship should be balanced. Such a balance has multiple dimensions, but the informational dimension is a vital one. The conclusions of this paper should allow us to answer whether information obligation is an important balancing tool, if it is sufficient as a mechanism, and what the most needed amendments are in that regard.

2 The Relevance of Information Obligation in Economics, Society, and Law

Information obligation is paramount not only because of its position in the law but also because of its vital economic and social role. Before analysing the legal significance and framework of information obligation, it is beneficial to consider it from the perspective of economic theories, as well as that of social life.

One of the main foundations of classic economics, especially its liberal stream, is the notion of a well-informed and reasonable buyer. [3] That buyer is aware of different prices, features of products, and how they will benefit from choices, so they buy the best quality for the lowest price. Liberal market theories are based on the idea of such a rational consumer and consequently represent idealised models of reality. One way to support the well-functioning of the whole market is to provide proper information to buyers (information paradigm). [4] For those reasons, information obligation is crucial from an economic point of view, as it allows clients to make informed decisions. [5]

Social and user acceptance of technology requires accurate information, which is supported by information obligation. When people do not understand how a system works, they are less willing to accept and use it. [6] As the potential risk is unknown, one cannot accurately assess if the benefits outweigh the risks, or at least balance them out. [7] Those risks may take various forms, such as an improperly functioning system or the stress associated with it, damage to the property, or physical harm. As AAL systems process personal data, many people express their privacy concerns, and consider it a serious risk. [8] People are not aware of their liability, legal rights, and obligations, because many technologies are new. All those sources of distrust towards innovations may be mitigated and even answered by proper information.

A crucial legal principle is that people make decisions, and they bear responsibility for them. In civil law, a lack of information may make an act void. In criminal law, insufficient or incorrect information, when justifiable, may absolve a person of guilt. In consumer protection law, one of the main obligations of a seller is to provide proper information, and to mislead a consumer through false, incomplete, or improperly given information is one of the most common offences. In the field of EU data protection and IT law, information obligation is one of the cornerstones of user protection. Data and information are more and more often recognised as assets, which shall be legally protected, and towards which multiple rights apply. [9] If law develops in that direction, more attention will have to be paid to the problem of distribution of control over data, and access to information.

3 Information Imbalance in the Context of AAL

The problem of informational imbalance occurs in the context of AAL. This problem was not researched yet, and further investigation is needed to provide a comprehensive analysis. For this paper, three aspects of the relationship between providers and users of AAL will be considered. Firstly, it is a classic relationship between consumers and providers. Secondly, the personal data of users is processed, so in their relations with providers they are data subjects, and providers are data controllers. [10] Thirdly, it may be argued that to some extent users of AAL are caretakers or at least people whose life quality depends significantly on the solutions they are using. [11]

AAL providers offer products that aim to support the quality of life. [12] Users may be considered consumers, as they are natural persons who acquire AAL solutions for purposes that are outside of their professional life. Therefore, all informational imbalances between consumers and sellers, well researched in the scholarship, occurs. [13,14] Providers of AAL have significantly more information about the market situation as a whole, than particular users. One of the reasons is that providers are companies that employ multiple people whose work may be diversified. Some employees may work exclusively on market analysis. Users, who are individuals, often senior ones, do not have access to that much market information, nor the ability to process that data. Moreover, providers obtain data on their own by analysing incoming inquiries, consumer preferences, and sells. Depending on applied technologies, providers may have access also to data about users' behaviour.

All AAL solutions largely deal with personal data. [11] Very often it is sensitive data, related to one's health condition and family life. Processing that data is considered by many people as privacy intrusive. [15] AAL users do not process any personal data of the providers, except for some contact details. The imbalance of knowledge results in the imbalance of power, and makes data subjects vulnerable. [16]

Support for the quality of life is the main goal of AAL systems, which may be perceived by many as caregiving. Indeed, if some products increase the level of independence or help to maintain health, it means that without it the user will be in a worse situation. The logic of the functioning of the AAL and applied technologies are quite advanced and sophisticated. [17] It is safe to assume that a significant majority of

potential users will not be able to understand the products offered to them. That makes them less willing to use AAL, as their information needs are not answered. [18] At the same time, providers, as collectives with various experts on board, have a full understanding of their products.

All mentioned imbalances impact users' position, perception of AAL, and its acceptance by people. Providers have significantly more market information, they process the personal data of users, and know how the technology works. That unbalanced power raises the risk of abuse. That is especially vital from the perspective of the EU competition and single market regulations. [19] Many ethical questions may be asked as well. [11] For the further development of AAL, and its acceptance by the users, it is necessary to identify and implement effective balancing tools.

4 Information Obligation as a Balancing Tool in the EU Law

Information obligation is one of the possible tools to answer the problem of informational imbalance. The imbalance between users and providers of AAL systems comes from the different amounts of information each party has, especially when it comes to market data, processing of personal data, and the understanding of technology. In two relevant EU legal acts, GDPR and AI Act, there are multiple information obligations. While GDPR is focused mostly on the context of personal data, and AI Act on the understanding of technology by users, they both address all three mentioned aspects of informational imbalance.

4.1 GDPR

General Data Protection Regulation applies to those computer systems which process personal data. Processing is defined in the GDPR as any operation or set of operations that are performed on personal data, in a particular collection, recording, structuring, storage (art. 4(2)). All AAL technologies are potentially covered by this regulation. [11]

Under the GDPR, the information obligation may be summarised as a duty to inform users that their data will be processed, how and for how long, and what rights they have in that regard (art. 13 and 14). They address mostly the problem of imbalance that arises from the processing of personal data by empowering data subjects in knowledge about what is happening with their data. GDPR grants rights that allow data subjects to keep some control over their data: access to data, rectification or erasure, or restriction of processing of personal data. It is worth noticing that also the imbalance connected with an understanding of technology is addressed by the obligation to disclose whether automated decision-making is involved, what is the logic of the process and its relevance for users (art. 13-14).

Informed consent is one of the legal provisions for the lawful processing of personal data (art. 4(11), 6(1)(a)). The provider must deliver all information needed to make a decision. The content of this rule in the law is not precise but can be deducted from the aim of this norm. The aim is to enable a consumer to understand what they are deciding

and what are the consequences. In the context of AAL, it means not only the processing of personal data but also the functioning of the technology.

4.2 AI Act

The proposed AI Act set up two similar obligations: transparency of the AI system, and information obligation. The obligation of transparency requires that users can interpret the system's output and use it appropriately (art. 13(1)). Users shall be also informed that they are dealing with the AI system (art. 52), who is the provider of the system and their contact details, and about the basic characteristic of the system, including human oversight measures (art. 13(3)). The conformity of the AI system with the EU rules shall be communicated by the CE marking (art. 49).

Information obligation under the AI Act is focused on the characteristic of a product. The purpose of that is to provide users with data essential for understanding the system. Informational requirements were designed to answer the most common concerns expressed by the people in the research used during the preparatory works. [20] The content of the information obligation under the AI Act addresses partially the imbalance connected with the market position of consumers by implementing well-known CE marking.

5 The Requirement of Effectiveness

It may be argued that information obligation must be carried out effectively. Firstly, it is a consequence of the teleological analysis of information obligation, which aim is to make consumers informed. Secondly, it is expressed in the law that information obligation requires communication to be comprehensive and understandable. For that reason, both GDPR and AI Act establish requirements for content, form, and language. The clear goal of that rules is to ensure that information obligation will be effective. Out of many theoretical and practical consequences of the requirement of effectiveness, three which are the most vital for providing informational balance will be pointed out.

5.1 Burden of Proof

In a case of a legal dispute concerning the information obligation in the context of consent, the burden of proof is on the provider of the product. Consent, which is one of the central concepts of GDPR, [21] is void if it is not informed. The explicit consent for processing for specified purposes is one of just a few conditions that derogate the general prohibition of processing special categories of personal data, which include data concerning health, genetic and biometric data, racial or ethnic origin (art. 9(1) and 9(2)(a)). All those types of data may be crucial for the effective work of AAL systems. The burden of proof in the matter of consent is extended to prove that the information obligation was fulfilled. [22]

Putting the burden of proof on the provider may contribute to informational balance. [23] Firstly, it can be an additional incentive for providers of AAL systems to comply

with information obligation rules. Secondly, it strengthens consumer protection and gives users a better procedural position in a potential trial.

5.2 Intelligibility

Providers of AAL systems should take care not only to deliver proper information but also to deliver it in an intelligible way. That intelligibility has three aspects: language, lengths, and structure. Simplification and avoidance of technical terms can make the document more understandable for an average consumer, but it goes with the lack of some information, and using somehow metaphorical language. [24] Consumers prefer shorter documents, and they tend to lose focus after a few lines if they know that the document is long. [25] A clear structure, similar for various products, makes information easier to be processed and used by consumers. [26] Moreover, it may be of great benefit to provide some information in a form of graphics or numeral labels. Consumers point out them as the easiest to understand, and they stated that they almost always “read” graphic or numeric labels, while many parts of text are skipped. [24] However, there is a risk that too simplified information will be no longer accurate. [24]

5.3 Harmonised Forms

The form in which information is given shall be harmonised to enhance the comparability of products. To compare things, it is necessary to have their analogous features known. In mathematics and natural sciences, it is also a matter of units. Comparison of two values expressed in different units is possible but requires knowing what the relationship between units is. In the context of the information obligation, it is vital to deliver users information presented in the form that makes it easier to compare two products. It can be achieved by the standardisation of forms by providers. In that endeavour, they may seek the support of scientists, and draw inspiration from other industries, with a long tradition of information obligation regulations.

6 Possible Inspirations from EU Banking Law

Still evolving regulations of information obligation in the financial sector may be a source of inspiration for regulating similar matters in the area of computer systems, including AAL. The first European act regulating that issue was the Prospectus Directive of 1989. [27] The main aim of the prospectus is to deliver a potential investor “necessary information” to make “an informed assessment” (art. 6(1)), and, in conclusion, an informed decision. A prospectus contains information about assets and liabilities, profits and losses, rights attached to the securities, and disclosure of the financial situation of the issuer. That rich and detailed content was criticised, as it provides more information than the consumer expects and can read, resulting in a rational ignorance – a person decides that reading the document is more costly than a potential benefit. [28] To answer those problems, a simplified prospectus was introduced. [29] It accompanies a full prospectus and is a kind of a summary. However, the simplified prospectus has

been criticised because it was often too lengthy, [30] and hardly comparable due to the different format. [31]

A simplified prospectus was replaced with Key Investor Information Document (KIID). [32] While the content is like the previous document, KIID has three important novelties. Firstly, all KIIDs must have the same structure, which should help consumers to compare products. Secondly, it is required to use “clear, succinct and comprehensible”, and “non-technical language” (art. 78(5)). Thirdly, it introduces a synthetic risk and reward indicator, that expresses the riskiness, given on a numeric scale from 1 to 7, and is supplemented by a narrative explanation (art. 8-9).

In 2014, one type of informational document for the whole group of products was introduced Key Information Document (KID), [33] to improve the quality of investor information, [34] and by that to improve the comparability of financial products. [33] The Regulation covers multiple types of “packaged”, complex, financial products based on their features, regardless of their form of construction. The focus is not on the legal or economic similarities, but on the perception of consumers, whether they consider products as similar or not. [35] KID should be drawn up as a short document of a maximum of three sides of A4-sized paper when printed, written in a way that promotes comparability (art. 6 (4)). The order of information is also regulated (art.8 (3)). Moreover, KID shall be “be clearly expressed and written in a language and a style that communicates in a way that facilitates the understanding of the information” (art. 6 (4)(c)). Those rules have been inspired by the research over KIID, [36] and elaborate consumer testing studies. [24] Rules regulating KID reflect consumers’ preference for short documents with clearly divided sections that include narrative explanations, and examples of potential benefits and loss.

It is hardly possible to already evaluate the effectiveness of KID as it fully replaced KIID only on the 1st of January 2022. However, KID illustrates three key factors of the effectiveness of information obligation:

1. Products that may be considered by consumers as similar, substitutional, shall be regulated together, regardless of their technical specification (horizontal approach).
2. An informational document shall be brief, and should have clear, standardised order.
3. Employed language must be understandable for consumers by avoiding technical jargon, and providing examples.

7 Conclusions

Information obligation is a valuable tool for consumer protection and supporting informational balance. Because of rules established in the GDPR, providers of AAL that process personal data have to provide users with comprehensive information. It is safe to assume that not all producers would do that without that regulation. Because the information has to be provided effectively, it is in the interest of producers to find the best forms and tools to deliver information.

Information obligation in its existing form is not a sufficient balancing mechanism. The main reason behind this insufficiency is the inability of individuals to use the delivered information. It may be accompanied by rational ignorance when an individual

is overwhelmed by the amount of information presented in an unintelligible way. One potential solution to this problem is to focus more on the form of informational documents. Experience from the field of European financial law suggests paying more attention to the language and structure, as well as to the harmonisation of documents, which facilitates comparability. Numerical labels and graphical information are preferred by consumers, as they are easier to read and understand. However, this approach may lead to oversimplification, raising the question of a trade-off between comprehensiveness and intelligibility.

Further research is required into the content and form of the information obligation. Interdisciplinary studies may help us propose labels or graphic forms that will be accompanied by text documents. Such innovations do not require changes in the law but can be introduced by the industry itself. Cooperation between providers of AAL systems and scientists can produce effective solutions, introduced in the form of guidelines, codes of best practices, or technical standards. Nevertheless, research on information obligation and its effectiveness also ought to be considered by lawmakers. Regulations inspired by the aforementioned research should be included not only in the proposed AI Act but also in future amendments to the GDPR, and other relevant acts.

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References

1. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). OJ L 119, 4.5.2016, 1–88.
2. Proposal for a Regulation of the European Parliament and of the Council laying down harmonised rules on artificial intelligence and amending certain Union legislative acts. COM/2021/206 final.
3. Howard Beales, Richard Craswell, Steven S. Salop. 1981. The efficient regulation of consumer information. *Journal of Law and Economics* 24 (1981), 491-539. <https://www.jstor.org/stable/725275>.
4. Stefan Grundmann, Wolfgang Kerber, Stephen Weatherill. 2012. Party Autonomy and the Role of Information in the Internal Market – an Overview. In *Party Autonomy and the Role of Information in the Internal Market*. eds Stefan Grundmann, Wolfgang Kerber and Stephen Weatherill (2012), 3-38. <https://doi.org/10.1515/9783110873030.3>.
5. Niamh Moloney. 2010. How to Protect Investors. Lessons from the EC and the UK. *International corporate law and financial market regulation*.
6. Hacer Guner, Cengiz Acarturk. 2020. The use and acceptance of ICT by senior citizens: a comparison of technology acceptance model (TAM) for elderly and young adults. *Univ Access Inf Soc* 19, (2020), 311-330. <https://doi.org/10.1007/s10209-018-0642-4>.

7. Fred D. Davis. 1989. Perceived usefulness, perceived ease of use and user acceptance of information technology. *MIS Quarterly* 13(1989), 319–340. <https://doi.org/10.2307/249008>.
8. Martina Ziefle, Carsten Rocker, Andreas Holzinger. 2011. Perceived usefulness of assistive technologies and electronic services for ambient assisted living. 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops (2011), 585-592. <http://dx.doi.org/10.4108/icst.pervasivehealth.2011.246044>.
9. Kean Birch, DT Cochrane, Callum Ward. 2021. Data as asset? The measurement, governance, and valuation of digital personal data by Big Tech. *Data & Society* 8 (2021). <https://doi.org/10.1177/20539517211017308>.
10. Michèle Finck. 2021. Cobwebs of control: the two imaginations of the data controller in EU law. *International Data Privacy Law* 11 (2021), 333–347. <https://doi.org/10.1093/idpl/ipab017>.
11. Alin Ake-Kob et al. 2021. State of the art on ethical, legal, and social issues linked to audio- and video-based AAL solutions. COST Action GoodBrother 2021.
12. AGE Platform Europe, Glossary & Acronyms, <https://www.age-platform.eu/age-glossary/a>.
13. Hans Thorelli, Sarah Thorelli. 1977. Consumer information systems and consumer policy.
14. Piotr Sitnik. 2020. Intricacies of Significant Imbalance as the Cornerstone of Protection against Unfair Terms in Consumer Contracts under EU Law. *Studia Iuridica* 82 (2020), 227-262. DOI: 10.5604/01.3001.0013.9789.
15. Daniel J. Solve. 2008. Understanding privacy.
16. Ryan Calo. 2016. Privacy, Vulnerability, and Affordance. *Cambridge Handbook of Consumer Privacy* (2017).
17. Slavisa Aleksic et al. 2022. State of the Art of Audio- and Video- Based Solutions for AAL.
18. Reijo Savolainen. 2012. Elaborating the motivational attributes of information need and uncertainty. *Information Research* 17 (2012). <http://informationr.net/ir/17-2/paper516.html>.
19. Ovidiu I. Dumitru, Andrei V. Tomescu. 2020. European consumer law in the digital single market. *Juridical Tribune* 10 (2020), 222-238.
20. European Commission. Explanatory Memorandum for the Proposal for a Regulation of the European Parliament and of the Council laying down harmonised rules on artificial intelligence and amending certain Union legislative acts. COM/2021/206 final.
21. Maciej Szpunar. 2019. AG Szpunar Opinion in Planet49. C-673/17, EU:C:2019:246.
22. Orange România SA v Autoritatea Națională de Supraveghere a Prelucrării Datelor cu Caracter Personal (ANSPDCP). C-61/19, ECLI:EU:C:2020:901.
23. Yuyut Prayuti. 2018. Implementation of Reversal Burden of Proof Principle at Consumer Dispute Settlement Agency (BPSK) as a Legal Protection Effort for Consumers. ICSTES 2018, 21-22 November 2018, Bali, Indonesia. DOI:10.4108/eai.21-11-2018.2282274.
24. London Economics, and Ipsos. 2015. Consumer testing study of the possible new format and content for retail disclosures of packaged retail and insurance-based investment products – Final Report. MARKT/2014/060/G for the implementation of the Framework Contract no EAHC-2011-CP-01. Retrieved January 10, 2022, from https://ec.europa.eu/info/sites/default/files/consumer-testing-study-2015_en.pdf.
25. OECD. 2005. Improving Financial Literacy: Analysis of Issues and Policies.
26. Leora Klapper, Annamaria Lusardi, and Peter van Oudheusden. 2015. Financial Literacy Around the World: Insights from the Standard & Poor’s Ratings Services Global Financial Literacy Survey.
27. Council Directive 89/298/EEC of 17 April 1989 coordinating the requirements for the drawing-up, scrutiny and distribution of the prospectus to be published when transferable securities are offered to the public. OJ L 124, 05/05/1989, 0008 – 0015.

28. Troy A. Paredes. 2003. Blinded by the light: information overload and its consequences for securities regulation. *Washington University Law Quarterly* 81 (2003), 417-476. <http://dx.doi.org/10.2139/ssrn.413180>.
29. Directive 2001/107/EC of the European Parliament and of the Council of 21 January 2002 amending Council Directive 85/611/EEC on the coordination of laws, regulations and administrative provisions relating to undertakings for collective investment in transferable securities (UCITS) with a view to regulating management companies and simplified prospectuses. OJ L 41, 13.2.2002, 20–34.
30. European Commission. 2008. Impact assessment of the legislative proposal amending the UCITS Directive. SEC(2008) 2264.
31. Karen L. Anderberg, and Jessica A. Brescia. 2009. UCITS IV: reforms to the UCITS Directive adopted by the European Parliament. *Euromoney's International Investment and Securitisation Review* 2009.
32. Directive 2009/65/EC of the European Parliament and of the Council of 13 July 2009 on the coordination of laws, regulations and administrative provisions relating to undertakings for collective investment in transferable securities (UCITS). OJ L 302, 17.11.2009, 32–96.
33. Regulation (EU) No 1286/2014 of the European Parliament and of the Council of 26 November 2014 on key information documents for packaged retail and insurance-based investment products (PRIIPs). OJ L 352, 9.12.2014, p. 1–23
34. European Commission. 2012. Explanatory Memorandum to the Proposal COM(2012).
35. Veerle Colaert. 2019. Product Information for Banking, Investment and Insurance Products. In *European Financial Regulation: Levelling the Cross-Sectoral Playing Field*. Eds Veerle Colaert, Danny Busch and Thomas Incalza. 2019, 303–316.
36. IFF Research and YouGov. 2009. UCITS Disclosure Testing - Research Report.

Robots and Virtual Assistants for Disabled and Older People



Challenges in the Provision Process of Dynamic Arm Supports and Robotic Arms as Perceived by End-Users

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Abstract. Neuromuscular disorders and other health conditions can lead to impaired upper extremity function, with severe consequences for independent daily functioning, autonomy, self-esteem and quality of life. Dynamic arm supports and robotic arms are assistive devices that can support persons with limited upper extremity function in various activities of daily living. To obtain a good match between user and assistive technology and to achieve optimal outcomes with respect to effectiveness, it is essential that the provision process runs smoothly. To inform the development of the optimized provision process, challenges in the current process were investigated from an end-user perspective. Semi-structured interviews were conducted with adult dynamic arm support and robotic arm users. The interview aimed to identify users' experiences with the provision process, and in particular regarding their awareness of this type of assistive technology, the information provided about the assistive technology and training. Challenges identified in the interviews included: 1) The need to involve experienced occupational therapists in the selection and decision making process. 2) Participants were unaware that this type of assistive technology existed and accidentally came across their dynamic arm support or robotic arm. 3) Referral is guided by previous experiences with a certain assistive technology supplier rather than by the needed functionalities of the device. 4) Too little attention was paid to training or helping participants to get used to their AT. 5) Communication between parties involved in the procurement process and technical assembly is often inadequate.

Keywords: dynamic arm support, robotic arm, provision process, qualitative research

1 Introduction

Various (neuro)muscular disorders and other health conditions can lead to impaired upper extremity function, with severe consequences for independent daily functioning [1-2], autonomy, self-esteem and quality of life [3-4]. Dynamic arm supports and robotic arms are assistive technology (AT) that can support persons with limited upper extremity function in various (self-care) activities of daily living (ADL) such as eating, drinking, brushing teeth and using a computer [5-6].

In 2021, a variety of 17 dynamic arm supports and three robotic arms were commercially available from three different suppliers in The Netherlands. Dutch health insurance companies reimburse dynamic arm supports and robotic arms under the Health Care Insurance Act (Section 1.4 AT devices, Articles 2.6 and 2.12). Previous studies among users with different diagnoses showed great variation in effects. A review comparing task performance with and without dynamic arm support showed a significant improvement [7]. Other studies showed that dynamic arm supports and robotic arms are not used to their full potential [1,8- 9]. In a study conducted among users who got their device reimbursed, in half of the cases, clients experienced a moderate benefit on the ability to perform ADL with their (reimbursed) dynamic arm support. Another group of users (5/19) did not experience an increased ability to perform ADL with their arm support at all. Although several factors were considered contributing to the lack of benefit, a suboptimal service delivery process was regarded as a major point to tackle [9].

A number of bottlenecks have been identified in the process of providing dynamic arm supports and robotic arms by conducting interviews with end- users [10-11]. These are for instance related to a lack of awareness regarding this type of AT, clients do not feel sufficiently involved in the selection process, there was no provision of training in most cases, AT cannot be tested in real life ADL or for a longer period of time, difficulties in getting the selected AT reimbursed due to reimbursement regulations [10], insufficient knowledge of care professionals about the (range of) AT devices, delivery time was too long, and cooperation between client, professionals and providers hampered [10-11].

Based on the outcomes of previous studies it was concluded that in order to achieve optimal outcomes with respect to effectiveness of AT devices, it is essential that the provision process runs smoothly, resulting in an optimal match between the individual clients' needs and abilities, the physical and social context, and AT devices [12-13].

Optimization of the provision process will follow all steps of the generic Dutch quality framework for the provision of AT [14]. As a result, roles and responsibilities of all stakeholders will be described in a protocol, divided into seven steps from "identifying a problem" to "evaluation". The protocol was developed in six interdisciplinary co-creation sessions (January 2020-March 2021) together with all stakeholders involved in the provision process (clients, occupational therapists, rehabilitation physician, suppliers, insurers). To inform the development of the optimized provision process, challenges and causes of these challenges were investigated from the perspective of end-users.

2 Methods

Semi-structured interviews were conducted with adult dynamic arm support or robotic arm users. Participants were recruited through convenience sampling, in project partners' networks. Informed consent was collected prior to the interviews. The interview aimed to identify users' experiences with the provision process, and in particular regarding their awareness of this type of AT, the information provided about the AT, and

training. These themes were chosen as in depth information on these themes was lacking. The interviews were audio- recorded and subsequently transcribed. Data were analysed using a directed content analysis [15], based on the seven steps of the generic Dutch quality framework for the provision of AT [14].

3 Results

In total six dynamic arm support and robotic arm users participated in the interviews. Participants comprised two men and four women. All participants had been using their actual or a prior version of their AT for several years. Participants' experiences and identified challenges regarding the different steps of the provision process with a focus on the awareness and information with respect to this type of AT and training are described in the following paragraphs.

3.1 Identifying a Problem

All but one participant became aware of the existence of the robotic arm or dynamic arm support through other users. This included friends, other contacts and wheelchair hockey. It was agreed upon that word of mouth advertising is important. One participant was told about the dynamic arm support by the occupational therapist (OT) or rehabilitation physician.

In general, participants believe that OTs and rehabilitation physicians know that these type of AT exists. However, participants agreed that there were differences in knowledge of therapists and physicians regarding dynamic arm supports and robotic arms. In general, several participants believe that professionals in primary care lack knowledge because they do not come across patients in need of this type of AT sufficiently to support in selecting the most appropriate type of AT.

3.2 Selecting and Trying Out

Four participants mentioned how a specific company was selected for a test session at home. They indicate that they were referred to a specific company by their OT/physician. This seemed to be related to the fact that these professionals did not see differences in types of dynamic arm supports and robotic arms between companies, that the OT has one established company with whom devices are tried out first, or participants already used AT from a specific company.

"I believe quite often rehabilitation centers have one preferred supplier and therefore they do not explore the possibilities of other suppliers and AT" (no. 3). However, apart from one, every participant had a test session at home (two with more than one company). Most of them tried several devices. Try out sessions are organized by placing, in most cases, a wheelchair next to the dynamic arm support or robotic arm to be tested on a tripod. Two persons acknowledge that it is impossible to fix such an AT to a wheelchair for a try-out, but using a device in such way differs widely from using it

in real life. Additionally, it is mentioned that a try-out period which lasts (in general) about 1,5 hour is insufficient to determine whether a device is useful in daily life.

3.3 Deciding

In general, participants indicate that the suppliers are very well able to inform clients about the possibilities of their robotic arms and dynamic arm supports. Two participants referred to their role in the decision process and think that their opinion was taken into account sufficiently. Regarding the available types of dynamic arm supports and robotic arms, two participants indicated that they would have liked to receive more information regarding the possibilities from their OT or supplier. Two participants were informed about the available types of dynamic arm supports and robotic arms through fairs they visited. Participants preferred an active role of the OT or physiotherapist. Reasons include support in finding (other) potential solutions for a specific task such as eating, and that your OT is familiar with your disease and situation. However, not in all cases an OT was present at try out or was able to provide sufficient information.

3.4 Procurement Procedure

Once decided which AT to obtain, health insurance companies need to approve the application. Subsequently, in order to attach the robotic arm or dynamic arm support on a wheelchair these companies need to cooperate with each other. The opinion of the participants is that this is a time consuming process in which communication between parties involved often hampers (apart from one who indicates that application was approved within a few weeks). The fact that it often takes a while is because of additional questions that insurance companies need to be answered, technical difficulties in attaching such AT on wheelchairs (including legal responsibilities) and communication issues.

Suppliers are believed to be well aware of the procedures, which is experienced as supportive by two participants. However, three participants indicated that the process of applying for such an AT is complex, resembles like a cobweb. It is important to provide the correct information in order to avoid a rejection.

“I have a paid job, and another job, which is my handicap” (no 4).

The way this type of AT is financed in the Netherlands makes it difficult for people living in an organization and receiving intramural care as these (expensive) devices need to be financed by the institutions from the same budget as personal care is. Moreover, participants indicate that people won't receive the AT of their choice because of contracts between AT companies and health insurance companies.

3.5 Delivery and Instruction of the Assistive Product

Most participants received a verbal instruction regarding how to control the AT and a (digital) manual. Training was not provided in the majority of the cases. Those who were trained to use their robotic arm or dynamic arm support said that training primarily focused on how to control the arm support or robotic arm. Most participants learned

how to use their AT by doing. They indicated that learning by doing is fine and that it takes time to learn how to use the AT. One participant said that it is important to get used to the device, as it is easy to return to old habits (i.e. drinking again with a straw instead of without). One participant mentioned that she broke her robotic arm gripper because she was unaware of the limits of the device. Two participants explained that they would have liked to train with the AT, as it is still difficult to use it for eating.

It was suggested that experiences and tricks of experienced users could inform the training, or training could be organized by doing games with the AT. Two other participants thought that they did not need training themselves, but that training would be good for some clients. Training could be provided by the OT (with expertise in this type of AT) or by the supplier according to the participants. The social environment could support the AT user in getting used to the device by not taking over activities when they notice they can do it faster for them.

3.6 Using the Device

With respect to use of such AT in daily life, there are different experiences with needed reparations. Some participants for example could use loan AT, others did not receive an alternative solution and needed to be supported with eating by others for three weeks.

3.7 Challenges

In summary, challenges identified in the interviews were related to: 1) The need to involve experienced occupational therapists in the selection and decision making process. 2) Participants were unaware that this type of assistive technology existed and accidentally came across their dynamic arm support or robotic arm.

3) Referral is guided by previous experiences with a certain assistive technology supplier rather than by the needed functionalities of the device. 4) Too little attention was paid to training or helping participants to get used to their AT.

5) Communication between parties involved in the procurement process and technical assembly is often inadequate.

4 Discussion

These interviews gave insight into the perspectives and experiences of end-users regarding the provision process of dynamic arm supports and robotic arms. In particular regarding information provision, creating awareness and training. The results are in line with the outcomes of previous studies in which bottlenecks were identified [9,11].

It was remarkable that all but one participants became aware that this type of AT exists through other users. This could be partly explained by the fact that all participants included were experienced users who had been using their robotic arm or dynamic arm support for several years, and at that time knowledge of this type of AT was less widespread. However, as a relatively high number of OTs has little knowledge of this AT it is to be expected that the number of clients that can benefit from such AT is much

higher than the current number of provisions in the Netherlands. It therefore is suggested to increase attention paid to this type of AT. This could be through education of health care professionals and information materials for end-users (i.e. objective information or providing a platform to share user experiences).

It became clear that many health care professionals (i.e. OT) have insufficient knowledge regarding the available AT and their possibilities in order to be supportive in the selection and decision process. This also includes knowledge on how and what type of AT could be used for certain problematic ADL. Reasons for this was that most OTs do not treat enough patients with this to have sufficient expertise. A potential solution could be to involve only experienced OTs in the provision process of dynamic arm support and robotic arms.

A weakness of this study might be that participants were recruited through the process of convenience sampling, through the network of the stakeholders involved in the OMARM study. It therefore is expected that this group of participants is a group of highly experienced users who are very able to express their needs and wishes with respect to AT in front of care professionals and suppliers, which might not be representative for all dynamic arm support and robotic arm users.

The identified challenges were taken into account when developing a protocol for the optimal provision process of dynamic arm supports and robotic arms. Additionally, these challenges led to the development of several tools among which are tools to increase the amount and objectivity of available information.

References

1. Graham C, Rose M, Grunfeld, E, Kyle S, Weinman J. A systematic review of quality of life in adults with muscle disease. *J Neurol*. 2011;258:1581-1592
2. Winter Y, Schepelmann K, Spottke AE, Claus D, Grothe C, Schröder R, Dodel R. Health-related quality of life in ALS, myasthenia gravis and facioscapulohumeral muscular dystrophy. *J Neurol* 2010;257(9):1473-1481.
3. Benito-Léon J, Manuel Morales J, Rivera-Navarro J, Mitchell A. A review about the impact of multiple sclerosis on health-related quality of life. *Disabil Rehabil* 2003;25(23): 1291-1303.
4. Janssen M, Bergsma A, Geurts A, de Groot I. Patterns of decline in upper limb function of boys and men with DMD: An international survey. *J Neurol* 2014;261(7):1269-1288.
5. Kumar A, Frances Phillips M. Use of powered mobile arm supports by people with neuromuscular conditions. *J Rehabil Res Dev* 2013;50(1):61-70.
6. De Witte L, Gelderblom G, van Soest K, Dijcks B, Goossens M, Tilli D, Rutten-van Molken M. MANUS: Een helpende hand. Een verkennende studie naar doelgroepen, indicatiecriteria, gebruik en aspecten van kosten-effectiviteit van de MANUS robotarm [MANUS: A helping hand. An exploratory study into target groups, indication criteria, use and aspects of cost-effectiveness of the MANUS robotic arm]. Hoensbroek, The Netherlands: IRv, Kenniscentrum voor Revalidatie en Handicap; 2000.
7. Gandolla M, Antonietti A, Longatelli V, Pedrocchi A. The effectiveness of wear-able upper limb assistive devices in degenerative neuromuscular diseases: A systematic review and meta-analysis. *Frontiers in bioengineering and biotechnology*. 2020 24;7:450.

8. van der Heide LA, Gelderblom GJ, de Witte LP. Effects and effectiveness of dynamic arm supports: a technical review. *Am J Phys Med Rehabil* 2015;94(1):44-62.
9. van der Heide L, de Witte L. The perceived functional benefit of dynamic arm supports in daily life. *J Rehabil Res Dev* 2016;53(6):1139-50.
10. van der Heide L, Roentgen U, van der Pijl D, de Witte L. How could the service delivery process of dynamic arm supports be optimized? *Technol Disabil* 2017;29(3):101-108.
11. Lund K, Brandt R, Gelderblom G, Herder J. A user-centered evaluation study of a mobile arm support. 2009 IEEE International Conference on Rehabilitation Robotics (pp. 582-587). IEEE.
12. Gelderblom GJ, de Witte LP. The assessment of assistive technology outcomes, effects and costs. *Technol Disabil* 2002;14(3):91.
13. Desideri L, Bizzarri M, Bitelli C, Roentgen U, Gelderblom GJ, de Witte L. Implementing a routine outcome assessment procedure to evaluate the quality of assistive technology service delivery for children with physical or multiple disabilities: Perceived effectiveness, social cost, and user satisfaction. *Assist Technol* 2016;28(1):30- 40.
14. VWS (Bestuurlijk Overleg Hulpmiddelen). (2017). Generiek kwaliteitskader hulpmiddelen-zorg. [VWS (Administrative Consultation on Assistive Technology Devices). Generic quality framework for Assistive Technology care.] Den Haag. <https://www.zorginzicht.nl/binaries/content/assets/zorginzicht/kwaliteitsinstrumenten/Generiek+Kwaliteitskader+Hulpmiddelen-zorg.pdf>.
15. Hsieh H, Shannon S. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277-1288.

Designing an Accepted Look for an Assistive Robot

Results of a Mixed Methods Study with People of Different Age Groups

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Abstract. In this contribution, the participatory design process for a service robot to assist people in old age or with disabilities is presented. In order to provide the platform with an attractive and accepted embodiment, a three-stage approach with potential users is envisaged. This article reports the results of phase 1. Three models with different head and body shapes were evaluated by a younger and an older age group. They were exposed to 3D models they saw in the room through augmented reality glasses. A mixed methods design was chosen: Respondents were asked about each of the models by using open questions in a questionnaire. Additionally, they had to rate the robot in a semantic profile. The potential users preferred a design with a rounded body and an implied face. Tendencies could be seen towards different results in the age groups concerning colour and human likeness. Most people in the younger age group voted for a model with a less humanlike face, while in the older age group a high proportion also chose a model with a human face on a monitor. Changes such as a friendlier expression, a lower height of the robot and a rounder shape of the body seem to be necessary. Involving potential user groups in the process proves useful, as it provides deeper insight into their needs. Augmented reality evaluation promises to be a time and material saving method, but further research is needed to validate procedures and results.

Keywords: Assistive Robot, Robot Design, Embodiment, Participatory Approach, Acceptance

1 Introduction

People in older age or with disabilities can benefit from digital technologies and robotic systems to stay self-determined and live more independently. The acceptance of a robot depends on its functionality, but also on its appearance as it evokes emotions in users (Hwang et al., 2013; Otterbacher & Talias, 2017) and reflects roles (De Grad & Allouch, 2015; Esposito et al., 2019).

In the following, the participatory design process for a service robot developed at Frankfurt University of Applied Sciences in Germany (Nauth et al., 2016) is presented.

The platform ROSWITHA (Robot System WITH Autonomy) aims to navigate in people's flat and to fetch and bring objects, such as a glass of water. In order to provide it with an attractive and accepted embodiment, a three-stage participatory approach with potential users is envisaged. In phase 1 and 2, based on a literature research, differently developed versions are realised as 3D models in augmented reality, which are evaluated by respondents from a younger and an older group. Finally, a physical prototype will be created (see Fig. 1). This article reports the results of phase 1.

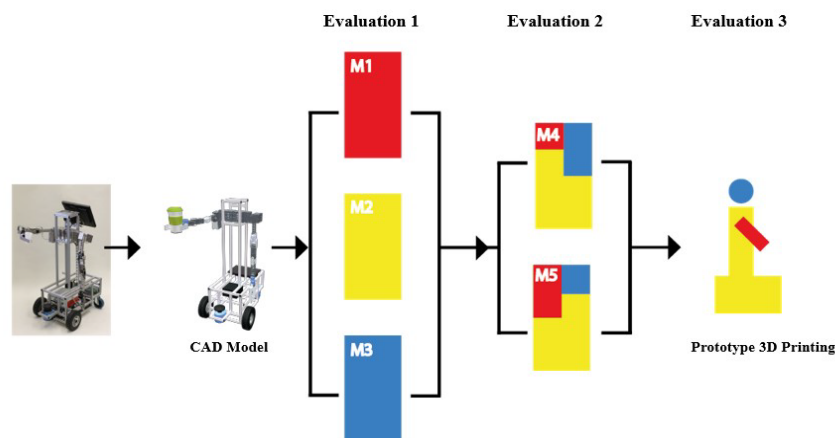


Fig. 1. Design and evaluation process: In the first and second evaluation phase, initially three and then two models are discussed after the potential user groups have seen them in augmented reality. In phase 3, they will evaluate a physical prototype (M1-5 = Model 1-5; picture ROSWITHA: J. Umansky, graphic: J. Sehr).

2 Methods

2.1 Design Process

Three designs were created based on a systematic literature review of people's preferences relating to the appearance of robots, the dimensions and technical requirements of the platform and the desired design elements. The objective of the exterior shape was that the robot should make an attentive, friendly, competent, but also reserved impression, so that it would not be perceived as intrusive in people's homes.

In phase 1, different head and body shapes were evaluated. For the head design, a neutral humanoid head, a playful cartoon-like head, and a head with a human-like face in a monitor were chosen. The bodies varied from angular to conical to round (see Fig. 2).

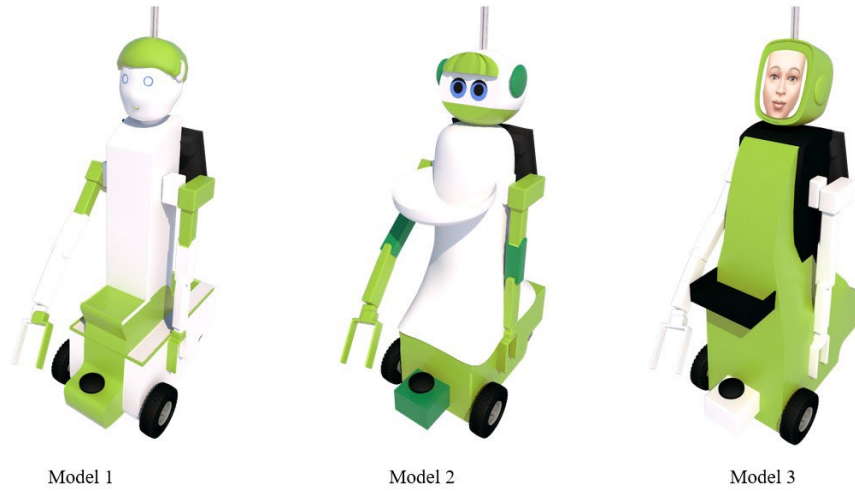


Fig.2. The three options for the first evaluation phase

2.2 Potential Users

A younger and an older age group were selected as there were indications of possible differences regarding their preferred robot appearances in the literature (Prakash & Rogers, 2015; Tu et al., 2020). The younger group consisted of 16 students (8 female, 8 male) between 23 and 52 years ($M = 29.19$; $SD = 7.20$) from subjects with a health or social, architectural or IT background. The older group was recruited through senior citizens' advisory boards and offers in city districts. It consisted of 14 persons (8 female, 6 male) aged 69-87 years ($M = 77.36$; $SD = 4.98$).

2.3 Procedure

The potential users were exposed to the 3D models they saw in the room through augmented reality glasses during appointments at the university, urban premises or in their home environment. A mixed method design was chosen: Respondents were asked about each of the models by means of open questions in a questionnaire, which were qualitatively evaluated. In the first and second question they were asked about their first impression and what feelings the robot evoked in them. After that, they had to rate the robot in a semantic profile on 7 characteristics which were chosen by the research team because they were intended to reflect the design characteristics of the robot in a range between -3 and 3. The items were: clumsy – elegant, incompetent – competent, striking – discreet, scattered – attentive, intrusive – withdrawn, unfriendly – friendly, unreliable – reliable. The last question for each model was about the changes the respondents would make.

In a more general part, the potential users should first rate to what extent they could imagine using such a robot in their home on a 4-point Likert-scale from very hard to imagine to very well to imagine and to name potential obstacles. Then they were asked

to specify the tasks for which they would like to use such a robot. Finally, they chose their preferred model of the three drafts and decided a colour out of green, blue and orange.

The answers to the open questions were categorized according to main topics, those from selection options were analysed quantitatively. Results are reported descriptively below. Due to the small number of persons, the median was calculated for the semantic profiles, since the mean value would have been stronger influenced by individual results.

3 Results

A strong majority of the younger group (12 out of 16) voted for the second model (see Fig. 2), as did a much narrower majority (6 out of 14) of the older group. This was followed by model 3 (two persons in the younger group and four persons in the older group) and finally 1 (one person among the younger, two persons among the older). Two persons in the older group and one person in the younger group indicated "none". Among the younger group of potential users, a clear majority (11/16) chose the colour green, among the older group orange (9/14).

The change requests of the younger group of potential users were mainly related to the face and body. For model 1, one person stated that the face and two persons that the body should be more human. For model 1 and 2, one respondent each wished for a less human face, and for model 2, two people wished for a less childlike face. For model 3, five people said they favoured a more abstract or robotic face. A friendlier facial expression was desired for all three designs. More rounded shapes were favoured for the corpus as well as a change of wheels. The round shelf on the front of model 2 was rather rejected, as was the flat colouring in model 3.

In addition to the face and body, the older group also had many comments about the size and controls. The size of approx. 1.50 m was rated as too high several times, and a screen as a control element at the front as well as more interaction options were desired. Four persons of the older group stated that model 1 should be more human (three of them the face) and one for model 3. Two persons noted this for model 2, one of them specifically for the face. A full face with a mouth was also desired by three persons and a friendlier look by two. However, two favoured a non-human appearance for model 3. Members of the group also preferred a rounder body and hiding the undercarriage.

The semantic profiles of the younger group showed medians in the neutral to slightly positive range (0 to 1 out of 3) for all traits recorded. Model 2 was rated median 2 as friendlier than the others, and model 3 was rated median -1 as more conspicuous than the others. The older group rated model 1 and 2 as clumsier (-0.5) and more conspicuous (-1.5) than the average and model 3 as more conspicuous (-1), the other values were in the neutral to slightly positive range.

When asked about the intended use for such a robot, a majority in both groups answered for household tasks and for fetching and bringing objects. The younger group could imagine the use of such a robot better (see Fig. 3) than the older group (see Fig.

4). Ten persons stated that they could imagine using it very well or well, and four poorly or very poorly. Two persons were undecided and voted between well and poorly.

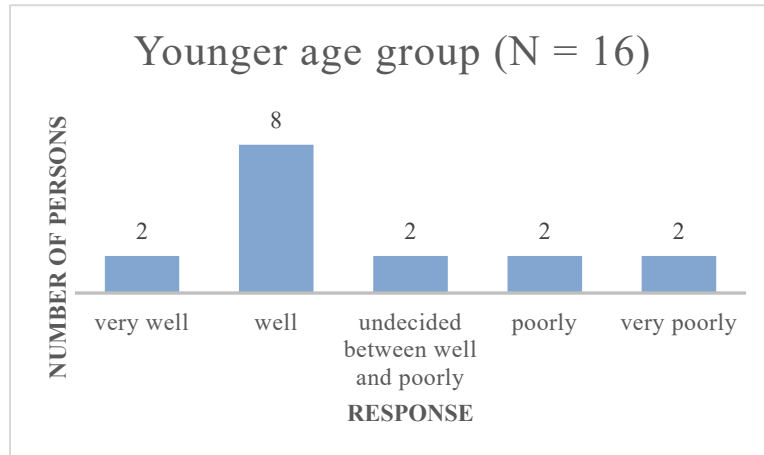


Fig.3. Response to the question of how well younger people could imagine using the robot

Half of the older group could well imagine the use of such a robot, the other half poorly or very poorly.

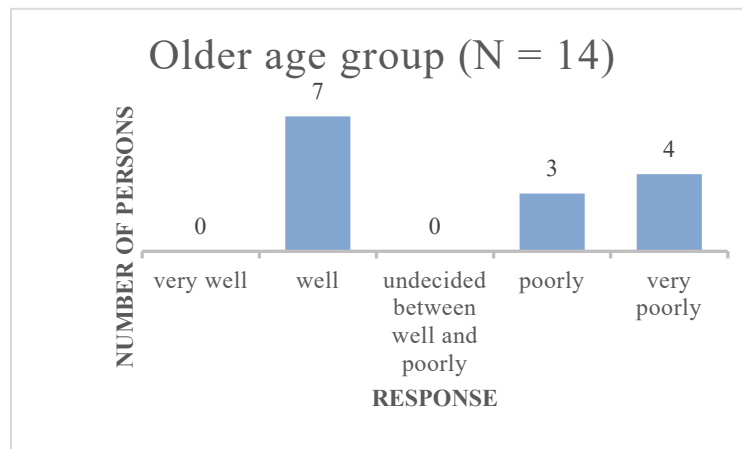


Fig.4. Response to the question of how well older people could imagine using the robot

4 Discussion

As the number of potential users was not representative, the results cannot be generalised, nevertheless often-mentioned features to improve face and body can be carried over to the next design phase, in which specific parts of the robot shall be further

developed. The results indicate to continue the work with models 2 and 3 which includes one design with a physical face on the head and one with a face on a monitor. Reducing the height of the robot and providing a rounder shape for the corpus also seems necessary to be more responsive to the needs of potential user groups.

As in Prakash & Rogers (2015) and Tu et al. (2020) there could also be seen tendencies towards different results in the age groups concerning human likeness. Most people in the younger age group voted for model 2 which has a less humanlike face than model 3 for which also a high proportion in the older age group voted. This was also the case when asked about future design changes with persons in the older age group preferring more humanlike designs in all conditions and a more diverse picture in the younger age group. Especially, model 3 with the humanlike face was rejected by more younger than older persons. This aspect will have to be considered in further development stages as well as the characteristics identified by the potential users in the semantic profile. However, since the scales were difficult to complete for some people in the older group, a more narrative approach should be adopted in future surveys to identify people's perceptions.

The use of augmented reality allows to see the models in real size in the existing room. It is seen as an innovative and flexible tool for product design (Sahin & Togay, 2016) and for imaging the equipment of rooms (Joshi et al., 2020). It also can be considered ecologically sustainable, since several prototypes do not have to be physically produced in each evaluation round. Despite the potential, use is currently not widespread (Bottani & Vignali, 2019). However, experience with the older group of potential users in particular showed that good personal support is necessary so that the test persons can see the model in an appropriate way and also use the three-dimensionality for their evaluation, for example by moving around in the room.

5 Conclusion

The phase 1 evaluation of the initial options for a possible embodiment of the assistive robot ROSWITHA revealed useful aspects for the further design process. Involving potential users in the process proves to help designing products that are closer to people's lives and ultimately lead to greater acceptance. Therefore, the design process will be continued in a participatory way.

Evaluation in augmented reality promises to be a time- and material-saving method, which offers the possibility to get a realistic image of the model e.g. at home. However, further research is needed, especially with older target groups, in order to validate procedures and to verify the results.

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References

1. Bottani, E. & Vignali, G.: Augmented reality technology in the manufacturing industry: A review of the last decade. *IIE Transactions* 51(3), pp. 284-310 (2019). <https://doi.org/10.1080/24725854.2018.1493244>.
2. Esposito, A., Amorese, T., Cuciniello, M. et al.: Elders prefer female robots with a high degree of human likeness. In: 2019 IEEE 23rd International Symposium on Consumer Technologies (ISCT). IEEE, pp. 243–246. <https://doi.org/10.1109/ISCT.2019.8900983>.
3. Graaf, M. M. A. de, Ben Allouch, S.: The evaluation of different roles for domestic social robots. In: 2015 24th IEEE International Symposium on Robot and Human Interactive Communication (RO-MAN). IEEE, pp. 676–681. <https://doi.org/10.1109/ROMAN.2015.7333594>.
4. Hwang, J., Park, T., Hwang, W.: The effects of overall robot shape on the emotions invoked in users and the perceived personalities of robot. *Applied Ergonomics* 44(3), pp. 459-471 (2013). <https://doi.org/10.1016/j.apergo.2012.10.010>.
5. Joshi, S., Walavalkar, P., Shetkar, P., Joshi, S., Mahale, S., Bhogan, S., Sawant, K.: Product Visualization Using Augmented Reality. *International Research Journal of Engineering and Technology* 7(5), pp. 6924-6929 (2020).
6. Nauth, P., Sharan, S., Michalik, R., Umansky, J., Schafner, R.: Development of a robot assisting elderly people. *Healthy Aging in Digitized Societies (HeADS)*, pp. 156 - 162 (2016).
7. Otterbacher, J., Talias, M.: S/he's too Warm/Agentic! In: Mutlu, B., Tscheligi, M., Weiss, A. et al. (eds) *Proceedings of the 2017 ACM/IEEE International Conference on Human-Robot Interaction*. ACM, New York, NY, USA, pp. 214–223. <https://doi.org/10.1145/2909824.3020220>.
8. Prakash, A., Rogers, W. A.: Why Some Humanoid Faces Are Perceived More Positively Than Others: Effects of Human-Likeness and Task. *Int J Soc Robot* 7, pp. 309–331 (2015). <https://doi.org/10.1007/s12369-014-0269-4>.
9. Şahin, D. & Togay, A.: Augmented reality applications in product design process. *Global Journal on Humanites & Social Sciences* 3, pp. 115-125 (2016).
10. Tu, Y.-C., Chien, S.-E., Yeh, S.-L.: Age-Related Differences in the Uncanny Valley Effect. *Gerontology* 66, pp. 382–392 (2020). <https://doi.org/10.1159/000507812>.

Designing Socially Assistive Robots

A Relational Approach

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Abstract. There is increasing interest in social robots as assistive technologies to support a wide range of potential user groups. Nevertheless, the widespread use of robots has been challenged in terms of their efficacy and benefits as well as the ethics of employing robots in social roles. For instance, it has been suggested that robots are incapable of being truly social and therefore that any use of social robots as assistive technology is intrinsically deceptive. This contribution addresses this controversy, building on a relational view of human-robot interaction, which asserts that sociality has less to do with the essential natures of the human and robot actors involved, and more to do with the patterns and consequences of their interaction. From this starting position we consider and explore four design principles for social robots and compare/contrast these with the view of design “transparency” that robots should behave to reveal their true machine nature.

Keywords: Social Robots, Robot Ethics, Deception, Relational Ethics.

1 Introduction

Social robots are increasingly used for assistive applications across the lifespan with populations across the entire spectrum of vulnerability [1-3]. Examples include as distraction devices for children undergoing painful procedures, as communication aids in children with autism, as mental health interventions in adults and children, and as interventions to reduce agitation in older adults living with dementia. Until recently, social robots were seen as somewhat futuristic and largely existed in the realm of research. However, the Covid-19 pandemic has substantially accelerated their use in a wide range of contexts from education to healthcare as part of a drive to maintain social connectedness while limiting close physical contact. As such, questions surrounding the ethics of social robots and the nature and morality of human-robot relationships are more pressing than ever, with important implications for how social robots are designed and employed in real-world settings. Here we consider different approaches to human-robot relationships, describe the key components of a relational approach, and propose four evidence-based design principles for the ethical design of social robots.

2 The Relational Approach in Robot Ethics

The relational view in robot ethics argues for a move away from essentialist (or substantialist) notions of what is a human, what is a robot, and what it means for them to have a relationship. Instead the relational view proposes that what matters are the patterns and consequences of social interactions between humans and robots [4-6], including their meaning and significance to the people involved, and their wider impact on social and relationship contexts [3]. This view can be seen as an alternative to more essentialist conceptions that seek to define what is (and what is not) a human (or a robot) in terms of fundamental character or attributes irrespective of context (see [7]). Essentialist views can be attractive ways to frame and explore certain ethical questions as they chime with many of our intuitions (for instance that all humans share a common “nature”) and language (which emphasizes objects acting on each other as opposed to systems with multiple interacting elements), however, they can be criticized on meta-physical grounds [8], for supporting outdated ideas of the human that can be exclusionary [9], and for failing to recognize the changing nature of our humanity, including through our interactions with our technologies [10, 11]. The relational view in technology ethics, on the other hand, is part of a broader interactivist turn in the social, cognitive and information sciences (e.g. [8, 12, 13]) that sees the units involved in a social transaction (e.g. humans and robots) as deriving “their meaning, significance, and identity from the (changing) functional roles they play within that transaction” ([8] p. 287).

While the debate between relational and essentialist views continues, we consider that it is useful to explore and set out some of the implications of the relational view for the design of assistive technologies, particularly, those such as robots, and other social AIs (e.g. smart speakers), that purport to have some social function, and whose benefits are considered to arise, at least in part, through their sociality.

The possibility that a robot could be deemed to be social is hotly contested. For instance, Sparrow [14] has argued that robots (and similar devices) are incapable of sociality, and that to present them as otherwise is intrinsically deceptive and morally deplorable. Reflecting on similar views, has led some authors to propose that, to be ethical, robots should be designed such that their machine nature is transparent. To enable this transparency, it is suggested that the user should be reminded, occasionally, if not continuously, that the device is a machine controlled by algorithms rather than a “genuine” social actor [15, 16].

Central to this debate is the question of what it means to be deceptive. We follow Danaher [17] who defines deception as involving “the use of signals or representations to convey a misleading or false impression” (p. 118). In robotics, deception is most often held to be about portraying a misleading impression about qualities that humans have, and that robots do not (or in principle could not) have. We might summarize these as anthropomorphic qualities, or more specifically, a sub-class of anthropomorphic qualities that are deemed controversial, most often psychological phenomena such as emotions, intentions, and self-awareness (in contrast, physical features such as having a head, two arms and two legs, are rarely considered deceptive or problematic). If robots exhibit qualities or functionalities that are viewed as deceptive, the further

question is whether this is, indeed, unethical. Broadly speaking, we see three general positions set out in table 1. The first two are broadly similar only differing in what they see as the solution to the ethical “problem” of social robotics. We identify with the third of these positions (of which there are multiple versions), which begins from a more nuanced view on the nature of deception in robotics.

Table 1. Views on deception and ethics in social robotics.

Are social robots deceptive?	Is this unethical?	What should we do about it?	Example authors
Yes	Yes	Avoid building or using them altogether	Sparrow [14]; Turtle [18]
Yes	Yes	Design it out, or minimize it through transparency	Boden et al. [19]; Wortham & Theodorou [16] Shim & Arkin [20]; Sorell & Draper [21]; Danaher [6, 17, 22]; Prescott & Robillard [3, 7, 23]
Not necessarily	Depends on the nature of the deception	Design to avoid damaging forms of deception	

Determining whether social robots are deceptive by nature requires reflection on our understanding of sociality. To rule out the possibility that an artefact could ever be social seems exclusionary given that we do not yet have a clear understanding of human sociality or how it is generated [7]. Moreover, embodied cognitive science is forcing a rethink about the nature of sociality as something that arises not in individuals but in the interactions that occur between them [12]. Applied to robots, this suggests that they need not have self-understanding, or intrinsic social competencies or properties to be authentically social [24].

Nevertheless, we might agree that present-day robots are not social in the same way that people are. If so, is it possible to defend the deliberate creation of an impression of human-like sociality (as, for example, artificial personal assistants strive to do)? A key idea here is that the tendency to anthropomorphize objects and devices occurs widely and pre-dates robotics and artificial intelligence [25, 26]. For example, we anthropomorphize dolls, cars, even trees and mountains.

A related point is that we may be able to distinguish different forms of deception, and that some of these may not be unethical. For example, anthropomorphism, has been described as being “honest” where it exploits people’s tendency to view artefacts as social actors, and does so overtly and for their benefit, using anthropomorphic features to provide a more engaging or effective interaction (for example, to provide navigation instructions in a vehicle, or to promote the effectiveness of a therapy) [27]. However, anthropomorphism can be seen as “dishonest” where it is used to deliberately

misdirect attention or conceal a robot capability. For example, to pretend that the robot is unable to see a person because its artificial eyes appear closed even while continuing to observe them with a covert camera [27, 28].

Danaher [17] has argued that some forms of honest anthropomorphism are not unethical even though they may be deceptive. Analyzing different forms of deception employed by robots, Danaher describes an “ethical behaviorist” approach, according to which judgements about whether a robot’s anthropomorphic behavior is permissible should be based on superficial observables—including the robot’s appearance, utterances and actions—and not on any presumptions about the presence or absence of human-equivalent robot inner states. This is termed “superficial state deception”. As Danaher puts it:

“According to ethical behaviorism, if a robot appears to have certain capacity (or intention or emotion) as a result of its superficial behavior and appearances, then you are warranted (possibly mandated) in believing that this capacity is genuine. In other words, if a robot appears to love you, or care for you, or have certain intentions towards you, you ought, *ceteris paribus*, to respond as if this is genuinely the case. [...] simulated feeling can be genuine feeling, not fake or dishonest feeling. Consequently, if ethical behaviorism is true, then superficial state deception is not, properly speaking, a form of deception at all.” (p. 122-3).

Danaher’s position can be likened to a strong version of the relational perspective (e.g. [24]), that is, that what matters is that the robot’s behavior, over the duration of its interactions, is consistent with its social utterances and expressions. This is a stronger constraint than you might at first imagine as explored further below.

3 Design Principles for Social Robots

Based on the above, and from a relational standpoint, we believe it should be possible to define design principles for ethical social robots. As an initial effort, we propose the following:

1. Promote **contextual integrity**: This principle advocates co-design of robot social capabilities for the role that the robot will fulfil and alignment of the robot’s behavior and capabilities with expectations and norms. Nissenbaum [29] introduced the notion of “contextual integrity” in the context of a framework for the design of sociotechnical systems, applying it particularly to concerns around information privacy; however, the idea has broad generality. Its application to robotics has been discussed further by Kaminski et al [27]. The key idea is that the capabilities and behavior of a robot should be judged in terms of their appropriateness to the context in which it is used. For example, if we encounter a social robot that is waiting tables in a restaurant, we might reasonably expect that it would enter the room unannounced, observe where people are sitting and approach them safely, monitor ongoing conversation and diner behavior for an appropriate point at which to intercede with and offer of service and so-on. The same robot, but in a home setting, might be required to observe quite different social etiquette, for example, never entering certain rooms,

asking before entering others, not using cameras or microphones at certain times of the day, or in some situations, unless specifically directed to do so.

2. Develop **honest anthropomorphism**: This principle requires that we evaluate the benefits and risks of anthropomorphic features and make decisions on their permissibility accordingly. “Superficial state deception” can be acceptable if consistent with expectations and norms; “hidden state deception”, such as where the robot conceals a covert feature that might violate contextual integrity, is unacceptable. Ethical behaviorism requires that the robot’s actions are consistent with its utterances. Thus, if a robot declares that it “cares about you a great deal and wants to be of help” then its subsequent behavior should not be to avoid or ignore the user. Whilst it is easy to program a robot to make these kinds of supportive declarations it is much more difficult to make its behavior consistent with them. For instance, to be genuinely helpful, the robot must be able to recognize individuals consistently, perhaps remembering past encounters, and be able to monitor and anticipate the person’s needs, at least to some degree. Few, if any social robots, are capable of this level of helpful behavior at present [30]. On ethical behaviorism grounds, we might consider that the robot’s statement that it “cares” and “wants” to help as problematic to the extent that it raises expectations about its wider behavior that cannot be met, however, a future, more care-capable robot might more reasonably make such statements. As a further example of honest anthropomorphism we suggest that robots could have the ability of robots to track and recognize human emotions, and to modulate their own emotional expressions to be aligned with those of their human interlocutor [31]. People seek interactions in which their sense of self is respected and valued on an emotional level, alignment with artificial emotions could help to create this experience; moreover, AI technologies for emotion recognition are at the point of this being technologically feasible [31].
3. **Clearly signal the robot capacities**: The requirement to avoid hidden state deception suggests the importance of *clear signaling*. Here anthropomorphism can have some direct benefits, for example, if the robot’s only cameras are mounted forward-facing on its head, and can be covered by opaque eyelids, then closing the eyelids, or turning the head away, will be sufficient to communicate that the robot can no longer observe you. This is an intuitive and easy-to-read signal that matches our experience and expectations from interactions with people and pet animals. On the other hand, if the robot has other cameras, in anthropomorphically unexpected places (e.g. a rear-facing camera on a humanoid), then their presence/use should be very clearly signaled—for example, it has become conventional for cameras on computers to illuminate a small pilot light when they are operating. Dynamic feedback—emitting signals when the context changes—is likely to be important. For example, a home robot might usefully signal a switch from standby mode to awake/monitoring mode to alert users that its sensors have become operational.
4. Note that honest signaling is not the same as “transparency”, at least as that term has been used by Wortham [16] and others to imply transparency about the internal processes of the robot that underlie its decision-making etc. Signaling is here intended to avoid hidden-state deception and is not about revealing the robot’s machine nature. Of course, if the robot is asked about its internal processes it should answer

honestly (to the extent that it is capable), as to do otherwise would contravene broader principles around truth-telling and deception (See Danaher [17] for further discussion on this).

5. **Be especially careful when designing for vulnerable users and/or for “thick” relationships** (i.e. longer-term interactions with deeper psychological involvement). In assessing the potential benefits and risks, the relational approach emphasizes the need to consider the role of the robot within the wider network of the user’s interpersonal relationships. Social robots are currently developed and implemented in populations typically considered vulnerable, such as children with autism or with mental health conditions, and older adults living with dementia. These populations may be less able to make sophisticated judgments about meaning and intentions in social interactions. Ethical risks can be addressed through appropriate consent procedures involving family and carers, monitoring, and through careful co-creation of robot capabilities in order that these are aligned with the values of end-users. Where there is deeper psychological involvement there is also more risk of harm, but also the potential of greater benefit from providing robots with richer set of social capabilities.

4 Conclusion

In this paper we have sought to outline some considerations for the design of future social robots based on a relational ethics approach. We have sought to distinguish this from approaches predicated on a more essentialist (or substantialist) view that emphasizes ontological differences between human machines. Some of the latter approaches have argued that sociality in robots is wrong in principle, and that anthropomorphic features such as the ability to convey emotional signals are deceptive. Against this, we have argued that sociality can be a desirable and valued capability and that anthropomorphic features should be evaluated according to their risks and benefits. Benefits include ease-of-use and intelligibility for people. For instance, in persons living with Alzheimer’s disease, there is evidence that emotional processing is more resistant to decline than cognitive processing [32]. In seeking to eliminate aspects of interaction that carry emotional connotations, there is a risk that this could make otherwise beneficial technologies less engaging and therefore reduce adoption. More broadly, the relational approach emphasizes the need to consider the social setting and relationship context in which a robot is deployed, and the alignment of its behavior with prevailing norms. This argues for a pragmatic and inclusive approach to the design of assistive social robots, that involves potentials users and other stakeholders, in evaluating when and how social capabilities and anthropomorphic features can be safely and beneficially deployed.

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References

1. Matarić MJ, Scassellati B. Socially assistive robotics. In: Siciliano B, Khatib O, editors. *Springer Handbook of Robotics*. Cham: Springer International Publishing; 2016. p. 1973-94.
2. Kabacińska K, Prescott TJ, Robillard JM. Socially assistive robots as mental health interventions for children: A scoping review. *International Journal of Social Robotics*. 2020. doi: 10.1007/s12369-020-00679-0.
3. Prescott TJ, Robillard JM. Are friends electric? The benefits and risks of human-robot relationships. *iScience*. 2021;24(1). doi: 10.1016/j.isci.2020.101993.
4. Coeckelbergh M. Robot rights? Towards a social-relational justification of moral consideration. *Ethics and Information Technology*. 2010;12(3):209-21. doi: 10.1007/s10676-010-9235-5.
5. Gunkel D. *Robot Rights*. Cambridge, MA: MIT Press; 2018.
6. Danaher J. Welcoming robots into the moral circle: A defence of ethical behaviourism. *Science and Engineering Ethics*. 2020;26(4):2023-49. doi: 10.1007/s11948-019-00119-x.
7. Prescott TJ. Robots are not just tools. *Connection Science*. 2017;29(2):142-9. doi: 10.1080/09540091.2017.1279125.
8. Emirbayer M. Manifesto for a Relational Sociology. *American Journal of Sociology*. 1997;103(2):281-317. doi: 10.1086/231209.
9. Szollosy M. EPSRC Principles of Robotics: defending an obsolete hu-man(ism)? *Connection Science*. 2017;29(2):150-9.
10. Haraway DJ. *Simians, Cyborgs and Women: the Reinvention of Nature*. New York: Routledge; 1991.
11. Hayles NK. *How we became posthuman: Virtual bodies in cybernetics, literature, and informatics*. Chicago: University of Chicago Press; 1999.
12. De Jaegher H, Di Paolo E, Gallagher S. Can social interaction constitute social cognition? *Trends in Cognitive Sciences*. 2010;14(10):441-7. doi: 10.1016/j.tics.2010.06.009.
13. Gunkel DJ. The Relational Turn: Third Wave HCI and Phenomenology. In: Filimowicz M, Tzankova V, editors. *New Directions in Third Wave Human-Computer Interaction: Volume 1 - Technologies*. Cham: Springer International Publishing; 2018. p. 11-24.
14. Sparrow R. The march of the robot dogs. *Ethics and Information Technology*. 2002;4(4):305-18. doi: 10.1023/A:1021386708994.
15. Bryson JJ. Patience is not a virtue: the design of intelligent systems and systems of ethics. *Ethics and Information Technology*. 2018;20(1):15-26. doi: 10.1007/s10676-018-9448-6.
16. Wortham RH, Theodorou A. Robot transparency, trust and utility. *Connection Science*. 2017;29(3):242-8. doi: 10.1080/09540091.2017.1313816.
17. Danaher J. *Robot Betrayal: a guide to the ethics of robotic deception*. *Ethics and Information Technology*. 2020;22(2):117-28. doi: 10.1007/s10676-019-09520-3.
18. Turkle S. *Alone Together: Why We Expect More from Technology and Less from Each Other*. 3rd ed. New York: Basic Books; 2017.
19. Boden M, Bryson J, Caldwell D, Dautenhahn K, Edwards L, Kember S, et al. Principles of robotics: regulating robots in the real world. *Connection Science*. 2017;29(2):124-9. doi: 10.1080/09540091.2016.1271400.
20. Shim J, Arkin RC. Other-Oriented Robot Deception: How Can a Robot's Deceptive Feedback Help Humans in HRI? In: Agah A, Cabibihan J-J, Howard AM, Salichs MA, He H, editors. *Social Robotics*. Cham: Springer International Publishing; 2016. p. 222-32.
21. Sorell T, Draper H. Second thoughts about privacy, Safety and deception. *Connection Science*. 2017;29(3):217-22.

22. Danaher J. The philosophical case for robot friendship. *Journal of Posthuman Studies*. 2019;3(1):5-24. doi: 10.5325/jpoststud.3.1.0005.
23. Robillard JM, Goldman IP, Prescott TJ, Michaud F. Addressing the Ethics of Telepresence Applications Through End-User Engagement. *Journal of Alzheimer's Disease*. 2020;Pre-print:1-4. doi: 10.3233/JAD-200154.
24. Damiano L, Dumouchel P. Anthropomorphism in Human-Robot Co-evolution. *Frontiers in Psychology*. 2018;9:468.
25. Heider F, Simmel M. An Experimental Study of Apparent Behavior. *The American Journal of Psychology*. 1944;57(2):243-59. doi: 10.2307/1416950.
26. Reeves B, Nass CI. The media equation: How people treat computers, television, and new media like real people and places. *The Media Equation: How People Treat Computers, Television, and New Media Like Real People and Places*. New York, NY, US: CUP; 1996.
27. Kaminski ME, Rueben M, Smart WD, Grimm CM. Averting Robot Eyes Symposium Essays from the State of Cyberlaw: Security and Privacy in the Digital Age. *Maryland Law Review*. 2016;76(4):983-1024.
28. Leong B, Selinger E. Robot Eyes Wide Shut: Understanding Dishonest Anthropomorphism. *Proceedings of the Conference on Fairness, Accountability, and Transparency*. Atlanta, GA, USA: Association for Computing Machinery; 2019. p. 299–308.
29. Nissenbaum H. *Privacy in Context: Technology, Policy, and the Integrity of Social Life*. Stanford, USA: Stanford Law Books; 2010.
30. Prescott TJ, Camilleri D, Martinez-Hernandez U, Damianou A, Lawrence ND. Memory and mental time travel in humans and social robots. *Philosophical Transactions of the Royal Society B: Biological Sciences*. 2019;374(1771):20180025. doi: 10.1098/rstb.2018.0025.
31. Robillard JM, Hoey J. Emotion and motivation in cognitive assistive technologies for dementia. *Computer*. 2018;51(3):24-34. doi: 10.1109/MC.2018.1731059.
32. König A, Francis LE, Joshi J, Robillard JM, Hoey J. Qualitative study of affective identities in dementia patients for the design of cognitive assistive technologies. *Journal of Rehabilitation and Assistive Technologies Engineering*. 2017;4:2055668316685038.