# 'Enabling Access': A Pilot Study on Access and Use of Assistive Products in the Northern Province, Sri Lanka

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#### **ABSTRACT**

**Purpose:** The need for suitable assistive technology is growing all over the world, not only for people with disabilities but also for the ageing population with functional decline and non-communicable diseases. Access to assistive technology promotes access to education, employment and active societal participation. The aim of this study was to assess the self-reported need by persons with disabilities and by people who were 65 years and older without disabilities in the Northern Province of Sri Lanka, for assistive products; and to identify barriers to accessing these assistive products.

Method: This mixed-methods pilot study included 76 participants who were either persons with disabilities or their caregiver or persons 65 years and older, from the Northern Province of Sri Lanka, affected by the now-ended 30-year civil war. To ascertain trends in the local need for assistive products, a translated version of the World Health Organisation's Priority Assistive Products List of 50 items was used. In addition, semi-structured interviews with key participants were conducted, to gain some insights into the barriers to accessing assistive products.

**Results:** The most widely used assistive products among persons with disabilities were connected to war-related injuries. In contrast, those used by the older age group of persons without disabilities were connected to non-communicable diseases and age-related frailty. The assistive products requested by both groups were aids to promote independence in daily activities and to support access to education and employment. The emergent themes included

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affordability, employment, independence in activities of daily living, stigma and psychological impact, and a lack of awareness and guidance in the use of assistive devices.

**Conclusion:** The findings highlight the need for policies and practices to be informed by local socio-cultural, historical and geographical realities.

**Key words:** Assistive products, Global South, Sri Lanka, war, priorities the Assistive Products List, Version.

#### INTRODUCTION

An assistive product has been defined as "any product (including devices, equipment, instruments and software), either specially designed and produced or generally available, whose primary purpose is to maintain or improve an individual's functioning and independence and thereby promote their wellbeing" (Khasnabis et al, 2015). The terms assistive products, assistive technology and assistive devices are used interchangeably throughout this paper. The WHO defines universal health coverage as "ensuring that all people can use the promotive, preventive, curative, rehabilitative and palliative health services they need" (WHO, 2016a). The concept of universal health coverage is pivotal to achieving the Sustainable Development Goal 3 of enabling healthy lives, and in promoting well-being for all citizens, young and old (WHO, 2017a). In fact, Tebbutt et al (2016) illustrate the symbiotic connection between assistive products as a 'mediator' and a 'moderator' to achieving all 17 of the SDGs so that 'no one will be left behind' (United Nations, 2016). However, access to assistive technology is limited in many countries (Borg et al, 2011; Marasinghe et al, 2015), with general agreement that the provision of assistive products within resource-poor contexts is a concern, reflecting limited service delivery models (Borg & Ostergren, 2015; Visagie et al, 2017).

With the large population of persons with disabilities and the growing population of older people, the need for assistive technology has been increasing exponentially. The number of people above 60 years of age, and older people experiencing functional difficulties, is expected to rise in low- and middle-income countries (Marasinghe et al, 2015). Tebbutt and colleagues (2016) identify people with disabilities, those who are frail or experiencing long-term illness, people experiencing mental health-psycho-social difficulties or those undergoing physical and cognitive changes due to ageing, as potential beneficiaries of assistive

products. Although the World Health Organisation (WHO) estimates that over one billion people around the world need one or more assistive products, only around 10% are said to have access to them (WHO, 2017b). This means that nine out of ten people requiring assistive products not only have no access to them but also by extension have little, unequal or no access to education, employment and all aspects of civic life. This is particularly apparent in children with disabilities who often have limited access to education and to economic participation in later life (UNICEF & WHO, 2015). There is, therefore, a wide gap between the need for assistive technology and the provision of these devices (MacLachlan et al, 2018). Viewed through a human rights lens, the access to individualised assistive technology offers persons with disabilities or older people the opportunity to continue to be active, contributing, valued and independent members of society (Disability Federation of Ireland, 2016; MacLachlan et al, 2018). Assistive technology enables individuals to fulfil their fundamental human right to autonomy and societal participation (Disability Federation of Ireland, 2016). The access to assistive technology is part of the wider concept of accessibility and a precursor to ensuring additional rights and avoiding social exclusion (MacLachlan et al, 2018) and reducing functional decline (Marasinghe et al, 2015). Therefore, access to currently available and affordable assistive products is also a right (Borg et al, 2011).

The systematic review of the available literature by Nicolson et al (2012), though limited to 5 studies, reported on the positive influence of using assistive technology on both children with physical disabilities and their caregivers. Additionally, social stigma associated with the uptake and use of assistive technology has been noted within low-income countries (WHO, 2011a). The lack of access to assistive products can entrap people in a downward spiral of poverty and marginalisation affecting the person, family and community (Tebbutt et al, 2016). MacLachlan and colleagues (2018) recognise the particular challenge to accessing assistive technology by the citizenry of resource-poor countries. Among the reasons for this are the high cost and the lack of availability of affordable high quality assistive products, particularly in poorer countries (WHO, 2008, 2011b). To be able to increase access to assistive products for those who require them in Sri Lanka, it is necessary to better understand the need within the local context. In a community survey on barriers to using assistive products for lower limb difficulties in Sri Lanka, Weerasinghe and colleagues (2015) identified poverty and financial limitations as the key deterrents to accessing and using assistive

technology, in addition to the lack of availability of products locally. The impact of lower limb difficulties and the lack of access to assistive devices for activities of daily living and employment were also highlighted.

#### The GATE Initiative

In order to respond to the growing inequalities and concern regarding the lack of access to assistive products, the WHO's GATE Initiative (Global Cooperation on Assistive Technology) has devised a Priority Assistive Products List (APL) of 50 key high-quality affordable assistive products (WHO, 2016b). The GATE Initiative, through the establishment of a GATE Research Group, recognises the urgent need for global research in this area. Its aim is to encourage Member States that have ratified the UNCRPD to develop their own locally-applicable assistive products list and to enable easier procurement and provision of assistive products for everyone, everywhere.

Within the backdrop of very limited access to assistive technology/products (WHO, 2008, 2011a, 2011b), there is an urgent need to respond to some key questions such as, what is the Provincial-level and country-level need for assistive technology/products in Sri Lanka? What are the local priorities for assistive technology/products? How do these priorities compare with WHO's Priority Assistive Products List? What are the challenges and facilitators to the process of production, procurement, distribution, continued use and maintenance of assistive technology/products?

# **Objectives**

The research questions for this pilot phase of the study were as follows:

- What is the self-reported need by persons with disabilities and by people, 65 years and older, without disabilities in the Northern Province of Sri Lanka for the assistive products on the WHO's Priority Assistive Products List and for any assistive products not listed?
- What are the self-reported barriers to accessing assistive products by persons with disabilities and by people, 65 years and older, without disabilities in the Northern Province of Sri Lanka?

### **METHOD**

## **Study Design**

A mixed-methods study design was adopted. A survey questionnaire for all participants offered quantitative data, and semi-structured interviews with key participants offered qualitative data. The survey questionnaire was aimed at gaining a better understanding of the local trends with regard to access to key identified assistive products. It was made available in Tamil, Sinhala and English. The survey was completed either via a face-to-face meeting or through telephone contact or email, or even via a postal survey, as chosen by each participant. The semi-structured interviews were undertaken with key participants using a simple interview guide in a language of their choice. The research team included first-language speakers of Tamil and Sinhala, which facilitated data collection.

#### **Ethical Governance**

Ethical approval was sought from the Ethics Review Committee of the Faculty of Medicine, Ragama, Sri Lanka. All participants were offered an information sheet and a consent form in the language of their choice (Sinhala, Tamil or English). Anonymity was maintained by assigning a participant code to each participant.

# **Study Sample**

The pilot study included two groups of participants:

- 1. Parents of children with disabilities and adults with disabilities,
- 2. Adults (65 years and older) without a medical- or self-diagnosis of a disability.

A convenient sampling method was used, with participants identified through contacts with Disabled Persons' Organisations and academic members of staff in the Northern Province. Attempts were made to include a representative sample from the two target groups of participants.

The rationale for including adults 65 years and older was because many older citizens are already using assistive devices or would require one or more assistive devices, such as a hearing aid or spectacles, due to age-related deterioration in skills, even if they did not have a medical diagnosis of disability or were self-identified as persons with disability.

The inclusion criteria were that participants should:

- Be a parent of a child diagnosed with a disability or an adult (over 18 years old) with a diagnosis of a disability or an adult 65 years or older without a medical- or self-diagnosis of a disability
- Be willing to be part of the study

The exclusion criteria concerned adult participants who were not able to understand the information sheet and therefore not able to give informed consent (as determined by one of the researchers who is a speech and language therapist).

## **Study Setting**

The survey questionnaire was administered to 76 participants in the Northern Province. Through contact with local Disabled Persons' Organisations, local residents who were sensitive to the needs of persons with disabilities were identified as research assistants to conduct the survey. In addition, research assistants with an academic background who were speech and language therapists, with experience in working with people with literacy difficulties and/ or proficient in all local languages including Sri Lankan sign language, were part of the research team. As per the request of each participant, the survey was conducted face-to-face, through telephone, via email or as a postal survey. The research assistant read out or, if required, signed the questions on the questionnaire to the participant, as well as wrote down the participant's responses, as needed.

# **Study Tool**

The survey questionnaire was compiled with reference to the WHO's Priority Assistive Products List (APL). With written permission to use the list with the accompanying pictures of the target assistive products, the first author developed the questionnaire with support from the second author, who is a person with a disability and a representative of a key Disabled Person's Organisation in the Northern Province. The questionnaire was reviewed by the three speech and language therapists of the team. The questionnaire, information sheets and consent forms were made available in Sinhala, Tamil and English. Arrangements were made to make it available through Braille if required.

The English version of the questionnaire was translated into Tamil by a bilingual person, who is a first-language speaker of Tamil and a lecturer in English as a Second Language (ESL) within the university system. The Tamil translation of the questionnaire was sent for comments to the second and third authors, who are trilingual (Tamil-English-Sinhala), working within the disability-development sector, with the former being a person with disabilities who is well-versed in the use of appropriate terminology. Comments from these two reviewers were added and the final version of the questionnaire was reviewed by the fourth and fifth authors, both first-language Tamil speakers who are speech and language therapists by profession. The fourth author works in the Northern Province and is therefore aware of any regional sensitivities and nuances regarding terminology and areas of questioning. A similar process was undertaken for the Sinhala translation of the questionnaire, with the first translation undertaken by a disability-inclusion officer who is a Sinhala-English bilingual. The translation was reviewed by the first author, who is a Sinhala-English bilingual working as a speech and language therapist.

The face validity of the questionnaire was assessed by the second and third authors who both lead disability-rights organisations in Northern Sri Lanka. The questionnaire was also reviewed by two senior colleagues of the local WHO office, with valuable feedback offered. Following on from the revisions to the questionnaire and translations, both the Tamil and Sinhala versions of the questionnaire were pilot-tested to assess the reliability, with one participant each from the Northern Province. This required the support of the fourth author, who was working as a local speech and language therapist.

The first and fifth authors, both speech and language therapists, devised a simple topic guide to aid the semi-structured interview, with open questions on the availability, use and barriers to assistive products. The topic guide was formulated with reference to the literature and with input from the second author, a person with disability and a key member of a disability-rights organisation in the Northern Province of Sri Lanka. The topic guide included the following prompts:

- Tell me about your views on assistive products.
- Tell me about your experience of accessing assistive products.

- Tell me about your experience of using assistive products.
- Tell me more specifically of the barriers to accessing and/or using assistive products.
- Tell me more specifically about the factors facilitating the access to and/or use of assistive products.
- Tell me your recommendations regarding access or use of assistive products.

#### **Data Collection**

This pilot phase consisted mainly of a combination of telephone interviews, face-to-face interviews and postal surveys. One participant completed the survey online through email correspondence. The face-to-face interviews were conducted by local Tamil-speaking disability rights advocates affiliated to Disabled Persons' Organisations in the area. These research assistants had all completed their Advanced Level examination and had at least 3 years of field experience in disability-inclusive development in the area. The interviews were conducted by three Tamil-speaking graduate speech and language therapists, including one working locally, either face-to-face or via telephone, as per the participants' request.

# **Data Analysis**

Percentage data was calculated to focus on the emerging trends with regard to the needs and the availability/non-availability of assistive products. This included the identification of the assistive products on the list that were reported as most required, the assistive products to which the participants have the most access at present and the assistive products most identified as required but not on the current list.

The qualitative interview data was translated into English by two speech and language therapists who are first language users of Tamil (authors 4 and 5). The data was thematically analysed using the key principles of framework analysis (Ritchie & Spencer, 1994) by the first and fifth authors, with author 4 reviewing the data analysis of five of the transcripts. Following close readings of the interview transcripts and familiarisation with the data by the first and fifth authors, the emergent themes were highlighted and colour-coded, with notes and definitions

stated directly on the text. A simple chart was devised with the emergent theme, operational definitions and examples from the participant data. Review of the chart enabled the identification of key themes and connected sub-themes.

The data was collected by speech and language therapists and disability advocates from the local community, which may have positively impacted on the data collection process. All the research assistants had some background in the disability field, which may have helped in conducting the interviews sensitively. The individual interview transcripts were re-checked with three of the participants who were easily accessible to the researchers. The emergent themes were reported back to 36 of the participants through the second and third authors, since the participants were linked to local disability-advocacy groups. Additionally, ten of the transcripts were re-analysed by a linguist who was not part of the research team. Comparable themes were noted within peer checking, with no further measurements required to reach consensus.

## **RESULTS**

#### Trends Observed

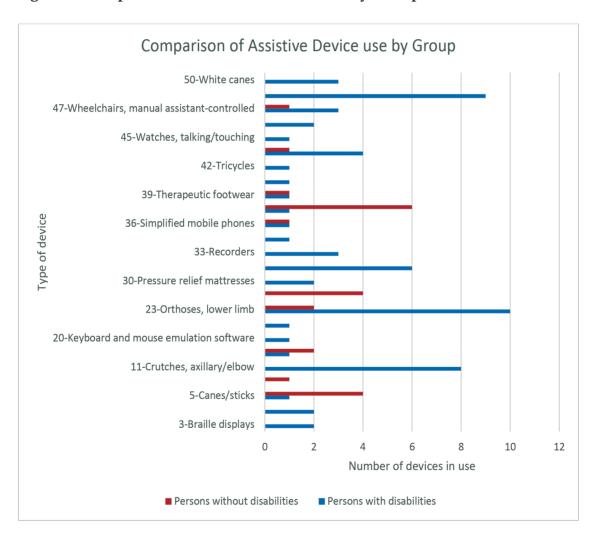
Of the 76 participants included in this phase of the study, 78.9% (N=60) were already using one or more assistive devices while 21% (N=16) were not. Only 3% of the assistive devices currently used by the participants had been received through a government scheme; 97% had received their devices through a non-government scheme (Table 2).

**Table 2: Source of Assistive Device** 

Government	Self-funded	Disabled Persons'	Non-governmental
Scheme		Organisation	Organisation
3%	27%	5%	65%

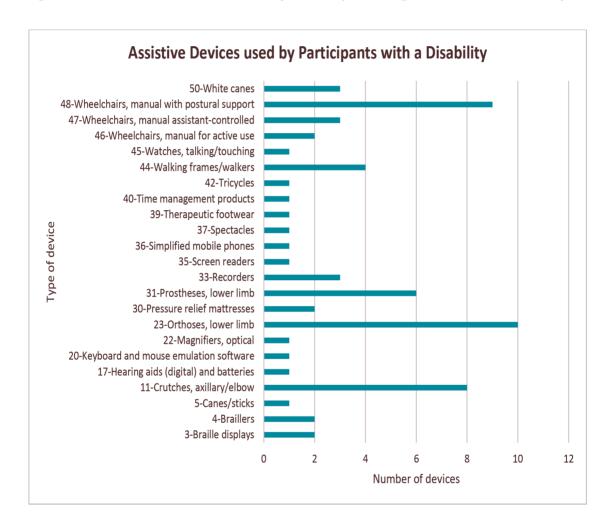
Of the assistive devices currently in use, orthoses, lower limb (23), crutches, axillary elbow (11) and wheelchairs, manual with postural support (48), were the most widely used as reported by the participants in the present study. This reflects the higher number of participants with mobility difficulties due to warrelated injuries or diagnosed medical conditions (Figure 1) included in this phase of the study.

Figure 1: Comparison of Assistive Device use by Group



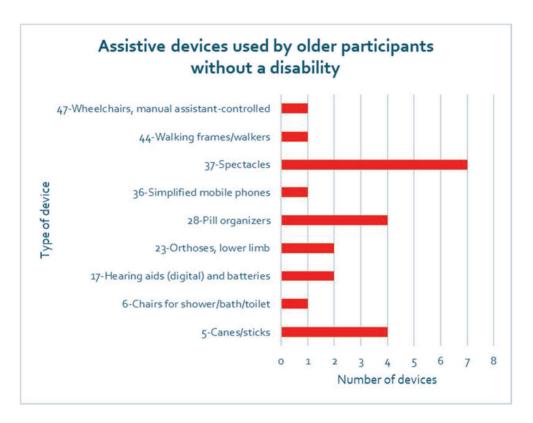
The assistive devices most commonly used by participants with a disability were, reportedly, mobility aids including manual wheelchairs (48), lower limb prosthesis (31), walking frames/walkers (44), lower limb orthoses (23) and crutches (11), as shown in Figure 2.

Figure 2: Assistive Devices currently used by Participants with a Disability



The assistive devices most frequently used by participants, 65 years and older, without a diagnosis of disability were spectacles and canes/sticks (5) due to agerelated difficulties and pill organisers (28), as seen in Figure 3.

Figure 3: Assistive Devices currently used by Older Participants without a Disability

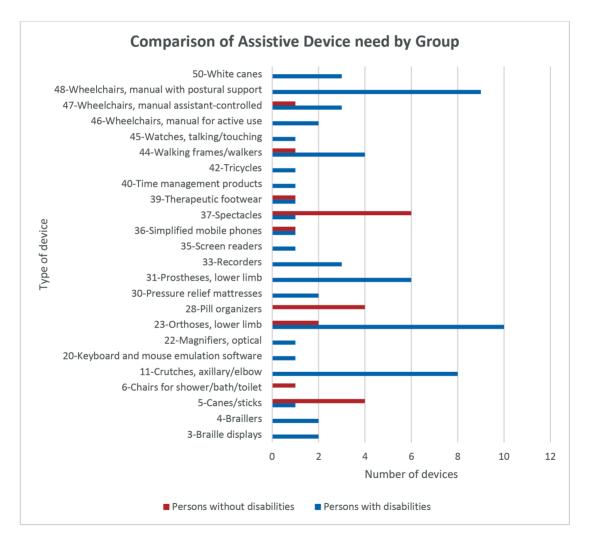


The assistive devices the participants identified as required but currently not available to them, were devices that enabled easier self-care during daily activities connected to leading a life of dignity and independence. These included chairs for shower/bath/toilet (6) and mobility devices of adjustable standing frames (38) and manual assistant-controlled wheelchairs (47).

Closer inspection of the data indicates that the group of participants with disabilities identified chairs for shower/bath/toilet (6), adjustable standing frames (38), tricycles (42), hearing aids (digital) and batteries (17) and communication boards/books/cards(9) as the assistive devices most required. The group of older

participating adults, over 65 years of age and without a diagnosed disability, who experienced mainly age-related difficulties with skills, identified manual assistant-controlled wheelchairs(47), walking frames/walkers (44), spectacles; low vision, short distance, long distance, filters and protection (37), chairs for shower/bath/toilet (6), canes/sticks (5) and therapeutic footwear; diabetic, neuropathic, orthopaedic (39) as most required devices, as shown in Figure 4.

Figure 4: Assistive Devices requirement per Group

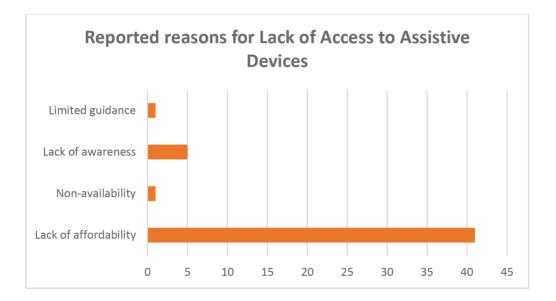


Of the 76 participants included in this phase of the study, 78.9% (N=60) were already using one or more assistive devices, while 21% (N=16) were not.

Apart from the 50 key items on the Assistive Products List, two participants identified the need for adult diapers and one participant reported his need for a voice amplifier.

The main reasons for the current lack of access to assistive devices were financial difficulties or the lack of affordability, inadequate guidance on the need for assistive devices by healthcare and educational professionals, as well as a lack of awareness on the need for assistive devices and on its availability locally (Figure 5).

Figure 5: Reported reasons for Lack of Access to Assistive Devices



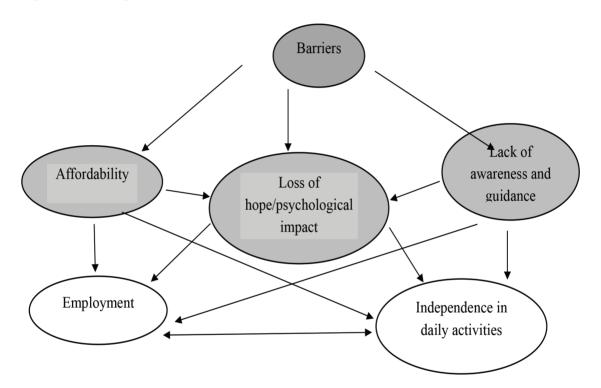
#### **Barriers to Access**

The qualitative data was gathered through discussions within the face-to-face and telephone-interview presentations of the survey with 15 key participants. Answers to the open question on the reasons for the lack of access, if any, to assistive devices, generated a number of emerging themes: affordability, employment, access to daily needs/dignity/quality of life, stigma, loss of hope/psychological impact, and the lack of awareness and guidance. The need for assistive devices was directly related to the participants' need for more access to the community and to employment, in order to be independent financially, less dependent on others for help and to live their lives with dignity and with a better quality of life.

The following excerpts from the interviews highlight the participants' opinions in this regard. Their views, expressed in Tamil, have been translated into Sri Lankan English and no changes have been made to words that may be deemed politically incorrect or offensive, in order to retain the authenticity of the participants' voices.

The key emergent themes and sub-themes are presented in Figure 6.

**Figure 6: Emergent Themes** 



Three themes - affordability, loss of hope/psychological impact and lack of awareness and guidance - emerged as the main barriers to accessing assistive devices. These three factors affected employment prospects and, similarly, influenced independence in daily activities. There was also a symbiotic relationship between independence in daily activities and employment opportunities.

# **Affordability**

Financial difficulties were identified as the main challenge to accessing assistive products.

"I don't have money to buy a prosthetic leg. Can you please help me?" (Participant P1).

"I am managing my day-to-day activities but I need a tricycle motor bike. I can't afford it, so please help me to get one. I am begging you for help" (Participant P7).

Although there was awareness among some of the participants regarding the urgent need for assistive products and clarity on how they may benefit from them, financial constraints were a barrier to access. Making this point succinctly, a young woman from Mannar with hearing loss said:

"I got a hearing aid donation from an NGO through the hospital. It was very useful when I was schooling. The hearing aid batteries don't work and the hearing aid is old now. I want a better hearing aid but they say it is 50, 000 to 80, 000 rupees. I can't afford it. I went back to the hospital for help, but they told me the donations are over" (Participant P36).

A graduate with low vision shared the hardships she was facing at the moment:

"I am a graduate, but I am unemployed. I used Braille at university. I would like to get a teaching job. My husband also has low vision. We both need devices but can't afford it. The government grant is 3000 rupees per month. My husband is doing a small job but we have a child and face severe financial difficulties. We don't need charity. If I can get a job, we can afford these devices" (Participant P30).

# **Employment**

The provision of assistive devices is the key to supporting equal participation in all aspects of civil life - from accessing education and employment to establishing friendship groups, and religious and political participation.

Tricycles were identified as the main assistive device that participants with motor difficulties hoped for, in order to have better access to work, be less dependent on public transport, be more independent and live with dignity. Some were using simple, home-made adapted tricycles which were worn-out, and they were in need of new, better quality and durable personal transport systems.

A man from Jaffna who had been diagnosed with polio said:

"I bought a hand-propelled tricycle with my own money but it is almost broken now. I urgently need a tricycle motor bike, which can be manually operated. My employment depends on my mobility" (Participant P3).

A young man from Jaffna with lower limb difficulties from birth shared similar sentiments:

"My main concern is that I am currently not in employment. If I have a tricycle motor bike, I can find work. I am begging you again to give me a tricycle" (Participant P7).

Akin to this, a person who had lost one hand through a war injury said:

'I don't have one hand, but I am able to ride a motor bike and do planting in my garden. But if I get a prosthetic hand, then I can increase my earnings and have a better functional life" (Participant P4).

# Independence in Activities of Daily Living

Many participants voiced the need for assistive products to support everyday activities, particularly for using the toilet more independently and with dignity.

A man who had lost both his legs during the war explained:

"My house is very simply built. It does not suit a person with a disability. It is difficult for me to use the toilet because of my impairment. It would be good if I can get a specialised sitting commode" (Participant P1).

Among the older participants who did not self-identify as persons with a disability, there was one who had been injured in an elephant attack in Mannar two weeks earlier. He said:

"My son and nephew made a makeshift toilet for me from a plastic chair because I can't walk much. I was in hospital for a week after an elephant attack. I am lucky to be alive. I need a better toilet" (Participant P24).

A few of the participants also made a clear connection between the lack of assistive products and how it deterred independence and a life of dignity. Explaining this cogently, a person with a spinal cord injury said:

"When people are visiting, I have no way to go to the toilet undetected. It is embarrassing. They can see me on the bed. It is not good for me as a young person. A special chair will be useful" (Participant P25).

Adding to this and making a point about his overall quality of life, another person with a diagnosis of spinal cord injury said:

"I faced difficulties with purchasing an air mattress for my bed. It costs too much. It is difficult for me to buy. So I have to suffer. Can you help me please?" (Participant P6).

### Stigma

There appears to be stigma attached to war-related disabilities, making the participants apprehensive about engaging in research. Nevertheless, since the researchers were introduced to the persons with disabilities through Disabled Persons' Organisations, the participants were a little more open to engaging in the study. Indicating a reluctance to divulge too much sensitive information, one person shared the following:

"You know, I was in the war. People look at me differently. I can feel it. It is not nice. They know I was part of the war because of my disability. ... It is difficult for me to ask for help from the government...or from anyone" (Participant P5).

Talking of the everyday prejudice she faced, a woman with mobility difficulties from birth said:

"I am employed as a seamstress. I stitch dresses at a shop. I have to go by tuktuk (colloquial term for an auto-rickshaw) every day. It is very difficult to find a tuktuk sometimes. They don't always stop for me and it takes a long time to find one and to travel from home to work. If I can get a tricycle motor bike, that would be better. Then, I can drive by myself" (Participant P2).

# Loss of Hope/Psychological Impact

The potential psychological impact of war-related injuries, the lack of perceived support and inability to purchase assistive devices to enable independence, echoed through some of the interviews with the participants.

Participant P5 who had sustained injuries in the war and had a spinal cord injury, was reluctant to engage in a long conversation, simply saying, "Nothing is useful as I am bed-ridden". He however reported that he received a donation of a wheelchair from an NGO some time back.

Participant P76, a young man with hearing loss after the war, put it bluntly when asked if his hearing loss was congenital: "No, it was your bombing". He went on to explain that he had got his hearing screened at a free medical camp a few years ago, but could not afford to buy a hearing aid, so had "given up on it".

In contrast, a 17-year-old from Mannar appeared desperate to secure a suitable assistive device. He spoke in very moving terms about the impact of hearing loss on his life:

"My parents did not get me a hearing aid. They did not prioritise it. They did not try. They are poor but they could have done something. I now need one urgently. I sat for my O/Ls last year but I did not pass it. School was difficult because I can't hear very well, no? I am now trying to find a job; a labourer job, but I need to hear better, no? They will not want to give a job to a deaf boy, no? I will feel better psychologically if I have one. ... more confident (cries)... I can't tell my mother" (Participant P35).

#### Lack of Awareness and Guidance

A few of the parents in the study did not have adequate awareness about assistive products that were available and may have been able to support their children. This lack of awareness was also reflective of limited guidance received from healthcare and educational professionals.

Stating this point a parent from Mannar, who had a 9-year-old son with bilateral hearing loss, explained:

"We did not know till recently when we were visited by a special speech teacher from an NGO, that he can't hear. We thought he was dumb. He goes to school but the teacher did not tell us anything, no? She said we need to get his ears tested and get a hearing instrument. She said he is a smart boy. We can't afford it, no? Aiyo, how can he learn in that school?" (Participant P48).

Another parent from Mannar, who had a 6-year-old son with cerebral palsy, added:

"We did not get proper guidance from anyone for my son. He has cerebral palsy. Some said 'no need for devices' and some said 'you must /continue to use it'. We were very confused. The hospital did not give us enough guidance. We are also poor, so we can't afford to buy him a wheelchair. Can you help us?" (Participant P38).

## **DISCUSSION**

The current pilot study was conducted in the Northern Province of Sri Lanka with 76 participants, with or without disabilities, using a mixed-methods design. Initial findings indicate that the most widely used assistive products among the study participants with disabilities were mobility devices (including orthoses/lower limb devices, crutches, axillary/elbow and wheelchairs). This finding may be reflective of the particular geographical region chosen for the pilot study, as many of the mobility difficulties were reported to be due to war-related injuries.

An estimated 40,000 people are said to live with war-related injuries in post-war Sri Lanka with almost 20,000 living in the Northern Province (Perera, 2015). This finding highlights the need to take account of local histories and realities, both at policy-level and in making particular assistive products accessible to local communities. In support of the above, MacLachlan and colleagues (2018) argue that any assistive technology policy should be tailor-made to the specifics of the local context, its realities and available resources.

In contrast, the other group of participants, 65 years and older, without a diagnosis of disability, reported the current use of spectacles, canes/sticks and pill organisers. The assistive devices in use are in line with what one would expect, given the predicted decline in mobility and visual skills with age.

Both groups of participants identified the need for certain assistive products to aid activities of daily living, such as chairs for shower/bath/toilet. This theme was reiterated within the interviews in which the participants explained how assistive products could promote activities of daily living and in so doing, safeguard dignity and encourage better quality of life. With reference to the International Classification of Functioning, Disability and Health - ICF (WHO, 2001), the assistive devices requested were with a view to gaining more agency of one's own; to be as independent as possible. Echoing this, Khasnabis and colleagues (2015) have made a strong claim that assistive products have the ability to maintain or increase functioning and encourage independence.

Reflecting age-related decline in visual acuity, spectacles were also identified as an assistive device required by participants over 65 years of age. This links to current country-level initiatives to curb preventable blindness and support vision as part of the global response to Vision 2020 (College of Ophthalmologists Sri Lanka, 2017). In addition, the group of older participants without a disability made a request for more mobility-related equipment including therapeutic footwear, canes/sticks, walkers and wheelchairs, mostly due to the rising impact of non-communicable diseases. As assistive products play a part in primary and secondary prevention of non-communicable diseases such as diabetes, and communicable diseases such as leprosy (Tebbutt et al, 2016), these would be priority items for this particular participant group.

Additionally, the group of persons with disabilities had identified a range of assistive products including standing frames and tricycles that could enable better access to employment. Again, participation as per the ICF model (WHO,

2001) and autonomy were key goals among this group of participants. This was reiterated by the key participants included in the interviews. The assistive products were said to facilitate better access to education for children, and to employment for adults.

The World Report on Disability (WHO, 2011) found comparatively lower educational attainment and employment among persons with disabilities than among people without disabilities. One-third of students out of school are reportedly children with disabilities (UNICEF & WHO, 2015). Assistive technology is recognised as offering opportunities to counter social exclusion (MacLachlan et al, 2018) from education, employment and from active direct participation within society and minimises inequalities (Tebbutt et al, 2016). Within a culture where arguably the charity model of disability prevails together with karmic narratives of disability (Attanayaka & Gunawardena, 2016), it is conceivable that any dependence may be construed as weakness, with persons with disabilities deemed requiring 'help' and pity; feeding into prevalent stereotypical notions of disability. With reference to the ICF (WHO, 2001), a disability or advancing age can influence how one performs in an activity (activity limitation), with implications for overall participation. Assistive products could minimise activity limitation and encourage participation by mitigating difficulties experienced by persons with disabilities. Assistive products encourage a life of independence and dignity (Tebbutt et al, 2016) which, in effect, may be powerful instruments that can challenge the archaic view of disability and empower persons with disabilities to live with independence and dignity, and to achieve their fullest potential.

The stigma surrounding disability, though not an unusual finding in Sri Lanka or South Asia, indicated a specific local reality within this study. Weerasinghe and colleagues (2015) found a psychological dimension among their participants as a barrier to using assistive technology, as assistive products were thought to signify a disability. From an ableist perspective (Campbell, 2009), the assistive product was thus viewed as an external symbolic reminder of disability or 'inability'. In the current study, while the assistive product was similarly symbolic of the disability, there was said to be a particular stigma related to post-war disability in the North. It was considered indicative of a possible combatant role, adding an additional layer of vulnerability. This presumed societal stigma manifested itself in a reluctance to engage in conversation on their lived experiences of post-war disability. Samararatne et al (2018), in their study on war-affected women

with disabilities, uncovered stigmatisation of war-related disability for women in particular. For women combatants of the war, the disability is said to be a permanent scar of shame within and outside the community, denoting their involvement in the war (Samararatne et al, 2018). It would be useful to explore this further, given the potential socio-cultural and human rights implications of such presumed stigma. In this post-war context, wider in-depth research may capture the intersectionality of disability, gender, and ethnicity (Samararatne et al, 2018), offering deeper insights.

The overall lack of awareness about available products and the need for professional guidance in identifying individual assistive products for children also emerged as key concerns. A similar lack of awareness of assistive technology related to lower limb disabilities, as well as financial barriers, was found by Weerasinghe and colleagues (2015). In India, an economically and culturally comparable country to Sri Lanka, limited awareness among users and professionals has hampered the widespread and equitable use of assistive technology (Kumar et al, 2009). This is said to be particularly evident among potential users living in rural communities and among older adults (Marasinghe et al, 2015), even within a welfare state like Sri Lanka in which some assistive products are offered free-of-charge.

Awareness of the benefits of using assistive technology is of paramount importance. As Marasinghe and colleagues (2015) argue, assistive technology will not be of benefit even when offered free or at a subsidised rate if users and professionals are unaware (and/or unconvinced) of its use. This reiterates the importance of increasing knowledge and awareness through training on assistive technology and how to use it, in order to improve the uptake of assistive technology. The inadequacy in the number of trained healthcare professionals in countries of the Global South has been raised as a concern (Marasinghe et al, 2015), which must be addressed as a matter of priority (World Health Organisation, 2011a). MacLachlan and colleagues (2018) note a lack of awareness among prospective users and healthcare-social care professionals on how assistive products can mitigate or surmount functional impairments. This, they argue, is relevant to both resource-rich and resource-poor countries, with the latter a specifically challenging context. The need for trained personnel, well-versed in assessing, prescribing, fitting, monitoring and offering maintenance facilities, and training of users has been raised within the literature (WHO, 2016b).

This was linked to affordability, which deterred easy access, with a heavy reliance on the NGO sector in procuring products within the local context. Enshrined within the concept of universal health coverage is a relief from the financial burden of accessing health issues (WHO, 2017a). Financial constraints have been uncovered as a major deterrent to the access and use of assistive technology in Sri Lanka, albeit specifically in relation to lower limb disabilities (Weerasinghe et al, 2015). Within a similar resource-poor South African context, the need for available and affordable assistive products has been emphasised (Visagie et al, 2017). The systematic review by Marasinghe et al (2015) found low-cost assistive technology initiatives in some low- and middle-income countries, which may be more affordable to local populations. These 'at risk' populations appear to be dependent on the NGO sector for donations in the face of arguably limited government support. One critique of this reliance on donations or 'charitable services' is the quality of the assistive products offered, which are often used second-hand devices (WHO, 2016b). It is conceivable that this 'dependence' on the NGO sector is inadvertently reiterating (rather than challenging) the currently prevalent charity model of disability, perpetuating notions of a lack of autonomy and agency. Given the range of assistive products that may be required by individuals and the very limited support from the government as reported at present, a list of priority assistive products required by the community would be an important start.

#### Limitations

As these findings are only trends observed from a pilot study, caution is required in interpreting their relevance. The key limitations of the study include the relatively small sample size from a specific geographical area that was chosen for the study, indicating a possible selection bias. The purpose of this pilot phase was only to gain some preliminary insights into the access and use of assistive products in Sri Lanka; it is anticipated that the findings could inform a broader study to be conducted in the future.

# **CONCLUSION**

The first-hand information gathered from end-users (persons with disabilities and older adults without disabilities) could inform the process of developing a Standard List of Assistive Products for Sri Lanka that acknowledges and accounts for local realities. This includes information garnered on the assistive devices currently used, assistive devices required but not currently used, explanations of the challenges faced in securing the devices needed, and how these assistive

devices have the potential to transform the lives of people to lead a life of dignity and independence, with better access to education, employment and community participation.

In terms of the lessons learnt, there appears to be stigma associated with disability, particularly with war-related disability, and sensitivity is required when interviewing participants. Postal surveys may not be an effective or efficient method to collect data as it places too much responsibility to return the completed survey on the participant. Given that the majority of participants are persons with disabilities, access to transport and the post office too may be a challenge. This must be kept in mind during the next phase of the study.

Future studies must be sensitive to the stigma associated with war-related disabilities, as in who approaches the participants and in how questions are framed, posed, and interpreted without judgement. In addition, the interviews could be carried out by a combination of researchers with and without disabilities, which may offer the participants a 'safe space' to speak. Also, future studies must include a better representation of persons with intellectual disabilities and persons experiencing psycho-social/mental health difficulties.

Follow-up studies should also include representation from the South and from other areas of the country, as the findings from the North may reflect war-related injuries and the need for assistive devices connected to these disabilities, which may not be the case in other parts of the country. The survey questionnaire should include a question on any long-term medical diagnoses, such as diabetes, that may generate valuable information for service providers and policy-makers. A door-to-door and face-to-face survey study of a small geographical area must follow, in order to gain information from a sample of participants, representing the complexity of the local population. This will also enable the participants to view the pictures of the 50 target items and to engage in more in-depth leisurely conversations. Finally, in-depth interviews with select participants from across the country may offer a better understanding of the intersectionality of disability, age, gender, and poverty, which will help to inform future policies and programmes on assistive devices.

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# **APPENDIX**

# **Demographic Details of the Participants**

No.	Age	Gender	District	Diagnosis, if available
P1	28	Male	Kilinochchi	Lost both legs in the war
P2	43	Female	Jaffna	Lower limb difficulties
Р3	39	Male	Jaffna	Polio
P4	55	Male	Kilinochchi	Lost one hand in the war
P5	44	Male	Vavuniya	Spinal-cord injury due to a war injury
P6	38	Male	Jaffna	Spinal-cord injury due to a war injury
P7	25	Male	Jaffna	Lower limb difficulties from birth
P8	69	Male	Jaffna	No diagnosis of a disability
P9	65	Female	Jaffna	No diagnosis of a disability
P10	26	Female	Mullaitivu	Visual difficulties (retinal detachment)
P11	68	Female	Jaffna	No diagnosis of a disability
P12	78	Male	Jaffna	No diagnosis of a disability
P13	72	Male	Vavuniya	Visual difficulties (registered blind)
P14	89	Male	Jaffna	Parkinson's disease
P15	75	Female	Jaffna	No diagnosis of a disability
P16	77	Male	Jaffna	No diagnosis of a disability
P17	66	Female	Jaffna	No diagnosis of a disability
P18	74	Female	Jaffna	No diagnosis of a disability
P19	66	Male	Jaffna	Mobility difficulties

P20	79	Female	Jaffna	Mobility difficulties
P21	21	Male	Jaffna	Visual difficulties
P22	24	Female	Jaffna	Visual difficulties
P23	74	Female	Jaffna	Mobility difficulties due to an accident
P24	65	Male	Mannar	No diagnosis though had a recent injury due to an elephant attack
P25	24	Female	Jaffna	Spinal-cord injury
P26	78	Female	Mannar	No diagnosis
P27	72	Male	Vavuniya	No diagnosis
P28	74	Male	Vavuniya	No diagnosis
P29	81	Male	Vavuniya	No diagnosis
P30	36	Female	Mullaitivu	Visual difficulties
P31	28	Female	Jaffna	Visual difficulties
P32	32	Female	Jaffna	Visual difficulties
P33	29	Female	Jaffna	Visual difficulties
P34	Child: 8 Parent: 30	Parent: Female Child: Female	Mannar	Polio
P35	Adolescent: 17 Parent: 47	Parent: Female Child: Male	Mannar	Hearing loss
P36	33	Female	Mannar	Hearing loss
P37	42	Female	Mannar	Lost leg due to a road traffic accident
P38	Child: 6 Parent: 29	Parent: Female Child: Male	Mannar	Cerebral Palsy
P39	44	Male	Mannar	Both legs affected due to a war-injury
P40	Adolescent: 17 Parent: 45	Parent: Female Child: Female	Mannar	Hearing loss
P41	68	Male	Mannar	Stroke
P42	56	Male	Jaffna	Total Laryngectomy
P43	69	Female	Mannar	Visual difficulties
P44	33	Male	Mannar	Lower limb weakness
P45	Child: 7 Parent: 32	Parent: Female Child: Male	Mannar	Cerebral Palsy

P46	33	Male	Mannar	Lost one leg to a war- injury
P47	34	Female	Mullaitivu	Lost legs due to a war- injury
P48	Child: 9 Parent: 35	Parent: Female Child: Male	Mannar	Hearing loss
P49	82	Male	Mullaitivu	No diagnosis
P50	76	Female	Mullaitivu	No diagnosis
P51	Child: 8 Parent: 37	Parent: Female Child: Male	Mannar	Cerebral Palsy
P52	Adolescent: 17 Parent: 38	Parent: Female Child: Male	Mannar	Cerebral Palsy
P53	Adolescent: 13 Parent: 48	Parent: Female Child: Female	Mannar	Hydrocephalus
P54	Child: 9 Parent: 49	Parent: Female Child: Male	Mannar	Cerebral Palsy
P55	Adolescent: 15 Parent: 46	Parent: Female Child: Female	Mannar	Cerebral Palsy
P56	Child: 10 Parent: 32	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P57	Adolescent:15 Adult: 40	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P58	Adolescent:16 Parent: 44	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P59	Child: 8 Parent: 36	Parent: Female Child: Female	Mullaitivu	Cerebral Palsy
P60	Adolescent: 18 Adult: 48	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P61	Adolescent: 16 Parent: 46	Parent: Female Child: Female	Mullaitivu	Cerebral Palsy
P62	Child: 10 Parent: 32	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P63	Child: 8 Parent: 27	Parent: Female Child: Male	Mannar	Cerebral Palsy
P64	Adolescent: 14 Parent: 31	Parent: Female Child: Male	Mannar	Muscular Dystrophy
P65	Child: 9 Parent: 34	Parent: Female Child: Male	Vavuniya	Cerebral Palsy

P66	57	Male	Mannar	Transtibial amputation
P67	53	Male	Mannar	Transtibial amputation
P68	61	Male	Mannar	Partial foot
P69	Adolescent: 13 Parent: 33	Parent: Female Child: Male	Mullaitivu	Cerebral Palsy
P70	63	Female	Mannar	Polio
P71	27	Male	Vavuniya	Cerebral Palsy
P72	38	Male	Vavuniya	Transfemoral amputation
P73	77	Male	Mannar	Diabetes
P74	46	Male	Vavuniya	Transfemoral amputation
P75	73	Female	Mannar	No diagnosis but defines herself as a 'person with a disability'
P76	Child: 9 Parent: 28	Parent: Female Child: Male	Mannar	Hearing loss