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# Views and Experiences of People with Intellectual Disabilities to Improve Access to Assistive Technology: Perspectives from India

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## ABSTRACT

**Purpose:** *People with intellectual disabilities are deeply affected by health inequity, which is also reflected in their access to and use of assistive technology (AT). Including the perspectives of adults with intellectual disabilities and their caregivers, together with the views of local health professionals, suppliers of AT and policy-makers, this paper aims to provide an overview of factors influencing access to AT and its use by people with intellectual disabilities in Bangalore, a southern region of India.*

**Method:** *Face-to-face interviews were conducted with 15 adults with intellectual disabilities (ranging from mild to profound) and their caregivers, and with 16 providers of AT. This helped to gain insight into the current use, needs, knowledge, awareness, access, customisation, funding, follow-up, social inclusion, stigma and policies around AT and intellectual disability.*

**Results:** *Access to AT was facilitated by community fieldworkers and services to reach out and identify people with intellectual disabilities. Important barriers were stigma, and lack of knowledge and awareness among parents. Factors related to continued use were the substantial dependence on the care system to use AT, and the importance of AT training and instructions for the user and the care system.*

**Conclusion and Implications:** *The barriers and facilitators related to AT for people with intellectual disabilities differ from other populations in need. The*

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*findings of this study can be used to inform and adjust country policies and frameworks whose aim is to improve access to AT and enhance the participation of people with intellectual disabilities within their communities.*

**Key words:** *developmental disability, assistive devices, assistive products, health inequity, inclusion, stigma.*

## INTRODUCTION

The seventy-first session of the World Health Assembly in 2018 stipulated the need for improving access to AT worldwide. Following the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Sustainable Development Goals (SDGs), especially SDG 3, it is shown that equitable and affordable access to AT needs to be an integral part of universal health coverage (World Health Organisation, 2018). However, there is a current gap in research and practice regarding the need, demand and supply of AT, as well as evidence of good practices for innovation and recommendations to improve access (WHO, 2018). The WHO Global Cooperation on Assistive Technology (GATE) programme was initiated to identify those contributions which provide scientific and/or practical inputs to improve the current situation of AT policy, products, provision, personnel and users (people).

A specific group of people who should not be excluded from AT initiatives and contributions are people with intellectual disabilities. People with intellectual disabilities are deeply affected by health inequity, are still regarded as a stigmatised and devalued group, and often marginalised from healthcare services (WHO, 2000; Hatton and Emerson, 2015 ). This is also reflected in their access to and use of AT services (Boot et al, 2017). Intellectual disability is defined by the American Association on Intellectual and Developmental Disabilities (AAIDD), the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) and the International Classification of Diseases (ICD-10, mental retardation) as an IQ below 70, manifested during the developmental period (onset before 18 years of age), with impairments in adaptive functioning, such as communication skills, social skills, personal independence, school or work functioning (AAIDD, 2013; American Psychiatric Association, 2013; WHO, 2016). It has been found that people with intellectual disabilities use fewer ATs compared to other people in need (Wehmeyer, 1995; Carey et al, 2005, Kaye et al, 2008; Hatton and Emerson, 2015), despite the fact that people with intellectual disabilities could greatly benefit from AT (Patja et al, 2000; Haveman et al, 2011; Hatton and Emerson, 2015;

Carmeli et al, 2016; Owuor et al, 2017). The benefits that relate to AT are that it (1) could be used to support cognitive limitations in order to enhance independence and inclusion, (2) could facilitate better management of chronic health conditions and comorbidities which people with intellectual disabilities experience more often compared to the general population, such as sensory impairments, speech and language impairments, and dementia( Jansen and Kingma-Thijssen, 2011; Hatton and Emerson, 2015), and (3) could support those with early onset of functional decline ( Haveman et al, 2011; Schoufour et al, 2015). People with intellectual disabilities follow the same ageing trend as the general population, and their demand for AT increases as they get older.

Although the UNCRPD and the SDGs stipulate the importance of access to AT for anyone in need, access to AT and AT use for people with intellectual disabilities is still a significant neglected area in research and practice (Hatton and Emerson, 2015; Boot et al, 2018). It is not known how many people with intellectual disabilities have access to AT globally, and which factors influence their access. Difficulties in accessing services and unmet healthcare needs for people with intellectual disabilities are more prevalent in low- and middle-income countries, but there is also a significant inequity in high-income countries.

In collaboration with the GATE programme, Boot et al started in 2016 an international research project called GATE-ID which aimed to identify the current barriers and potential facilitators for people with intellectual disabilities to access and continuously use AT in differently resourced settings. One of the countries included in the GATE-ID programme was India.

India is classified as a lower middle- income country according to the World Bank data (World Bank, 2018). The country has a variety of social-economic classes, healthcare systems and cultures. Healthcare resources and facilities are unevenly distributed and, in general, services are concentrated in urban areas. The prevalence of people with intellectual disabilities in India is estimated at 2-3% (Kalgotra and Warwal, 2017), but most of these individuals have not been formally identified. It is estimated that 26 million people have intellectual disabilities in India, out of which more than 15 million are under the age of 10 years (Kalgotra and Warwal, 2017). The prevalence is higher in rural compared to urban areas. According to the national sample survey, the main causes of intellectual disabilities in India are illness during childhood (42%), head injury during childhood (10%), and pregnancy or birth-related impairments (3%) (Kalgotra and Warwal, 2017). The majority of individuals live at home, supported

by family caregivers (Meena, 2015). India ratified the UNCRPD in 2007, which led to the adaptation of the Rights of Persons with Disabilities Act in 2016. To monitor and achieve the SDGs and associated targets, a National Indicator Framework (NIF) has been developed which serves as a key tool for policy making, implementation strategies, and allocation of resources, researchers and other stakeholders (India, 2015).

## **Objective**

An important aspect of the current research project was to include the views and experiences of people with intellectual disabilities and their families. These perspectives are the key to a better understanding of the barriers they currently encounter in accessing and continuing to use AT. Together with the views of local health professionals, suppliers of assistive products and policy-makers, this paper aims to provide an overview of factors influencing access to and use of AT for people with intellectual disabilities in the Bangalore region of southern India.

A phenomenological approach was used to answer the following research questions: Which barriers and facilitators to provide the essential assistive products for people with intellectual disabilities are currently present in India? And, how can the improved provision of AT aspired to by GATE, specifically for people with intellectual disabilities, be realised?

## **METHOD**

This study is part of the larger cross-sectional GATE-ID research project. The methods described below are similar to the methods of the GATE-ID research project conducted in South Africa and Ireland (Boot et al, 2019). A full description of the development of the interview guides, the interviewing method and analysis has been published elsewhere (Boot et al, 2019).

### **Study Design**

This study consisted of a qualitative research design using semi-structured face-to-face interviews with a phenomenological approach. Relatively few people with intellectual disability are able to read, write and fill in written questionnaires. Therefore, interviewing is the most appropriate method to elicit personal views from people with intellectual disabilities.

## **Participants**

Purposive sampling was used to recruit participants. They were put into two main groups: 1) adults with intellectual disabilities, and 2) providers of AT.

Participants of group 1 - adults with intellectual disabilities - were approached through an Indian rehabilitation centre in Bangalore. The manager of the rehabilitation centre and the community fieldworkers were informed about the study and asked to recommend adults with intellectual disabilities who might be willing to participate in an interview, either as users or non-users of AT. The information leaflet and consent form were adjusted to the cognitive level of the participants (i.e., easy to read, larger font size, few words per row and the use of symbols) and were translated into the three main local languages of the Bangalore region: Kannada, Tamil and Urdu. If the participant was not able to give informed consent, his or her legal representative (family member) did so.

Participants of group 2 - providers of AT- consisted of health professionals, community field- workers, suppliers or retailers of AT, and governmental commissioners. They were approached through the network of the rehabilitation centre in Bangalore and snowball sampling was used.

## **Data Collection**

Interviews of the participants took place in July 2018. The semi-structured interview guide focused on the current use of AT, needs, knowledge, awareness, access, customisation, funding, follow-up, social inclusion, stigma, and policies. At the start of each interview, ATs were defined using a booklet containing images of different varieties of ATs. These included any low- or high-tech product to maintain or improve a person's functioning in the domains of vision, hearing, mobility, communication, cognition, environment and personal care. The questions were adjusted to the level of persons with intellectual disabilities, and the family members aided participants in understanding questions they found challenging.

## **Data Analysis**

The recorded interview data was first transcribed verbatim. The technique of constant comparison analysis, as described by Elliott and Timulak (2005), was used to analyse the data. Accordingly, the data was divided into meaning units – units by which the analysis was conducted. Meaning units are segments of the

data that, even if interpreted out of context, would provide adequate information to the reader. To organise participants' responses, the meaning units were sorted into three themes: 1) stigma, 2) access to AT, and 3) continued use of AT. The meaning units were subsequently organised as per theme into broad headings or domains, to provide a conceptual framework for each theme. Next, the meaning units were coded into categories within each of the domains. The categories emerged from the meanings in the meaning units.

### **Ethics Approval**

Ethical approval for this study was granted by the Bangalore Baptist Hospital Institutional Review Board. Ethical approval for the overall GATE-ID research project was obtained from the Health Policy & Management/Centre for Global Health Research Ethics Committee, Trinity College Dublin, Ireland (04/2017/01) and Maynooth University Research Ethics Committee, Ireland (SRESC-2017-053). The study adhered to the Declaration of Helsinki for research involving human subjects.

## **RESULTS**

The results represent the perspectives of the participants of both groups, shown as an overview of factors (both facilitators and barriers) related to stigma, access to AT and continued use of AT for people with intellectual disabilities.

### **Participants' Characteristics**

In total, 31 participants were interviewed. Table 1 presents the characteristics of participants in group 1 - adults with intellectual disabilities (n=15), and group 2 - providers of AT (n=16). Three participants of group 1 were professionally assessed for their intellectual function prior to the interview. The level of intellectual disability of the other 12 participants was assessed by the researcher at the time of the interview, based on the researcher's experience as a specialist intellectual disability physician, and categorised as either mild-moderate or severe-profound intellectual disability. All adults with intellectual disability were accompanied by their caregivers (family member or carer) during the interview, to support them where needed. Often parents would take the lead in answering the questions intended for their child with intellectual disability. Six adults were non-verbal and/or had a severe-profound intellectual disability, in which case the caregivers answered all the questions on their behalf.



**Table 1: Participants' Characteristics**

Characteristics	People with intellectual disabilities (n=15)	Characteristics	Providers (n=16)
Age (mean)	31 years	Age (mean)	50 years
Female gender	8	Female gender	4
Level of intellectual disability		Work field	
Mild-Moderate	11	S&L therapist	1
Severe-Profound	4	Audiologist	1
Aetiology		Ophthalmologist	1
pre- or perinatal infection	2	Physiotherapist	1
Down syndrome	1	Social worker	1
Meningitis / encephalitis	1	Special educator	1
Rhesus disease	1	Community fieldworker	2
Asphyxia	1	Supplier of AT	2
Unknown	9	Manager care facility	1
Care setting		Policy maker	5
Centralised setting	5	Urban	16
With Family	10		
Semi-urban	6		
Urban	9		

*S&L = Speech and language*

### Assistive Technology in Use

Table 2 shows the AT which participants were currently using. On average, participants from group 1 - adults with intellectual disability - used two products per person, ranging from 0-3, with one participant using nine products. The products most commonly used were in the domains of communication (mobile phones) and environment or self-care (shower stools or chairs).

**Table 2: Current AT in use by Participants of Group 1 - Adults with Intellectual Disabilities**

Code participants	Total no. of AT in use	Hearing	Vision	Communication	Mobility	Cognition	Environment and self care
INT_ID_IND_001	1	0	0	1	0	0	0
INT_ID_IND_002	0	0	0	0	0	0	0
INT_ID_IND_003	9	0	5	1	1	0	2
INT_ID_IND_004	0	0	0	0	0	0	0
INT_ID_IND_005	2	0	0	1	0	0	1
INT_ID_IND_006	1	0	0	1	0	0	0
INT_ID_IND_007	2	0	0	2	0	0	0
INT_ID_IND_008	3	0	0	1	0	0	1
INT_ID_IND_009	2	1	0	1	0	0	1
INT_ID_IND_010	3	0	0	1	1	0	1
INT_ID_IND_011	2	0	0	0	1	0	1
INT_ID_IND_012	2	0	0	1	1	0	0
INT_ID_IND_013	3	0	1	0	0	0	2
INT_ID_IND_014	2	1	1	0	0	0	0
INT_ID_IND_015	1	0	0	0	1	0	0
Total	33	2	7	10	5	0	9
Average	2	0	0	1	0	0	1



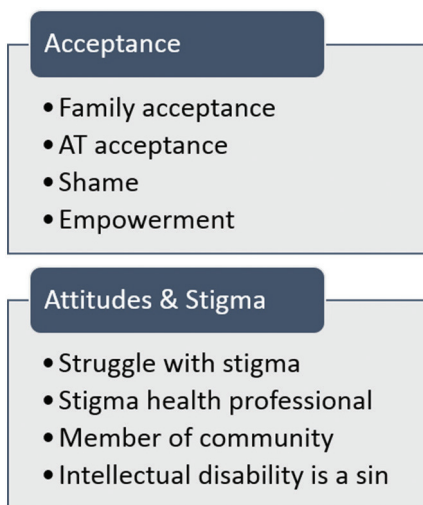
## Qualitative Analysis

The results of the qualitative analysis are presented below, with the themes and domains as headings and subheadings respectively. Domains and categories per theme are illustrated schematically in Figures 1-3; these domains are not presented in order of importance, nor do they imply any hierarchy.

### Theme 1 - Stigma

Data analysis resulted in two domains for stigma: Acceptance, and Attitudes and Stigma. The meaning units were coded into four categories for both domains (see Figure 1).

**Figure 1: Domains and Categories for Stigma**



### Acceptance

Family acceptance and shame played an important role in AT provision for people with intellectual disabilities. Participants explained clearly how shame had influenced isolation of both the person with intellectual disability as well as the family members. For example, one mother explained that she did not accept that her child had intellectual disability, which led to her keeping her child indoors all the time. As a result, her child had never been assessed for any AT support. One participant clearly described the importance of family acceptance as a first step before AT can be accessed.

*“The family gives up on them, thinking that he is good for nothing, then he becomes a burden in the family and that makes them feel even lower all the*

*time....they are made to believe they are not wanted..... These are all necessary [pointing at AT] but this is even secondary. Make them believe that they come out, and work and succeed.” (INT\_PRO\_IND\_004)*

Acceptance of AT also played a role and was influenced by modern mainstream AT developments.

Participant: *“But in India people will have that feeling, nobody should notice I am wearing a hearing aid.”*

Researcher: *“Do you think it is more stigma then as well?”*

Participant: *“It is a bit, but now it has changed, because now everyone goes with the headphones.” (INT\_PRO\_IND\_008)*

### **Attitudes and Stigma**

Worldwide, people with intellectual disabilities still have to face stigma which negatively influences access to and use of AT services. In many regions of India, and within many beliefs, intellectual disability is still seen as a sin.

Participant: *“It is still considered as something linked to your karma and all those things and a lot of superstitious beliefs and other things. And in some places that some of those people have been sacrificed in the name of this or that.” (INT\_PRO\_IND\_002)*

Some parents struggled with negative attitudes from other family members towards their child with intellectual disability. Others shared their experience of positive attitudes from neighbours and the local community. However, in general, the community did not see people with intellectual disability as productive members of society. These attitudes were more present in urban than in rural areas, which was explained by lower expectations within rural areas and the type of work that people with intellectual disability could do there. In addition, stigma from health professionals was also present. Participants with intellectual disability explained that health professionals did not include them during consultation and would mainly focus on the parents.

Researcher: *“And could you choose the glasses, choose yourself which glasses you want?”*  
Participant: *“My parents selected.” (INT\_ID\_IND\_003)*

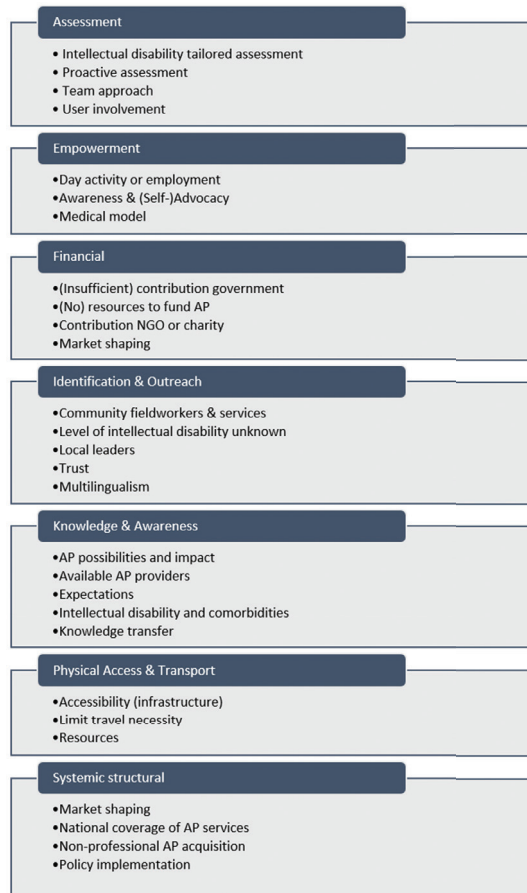
Health professionals also misled parents, providing incorrect information on intellectual disability.

Participant: *“Some of them are also misled by doctors. Professional doctors where they go for a treatment. They say your child will become alright after ten years. They want to escape from the parents asking questions so they say something and send them out. So these parents are in the impression that my child will become alright one day.”* (INT\_PRO\_IND\_015)

## Theme 2 - Access to AT

Data coding developed into seven domains for access to AT: Assessment; Empowerment; Financial; Identification & Outreach; Knowledge & Awareness; Physical access & Transport; and Systemic Structural (e.g., policies, resources and the organisation of AT services) (see Figure 2). The meaning units were coded into 3-5 categories per domain.

**Figure 2: Domains and Categories for Access**



## Assessment

Proactive and intellectual disability tailored assessments were rare. The majority of participants from group 1 were never tested for hearing, vision, or communication and did not go to the dentist. Participants from group 2 explained the difficulties in assessing a person with intellectual disability.

Researcher: *“Can you test every person with intellectual disability and low vision?”*

Participant: *‘It is difficult for me to assess an intellectual disability child’s vision. Assessment is very, very difficult because they do not have language skills, they do not have understanding of objects. So, difficult.’* (INT\_PRO\_IND\_015)

Providers of AT did mention that they were aware of the importance of including the user with intellectual disability during AT assessment. Participants from group 2 highlighted an important facilitator for access to AT, namely networking and collaboration, to ensure assessments for different health needs. For example, the local rehabilitation centre worked closely together with other professionals to provide those ATs which the rehabilitation centre could not provide. Networking was mentioned as a substantial aspect of the work of the community fieldworkers.

## Empowerment

It is expected that empowerment of people with intellectual disabilities will lead to greater access to AT. It was mentioned that after liberalisation took place in India, people became more aware and demanding of their rights. However, various answers were given related to this topic. On the one hand participants stated a lack of advocacy.

Participant: *“Persons with mental illness and intellectual disability, they are not able to voice their needs..... We don’t have such an association who speak for them.”* (INT\_PRO\_IND\_010)

On the other hand, participants believed that people with intellectual disabilities were well able to advocate for themselves. During the interviews it became clear that the medical model of disability was still very much in place.

Researcher: *“Are there any ATs that she doesn’t have but she thinks she could use it?”*

Participant: *“She does not require any assistive device according to her [mother] when she [mother] is with her.”* (INT\_ID\_IND\_001)

The voice of the person with intellectual disability was often neglected.

Researcher: *“Do persons or their parents, do they always know what they need?”*

Participant: *“...Sometimes the children do express that need. But parents could deny that need, thinking that this person is not capable enough to express such needs.”*

Another participant: *“The needs expressed by the person and the caregivers are totally different. So many times we professionals go with the caregivers, neglecting the person with intellectual disability.” (INT\_PRO\_IND\_010)*

Perhaps as a reflection of the medical model, it was observed during the interviews that parents were often taking the lead in answering the questions for their child with intellectual disability, even though the person with intellectual disability would have been capable of answering questions.

Related to empowerment is having a day activity or employment, which can also function as an access point to AT (Boot et al, 2019). However, most of the participants did not have a day activity or employment.

## **Financial**

The government in India provides identity cards (Aadhar), below poverty level cards, and disability certificates, which assist in entitlement for a monthly pension for people with intellectual disabilities, travel concession passes and funding for certain ATs (Ministry of Railways, 2009; MoSJE, 2017). The introduction of disability certificates has resulted in carers taking their family members outside the home, instead of hiding them, in order to visit the health professionals and qualify for funding. The type and quality of AT funded by the government was limited to certain basic varieties. For example, communication devices were not eligible for government funding. In addition, the implementation of funding policies did not always happen, according to some participants.

Participant: *“They [the government] have formulated 10 schemes and they said that these schemes will be implemented now....Now after two years the whole thing is in a state of collapse. These 10 schemes are now put in cold storage. Why, they have no money. They don't release the funds for that.” (INT\_PRO\_IND\_014)*

People with intellectual disability or their families were not always in a position to afford ATs or afford the correct AT that would suit the person's need. In the Bangalore area there were some NGOs and charities to raise funds to support the

costs for ATs. Participants did notice a change in the AT market, making AT more affordable. However, specific ATs with a low demand remained very expensive.

### **Identification and Outreach**

Community fieldworkers played an important role in identifying people with intellectual disability and linking them to AT providers.

Participant: *“With these people we can definitely access the person who is in the far remote area of the village. We can identify the person with disability in a particular village and find out what are all his needs and bring him to the district level hospital and see that all the needs are fulfilled.”* (INT\_PRO\_IND\_011)

Community fieldworkers required the help of local leaders, such as ward councillors, who would know their area and are in touch with the community members. Yet it was not always known which community members had intellectual disabilities, and assessments rarely took place. The multilingualism in India was also mentioned as a big challenge to reach out to people with intellectual disability and their families.

### **Knowledge and Awareness**

Lack of knowledge and awareness regarding intellectual disabilities and AT, and the possibilities for AT to effectively address impairments, were often mentioned by the participants as a barrier to acquiring AT.

Participant: *“The receiver does not know what to ask for. The service provider also does not know what to offer. So there is a gap.”* (INT\_PRO\_IND\_002)

Some participants explained that they did not think about AT possibilities for people with intellectual disabilities because their main focus was on the intellectual disability aspect of the person. Parents often thought that AT would have a negative impact on their child’s development and were convinced the child did not need any AT, such as for example communication AT.

Participant: *“This is not going to make the child speak, so why are we doing this?”* (INT\_PRO\_IND\_009)

Participants were not aware of the higher prevalence of comorbidities among people with intellectual disabilities, and officials misunderstood the definition of intellectual disability.

Participant: *“According to them, intellectual disability means that they should have a mongoloid face, there should be liquid coming out from their mouth, and also they should be doing some seizure moments. If all of these are absent, according to them the child does not have intellectual disability.”* (INT\_PRO\_IND\_015)

The importance of training and education were clearly stated.

Participant: *“First we have to educate the people, then only whatever changes will come, we benefit. Otherwise it won’t work.”* (INT\_PRO\_IND\_013)

Opportunities noted for knowledge transfer and raising awareness included online training initiatives and peer learning activities organised by community fieldworkers or local leaders. The participants with intellectual disabilities all mentioned that they would ask their family members if they needed information on AT.

### **Physical Access and Transport**

The lack of accessibility was often mentioned as a barrier to access AT services.

Participant: *“The road....Any hospitals.....slowly it’s developing, but not everywhere. Only high-level hospitals, normal hospitals don’t have. If I go to any hospital or the dentist we have to carry him.”* (INT\_ID\_IND\_010)

To be physically able to travel is one thing, but people with intellectual disabilities often need cognitive support to be able to travel and to understand the information provided by the health professional.

Researcher: *“And how do you get to [X], if you need to go there?”*

Participant: *“Father will drop me.”* (INT\_ID\_IND\_003)

Instead of letting the user travel to different professionals, some professionals collaborated over the phone or online to discuss AT needs or customisation for a specific user. Sometimes on-site visits were organised to help people with intellectual disability who found it difficult to travel or simply lacked the money to do so.

### **Systemic Structural**

Lack of AT resources (services and professionals) especially in the rural areas was often mentioned by participants.



Participant: *“We do design, we do plan the programmes in such a way to reach the services and to reach the population, but due to lack of manpower, lack of qualified persons’ availability in the rural areas, it tends to be a difficult task.”* (INT\_PRO\_IND\_011)

Available AT services often did not provide professional help. Participants mentioned that people in India often buy ATs in the so called ‘surgical-pharmacy shop’ without any professional assessment or advice, and according to availability in the shop.

Participant: *“They usually don’t go to the rehabilitation centre because they are not aware. So straight they will go to the surgical shop. With brake, without brake, whatever, they will just buy it.”* (INT\_ID\_IND\_010)

Lack of policy implementation was stated as a systemic barrier to access AT.

Participant: *“The government has lots of schemes and grants for various kinds of assistive devices. But to access these grants is so difficult. There are so many channels, and so many things....to get the file moved from here to that ministry of Delhi, it becomes a nightmare.”* (INT\_PRO\_IND\_002)

The implementation of the Disability Act (2016) was limited.

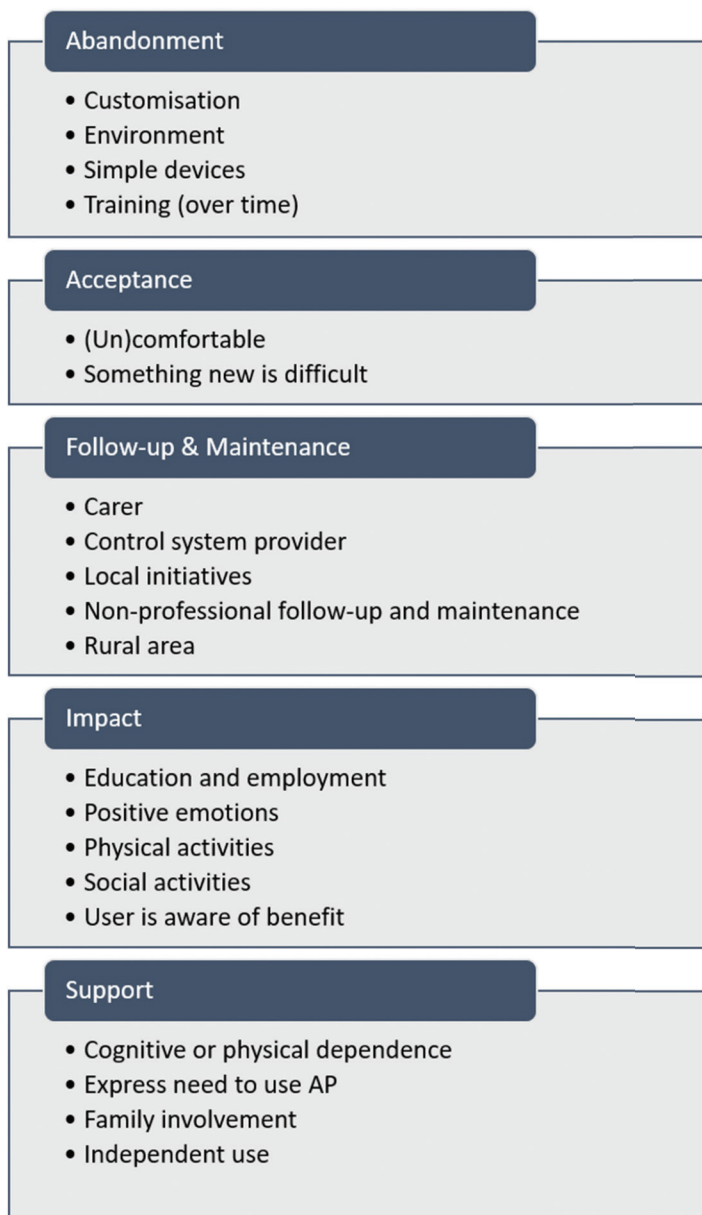
Participant: *“The Act is very clear, which is on paper. It doesn’t happen in reality.”* (INT\_PRO\_IND\_015)

The need for an AT policy adapted to the Indian context was often supported.

### **Theme 3 - Continued Use**

Data coding developed into five domains for continued use of AT: Abandonment; Acceptance; Follow-up and Maintenance; Impact; and, Support (see Figure 3). The meaning units were coded into 2-5 categories per domain.

**Figure 3: Domains and Categories for Continued Use**



### **Abandonment**

The importance of customisation to prevent abandonment of AT and ensure continued use was stated by all professionals. Parents and users were not aware of the advantages of customisation or the possibilities on offer. Those who acquired AT without assessment of a (health) professional did not receive customised

AT. In addition, AT acquired and funded through the government often did not involve a health professional and did not include customisation.

Participant: *“With the tender only a few fabricated assistive devices are available, for example, walker, crutches, wheelchair; one design for everyone. .... People are receiving the product that is not suiting them. Because government is free of cost, so they go and collect it. By the end of the day the collector tries to use it, they are not able to use it effectively. It’s not useful to them. So they keep the devices somewhere in stored places.”* (INT\_PRO\_IND\_001)

Logistical barriers also resulted in AT abandonment, such as the difficulty in transporting the AT from one place to another due to its size or the inaccessible infrastructure of India. It was stated that with the development of new technologies, AT had become easier to use for people with intellectual disabilities, and had resulted in less abandonment. Training was needed for people to understand how to use the AT which was provided. To prevent abandonment, training was essential for the users, for their caregivers, and also for people involved with their daily activities or employment.

Participant: *“I go to the workplace, where we explain to the employee this is what the person’s problem is; this is how he does work. This is what he needs to work. And this is what we’re providing him. And you should collect it from him every evening, send him home without that; when he comes back next morning, give it to him to use for during the work.”* (INT\_PRO\_IND\_015)

## **Acceptance**

If the person with intellectual disability felt comfortable using AT, the product was easily accepted. If there was any discomfort, the users did not want to use the AT.

Participant: *“She is not willing to use that shoe. She used to cry. When she used to wear that shoe, she would start crying, screaming, I don’t want this, like that.”*

Researcher: *“Do you think she also felt ashamed that she had to use it?”*

Participant: *“No not like that. She was not feeling comfortable, so she was screaming.”* (INT\_ID\_IND\_002)

Participants stated that acceptance of new AT can be difficult for people with intellectual disability and it takes time for them to get used to it.

## Follow-up and Maintenance

Users indicated that they did not know how often they would have to go for follow-up; they depended on their carers to indicate the need and arrange the follow-up. They also indicated that if their AT broke, they would go to a family member to ensure repair.

Researcher: *"How often do you have to go back to the shop, to check if the glasses are still ok?"*

Participant: *"My brother came and took me."* (INT\_ID\_IND\_013)

Frequent follow-ups, according to international standards, were not organised by most providers. Some families were very punctual regarding follow-up, but the majority would only attempt follow-up if the AT had broken down.

Participant: *"Maybe after 6 months. We ask for 3 months, but maybe after 6 months they come, because at that time the belt might be broken or they want to repair it. So not according to our instructions, but according to their need they may come, that way."* (INT\_PRO\_IND\_001)

As an alternative, some providers arranged for parents to contact them for follow-up if visiting the professional was not an easy option. For example, there was the option to phone the provider or send photos by email. Based on these photos, the provider could send the parts that were needed for the AT. Living in rural areas was definitely seen as a barrier to follow-up. The equipment needed to repair the AT would not be available in rural areas and people would not be able to travel to urban areas. This led to non-use of AT in some cases. Participant: *"Prescribed hearing aid, it expired after some time, but repair was not possible there. So we dropped it for some years."* (INT\_ID\_IND\_014)

Local initiatives where professionals would make on-site visits for follow-up were seen as a good method to ensure continuing contact with users. If individuals with intellectual disability lived at a great distance from the service provider, they would be allocated an option for follow-up and maintenance at a local centre. Community fieldworkers and self-help groups were mentioned as important facilitators to ensure follow-up when professional resources were scarce. Providers indicated the importance of follow-up and maintenance by a professional and not by people who are untrained or not equipped to do so. However, most parents did not see any problem in going to a non-professional shop. AT provided through the government did not receive any follow-up.

Participant: *“That’s a good question actually. No, we don’t have any follow-up.... We distribute to the people. Following up is not there.” (INT\_PRO\_IND\_005)*

## **Impact**

The impact or benefit that AT has for a user or the carer can be regarded as a very important facilitator for use of AT in daily life. Some participants were well able to describe the benefit of the AT they were using.

Researcher: *“And how will the crutches help you?”*

Participant: *“With the crutches I have a support and I’m able to slowly walk.”*

Researcher: *“Can you walk without the crutch?”*

Participant: *“No.” (INT\_ID\_IND\_003)*

Another participant attended adult classes where he used a recorder.

Participant: *“Sometimes volunteers won’t be available to explain to him [in classes]. Another thing, classes will be noted, so many classes he will miss, that time he uses recording.” (INT\_ID\_IND\_003)*

One aspect of impact was the emotions generated by using the AT, which could influence continued use.

Researcher: *“And how does it make you feel to use the iPad, does it make you happy or sad?”*

Participant: *“Happy, satisfied.” (INT\_ID\_IND\_007)*

Using AT also enabled some users to increase social interaction.

Researcher: *“Does it make her feel more included in society?”*

Participant: *“Yes..... All her difficulties e.g., school issues, she expresses [over the phone].” (INT\_ID\_IND\_004)*

## **Support**

Users frequently needed their carer to help them use the AT on a daily basis, either because they did not understand how to use a specific AT or were physically unable to do so. For example, a lot of adults with intellectual disability and motor disabilities enjoyed using the mobile phone to call friends or family, but they would need their parent to dial the number and hold the phone to their ear. Some users would forget to use their AT and depended on their carer to remind them.

Researcher: *“Do you remember yourself to use the glasses?”*

Participant: *“I know.”* [Mother does not agree, laughing]

Mother: *“For anything I need to remind him 10 times.”* (INT\_ID\_IND\_003)

To ensure continued use of AT, it helped if the users could indicate and say when they wanted to use their device.

Researcher: *“And it’s the phone of father?”*

Participant: *“Yes, father’s.....She can express that she wants to talk, then he [father] gets the phone.”* (INT\_ID\_IND\_004)

Providers indicated the importance of involving parents when new AT was acquired. When the family did not support the AT, the person with intellectual disability would not use it.

Participant: *“If we work with the whole family, the rehabilitation will happen. If you only do it for the person with disability [it does not work]....and if we withdraw, the family will take care.”* (INT\_PRO\_IND\_003)

If the person with intellectual disability were able to use the AT independently, without any support, continued use would be guaranteed. Some providers indicated the importance of working with them individually, to encourage independent use.

Researcher: *“Can you remember to get the crutch and use it, or does somebody help to remind you?”*

Participant: *“I take it.”* (INT\_ID\_IND\_012)

## DISCUSSION

This study presented the views and experiences of people with intellectual disabilities, their carers, local AT providers, health professionals and government officials in the Bangalore region of India, regarding access and continued use of AT for people with intellectual disabilities. The findings showed that stigma and negative attitudes towards intellectual disabilities were still present as an important barrier to access AT. Empowerment and self-advocacy were mentioned as opportunities to break this. However, the strong medical-model approach to disability seen within India may present a challenge to individual AT user empowerment. The medical model of disability may create low expectations for

some individuals with intellectual disability and may lead to individuals actively reducing independence, choice and control of their own lives. People with intellectual disability are seen as persons who need carers and professionals to make decisions for them. People with intellectual disability want to be empowered to individually choose and use AT, but they cannot do this in an environment that is not supportive of such choices (Shogren and Broussard, 2011). While in Indian policy documents there has been a shift from a charity model to a rights-based model, in daily practice this shift remains limited for people with intellectual disability (Chavan and Rozatkar, 2014).

Another important barrier to access AT was a lack of knowledge and awareness on the impact and possibilities of AT for people with intellectual disability. First, the possibilities of AT to support people with intellectual disability in their limitations of cognitive functioning were not known; none of the participants were using any type of AT which supported cognition. Second, AT which could be used to support any co-existing impairments or health problems that the person with intellectual disability might have, was often not assessed; it was found that it was difficult for carers, or others involved, to look beyond the intellectual disability of the person. Parents also had difficulties in accepting their child with intellectual disability, as they had expectations for typical development, which in turn led to a non-acceptance of supporting AT, e.g., communication AT. This expectation of typical development was, on occasion, fed by health professionals providing parents with incorrect information on intellectual disability, including the changes to be expected over the course of an individual's life. Increasing knowledge and providing education on intellectual disability and assistive technology for both professionals and carers was mentioned as a facilitator to increase access to AT. Methods of knowledge transfer and education around AT that participants mentioned were via interactions with community fieldworkers and by accessing information online. E-learning is often defined as the use of online information technology to enhance or support learning. E-learning is becoming more frequently used as a method of delivering education and training in isolated and rural areas, and it has been suggested that E-learning is a potential sustainable option for capacity building in low- and medium-resource countries (Karly Michelle et al, 2015). Indeed, E-learning through mobile devices could be applicable, as smartphones are becoming more affordable worldwide. However, it will remain a challenge to ensure that E-learning is accessible and adjusted to the specific needs of people with intellectual disabilities.



Abandonment was found to be an important barrier which negatively influenced continued use of AT by people with intellectual disability. Factors which led to abandonment were the lack of customised ATs, unsuitable environments to use AT, and a lack of training over time. As this study also showed, people with intellectual disability often need daily support from their care system to use (or be reminded to use) the AT. For a person with intellectual disability to be capable of using AT independently, training that is adjusted to the level of the respective intellectual disability is needed during the introduction of AT. In addition, recurrent training is required to remind the user how to use the AT over time. Training methods also have to be adjusted to the communication method preferred by persons with intellectual disabilities e.g., use of visuals and gestures (van Schrojenstein Lantman-de Valk and Walsh, 2008).

### **Recommendations**

The findings of this study can be used to inform and adjust AT implementation programmes of countries whose aim is to improve access to AT for people with intellectual disabilities. The barriers and facilitators related to AT for people with intellectual disabilities are different from other vulnerable populations and should be taken into account in country-specific policies and frameworks. AT can have a huge impact on the quality of life and inclusion for people with intellectual disabilities. Training programmes on AT selection and use should be implemented to support community-based initiatives to identify people with intellectual disabilities and refer them to the appropriate services.

### **Challenges and Opportunities**

The health needs of people with intellectual disabilities are often unrecognised and unmet (Hatton and Emerson, 2015). This is also reflected in a lack of assessments and under-diagnoses of health problems, such as hearing and vision loss, which could be better managed with AT. People with intellectual disabilities have twice as many health problems as the general population (van Schrojenstein Lantman-de Valk and Walsh, 2008). Outreach and identification of people with intellectual disabilities and, if possible, their cause, need to be prioritised in order to proactively screen for health problems in these people. Intellectual disability assessments are needed, to know which members of the community actually have the condition. It may be particularly important to identify people with mild intellectual disability who often go unrecognised. The government in India has

shown commitment to improve information on epidemiology, support systems and services for people with intellectual disabilities in the country, but there is still a long way to go (Girimaji and Srinath, 2010). The results of the current study also indicate the importance of aiming to address the five strategic Ps - policy, products, personnel, provision and people - whilst also taking into account the five contextual Ps - procurement, promotion, pace, partnership and place - which strongly influence the extent to which the strategic Ps can be addressed, and may suggest alternative ways of doing this, through a systems-thinking approach (MacLachlan and Scherer, 2018).

## CONCLUSION

The findings of this study provide opportunities to support implementation of the UNCRPD through AT and to advance population health by realising basic human rights for people with intellectual disability. Countries such as India, who have ratified the UNCRPD and who have also agreed to work towards the achievement of the SDGs, will need to take action to realise these commitments, so that every person with intellectual disability in need of AT can have access to quality affordable products.

## ACKNOWLEDGEMENT

The authors would like to thank all the staff and service users from Mobility India for their collaboration.

This research was supported by funding from the charity RESPECT and the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme (FP7/2007-2013) under REA grant agreement no. PCOFUND-GA-2013-608728.

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