



# DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

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## Editorial

### What do Covid-19, Conflict and Climate Change have in common?

At first sight these three challenges have nothing in common except that all three issues start with the letter 'C'. However, on taking a closer look, one may recognise more similarities than are apparent at first sight.

Rapid demographic and epidemiological transitions are increasingly posing a threat to the world in which we live. For instance, the Covid-19 pandemic has seen significantly higher morbidity and mortality levels, which brought healthcare systems in some countries to the verge of collapse. We do not know as yet how many people will end up with disabilities as a result of long-Covid, but we do know that it has had a great impact on the functioning of people and, in all likelihood, may cause serious socio-economic consequences in many lives.

While there have always been conflicts and wars, one notices at this moment geopolitical developments with dormant conflict in several parts of the world. Large populations, especially in remote places, face the results of 'old and forgotten' wars. Autocratic leaders continue to ruthlessly murder thousands of innocent people. While we see and read about those who are killed, seldom do we hear about the number of people who end up with permanent disabilities, both physical and mental.

Do we realise that the effects of climate change will be pretty serious for many countries and communities, affecting the lives of the poor rural (and urban) population with disability the most?

You may argue – and I am happy if you do so – that these three aspects have only one thing in common: the letter 'C'. As part of a recent evaluation of a large number of community-based rehabilitation programmes, we had a discussion with the director of a large organisation, who was convinced that these are the three main challenges that countries like India - in general - are facing. On further reflection, I realised that this is not just a prophetic perspective but in fact is already part of the global situation. While some among us do not want to recognise it, for many this has already become reality: the daily threat of survival for people with and without disabilities. The sad thing is that those who live in wealthy countries, with access to good healthcare, to the most recent therapies and high-tech interventions, have been feeling more or less autonomous until

faced with the threat of war. Look at what is happening in Europe, with Ukraine being destroyed by a ruthless dictator and his war machine, along with gross violation of human rights on a massive scale.

Amid these developments we – rightfully – continue to talk about the inclusion of people with disabilities. We develop grand plans, new ideas and new terms. We argue and disagree with each other, but, most often, we do this without including people with disabilities themselves. We may invite organisations of people with disabilities but how often are those who are most affected, those living in absolute poverty, being heard? It is the well-educated elite that is heard, as much as it is the powerful international agencies and organisations that make the decisions.

Most of the readers, like me, are not policymakers, but the perspective of what we are seeing and what we are hearing from the field is the basis for our reflections and actions.

Policymakers need to recognise that the divide between the wealthy and middle-class on one hand, and the (ultra) poor on the other, has become bigger during the past decades and that this is a recipe for (further) conflict. Those who are poor and living in low- and middle-income countries are most affected by Covid-19, conflict, and climate change. The - at times small - NGO programmes supported by development agencies (some known to be working in the field of disability but many others who are not at the forefront of our discussions) often form the only source of assistance for people with disabilities. Their situation will not change soon. Governments may have a complete disinterest in the (ultra) poor but of course they will not tell you. Ratification of the UNCRPD is by no means a guarantee that anything has changed or will change for the ultra-poor, with and without disabilities. As long as there is no access to the most essential basic resources and the most basic rights are not being met, do not expect that people are much interested in 'hearing about higher level individual rights'. We need, in my view, a wake-up call about the real situation, the reality, and not the parallel universe in which some people and organisations operate.

What actions are needed?

- Listen carefully to people at the grassroots: you may not hear the development jargon but if you take time to truly listen, you will certainly hear about their needs, concerns, hopes, and dreams.

- Ensure that the WHO in its Rehab-2030 strategy emphasises the importance of creating and facilitating access to rehabilitation for the (ultra) poor, with and without disability. This means that emphasis should not be placed on increasing the numbers of highly trained rehabilitation professionals. It will simply take too long to get them interested in working in the conditions we are talking about. The WHO and others should emphasise the need for well-trained mid-level rehab workers who can deliver meaningful services to people with the most common conditions and disabilities. Thousands of them are needed; governments need to be made aware of this, and good quality training, support and supervision need to be offered. A true advocacy task for (influential) UN bodies such as the WHO!
- These mid-level rehab workers would need support and supervision from professionals, as they require training for a different role than those who work in affluent societies. Copying western care and rehabilitation systems is not the solution. Copying western training is assuredly not the answer to the reality of the rural and urban poor. Instead, face the criticism one will receive from professional boards and develop curricula that fit the local situation. Realise that professionals and their organisations have vested interests; do not be naïve! Allow for flexibility and be bold to oppose western standards.
- Study innovative models, e.g., the government of Nepal started a CBR programme with hundreds of CBR field staff employed by government in Province No.1.
- Build capacity of national OPDs and help them become true watchdogs. But, at the same time, realise that this often requires a lot of careful manoeuvring in terms of used terminology, actions, advocacy/lobby, given that a large number of countries have political systems that do not allow activities that may be seen as subversive.

We should see and recognise the **community** as key to the furtherance of disability inclusion. Disability inclusive development should be based on three elementary values: **solidarity**, **social justice** and **social friendship**. Such an approach, based on classical principles of community development, offers – in my view – more direction for the future than any debate about terminology.

Community engagement and participation were important principles of the Alma Ata Declaration in 1978 and are in line with the Primary Health Care movement, as well as with Community-based Rehabilitation. More than 40 years later, this

sounds like a faraway dream. Social movements and activists defending rights are facing increasing pressure all over the world and citizens' control stands at an all-time low in an increasing number of countries.

Isn't it time to start with more bottom-up processes, helping communities to help themselves, including those who are with disability? Isn't it time to think with the broader movement for human rights on how we can strengthen social movements that are inclusive for all, and work towards more control of communities in their own development?

Huib Cornielje  
Editor-in-Chief  
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## ORIGINAL RESEARCH

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# Assistive Devices for Persons with Visual Impairment and Low Vision: Preferences and Expectations of Users in the Southern States of India

Tagore Govindarajan\*

### ABSTRACT

**Purpose:** *Persons with visual disabilities use various assistive devices to support, uphold or progress in their functional abilities. Under the ADIP scheme of the Government of India, persons with any form of disability are provided with assistive devices to suit their needs. This study focused on finding out the preferences of persons with visual impairment in selecting and using their assistive devices. It also aimed to understand their expectations and measures for assessing the utility of assistive devices.*

**Method:** *Data was collected by using semi-structured interview schedules from 227 respondents in the Southern States of India and the Union Territory of Puducherry (Pondicherry). The expectations and suggestions made by the study sample are discussed in detail.*

**Results:** *Assistive devices of any sort are considered in terms of durability, availability and suitability. The study findings revealed that 90% of the users preferred assistive devices such as Braille Slate-Interpoint A4, Taylor Frame, Daisy Player, JAWS Screen Reading Software, NVDA Screen Reading Software, Chessboard and Audible Cricket Ball, which were extremely helpful for their independent living. They had used most of these assistive devices in the optimal way.*

**Conclusion:** *Assistive devices distributed to persons with visual impairment under various schemes are beneficial in enhancing their progress in education, employment, social participation and recreational aspects of life. The expectation of the respondents/users was that assistive device services be made easily accessible.*

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*Key words: assistive devices, visual impairment, expectations, preferences*

## INTRODUCTION

As per Census 2011, it has been estimated that the population of persons with disabilities in India is 2.68 crore, or 2.21% of the total population of the country. The total number of people with visual disabilities constitutes 19% of the population with disabilities (NSSO, 2016). Assistive devices play a pivotal role in fostering independence with or without minimal assistance, thereby paving the way for all-round rehabilitation and social inclusion. Assistive devices provide the means to access and participate in educational, vocational, social, and recreational opportunities, empower greater physical and mental function, improve self-esteem, and reduce costs for educational services and individual support (Alquraini & Gut, 2012). The use of assistive devices enhances the functional abilities of persons with disabilities and improves community participation. Active participation of these individuals in the community contributes to their own well-being as well as the development of an inclusive society for all.

Even though the use of assistive devices has its developmental dimension, many people with disabilities and their families are unaware of assistive products and services (Kamaleri & Eide, 2011). The development of assistive technology does not always follow user needs and expectations, thereby affecting its usability and effectiveness (Paredes, Fernandes, Martins & Barroso, 2013). The high costs of specialised devices acts as a deterrent to using assistive technology (Brady, Thies & Cutrell, 2014). Furthermore, assistive technology services are often scarce and located far from the homes of people with disabilities (WHO, 2011).

These statements express the various concerns related to the use of assistive devices. The present study focused on filling in a few of the abovementioned gaps by gathering multidimensional data about the usefulness of assistive devices and users' expectations of the products. This information reflects the practical usability of assistive devices and how effectively they manage to fulfil the functional needs of people with disabilities.

International mandates issued by statutory bodies such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the Incheon Strategy, and legislation like "The Rights of Persons with Disabilities Act, 2016", emphasise the role of assistive devices in providing accessibility and developing independence for people with disabilities. The government of India

has taken many steps to implement these mandates. The National Institute for the Empowerment of Persons with Visual Disabilities (Divyangjan) (NIEPVD), located in Dehradun, is an apex organisation working under the Ministry of Social Justice and Empowerment to produce assistive devices for persons with visual impairment and distribute them at an affordable cost (NIEPVD, 2022). Additionally, the Artificial Limbs Manufacturing Corporation of India (ALIMCO) has been set up to manufacture and supply quality aids and appliances at an affordable cost.

Assistive devices which are commonly used by persons with visual impairment are manufactured by ALIMCO, NIEPVD and other organisations within and outside the country; these are procured and distributed under the scheme of “Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances” (ADIP). Since the ADIP scheme is sponsored by the government, the costs of the devices are low, and the population with low economic status in the country is mainly targeted through this scheme. This scheme also creates awareness about assistive devices among people with disabilities and their organisations. In addition, the Government of India runs ADIP camps and gives assistive devices to people with all kinds of disabilities in all parts of the country (DEPwD, 2022).

With this background, the current research study was undertaken to identify the usefulness of aids and appliances used by people with visual disabilities. The study considered the software commonly used by persons with visual impairment and the assistive devices that are distributed through the ADIP scheme.

The users’ feedback about usefulness, preferences and drawbacks/difficulties of using the devices was consolidated, and their suggestions were elicited for enhancing the use of assistive devices.

### **Description and Functional Importance of Assistive Devices selected for the Study**

Assistive devices that are universally used were selected for this study. The basic structure and function of the majority of these devices are the same globally and there are minimal adaptations depending on the manufacturers.

#### **Devices for Independent Living**

The three types of canes listed below ensure that people with visual impairments have reliable mobility, allowing them to develop self-confidence in their pursuit

of education, employment, and social inclusion.

- *Rigid White Cane (Long Cane)*: Non-foldable stick.
- *Folding White Cane*: A stick with four or five segments that are joined and foldable with the help of an elastic band.
- *Smart Cane*: A small sensor attached to the stick which detects obstacles up to a distance of 3 metres in front.

The devices listed below are used to identify the time independently:

- *Talking Wristwatch*: This is a watch that has audio features.
- *Braille Wristwatch*: Embossed dots present in the watch help to indicate the time.

## **Devices for Education and Employment**

### **a) Software**

Screen reading software converts the text that appears on the computer screen into speech, which enables people with visual impairments to access the content. This software facilitates their education and provides various employment opportunities in computer-oriented jobs. JAWS (Job Access with Speech), NVDA (Non Visual Desktop Access), Orca and Narrator are universally used screen reading software. Apart from these, screen reading software such as Talks, eSpeak, Google text-to-speech, Shine Plus, VoiceOver and TalkBack are used on mobile-based platforms.

Screen magnification software assists in magnifying the contents on the computer screen, thereby enabling people with low vision to access the content. This software enhances the education and employment of people with low vision. MAGic, Dolphine SuperNova, Microsoft Magnifier, Orca and ZoomText Magnifier are some of the most popularly used computer-based screen magnification software. Software like Talks&Zooms and Mobile Speak are used to make the screen bigger on mobile-based apps.

### **b) Reading and Writing Devices**

The following devices are used universally for the education of persons with visual impairment and low vision. These modified devices make the teaching

and learning process easier. Small variations are present in the devices that come from different manufacturers.

### **i) Braille reading and writing devices**

Braille is a system of tactile reading and writing for people with visual impairments, in which raised dots represent the letters of the alphabet, numbers, punctuation, etc. Documents in Braille format are accessible to people with visual impairments.

For Braille writing, Braille Slate-Interline (small and large), Braille Slate-Interpoint A4 and a Pocket Writing Frame are used. A Round Head Stylus and a Concave Head Stylus are used to make the embossment on the Braille paper. Embossed dots present in the Braille Scale are used to identify the measurement markings. A Brailler is a typewriter used to type Braille letters. A Braille shorthand machine is used to take down shorthand instructions in Braille, just like in other languages. The Signature Guide assists people with visual impairments to sign the correct place in the document.

### **ii) Mathematical devices**

A Taylor Frame is a device used by people with visual impairment to do mathematical calculations. The abacus (Cranmer) is a simple instrument for performing rapid arithmetic calculations. People with visual impairment can use the Modified Geometric Mathematical Kit to access geometry content. Tactile markings on the measuring tape help to identify measurements. A set of embossed diagrams in the mathematics and science content helps people with visual impairments to understand the concepts easily. A tactile Drawing Board assists in creating embossed diagrams.

A Radio-cum-CD player plays the content in audio format. The Daisy Player is a mobile phone-like device that has the features of reading books in DAISY format (Digital Accessible Information System), audio books, text documents and supporting MP3 music files. These devices are used by people with visual impairments to listen to audio-formatted content.

### **Low Vision Devices**

Low vision devices are used to magnify the contents for people with low vision. Spectacles enable people with low vision to see objects magnified through

aspheric lenses. The Illuminated Handheld Magnifier provides magnification facilities along with illumination features. The handy Tabletop Magnifier is ideal for magnifying printed matter, artworks, maps, etc., by moving the Stand Magnifier over the content of the material placed on the table.

## **Recreational Devices**

Simple changes made to regular playing materials allow people with visual impairments and low vision to actively participate in sports and games. The Audible Cricket Ball enables the player to locate the ball by tracking the sound. Devices like the adapted chessboard and playing cards provide an inclusive playing environment in which people with visual impairments and sighted people can play together.

## **Objectives**

The study had the following objectives:

- To find out the usefulness of already existing assistive devices for persons with visual impairment and low vision.
- To identify the preferences for selecting the existing assistive devices.
- To find out the reasons for the non-use of the devices.
- To find out the expectations of the users.
- To suggest measures to improve the usability of assistive devices for persons with visual impairment and low vision.

## **METHOD**

### **Study Design**

The study is descriptive in nature. It has two components. The quantitative part describes the percentage of sample responses, which indicate the usefulness and preference for the devices. The qualitative part describes the useful features of the individual device, reasons for preferring the device, shortcomings of the device, expectations and suggestions from the end-user.

### **Sampling**

Organisations working for persons with visual impairment and low vision in the Southern States of India (Tamil Nadu, Kerala, Andhra Pradesh, Telangana, Karnataka and the Union Territory of Puducherry) were selected for this study through a stratified random sampling technique. The samples from the individual organisations were selected through a simple random sampling technique. They consisted of 227 persons with visual disabilities who use any kind of assistive device.

### **Study Instruments**

A semi-structured interview schedule was prepared and pilot tested. Content validity was obtained from professional experts. The semi-structured interview schedule consisted of four components. The first part covers personal information; the second part has a 5-point rating scale to assess the usefulness of the assistive devices; the third part consists of questions related to ranking the preferred devices and new devices to be designed; and the fourth part gathers information regarding the useful features of the device, reasons for preferring the device, its drawbacks, reasons for discarding it, the user's expectations about the device and suggestions to improve its usability.

### **Data Collection**

Data was collected from 26 organisations situated in the southern parts of India.

The interview schedule was administered to 227 persons with visual impairment, to collect details about the devices. The duration of the interviews ranged from 1 - 1½ hours. The interviews were conducted on a one-to-one basis with 101 persons with visual impairment. Data was also collected from 24 small groups (each group consisting of 3-6 persons with visual impairment) in places such as special schools. Since many students were available at the same location and the interview questions were the same for each person, this mode was chosen for data collection. The interviews were recorded with the consent of the individuals.

### **Data Analysis**

The percentile representations and mode were used to describe the sample responses. The responses were described qualitatively in the report and were consolidated. A single technical committee was formed to analyse the consolidated responses to all the devices and the suggestions received. The committee

examined the different dimensions of the responses, like technical aspects, service delivery, manpower availability, etc., and checked the authenticity of the feedback; for example, whether the problems stated by the respondent due to a lack of awareness. The committee also checked the feasibility of the suggestions made by the users.

### **Ethical Considerations**

In the present study, there was no risk to the physical and mental well-being of the respondents. The purpose and outcomes of the research were intimated to the respondents and a consent letter was obtained from each individual prior to the interview.

## **RESULTS and DISCUSSION**

### **Respondents' Background Characteristics**

The sample population consisted of 227 people, of whom 145 (63.88%) were people with visual impairment and 82 (36.12%) were people with low vision. There were 84 (37%) female respondents and 143 (63%) male respondents. Among them, 180 (79.30%) had the onset of disability before the age of 3 years and 47 (20.70%) acquired the disability after the age of 3 years. The respondents' age range was from 9 to 57 years, and the average age was 23.33 years (SD = 11 years). Table 1 gives insight into the categories of the respondents for this study sample.

**Table 1: Categories of Respondents for the Study**

Sl. No.	The Category of the Respondent	No. of Samples	Percentage (%)
1	School student	68	29.96
2	College student	91	40.09
3	Vocational trainee	13	5.73
4	Unemployed	2	0.88
5	Govt. employed	19	8.37
6	Self-employed	2	0.88
7	Private employed	32	14.10
	<b>Total</b>	<b>227</b>	<b>100.00</b>

Since most of the devices under consideration were relevant to the field of education, more students with visual impairment took part in this study.



## The Usefulness of Assistive Devices for People with Visual Impairment or Low Vision

The usefulness of assistive devices has been measured by two different methods.

1. The users were asked to express the level of usefulness of each device on a 5-point Likert scale. The scores were coded as: '1-Not at all useful', '2- Slightly useful', '3-Somewhat useful', '4-Very useful', and '5-Extremely useful'.
2. The users were asked to describe the useful features of their individual assistive devices.

Tables 2 to 6 summarize the usefulness of various assistive devices for various life domains .

**Table 2: Level of usefulness of 5 different Assistive Devices for Independent Living of People with Visual Impairment**

Sl. No.	Type of Assistive Device	1		2		3		4		5		Total No. of Users
		N	%	N	%	N	%	N	%	N	%	
1	Rigid White Cane (Long Cane)	0	0.00	12	19.05	26	41.27	17	26.98	8	12.70	63
2	Folding White Cane	0	0.00	3	1.95	24	15.58	56	36.36	71	46.10	154
3	Smart Cane	1	1.23	13	16.05	18	22.22	18	22.22	31	38.27	81
4	Talking Wristwatch	1	0.65	2	1.30	26	16.88	44	28.57	81	52.60	154
5	Braille Wristwatch	0	0.00	3	3.19	15	15.96	24	25.53	52	55.32	94

**Table 3: Level of usefulness of Educational Software for People with Visual Impairment**

Sl. No.	Type of Assistive Device	1		2		3		4		5		Total No. of Users
		N	%	N	%	N	%	N	%	N	%	
<b>Screen Reading Software – Computer</b>												
1	JAWS(Job Access with Speech)	0	0	0	0	4	2.06	43	22.16	147	75.77	194

2	NVDA(Non Visual Desktop Access)	1	0.69	4	2.78	7	4.86	59	40.97	73	50.69	144
3	Inbuilt Screen Reading options in Computer (ORCA)	0	0	1	3.33	1	3.33	11	36.67	17	56.67	30
<b>Screen Reading Software - Mobile Phone</b>												
4	eSpeak	0	0	0	0	4	10.81	9	24.32	24	64.86	37
5	Talks	0	0	0	0	0	0	8	32	17	68	25
6	Shine Plus	0	0	0	0	0	0	0	0	4	100	4
<b>Inbuilt Screen Reading option in Mobile Phones</b>												
7	TalkBack	0		0		15	14.56	31	30.09	57	55.33	103
<b>Screen Magnification Software</b>												
8	Computer-based Screen Magnification Software (MAGic)	1	6.67	0	0	4	26.67	8	53.33	2	13.33	15
9	Inbuilt Screen Magnification options in a Computer	3	8.57	0	0	5	14.29	18	51.43	9	25.71	35
10	Screen Magnification Software – Mobile Phones	0	0	0	0	3	6.00	14	28.00	33	66.00	50
11	Inbuilt Screen Magnification options in Mobile Phones	0	0	0	0	7	10.45	19	28.35	41	61.19	67

**Table 4: Level of usefulness of Educational Devices other than Software for People with Visual Impairment**

Sl. No.	Type of Assistive Device	1		2		3		4		5		Total No. of Users
		N	%	N	%	N	%	N	%	N	%	
<b>Reading, Writing and Mathematical Devices</b>												

1	Braille Slate-Interline (Small and Large)	10	9.35	19	17.8	15	14.02	22	20.56	41	38.32	107
2	Braille Slate-Interpoint A4	0	0	2	0.93	3	1.39	39	18.06	172	79.63	216
3	Round Head Stylus	18	8.78	17	8.29	32	15.61	70	34.15	68	33.17	205
4	Concave Head Stylus	3	1.62	6	3.24	21	11.35	34	18.38	121	65.41	185
5	Pocket Writing Frame	1	0.88	5	4.42	27	23.89	38	33.63	42	37.17	113
6	Signature Guide	2	3.64	2	3.64	22	40	12	21.82	17	30.91	55
7	Taylor Frame	3	1.6	0	0	9	4.81	36	19.25	139	74.33	187
8	Abacus	2	1.54	5	3.85	30	23.08	32	24.62	61	46.92	130
9	Geometric Kit	1	0.9	6	5.41	33	29.73	38	34.23	33	29.73	111
10	Measuring Tactile Tape	0	0	2	2.89	12	17.39	29	42.02	26	37.68	69
11	Braille Scale	0	0	4	3.28	31	25.41	45	36.89	42	34.43	122
12	Tactile Diagram Set	0	0	1	1.54	11	16.92	30	46.15	23	35.38	65
13	Braille Shorthand Machine	0	0	1	7.14	5	35.71	1	7.14	7	50	14
14	Braille	0	0	5	2.98	15	8.93	44	26.19	104	61.9	168
15	Tactile Drawing Board	0	0	0	0	17	38.64	12	27.27	15	34.09	44
16	Radio- cum-CD Player	2	1.18	1	0.59	27	15.88	61	35.88	79	46.47	170
17	Daisy Player	0	0	1	0.73	10	7.25	27	19.56	100	72.46	138

**Table 5: Level of usefulness of Low Vision Devices**

Sl. No.	Type of Assistive Device	1		2		3		4		5		Total No. of Users
		N	%	N	%	N	%	N	%	N	%	
1	Spectacle	0	0.00	0	0.00	5	26.32	3	15.79	11	57.89	19
2	Illuminated Handheld Magnifier	1	7.69	2	15.38	2	15.38	6	46.15	2	15.38	13
3	Stand Magnifier	3	42.86	0	0.00	1	14.29	2	28.57	1	14.29	7

**Table 6: Level of usefulness of Recreational Devices for People with Visual Impairment**

Sl. No.	Type of Assistive Device	1		2		3		4		5		Total No. of Users
		N	%	N	%	N	%	N	%	N	%	
1	Chessboard	0	0.00	2	1.05	6	3.14	32	16.75	151	79.06	191
2	Braille Playing Cards	6	6.52	7	7.61	14	15.22	23	25.00	42	45.65	92
3	Audible Cricket Ball	0	0.00	0	0.00	10	5.71	24	13.71	141	80.57	175

The description and functional importance of each of the devices mentioned above are described in the earlier section.

The respondents stated that they found devices like JAWS Screen Reading Software, Braille Slate-Interpoint A4, Chessboard, Audible Cricket Ball, Mobile Screen Magnification Software, Taylor Frame, Orca Screen Reading Software, Daisy Player, NVDA Screen Reading Software and Talks Screen Reading Software extremely useful. This is clearly reflected in the score of more than 90%, which is the combination of scores for extremely useful (rating 4) and very useful (rating 5).

At the next level, devices like Inbuilt Screen Magnification options in Mobile Phones, eSpeak Screen Reading Software, Braille, TalkBack Screen Reading Software, Concave Head Stylus, Folding White Cane, Radio-cum-CD Players, Tactile Diagram Set, Talking Wristwatch and Braille Wristwatch got scores ranging from 81% to 90% (rating 4 and rating 5) from the users. Except for the Stand Magnifier and Rigid White Cane, all the devices had a score of 50% (rating 4 and rating 5) or higher from the users. Assistive devices are being distributed at present under the ADIP Scheme for persons with visual disabilities, either manufactured by NIEPVD or other agencies, and the software considered in the present study is extremely useful for the end-users.

Independent mobility is one of the most important requirements for persons with visual impairment in order to attend school, work, and other social gatherings. Advancements in mobility devices and mobility training enable them to move independently and actively participate in community life. Devices like Braille wristwatches and talking watches reduce their dependence on others for assistance in time management.

Inaccessible educational materials and inappropriate teaching strategies act as impediments to the educational advancement of people with disabilities. Adaptations in educational materials and teaching methodologies make education accessible to people with visual impairment. The aforementioned educational tools and software play an important role in ensuring that students with visual impairments receive the education they require.

The majority of workplace content is only available in print and consequently inaccessible to people with visual impairment. This situation restricts their ability to perform particular jobs. Screen reading software, screen magnification software, and other assistive devices make it easier for them by converting printed materials to audio format or by magnifying the content. This creates lots of employment opportunities for people with visual impairments in computer-oriented jobs.

Recreational and leisure activities are important elements in every person's life. Due to a lack of adapted playing materials, people with visual impairments stay away from most games. Recreational devices like adapted chessboards, audible cricket balls and playing cards provide the opportunity for people with visual impairments to actively participate in sports and games.

According to users, the most useful features of the specific devices are as follows:

- The alarm facility in the talking wristwatch is useful (24.67%, n=38).
- The Braille wristwatch has better durability than the talking wristwatch (11.70%, n=11).
- eSpeak screen reading software for mobile phones supports regional languages like Tamil, Malayalam, etc., (27.03%, n=10). It also has different voices and options for modifying the voice (8.10%, n=3). It automatically converts the speech output as per the language of the text (5.40%, n=2).
- JAWS Screen Reading Software has good audio clarity (7.73%, n = 15) and good English pronunciation (4.12%, n = 8).
- NVDA Screen Reading Software supports regional languages like Tamil, Malayalam, Telugu, Kannada, etc., (23.61%, n = 34).
- Folding White Cane is portable in nature (27.92%, n = 43).
- Users can easily identify obstacles when using the Smart Cane (6.17%, n = 5).

- Braille Slate-Interpoint A4 helps to take notes easily in the classroom (3.70%, n = 8).
- The Concave Head Stylus does provide a good grip while writing, as it has been equipped with a good grasping handle. Therefore, writing is not only easier but also faster (18.92%, n = 35).
- The Pocket Writing Frame is handy in size and therefore can be carried and handled with ease (13.27%, n = 15).
- The Tactile Diagram Set is effective for teaching science and mathematics concepts through embossed pictorial presentations (6.15%, n = 4).
- Recording clarity is good in DAISY Player (16.67%, n = 23).

### **Preferences in Selecting the Existing Assistive Devices**

Two distinct methods were used to collect data on user preferences for assistive devices.

1. The users were asked to rank the various assistive devices in order of preference.
2. The respondents were asked to describe their reasons for preferring a particular device.

As per the results obtained, the users prefer Daisy Player (68.84%, n = 95), Braille Slate-Interpoint A4 (68.52%, n = 148), Folding White Cane (51.30%, n = 79), JAWS Screen Reading Software (50.52%, n = 98), Taylor Frame (42.78%, n = 80), Chessboard (40.84%, n = 78), Audible Cricket Ball (36.00%, n = 63), Smart Cane (28.40%, n = 23), NVDA Screen Reading Software (27.08%, n = 39), Braille (26.19%, n = 44), Talking Wristwatch (25.97%, n = 40), TalkBack Screen Reading Software (23.30%, n = 24) and Braille Wristwatch (22.34%, n = 21). The respondents from Kerala preferred Orca Screen Reading Software (53.33%, n = 16).

The major reasons stated by the users, for preferring a particular assistive device, are as follows:

- By using the Rigid White Cane, as compared to other types of canes, the users can identify obstacles clearly (12.69%, n = 8).
- The Folding Cane is preferred over the Smart Cane because the Smart Cane vibrates constantly when there are objects and confuses the user finding the right path (4.54%, n = 7).

- The Talking Wristwatch can be used by people with visual impairment who do not know Braille (5.84%, n = 9).
- While using the JAWS, language proficiency skills are improved (1.03%, n = 2).
- In comparison to the Round Head Stylus, the Concave Head Stylus is more comfortable. (3.78%, n = 7).

### **Reasons for Non-use of Assistive Devices**

The users were asked about the minimal use or non-use of their devices. They were asked to give their reasons for not using any particular device.

- There were hardly any minimally used or non-used devices. However, it was pointed out that the Talking Wristwatch becomes unusable due to a lack of repair facilities, so users prefer to purchase a new watch instead of repairing it (42.85%, n = 66).
- Due to the limited/remote possibility of repair facilities, the Daisy Player (29.71%, n = 41) and Brailier (6.55%, n = 11) are not in use.
- Due to a lack of training (16.21%, n = 18), the Geometric Kit is not used.

### **Users' Expectations regarding Assistive Devices**

The users' expectations have been elicited in two different ways.

They were asked to respond to the following questions:

1. Mention the assistive devices needed but not available on the market or yet to be designed.
2. Describe their expectations of individual assistive devices.

The participants expressed their desire to use new assistive devices compatible with their growing needs. Assistive devices like bus number identifiers (n = 22) and Optical Character Recognition Software in the Regional Languages (n = 11) are much anticipated devices by the majority of users, and also devices (n = 4) and Audible Power Bank (n = 1).

Major findings about the expectations of the specific devices, as stated by the users, are:

- A standard - size Talking wristwatch is desired instead of a large - sized watch (9.74%, n = 15).
- JAWS Software could support more Indian regional languages (11.86%, n = 23).
- The accent and pronunciation in NVDA software can be changed to sound more like a human voice (8.33%, n = 12).
- Large size Taylor Frame may be introduced again to facilitate bigger calculations (6.95%, n = 13)
- Training is needed for using the Geometric Kit (14.41%, n = 16).
- Audio output in regional languages is needed in DAISY Player (Plectalk) (4.35%, n = 6).
- People with visual impairments need a bigger chessboard so that they can play with their sighted friends (8.38%, n = 16).

### **Suggestions from Users regarding Assistive Devices**

The users were asked for device-specific suggestions to improve the utility of the device.

Some suggestions were:

#### **Rigid White Cane**

- The present height of the cane is suitable for adults but not for children. Since children start orientation and mobility training with the rigid white cane, the length of the cane may be in two or three sizes, suitable to the child's height (4.76%, n = 3).

#### **Smart Cane**

- Using the Smart Cane during the rainy season may damage the sensor and the speaker as rainwater gets into the device. In order to prevent this, a waterproof sensor can be fitted to the Smart Cane (14.81%, n = 12).

#### **Braille wristwatch**

- The dial of the Braille watch is white in colour and it becomes dusty due to regular use; this makes the display dull. To overcome this, a coloured dial may be used in the watch (1.06%, n = 1).



## eSpeak

- Instead of reading the numbers separately, it reads the entire digits. For example, while reading the mobile number, instead of reading ten numbers separately, it reads the whole ten digits in words. An individual number reading option is suggested (8.11%, n = 3).

## Taylor Frame

- The embossed dots/surfaces presented in the Algebra and Arithmetic pegs become rounded and flattened due to regular use. To overcome this, it is desirable to have pegs made out of thick plastic material (3.21%, n = 6).
- The storage container of the pegs may be fixed at the bottom of the Taylor Frame with bifurcation to hold/store Algebra and Arithmetic Types separately in order to facilitate easy handling at the time of the examinations (7.49%, n = 14).

## Braille Scale

- The sharp edges of the scale sometimes cause injuries. To prevent injuries, the sharp edges could be blunted and rounded (4.92%, n = 6).

## Chessboard

- A folding type of chessboard is suggested (6.81%, n = 13).
- The coins containers on both ends of the chessboard could be provided with sliding doors for storing the coins while not in use (4.19%, n = 8).
- At present, one set of chessboard coins is sold with the chessboard. In the case of coins getting lost, provision may be made for buying only a new set of coins (0.52%, n = 1).
- Braille markings on the sides of the cells, indicating the position of the square in sequential numbers, will facilitate easy identification of the exact square while playing (0.52%, n = 1).

## Audible Cricket Ball

- Bright-coloured balls are preferred instead of the white ones being used at present, to suit people with low vision (2.29%, n = 4).

## Recommendations

- According to the research findings, the devices considered for this study that are being distributed at present under the ADIP Scheme for persons with visual disabilities are extremely useful for the end-users. The same devices that are manufactured by NIEPVD and other agencies should continue to be distributed under the ADIP Scheme.
- The sales counters for assistive devices for people with visual impairment are located in different parts of the country. These sales counters could make provision for selling spare parts for various assistive devices, such as chessboard coins, elastic bands and tips for the folding cane, guider for the Braille slate, etc. The sales counters could also be upgraded into workshops for servicing assistive devices, as very few facilities are available right now to undertake after-sales service.
- The users expressed their desire to have some new assistive devices that are designed to meet their specific needs. For example, a device to identify/ announce the bus numbers at bus stops, OCR software in the regional languages and a few more assistive devices can be considered for future research and development. The needs may be communicated to the manufacturers with assistive devices to design and promote new products.
- Very few technical people are available to service faulty assistive devices. It may be a good move to start short-term and long-term training programmes, which will certainly lead to an increase in qualified manpower.
- The scarcity of adapted sports equipment prevents people with visual impairments from participating in sports activities. Therefore, it is desirable to develop more adapted games for them.
- An accessible format of the user guide for assistive devices will be of great help to users in understanding how best to use these devices.

## Limitations

This study did not include technologically advanced devices used in organisations, such as refreshable Braille displays, Braille printers and other devices. The study focused only on the devices commonly used by individuals, rather than on the ones used in organisations.

## CONCLUSION

The users expressed device-specific expectations concerning its usefulness and provided useful feedback to improve the utility of most of the devices. The suggestions are consolidated and presented in this research report and may offer useful feedback to the manufacturers of each of the devices for further refinement on quality, durability and to fulfil the users' expectations of the devices.

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# A Qualitative Approach to Study the Identity Development of Deaf Students in India

Sunita Kathuria\*

## ABSTRACT

**Purpose:** *This research aimed to explore the deaf identity development process and to compare the identity status of deaf children in India, based on their exposure to inclusive and segregated educational institutions. The first section of the paper presents the Deaf Identity Development Models proposed by other researchers, while the second section deals with the information acquired from the deaf students in the study sample.*

**Method:** *Forty pre-lingual deaf students were selected through a purposive sampling technique. The study tool was an adapted version of the Deaf Identity Development scale. The data was analysed qualitatively through content analysis. Identified themes were presented along with the verbatim statements.*

**Results:** *The findings revealed that the age of onset of hearing loss, degree of hearing impairment, parents' hearing ability, family's socio-economic status, parents' education, family environment, the attitude of parents, social exposure, present and past experiences and social acceptance of the deaf child contribute tremendously to the development of an identity. The study also found that most of the deaf students who had not attended special schools possessed a culturally marginal identity, whereas students with prior special school experience possessed a bicultural identity and were better adjusted in the inclusive schools as compared to their counterparts.*

**Conclusion:** *Further research is suggested, with a special focus on how people with different degrees of congenital hearing impairment experience and negotiate their identity in context.*

**Key words:** *deaf identity development, hearing impairment, influential factors, deaf culture, inclusive school*

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## INTRODUCTION

*In the social jungle of human existence, there is no feeling of being alive without a sense of identity”-Erik Erikson*

Identity is a representation of the self and in its absence an individual is like a person without life. Its formation is a dynamic and complicated process (Howarth, 2002). Formation of identity is an on-going process which is greatly influenced by one’s prior and current experiences and also by the behaviour of others towards one (Glickman,1996).

In the initial stage of life, the deaf child lives in a protected world along with his/her family members. If the family decides to educate the child, there are two options - either to send the child to a special school for the deaf, or to a mainstream school where all the children study together without discrimination, (which however generally doesn’t happen in a real world scenario). During this whole process, a child develops his/her identity. The focus of the current study is on how, at this initial stage, the family and teachers react and contribute towards the identity formation of a deaf child.

### **Identities of the Deaf People: Background**

The advent of Deaf culture (in this paper, the upper case ‘Deaf’ is referred to a particular group of deaf people who share the same culture whereas lowercase deaf is referred to the audiological condition of not hearing) and ongoing developments in research related to identity studies fuelled by cultural multiplicity, have highlighted the concern for ‘deaf identity’. Around the 1980s, parallel to the racial and ethnic identity development movement, the cultural minority movement came into existence. Protest against the marginalisation displayed by the hearing community towards the deaf community gave rise to the theory of identity development of deaf people (Glickman, 1993; 1996). People belonging to the deaf community started demonstrations advocating for the acknowledgement of Sign Language as a valid language. Based on this, several research projects were conducted and a Deaf Identity Development model has taken shape. In 1979, Schowe, a deaf scholar, presented ground-breaking insights into the subject of identity and deafness, and highlighted the significance of social engagement with respect to identity formation and its process. His work in this area has provided a platform for other researchers to investigate the diversity of cultural, physiological and social circumstances, and their interactive, cumulative effects

on deaf people's lives. Glickman (1996) theorised that with the passage of time and different experiences, individuals gain a better understanding of themselves and pass through predictable and recognisable stages which ultimately help in their identity formation. Identity is recognised as part of psychological functioning which is a significant aspect for a sense of welfare and positive personal progress. It includes self-representation or self-perception which develops during various social activities. The more the individual gets involved in social engagements (which include social expectations and cultural contexts), the more the process of identity restructuring takes place. It is a process that is complex, very dynamic and continuous.

To assess the deaf identity, Glickman (1993) constructed a tool called the Deaf Identity Development Scale (DIDS) and explored a continuum of identities; these were categorised into four major deaf identities.

### **Minority Identity Development Theory**

The identity of a person is described by various educationists as the 'complete representation of the self' (Howarth, 2002), which is greatly related to an individual's previous and present experiences and includes direct and indirect engagements of an individual with the surrounding social environment. Minority Identity Development models cropped up at the time of the civil rights movements, wherein the huge change in the identity of people belonging to racial and ethnic minority backgrounds who live and grow up in the context of oppression and discrimination was observed between the pre- and post- liberation phases. The understanding of such Minority Identity Development models has contributed to theories of multicultural/cross-cultural therapies. The typical Minority Identity Development model proposes four significant stages of identity development:

- Pre-encounter/ Conformity Stage: People perceive the world as being non-minority or anti-minority and disrespect the minority identity.
- Encounter/ Crisis Stage: This is the stage after the pre-encounter stage where people become aware of what a minority is, get to know about minority norms and values, and also start to value themselves as a minority.
- Immersion/ Moratorium Stage: In this stage, people reject non-minority culture and accept the minority values completely.

- **Internalisation/ Identity Achievement Stage:** This is considered to be the last stage where people achieve a secure minority identity and show inclination towards the minority culture.

The models of Minority Identity Development are based on the assumptions that people belonging to an ethnic, racial or marginalised community (based on gender, disability, class or sexual orientation) face discrimination and oppression by the non-marginalised community.

### **Theory of Deaf Identity Development**

Identity has always been the central issue of debate and discussion with respect to deaf people. As the deaf community possesses cultural norms which are different from those of people belonging to other cultures, it gives rise to a separate cultural and linguistic identity. Basing his research on deaf identity development, Glickman (1993) emphasised that there is a cultural difference between deaf people and hearing people, and stated that the Deaf culture must be acknowledged in the society, just as other cultures of minorities are accepted.

The Deaf Identity Development model is based on another model of Minority Identity Development, and is similar to the Black Identity Development model. A series of social movements within the disability rights and cultural diversity movements encouraged people belonging to the deaf and hard-of-hearing community to take a lead in adopting a position of equal respect for them in the society. Such activities were observed as the 'Deaf Cultural Movement'. The Deaf Cultural Movement gained momentum in the 1980s, which motivated educationists to study and explore the Deaf culture and identity. The first research study published in the area of deafness and identity crises was by Schowe in 1979, in which the researcher studied the pattern of identity development among deaf people in relation to their ways of adjustment to deafness. Schowe's work (1979) highlighted the 'identity crises' amongst deaf people and revealed that the deaf individual who compares self with the hearing norm, experiences marginality. Similar findings were reported by Weinberg and Sterritt in 1986.

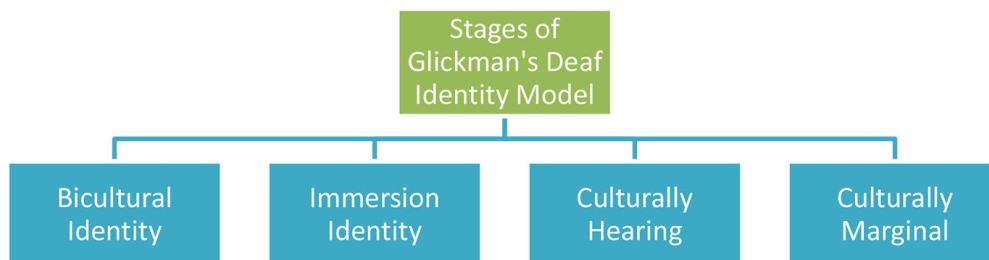
In the current research, the author presents some of the ground-breaking insights on the deaf identity models and the development of identities amongst the deaf sample in this study.



## Glickman's Deaf Identity Model (1993, 1996)

Glickman, with the objective of measuring the cultural identity in deaf individuals, constructed a Deaf Identity Development Scale and also proposed a model with four major developmental stages. The main idea behind proposing the model was to focus on the "cultural difference" between the hearing and the deaf community. This model proposes 4 stages that inform how a deaf individual thinks about himself/herself, the community and the hearing world (see Figure 1.1).

**Figure 1.1: Stages of Glickman's Deaf Identity Model**



The identified stages are as follows:

**Bicultural Identity:** The deaf attribute worth equally to both the cultures - the hearing and the deaf. The person is fair enough in appreciating and rationally determining the differences between the two cultures.

**Immersion Identity:** The deaf are completely immersed in the deaf world and unable to accept/adjust to the hearing world, finding their own culture the best.

**Culturally Hearing:** The deaf people try to become more like the hearing people. They avoid deaf people in general and associate themselves more with the hearing world.

**Culturally Marginal:** The identifying characteristic is that these deaf people have a sense of isolation. They try to fit themselves in both cultures but never become comfortable in either.

## Holcomb's Deaf Identity Model

After Glickman's Identity Model, Holcomb (in 1997) proposed a model with seven identity categories, based on the exposure a deaf individual receives with the deaf community. The seven categories are:

**Balanced Biculturalism:** Deaf people with their identity have a balanced approach towards both cultures, i.e., the hearing and deaf cultures, and are said to be comfortable with both communities. Deaf persons with this identity may or may not wear hearing aids or speak fluently, but their ability to use sign language, oralism and residual speech allows them to adjust well with both cultures, so generally no preference is shown for either of these two groups.

**Deaf Dominant Biculturalism:** This category consists of deaf individuals who function well within both the groups, be it hearing or deaf, but given the opportunity would prefer the deaf community.

**Hearing Dominant Biculturalism:** Deaf people with this type of identity are comfortable with both groups - hearing and deaf – but are more inclined towards the hearing group. If asked their preference, they would definitely choose hearing people over the deaf.

**Culturally Separate:** In this category deaf people purposely keep limited contact with people belonging to the hearing world. Most of the time, they try to avoid interactions with hearing people. They prefer to attend deaf events/ society.

**Culturally Marginal:** This category is formed by deaf individuals who find themselves neither part of the hearing world nor part of the deaf community. They are neither perfect in sign language nor good enough in oralism and speech. They experience difficulty in communicating with both communities. They have very limited social skills.

**Culturally Isolated:** This group consists of individuals who lead a life of loneliness and isolation, and remain aloof in the mainstream. They reject sign language, the deaf culture and may also have oral failures. Most of the time, they choose not to be affiliated with the deaf community.

**Culturally Captive:** The main characteristic of the deaf individual belonging to this identity is one of growing up without any knowledge of the deaf community.

In 1999, Melick proposed a model with four progressive phases. In the first phase, the deaf person identifies himself/herself as ‘an outsider’ and attempts to exhibit the characteristics of a hearing person. In the next phase, the deaf person gets exposed to the deaf world; this phase is identified as a connecting phase. And, in the third phase, i.e., the transitioning phase, the deaf individual starts accepting and adopting the Deaf culture. After the third phase, the individual enters into the last or the fourth phase, i.e., self-definition. In this phase, the deaf person

understands his/her identity and standing in the community, and does not allow anyone to make him/her feel like an outsider.

## **Review of Related Literature**

Chapman and Dammeyer (2016) carried out a study on the significance of deaf identity for psychological well-being and found that deaf people with bicultural and hearing identity had better levels of psychological well-being than those with a marginal identity. This study revealed that other factors like additional disability, educational status and feelings of discrimination have an independent and interactive effect on the psychological well-being of deaf people.

A study by Carter (2015) on “Deaf Identity Centrality: Measurement, Influences and Outcomes” found, through an online survey with 346 deaf people to assess aspects of their deaf identity, that age, the onset of deafness, degree of hearing impairment and mode of communication (sign language or oral) influence Deaf Identity Centrality. This study also revealed that the degree of Deaf Identity Centrality influences the self-esteem and self-concept of the deaf individual, and ultimately leads to a happy and comfortable adjustment in the deaf community.

Cornell and Lyness (2005) in their study titled ‘Therapeutic Implications for Adolescent Deaf Identity and Self-Concept’ discovered a positive correlation between deaf identity and self-concept. The findings of the study revealed that deaf people who associate themselves with both cultures have better self-concept, whereas deaf people with marginal identity experience low self-concept.

Singleton and Morgan (2005) highlighted the importance of bilingual deaf education and acknowledged that a child with bilingual skills possesses linguistic, cognitive capabilities with a better understanding of his/her own identity. Such clarity in understanding equips the deaf person with all the skills needed to participate and associate himself/herself with the hearing and Deaf cultures.

Nunes, Pretzlik & Olsson, (2001) researched deaf children’s social relationships in mainstream schools, and found that though deaf students are not rejected, they may feel isolated and are more likely to be neglected by their peers. The researchers used peer ratings, sociometric status and an interview schedule as tools to collect data. It is suggested in this study that the school can play a proactive role in removing the communication barriers and help to develop a positive attitude towards hearing impaired students.

Bat-Chava (2000), through the use of cluster analysis, observed the existence of three identities, i.e., culturally hearing identity, culturally deaf identity, and bicultural identity. The 56 deaf people in the sample were interviewed and it was found that those with culturally deaf and bicultural identities have higher levels of self-esteem.

Glickman and Carey (1993) in their study titled "Measuring deaf cultural identities: A preliminary investigation" developed a tool, the Deaf Identity Development Scale (DIDS), to study and measure how deaf people identify with the deaf community and Deaf culture. The tool has 60-items, developed and translated from English to American Sign Language (ASL) and back for validation. The tool was administered to 105 deaf university students and 56 other deaf people (between 27–75 years of age). From the initial administration of the DIDS to compare 2 samples of deaf students, the findings of the study revealed that DIDS can be employed to distinguish different deaf cultural orientations.

The review of literature demonstrated that in previous research (e.g., Glickman and Carey, 1993; Bat-Chava, 2000; Nunes et al, 2001; Singleton and Morgan, 2005; Carter, 2015; Chapman and Dammeyer, 2016) it was found that the deaf people who have exposure to the hearing and Deaf cultures have higher self-esteem, self-concept, good psychological well-being, and live a better life as compared to the individuals who have a marginal identity. Furthermore, the literature also explains the factors that influence deaf identity development. Some of the factors identified in past research were age, the onset of deafness, degree of hearing impairment and mode of communication. In the meta-analysis of the literature reviewed by the author of the current article (mentioned in the references section), it was found that little research has been conducted on the identity development of deaf people in India.

Despite having good cognitive skills and good Intelligence Quotient, deaf students in Indian inclusive schools have, in general, low academic performance, low enrolment and high drop-out levels (Uddin, 1995). The poor self-concept, self-esteem, self-respect and self-identity reported in more recent research studies have become a matter of concern for educationists and researchers to explore this area (Aruna and Reddy, 1996; Kumari and Bhatt, 2014; Chapman and Dammeyer, 2017). It was acknowledged in other research works (Foster, 1989; Glickman, 1993 & 1996; Bat-Chava, 2000) that educational placements have a significant role in the process of identity formation of a deaf child. In the present research, an

attempt is made to explore the current scenario with respect to the deaf identity of deaf students studying in inclusive schools of Delhi, India.

### **Research Questions**

This research was based on the premise that deaf children vary in the degree of awareness of the culture which contributes to their identity formation. The research questions were:

- Are there identifiable and foreseeable stages in the identity development of deaf children?
- What are the factors which influence the process of identity formation in deaf children?
- How did the educational placement experience contribute to the formation of identity in the life of a deaf child?

Based on these research questions, the objectives were formulated.

### **Objectives**

- To study the identity of the deaf students studying in inclusive schools of Delhi, India.
- To compare the identity status of deaf students on the basis of their different educational placement experiences.
- To explore the factors influencing the process of identity formation in deaf students.

## **METHOD**

### **Study Design**

This was an explorative descriptive study with qualitative methods employed in data collection and analysis. The paper discusses the process of identity development with special reference to the identity formation of a deaf child in the hearing world.

### **Participants**

The study population consisted of all the prelingually deaf students studying in government inclusive schools in the Delhi region. They were children with

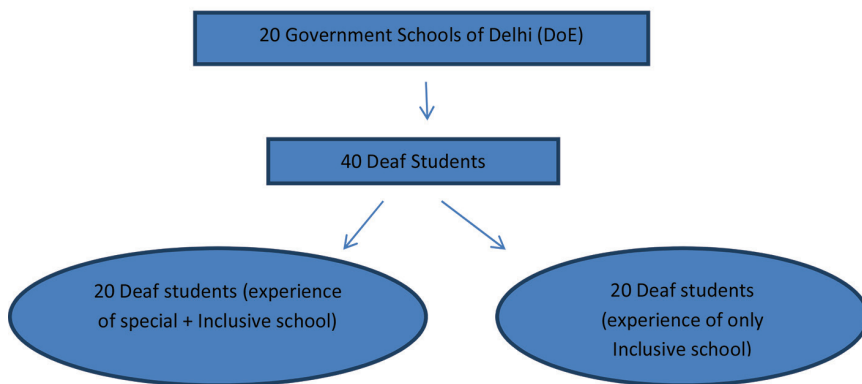
moderately severe, severe and profound hearing impairment, who had hearing parents.

The study sample was selected through a non-probability sampling technique (purposive sampling) and comprised 40 deaf students. The inclusion criteria were:

- a) Children brought up in a hearing-oriented environment (with a hearing family);
- b) Those who were prelingually deaf; and,
- c) Those studying at the upper primary level (12-16 years age group) in inclusive government schools in Delhi.

Among the deaf students in the sample, 20 were educated in inclusive schools and had never been to a special school, whereas the other 20 students had attended special schools in the initial years of their life and were studying in the inclusive school at the time of the research (see Figure 1.2).

**Figure 1.2: Sample Design**



### Study Tools and Techniques

To find how social engagements have shaped the identities of deaf students, the researcher conducted several informal and in-depth verbal and non-verbal engagements over a period of 6 months. The life stories of deaf students were elicited in this way, giving the participants the opportunity to describe their present and past experiences with and within their families, the community and school. After doing an extensive study in the area of deaf identity and as per the socio-economic-cultural aspects of the deaf individuals in India, the researcher

prepared a Deaf Identity Scale, which was an adapted version of Glickman's Deaf Identity Development Scale. The scale has four dimensions (Culturally Hearing, Culturally Marginal, Immersion and Bicultural) with statements based on three factors in each dimension. The factors covered were:

- a) Culturally Hearing Dimension: Medical view of deafness, inclination towards the oral-aural mode of communication and interest in being a part of the hearing world.
- b) Culturally Marginal Dimension: Disaffection with the hearing world, neutral attitude towards the mode of communication, and disaffection with the deaf world.
- c) Immersion Dimension: Discontentment with the hearing world, minority agenda, proud association with Deaf culture.
- d) Bicultural Dimension: Acceptance of hearing and Deaf cultures, self-knowledge, advocacy of both hearing and Deaf cultures.

The tool had 8 statements in each dimension; hence there were 32 statements in all, with a 3-point Likert-scale for responses. The responses were assigned the scoring: 'Agree=3', 'Don't Know=2', and 'Disagree=1'. To score the tool, a mean score of each dimension was calculated and the subject was said to have an identity having the highest mean score dimension. The content and face validity of the tool was established by 4 experts (2 were from the Disability Studies domain and 2 had research expertise). The reliability (external consistency) of the tool was measured by the test-retest method and found to be 0.79. There was a difference of 50 days between the first and the second administration of the tool for consistency check. Table 1 presents the tools and techniques used in the study.

Interviews and literature survey were used as data collection techniques in this study.

**Table 1: Tools and Techniques used in the Study**

Sl. No.	Tool/ Technique	Objectives	Type of Items
1.	Deaf Identity Scale (DIS)	To study and compare the identity (identity status) of deaf students attending the Inclusive Schools	Demographic details (8 items) and Statements (32 items)
2.	Interview	To explore the factors influencing the process of identity formation in deaf students	Informal, unstructured, face-to-face interactions

## Data Analysis

The collected data was analysed through content analysis and the percentage and frequency analysis method.

## RESULTS

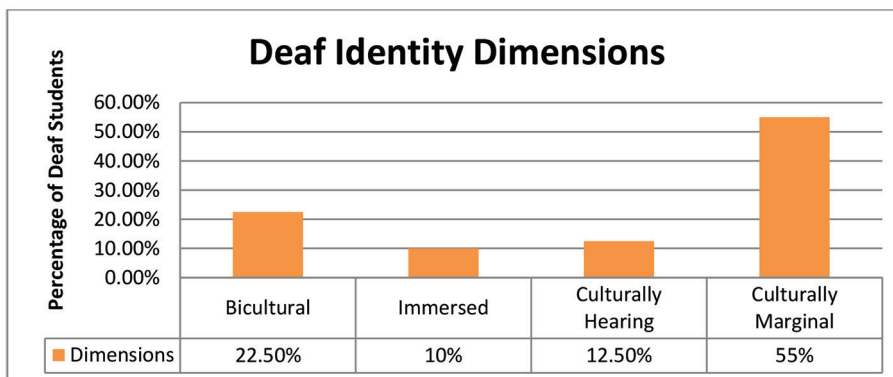
The analysis of the data is presented below and organised according to each research objective.

**Objective 1:** In order to study the identity of deaf students in inclusive schools of Delhi, India, 40 deaf students were selected through the purposive sampling technique. The Deaf Identity Scale was administered by the researcher and the findings are presented in Table 2 and Figure 2

**Table 2: Analysis of Deaf Identity Scale**

Sl. No.	Sample	Categories	Percentage
1.	40	Bicultural	22.5% (9/40)
2.		Immersed	10% (4/40)
3.		Culturally Hearing	12.5% (5/40)
4.		Culturally Marginal	55% (22/40)

**Figure 2: Percentage of Deaf Students representing Identities**



**Interpretation:** The data revealed (see Table 2) that more than half of the students, i.e., 55% of the students studying in inclusive schools of Delhi, had a culturally marginal identity. Dissatisfaction with the hearing and Deaf world was found



in 30% of the responses, and a neutral response of 25% towards the mode of communication was also observed. This illustrated that in an inclusive setup, students with severe to profound hearing impairment were feeling neglected and isolated (this was interpreted through the verbatim recordings made during the data collection, that are presented further on). Most of the deaf students who had never been to a special school were still at the initial stage of their identity development. It was found that deaf students like to keep limited contact with the students belonging to the hearing world, and behave as though they belong to neither the hearing world nor the deaf world. The data revealed that deaf students like to live an isolated life and do not enjoy Deaf and hearing cultures. They also find deafness a terrible disability. Most of the students acknowledged that it was hard for them to make hearing friends. During an informal conversation in the lunch break one of the deaf students said:

*“I take lunch most of the time alone or sometimes with my bench-mate. My bench-mate understands what I want to say to some extent, but not fully. But she has her hearing friends; she likes to talk to them most of the time rather than to me. She has got many options to talk with and make friends, but I have only one.”*

These students reject sign language, deaf culture and also have oral failures. They were not able to relate to any of the cultures, neither the hearing culture nor the Deaf culture. The students appeared to be confused about their identity and were not sure whether they like or dislike the hearing or the deaf world. One of the deaf students acknowledged:

*“I have not met with any deaf person ever. I am the only deaf individual in my family. But yes! I want to meet someone who is like me and want to ask how life is for them. How shall a deaf person make others understand his/her feelings?”*

It was also observed that the social and academic adjustment of deaf students in inclusive schools was very poor. Hence, it was interpreted that the identity formation and association of self with some culture or group of people is very important to live a healthy balanced life. The data showed that 10% of the students had Immersed identity (see Figure 2). This meant that despite having hearing parents, 10% of the students identified themselves as belonging to the deaf world only and were found to be unhappy in inclusive schools. These were the students who had prior experience of being in a special school. Discontentment with the hearing world was observed in the responses. During casual interactions (in sign language) with the researcher, it was found that these students were not happy

in communicating through the oral-aural mode and demanded that the teaching must also be done in sign language in inclusive schools. A proud association with the Deaf culture could be sensed in the discussions. They expressed concern regarding their existence in an inclusive setup. One of the students communicated in sign language:

*“I can’t hear what my teacher teaches. My teacher can’t understand my signs completely. I ask her my queries by writing the question in the notebook. But I can’t ask all my doubts through writing every time in class, due to which I miss lots of her teaching. We must have an interpreter in the class or I should be sent to a special school where I can find many of my kind.”*

The data (see Figure 2) also showed that there were 12.5% of the students (5 out of the 40) who had a culturally hearing identity, which revealed that some deaf students were happily adjusted to the hearing culture and with hearing people. They showed interest in being part of the hearing world, were keen to learn lip-reading, and exhibited acceptance of oral-aural mode of communication. Furthermore, there were 22.5% deaf students (9 out of 40) who had a bicultural identity, which indicated that close to 25% of the students had a balanced approach towards both the communities and were using hearing aids, signing, and oral-aural modes for communication with hearing friends. Acceptance of people of both communities and advocacy of both cultures was observed. The students were found to have good self-realisation and believed deafness to be a biological problem. One of the students said:

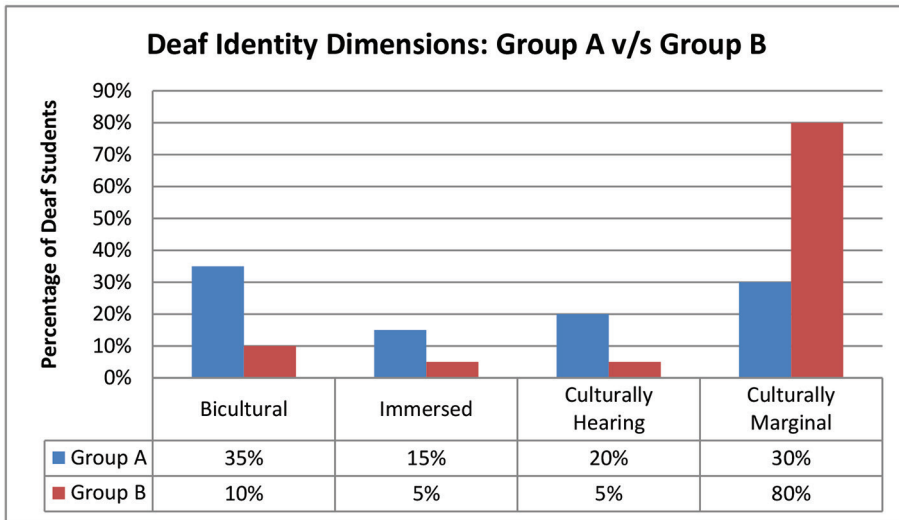
*“I have a hearing problem and I know it, but with time I will learn to interact with hearing people and soon my life would be as normal as of others. I have already made some friends here, they help me.”*

**Objective 2:** In order to compare the identity status of the deaf students currently studying in inclusive schools but who also have past experience of studying in a special school, the 40 deaf students were placed in 2 groups on the basis of their educational placement experience. Twenty deaf students with special and inclusive school experience were put in Group A, and 20 deaf students with only inclusive school experience were placed in Group B. The Deaf Identity Scale was administered to the sample by the researcher. The findings are presented in Table 3 and in Figure 3 with the interpretations.

**Table 3: Analysis and Comparison of Group A and Group B: Deaf Identity Scale**

Sl. No.	Groups	Categories	Count	Percentage
1.	Group A (with past experience of a special school and now in an inclusive school)	Bicultural	7/20	35%
		Immersed	3/20	15%
		Culturally Hearing	4/20	20%
		Culturally Marginal	6/20	30%
2.	Group B (with no experience of a special school)	Bicultural	2/20	10%
		Immersed	1/20	5%
		Culturally Hearing	1/20	5%
		Culturally Marginal	16/20	80%

**Figure 3: Analysis and Comparison of Group A and Group B: Deaf Identity Scale**



**Interpretation:** Table 3 shows that 35% of the students in ‘Group A’ had bicultural identity whereas in ‘Group B’ only 2 students or 10% were found to possess bicultural identity. This indicated that the students who had an association with a special school in the past or any kind of association with Deaf culture (deaf

teachers, Indian Sign Language (ISL), etc.) seemed to be better adjusted to both cultures. It was observed that these students associated themselves with both the Deaf and hearing cultures, as they had accepted the norms, lifestyle and life pattern of both cultures. It was also noticed that students with bicultural identity had a number of hearing friends in the inclusive school, and were trying to use different modes of communication to make other people understand them. These students were taking part in the class activities and were sharing their belongings with hearing students. During the casual interactions with these students, it was also seen that they did not feel offended at being called or labelled 'deaf'. It was very normal for them to be categorised as 'deaf'.

On the other hand, there were 30% of the students in 'Group A' and 80% in 'Group B' who had culturally marginal identity (see Figure 3). It showed that students who had never associated with or been made aware of Deaf culture, were leading a life of isolation and confusion. Most of the deaf students who had never attended a special school before joining an inclusive school were possessed of a culturally marginal identity; they were unable to relate to or feel attachment for any of the cultures. These students were found to be living in a world of their own, busy scribbling on paper or on the bench, hiding their faces in most of the group discussions in class, were not good at any form of communication (neither sign language nor oral-aural) so they were unable to have healthy interactions with others. Since they were in an inclusive setup where most of the students were children with hearing, they did not have any friends. It was observed that these students were attempting to be comfortable in the classroom but were failing due to the communication gap. It was also noticed that when a deaf child was exposed to Deaf culture, in most of the cases he/she developed a good understanding of both cultures. There were more culturally marginal students in 'Group B' as compared to Group A. Therefore, one can conclude that identity is explained very well with the Social Identity theory. A deaf child constructs his/her identity based on the response he/she receives from society. It is said that identity is a negotiation which is carried out by the individual between self and surroundings (Berger et al, 1966).

**Objective 3:** To explore the factors influencing identity formation in deaf students, the researcher reviewed the literature and, using Indian Sign Language, had informal interactions with the deaf students about their life, family, neighbours and society. The signs were transcribed into text and content analysis was done. The following themes were identified by the researcher as the contributing factors that influence the identity formation process:

- a) **Age of Onset of Hearing Loss** - It was observed that the age of onset of hearing loss determines many aspects of the deaf individual's life, including the inter-individual differences. Auditory capacity and speech understanding are the two main components that completely depend on the age of onset of hearing impairment, and determine the identity and personality formation of the deaf child. The early onset of hearing loss leads to an identity which may be culturally immersed and culturally marginal; if the hearing loss occurs late in life, it leads to an identity that is bicultural and culturally hearing. Therefore, it was observed that the late onset of hearing loss causes less damage to personality and identity formation.
- b) **Degree of Hearing Loss**- The degree of hearing loss was also found to be one of the influential factors of the identity development process. The greater the severity of the impairment, the more marginalised is the identity of the deaf child.
- c) **Educational Experience**: The educational placements provide an opportunity for the deaf child to interact and become aware of the Deaf culture or hearing culture. It was observed in this study that awareness and exposure to both cultures are important for the balanced development of the deaf child. Acquaintance with the Deaf culture is as important as the introduction to the hearing culture. Most researchers acknowledge the benefits of having a bicultural identity amongst deaf people. Hence, if it is so beneficial, it becomes important for the stakeholders to expand the scope of interaction with both hearing and deaf people, for the deaf children.
- d) **Parental Hearing Status**: Through interactions with the sample about the hearing status of their parents and their behaviour towards them, it was observed that deaf parents were more sensitive and understanding towards deafness as they had experience of it themselves. Consequently they educate their deaf child about Deaf culture, while the child gets exposure to hearing culture through interactions with the neighbours or in school. In this manner, the growth of such children is found to be balanced. On the other hand, it was felt during the interactions that the hearing parents are more concerned and focussed on the disability of their child rather than on his/her abilities and either became over-protective towards the child or neglectful. The analysis of the research data as well as the literature confirms that parental acceptance of the child with his/ her disability is observed among very few hearing parents (Abu Shaira, 2013; Monika and Mishra, 2013). Therefore, the

hearing status of the parent is acknowledged as an influential factor in the identity development of the deaf child.

- e) **Family's Socio-economic Status:** It was observed that financially well-settled families can provide better opportunities to deaf children to explore more about both cultures, which helps them to gain a satisfactory bicultural identity. The families with poor socio-economic status are not able to pay much attention to the personal and identity needs of their deaf child.
- f) **Parent's Educational Status:** The literature revealed that the educational status of the parents was also one of the factors in identity development (Abu Shaira, 2013; Monika and Mishra, 2013; Long et al, 2021). Through interactions with the sample, it was also found that better educated parents were more sensitised towards the disability issue and were more aware of the causes, consequences and possibilities of their deaf child. Thus, it is interpreted that the educated parents were better with respect to the identity formation and self- image of their children, as compared to the parents who had low educational backgrounds.
- g) **Family Environment:** The existing literature revealed that the family environment plays an important role in the process of identity formation of a child. The child who is neglected by the family would have poor self-image and identity crises as compared to the child who has a loving and caring home environment (Arana and Reddy, 1996; Cornell and Lyness, 2005). Moreover, if the care, sympathy and love needed by a child are provided at home, the child gets the strength needed to fight against all odds. This finding of the literature review could also be observed in the conversations with the sample (deaf students) during the data collection phase. Most of the students in the sample acknowledged the dearth of love, support, care and motivation from their near and dear ones. Therefore, a positive family environment is very important for the deaf child to develop a positive identity.
- h) **The Attitude of Parents and School towards Disability:** The family's deafness orientation is also a deciding factor in the identity formation of deaf children. The communication philosophy of the parents - whether to choose sign language or oral-aural method of communication - also contributes to the identity development of the deaf child. Not only this, the attitude of the school towards disability also plays a major role in influencing the identity of the child.

- i) **Social Acceptance:** It was also found during the interactions that the acceptance level exhibited by the known and unknown people around the deaf child also contributes a lot to the identity development process. The deaf child who has high acceptance among both the deaf and hearing people lives a more balanced life as compared to the child who faces low social acceptance.

## DISCUSSION

There are some people (with disability) who like 'identity first' language, i.e., the choice of being addressed by the society with their diagnostic term first, as they believe the word 'deaf' represents empowerment, rights and culture (Friedner, 2011). However, there are people (with disability) who prefer to be identified first as a person and then by their disorder, and reject their disorder as the way to define them. In Deaf culture in India, it is observed that people with deafness prefer the 'identity first' language and choose to affirm their identity (**deaf**) when they are addressed (Friedner, 2011). The researcher agrees that each child with impairment must be accepted as a human being with disability and not as a 'disabled person', but at the same time society must acknowledge and accept the way that people want to be addressed. Hence, in this research, the researcher addressed students with profound hearing loss as deaf students.

Furthermore, as the global society is moving towards an inclusive world wherein the target is to transform even the general schools into inclusive schools (Ydo, 2020; <https://unesdoc.unesco.org/ark:/48223/pf0000374246>), this study proves to be beneficial in providing a better understanding of the need and means of addressing the identity formation of hearing impaired students in the inclusive setup. During the researcher's engagements with deaf children over a period of 6 months, it was observed that the majority of discourses were either focusing on normalcy, or differences or on the Deaf culture. The study found that the mode of communication plays a significant role in the identity development of a child. Almost all the deaf students mentioned the concern of communication, when the researcher engaged with them. It was noticed that the students who were using only the oral mode of communication were more prone to feelings of shame, depression, isolation and alienation, than the students who were raised in an environment where they were allowed to use sign language and address their challenges by different means. Furthermore, the researcher found that even today, among many families and in schools (special and inclusive schools), deaf

children were prohibited from using sign language. The reason for the objection was the fear that 'the child may develop a culturally deaf identity or may get lost to the world which is limited to deaf' (Bat-Chava, 2000), which could lead to non-integration of deaf children with the hearing ones. It was noticed that in India, the prime objective of Deaf Education continues to be 'preparing a deaf child to speak, lip read, use the residual hearing, use technology to hear others' and is not about making them responsible and contributory citizens. All the efforts are geared towards making the deaf child ready to be like other hearing people or adapt the identity which is very similar to that of the identity of hearing people' (Zhang and Wang, 2009). The irony of the present system is that the stakeholders in education are still confused regarding the identity that the deaf child should develop, rather than discussing and brainstorming on inclusive methodologies which can be adapted to improve the current situation.

This research noted that the early experience of a bilingual approach adopted in special schools helped the deaf children to be aware of the Deaf culture and allowed them to choose their own identity. With respect to the development of the identities, the study found that the deaf students are raised with more than one identity. Sometimes, in deaf students, two different identities were contested, or coexisted or overlapped. Consequently, the researcher feels that categorising the children with deafness into one of the 4 identities and then arriving at a result, seems to be unjust to some extent.

### **Limitations**

- The use of a self-developed Deaf Identity Development scale rather than a standardised scale is seen as a limitation of this study. However, the researcher argues that due to the non-availability of a culture-free scale, this scale had to be constructed based on the requirements (issue under study) and characteristics of the sample.
- As the instrument used in the study is a self-administered tool, the respondent's choice of self-representation may impact the results of the study.

### **Strength**

- The strength of the research lies in its mixed method approach- the qualitative (in-depth, informal interactions over 6 months) and the



quantitative (the Deaf Identity Development scale). Identity assessment is a complex phenomenon to be studied with the Deaf Identity Development scale which is a quantitative measurement instrument (with a one-time measure which reflects only a snapshot of the issue under study); hence the researcher employed qualitative tools to make the findings more valid and reliable.

## CONCLUSION

The role of the Deaf culture in developing identity in deaf individuals is this research's main area of concern. In other words, every culture must be given due importance and must not be dominated by the majority (Fraser, 2007). The Deaf culture has its own language which is not of less value than any other language and is equally capable of expressing abstract ideas and thoughts. From the age of 12, children become reflective about their community, culture, state and nation, and their interactions with society make them conscious about their identity (Piaget, 1968; Emler and Reicher, 1995). At times, identity consciousness changes into identity crises due to conflicts (Erickson, 1968). Similarly, deaf children when growing up as non-hearers in a hearing society, with no contact with the Deaf community, may face identity crises and develop lower levels of self-esteem (Spence, 2010). This research is hopeful that the caregivers (especially the hearing ones) and other stakeholders understand the process of identity development of deaf individuals, and help their deaf children to have positive experiences so that they may also have positive self-image and self-concept and become responsible and contributing members of society.

In anticipation of the world where there are cultural differences which are well-acknowledged, accepted and understood, the researcher concludes the paper by stating that the person with a disability has the right to a dignified identity in society and this must be acknowledged.

## Implications

Various studies have highlighted how the identity of an individual affects the life-outcome variables, for example, self-esteem, life satisfaction, psychological well-being, and so on and so forth (Fraser, 2000). It is suggested that:

- For the educational inclusion of deaf students in an inclusive setup, there is a need for all the stakeholders (parents, teachers, school management,

curriculum makers, policy makers, etc.) to understand, acknowledge and accept the Deaf culture. The school curriculum must have some chapters related to Deaf culture in order to sensitise other students and spread awareness.

- Provision for teaching and learning sign language should be an option for all (hearing impaired and non-hearing impaired students) at the upper primary or secondary level of schooling. This would bring equity in word and action too.
- Technological assistance could be given in the form of CDs (compact discs, recordings) of lesson plans of all the subjects in sign language, until the time that all teachers are trained in sign language. Alternatively, the school should appoint a sign language interpreter. However, having only one sign language interpreter may not help the child and the school, so other alternatives could be explored like providing opportunities to the hearing students to learn sign language. This would be a healthy approach to help the deaf students and make up for the lack of interpreters. Also, creating a buddy system in class may help in classroom learning (Kathuria, 2018). Sign language could also be offered as one of the optional language subjects in the school curriculum for all students. A scarcity of resources, teachers and interpreters are observed in low- and middle-income countries. The question of hiring an interpreter for only one or two deaf students may be unaffordable. However, considering the global learning crisis (<https://www.worldbank.org/en/news/immersive-story/2019/01/22/pass-or-fail-how-can-the-world-do-its-homework>), the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and the local laws and policies, it is relevant to pay attention and provide services as per the needs of the students, even if there is only one student who requires help.
- There is an urgent need to prepare teachers at pre-service and in-service teacher education programmes to cater to the identified needs of children with disabilities. There should be a component on 'development of transitioning competency skills' in the teacher education programme, to prepare teachers competent in transitioning activities such as participating in a multi-disciplinary team, assessing and teaching social skills, teaching job-seeking skills, assessing vocational preferences, managing maladaptive behaviours, writing Individualised Educational Plans, teaching daily living skills, teaching money management and skills related to providing career education and exploration, etc.

- Facilities for guidance and counselling must be provided to the students with disabilities in the school setup, on a compulsory basis. In addition to this, a short and compulsory training programme for regular teachers must be organised on development and up-skilling of guidance and counselling skills, so that need-based assistance can be provided from time to time to the students.
- Teachers, parents and other stakeholders must be made aware of the factors which are responsible for identity development, as identified in the research, so that timely interventions can be planned for the deaf students.
- The teachers should organise curricular and co-curricular classroom/school experiences to promote healthy social functioning.
- The special schools for the deaf and the inclusive schools must work as a team. There should be sharing and exchange of information, physical resources and human resources. Teaching strategies used by special schools must be adopted by the inclusive schools to make learning possible for deaf students in the inclusive classrooms.
- Disability research must focus on ways to promote the healthy identities of people with disabilities in this complex world.

Through this research, the investigator presents the argument for a more flexible and dynamic understanding of Deaf culture and the process of deaf identity formation with respect to people with hearing impairment (profound). It is suggested that future research could have a special focus on how people with different degrees of biological impairment experience and negotiate their identity in context.

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# Reporting Behaviour of People with Disabilities in relation to the Lack of Accessibility on Government Websites: Analysis in the light of the Theory of Planned Behaviour

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## ABSTRACT

**Purpose:** *The observance of inclusive practices in e-government has been overlooked in several countries, and surveillance and action taken by official bodies is often inefficient especially in low-and middle-income countries. This article investigated factors that influence the behaviour of people with disabilities concerning filing formal complaints about accessibility barriers of government portals in Brazil.*

**Method:** *Five people with disabilities and three prosecutors were interviewed. A content analysis by category, using the Theory of Planned Behaviour, was performed.*

**Results:** *Interviewees emphasised aspects such as government websites being accessed with low frequency; lack of a combative culture; disbelief in the effectiveness of filing a complaint; ignorance or superficial knowledge about the laws; the technical ignorance of the user; lack of awareness of the severity of communication barriers; unfamiliarity with the role of the Public Prosecutor's Office; excessive formalism; and, the influence of close people.*

**Conclusion:** *There is a need to promote cultural change so as to value and respect people with disabilities as equal citizens.*

**Key words:** *disability rights oversight, web accessibility, e-government, Theory of Planned Behaviour, Public Prosecutor's Office*

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## INTRODUCTION

The access of all citizens to the information available on websites, as well as in their respective applications on mobile devices, is still a challenge for society. Even with all legal obligations and accessibility guidelines, there are persistent accessibility barriers on government websites.

In Brazil, the Internet Governance Committee (2010) found that 98% of .gov.br domain pages did not respect the accessibility standards of the Brazilian government's e-Government Accessibility Model (e-MAG). In line with this finding of the year 2010, several more recent research studies have shown that Brazilian government portals are not in line with accessibility guidelines in Brazil (Oliveira & Eler, 2015; Maia, 2015; Silva & Rue, 2015; Carvalho, Cagnin & Paiva, 2017; Oliveira & Souza, 2017). Thus, numerous people, including people with disabilities, are unable to use government portals.

The problems of lack of accessibility in Brazilian governmental portals present limitations in guaranteeing the rights of people with disabilities that are provided for in the UN Convention on the Rights of Persons with Disabilities (2006), of which Brazil is a signatory, as well as the Brazilian Inclusion Law promulgated in 2015. This is due, in part, to the lack of surveillance and denunciations from society. This is because laws are not self-executing and enforcement tools are needed (Lazar, Goldstein & Taylor, 2015).

In Brazil, the oversight role is exercised by organs such as the Public Prosecutor's Office. Thus, among the main practical areas of action of the Public Prosecutor's Office for the defence of diffuse and collective rights of persons with disabilities, the Public Prosecutor's Office acts in the inspection and implementation of the accessibility conditions foreseen mainly in the Brazilian Inclusion Law, n° 13.146 / 15 (Macêdo & Ogrizio, 2016). In view of this lack of accessibility in government portals, it is fundamental that society is made aware of the role played by this institution and of the way to denounce these illicit acts in order to provoke action by the Public Prosecutor's Office.

Therefore, this article aims to understand the factors that influence the denunciation behaviour of people with disabilities. To this end, the authors conducted research on secondary sources and held interviews. Secondary data search involved seeking for related work that deals with reporting behaviour. The authors also investigated the existence of formal complaints addressing accessibility issues in public digital services that impede or hinder access to such

services by persons with disabilities or that constitute violations of accessibility standards. Five people with disabilities and three prosecutors were interviewed. Content analysis of the gathered data was performed using categories based on aspects of the Theory of Planned Behaviour (TPB).

The TPB has been used widely in the areas of Management and Information Systems, with strong influence on theories that explain the adoption and use of systems in organisations. Ajzen (1985) states that all actions are preceded by planning, whether conscious or unconscious, to guide the sequence of acts, and that actions are controlled by intentions, but not all intentions come true, some are abandoned or modified to suit circumstances. Thus, Ajzen (1985) understands that it is possible to predict the actions from the previous knowledge of the intentions in relation to certain behaviours.

According to TPB, intention is the result of three determinants, namely: attitudes concerning personal aspects, subjective norms related to social influence, and perceived behavioural control, which is the individual's need to have the support, resources and opportunity to perform a specific behaviour (Ajzen, 1985). Ajzen (1991) observes that behaviour, for the most part, depends not only on the individual effort invested, but also on the control that the individual exerts on other internal and external factors.

Thus, from the study of this theory, three categories of analysis were established, namely: attitudes, subjective norms and perceived behavioural control. Subcategories were then created from the interviewees' speech analysis.

## **METHOD**

### **Study Design**

Research on secondary sources was conducted, and interviews were held with five people with disabilities and three prosecutors.

### **Procedures for Conducting Documentary Research**

The authors carried out documentary research to investigate the practices of reporting and monitoring the accessibility of public e-government services by people with disabilities. The data collected is related to complaints made to the Public Prosecutor's Office of Minas Gerais in the first half of 2016. The authors also investigated processes related to web accessibility at the federal level and complaints made to the Federal Ombudsman.



## Procedures for Conducting and Analysing Interviews with People with Disabilities and Prosecutors

Semi-structured interviews were conducted with eight participants. Of these, five were people with disabilities and three were prosecutors from the Public Prosecutor's Office of Minas Gerais. Among the people with disabilities, there were three visually impaired people and two people with physical disabilities. The selected interviewees included representatives from academia, the government, and primary and secondary education.

Based on the analysis of the interviewees' answers, subcategories were created, namely, access; culture; effect; knowledge of laws; technical and procedural knowledge; consciousness; knowledge of the Public Prosecutor's Office; formalism; and influence of people. Where excerpts from the interviewees' contributions are mentioned, they are attributed to the respective participant - PD for Person with Disabilities, and PP for public prosecutor – along with their respective numbers.

Table 1 provides a summary of the content analysis, with categories, subcategories and summary explanation.

**Table 1: Perception of the Interviewees in relation to the Factors that Influence the Intention of the Complaint Behaviour**

Categories	Subcategories	Guiding Concept
<b>Attitudes</b>	Access	Governmental portals are poorly accessed by people with disabilities.
	Culture	Lack of a combative culture. Instead of resorting to oversight agencies, people often prefer to resort to alternative ways to demonstrate dissatisfaction, such as social networks.
	Effect	Disbelief in the effectiveness of the complaint.
<b>Perceived Behavioural Control</b>	Knowledge of Laws	Lack of knowledge about laws that deal with the right of access to information and communication technologies.
	Technical and Procedural Knowledge	The user may not know how to identify that the difficulty of navigating is a problem of lack of accessibility and not having the technical knowledge to report the problem in a complaint. Thus, the issue of ignorance about where and how to report was also mentioned as a limiting factor.

	Consciousness	Lack of awareness that the communication barrier is as criminal as any other type of barrier.
	Knowledge of Public Prosecutor's office	Unawareness of the performance of the Public Prosecutor's Office.
	Formalism	Fear of the formalism to be faced for denunciation.
<b>Subjective Norms</b>	Influence of People	Close people generally support and encourage reporting behaviour and often take the initiative to report.

### **Ethical Considerations**

The interview scripts and study design were submitted to the Research Ethics Committee of the authors' institution and were approved with protocol CAAE 80842317.4.0000.5148.

## **RESULTS and DISCUSSION**

The general aspects reported in the interviews with people with disabilities and with the prosecutors are presented first, followed by a specific report and discussion of the specific points concerning the categories of analysis derived from the Theory of Planned Behaviour.

### **Complaints about Web Accessibility: Investigation of the National Scenario**

The authors carried out a search in the official electronic journal of the Public Prosecutor's Office of Minas Gerais in order to find complaints about accessibility problems in public sites. The survey refers to the first half of 2016. The authors verified the existence of 1,146 complaints involving people with disabilities. Of these, 164 procedures dealt with complaints about accessibility problems, which are mostly about architectural, transportation and urbanistic barriers, respectively. No denunciations involving the issue of web accessibility were found, despite ample evidence of lack of accessibility in websites in Brazil.

To date, only three processes have been found regarding web accessibility at the federal level in Brazil. The first one refers to the action filed in 2013 by a lawyer who has visual disability. The complaint addresses Resolution 185/13 of the National Council of Justice, where the electronic judicial process system was instituted. By this resolution, it was determined that all petitions and other judicial proceedings be conducted electronically. However, the change from the physical process to

the electronic process occurred without guaranteeing the broad and unrestricted access to sites for people with disabilities (Federal Court of Justice, 2014; National Justice Council, 2013).

Also in 2013, the Federal Public Prosecutor's Office filed a public civil action against the Federal University of Minas Gerais, in order to compel the University to "adapt the facilities of all its buildings to the rules of architectural accessibility, urban planning, communication and information". Among the problems of accessibility found in the University, the Federal Public Prosecutor's Office pointed out the lack of accessibility in the virtual learning environment Moodle system. The University was required to adapt to the guidelines provided in the federal accessibility standards e-MAG (Federal Regional Court, 2018).

Regarding the portals of private institutions, in 2014 the Federal Public Prosecutor's Office in São Paulo proposed a civil public action seeking to prohibit government advertising on sites that were not accessible. The civil inquiry was established by virtue of representation submitted by the National Foundation for Education and Integration of the Deaf, reporting that the largest information centres in the country, such as Record, UOL, Estadão, Terra, Globo, Folha, SBT, IG, Band and Yahoo, are not accessible to people with hearing impairment (Federal Public Ministry, 2018).

Nevertheless, in May 2018, the authors of this paper sent a freedom of information request to the Federal Ombudsman's Office requesting information on the existence of formal complaints addressing accessibility problems in public digital services. The agency verified the existence of 2 complaints compatible with the request. The complaints were about a problem with CAPTCHA that does not have audio but is needed to ensure that people with visual impairment have proper access to information. However, both complaints were sent by members of an outreach project called "Digital Accessibility", in which the authors are involved.

### **Interviews with People with Disabilities: General Aspects**

Some general aspects of the interviews with people with disabilities are discussed here. The first item refers to what respondents understand as an "accessible society". From the interviewees' testimonies, it is possible to understand that an accessible society would be one in which people with disabilities live on equal terms with other people, having full freedom to come and go without any barriers.

Respondents were questioned about their participation in institutions that support people with disabilities, in order to understand how these people are active in monitoring and making effective demands of their rights. Only two participants (PD-04 and PD-05) responded that they actively participate in these institutions, while the others stated that they have participated but are currently not involved.

Regarding their actions in denouncing violations of their rights, being of any nature, two interviewees stated that they do not usually denounce although they recognise the need to be more active in this regard, while three said they have a habit of reporting. All the interviewed people with disabilities affirmed that they have already faced several problems of accessibility in society, of which attitudinal, architectural and urbanistic barriers stood out.

### **Interviews with Public Prosecutors: General Aspects**

All the prosecutors stated that neither did they have any type of training nor had they attended a training course on web accessibility. The interviewees showed limited knowledge about the subject and criticised the lack of training in this area, which ends up hampering the institution's performance.

The most common types of complaints mentioned by the prosecutors were: difficulty in accessing education and the public health system, and architectural barriers. This assertion is in line with the research carried out in the official electronic journal of the Public Prosecutor's Office of Minas Gerais, from which it was verified that most manifestations about accessibility problems deal with architectural barriers.

With regard to accessibility in government portals, one public prosecutor (PP-03) noted the importance of providing, as a point of departure, the opportunity of self-correction to the public agency itself. Thus, this prosecutor (PP-03) suggested that the person with disability should directly seek a solution to the problem through a complaint to the manager or head of the department, or to the Ombudsman. If the person with disability does not obtain the solution to the problem, he/she should seek the public prosecution service which, as a prosecutor of the Law, will verify the omission in relation to the direct complaint which induces the correction through this external inspection. Nevertheless, this prosecutor (PP-03) observes the importance of the Public Prosecutor's Office to be open to self-criticism regarding compliance with the accessibility standards,

before demanding it from other public bodies. This is because the accessibility of public institutions cannot be demanded while the Public Prosecutor's Office does not guarantee full accessibility of its own services.

Another prosecutor (PP-02) has suggested that people with disabilities communicate accessibility problems in government portals to both the Public Prosecutor's Office and the Councils of People with Disabilities, in the sense that they also fulfil their advocacy role and are deliberative to compel the public entity to promote full accessibility of public governmental websites.

## **Factors that influence Reporting Behaviour**

### **Attitudes**

The construct "attitude", in relation to behaviour, refers to the positive or negative assessment performed by the individual on a given behaviour (Ajzen, 1985). From this category, the authors created three subcategories based on the analysis of the interviewees' answers: access, culture and effect, which are explained below. The categories represent the main subthemes that emerged from the observation of the interviews.

### **Access**

Respondents mentioned that the intention of performing the reporting behaviour is related to the fact that government portals are not frequently accessed by people with disabilities. Thus, it is unusual for people with disabilities to deal with accessibility issues at these sites. Respondents noted that when people with disabilities encounter these problems, they prefer to resort to the help of others instead of formally demanding the assurance of their rights.

The authors did not find data or research confirming the claim that government portals are poorly accessed by people with disabilities specifically. However, a possible explanation for this phenomenon may be related to the lack of accessibility of Brazilian electronic government sites for everyone, so that people with disabilities can avoid accessing them. Another possible explanation relates to the fact that information and services on government sites are not part of people's daily lives and are accessed only when necessary.

Carter and Bélanger (2004) note that ease of use is related to how much an innovation is viewed by the adopter as relatively difficult to use and to understand,

this being a factor that may influence the adoption of e-government. Thus, the fact that government sites are not accessible to people with disabilities can be seen by the potential adopter as an aspect that hinders the use of ICT and is therefore a factor that influences the issue of access to governmental sites.

## **Culture**

Respondents also mentioned the lack of a combative culture as a factor influencing the intention of performing the reporting behaviour. According to the interviewees, people do not seek official means to request the fulfilment of their rights. Instead, they prefer to look for alternative ways, such as social networks, to demonstrate dissatisfaction.

A public prosecutor (PP-02) explained that the culture of defending the rights of people with disabilities is relatively recent, so that the basic rights of people with disabilities, such as education and health for example, are not yet guaranteed. Thus, promoting access to the media and information may not be perceived as a priority. People with disabilities still face significant challenges in accessing basic rights. In the interviews, all people with disabilities reported several accessibility problems, mainly of an architectural, urban and attitudinal nature.

Also, according to another prosecutor (PP-03), there is a change in society's attitude towards the complaint, in which people in general, and not only people with disabilities, use social networks to express dissatisfaction. However, the prosecutor observed that this instrument is not usually intended to report the fact in a purposeful way to solve the problem. He was of the opinion that this is a cultural problem, in which people make complaints as an outburst, rather than directing them towards solving the problem.

## **Effect**

Among the people with disabilities who were interviewed, four showed that they did not believe in the effectiveness of making the complaint, whereas just one respondent (PD-01) believed that denunciation was the best route even though the response was not idealised and affirmed that they had positive responses.

Most respondents (people with disabilities) expressed disbelief that the complaint promotes changes or improvements to the reported problem. Respondents were of the view that denunciation is only effective when it acquires publicity or when

it is performed by a large group of people. Another aspect that emerged was disbelief in the state's punitive and oversight power.

Some interviewees stated that they did not believe in the effectiveness of making a complaint in view of negative experiences in the past. A visually impaired person (PD-04) reported that he was walking on the street and hit his eye on a trashcan which resulted in a stroke around the eye. He reported that the incident occurred because the dump was not placed at the right height and did not meet the standards established by legislation. The same person mentioned a situation in which a car remained parked on the pedestrian lane for five days, making it impossible to cross the lane. The interviewee reported that despite successive complaints to the competent institution, no action was taken.

Regarding government portals, three people said that they had already encountered barriers in these sites and that they sent an e-mail to the site's own organ explaining the problem and requesting correction. This contact was made by e-mail and none of the appeals were answered.

One of the interviewed persons with disabilities (PD-05) mentioned that it is necessary to make a lot of change in the policy to believe in the effectiveness of the complaint. In relation to the interviewee (PD-01) who believed in the effectiveness of complaint, it is important to mention that this person works in the Public Prosecutor's Office, which possibly influenced his/her response.

The effect of the complaint was pointed out in other studies as an element of influence on people's reporting behaviour. Baldrige and Veiga (2001) stated that if individuals have the perception that adequate reaction is unlikely, there is a high probability that they will not place the request, since they feel discouraged by the resistance of their employers to make the request. In line with results obtained by Baldrige and Veiga (2001), an assumption in the present study is that people with disabilities fail to report because they believe that improvements or changes in relation to the reported problem are unlikely. In addition, earlier negative experiences in relation to the public administration, in which there was no government action to solve the reported problem, can be a factor that negatively influences the denunciation. Therefore, Baldrige and Veiga (2001) assume that if people with disabilities believe that the complaint will not evoke a satisfactory result, the probability of filing a complaint decreases significantly, corroborating the results obtained in the present research.

## **Subjective Norms**

The subjective norms are related to the perceived social pressure whether to perform a certain behaviour or not (Ajzen, 1991). Ajzen (2002) further notes that subjective norms are composed of injunctive and descriptive norms. The injunctions refer to the perceptions of the reference groups regarding the approval or disapproval of the behaviour and the value that the individual attributes to these perceptions, encompassing normative beliefs and the motivation to perform the behaviour. The descriptive norms are related to the perception that the reference groups themselves are involved in the target behaviour and the motivation in executing it. From this category the authors created a subcategory, namely, influence of the people.

## **Influence of Other People**

In this subcategory of analysis, the authors addressed answers to questions about the support of close people, such as family and friends, regarding the denunciation in order to guarantee their rights. Most respondents stated that close friends and family generally support and encourage reporting behaviour, with one individual (PD-03) reporting that friends and family often take the initiative to report. Only one respondent (PD-04) stated that the family does not speak out. This respondent (PD-04) added that he/she believes there are still families who repress people with disabilities, out of fear, protection or even shame. Another aspect mentioned in the interviews concerns the fear of making a complaint, in view of the fear of being indisposed or inconvenienced.

The influence of close people is embedded in subjective norms. In general, when the people relevant to the individual believe that he or she must perform a certain behaviour, the person will perceive the social pressure to execute it (Ajzen, 1985). Manning (2009) has noted that social pressure inevitably affects people's behaviour. Feng and Wu (2005) found that nurses who believed that others wanted them to report suspected child abuse were more likely to report abuse.

Baldrige and Veiga (2001) found that the perceived social obligation is greater when the individual believes that people think he or she should defend his or her rights. This can be explained in view of the fact that the requirement for reasonable accommodation is seen as a continuation of activism in the defence of the rights of people with disabilities, which have been hard won. Likewise, the denunciation of accessibility problems in government sites can be seen by people



with disabilities as a way to help future requests and follow the achievement of the rights of people with disabilities.

### **Perceived Behavioural Control**

Behaviour, for the most part, depends not only on the individual effort invested but also on the control that the individual exerts on other internal and external factors (Ajzen,1991). Control beliefs are related to the presence or absence of resources and opportunities required to perform a given behaviour. From this category, the authors created five subcategories: knowledge of laws, technical and procedural knowledge, conscience, knowledge about the Public Prosecutor's Office, and formalism.

### **Knowledge of Laws**

In this subcategory of analysis, the authors listed issues related to knowledge of laws that discuss the right of access of people with disabilities to information and communication technologies. All respondents (people with disabilities) claimed that they know their rights. However, throughout the interviews, the authors realised that the interviewees had limited knowledge about the laws that deal with this issue. One of the interviewees (PD-03) pointed out that he knows the laws that are closest to his reality, that is, that directly affect his life, such as the quota law for people with disabilities in public contests for civil servant positions.

Among the aspects that influence human behaviour, Ajzen (1985) mentions the information that the individual possesses on the subject as an internal factor. In this case, the interviewees showed little knowledge about legislation that determines that government sites should be accessible, or about the existence of accessibility guidelines.

### **Technical and Procedural Knowledge**

The technical knowledge refers to the ability of the person to know how to identify that the difficulty of navigating is an accessibility problem, as well as the ability to describe the problem in a complaint. Thus, the procedural question is related to the lack of knowledge about where and how to report. This was also mentioned in the interviews as a limiting factor.

The issue of technical and legal misconduct may be related to the lack of disclosure and awareness regarding web accessibility issues. The prosecutor (PP-

03) mentioned the importance of proposing a discussion of this topic, in order to bring this problem to the knowledge of society. This also demonstrates the need for greater disclosure about the role of control institutions and how the population can gain access to those services.

## **Consciousness**

The lack of awareness of people with disabilities that the problems of accessibility to information and communication technologies are as serious as any other problem of accessibility was also a factor mentioned in the interviews. The authors observed that people with disabilities tend to be bothered about architectural, attitudinal, transport and urbanistic barriers, but do not perceive or bother with the problems of accessibility to the media. This information refers to the data collected in the official electronic diary of the Public Prosecutor's Office of Minas Gerais, which showed absence of any complaint involving the issue of web accessibility. The question of consciousness is also related to the cultural aspect.

Another aspect addressed in the interviews concerns the need for collective awareness in order to publicly state that problems exist. A visually impaired respondent (PD-04) stated that before he became blind, he did not know the problems that a person with disability faces daily. The person who does not have a disability and does not live with someone with a disability has no direct and frequent contact with the problems of people with disabilities. Faced with this, it is extremely important to promote collective awareness.

## **Knowledge about the Public Prosecutor's Office**

The prosecutors believed that the lack of knowledge of the people in relation to the duties of the Public Prosecutor's Office may be a factor limiting the denunciations. People are unaware of where, how and to whom they should report such problems. This field is still new and unknown to them. Two prosecutors (PP-02 and PP-03) stated that the lack of knowledge regarding this aspect of the Public Prosecutor's Office is related to the lack of publicity to guide the population in this regard.

## **Formalism**

This item is related to the shyness in denunciation due to the formalism that exists in the public sector. There is a perception that denunciation involves a time-

consuming, labour-intensive process without expectation of success. Thus, the fear of bureaucracy and slowness discourages people from formally denouncing problems of accessibility. In addition, one prosecutor (PP-03) observed that the physical structure of the premises, which requires formal dress for access to the Public Prosecutor's Office or the court- room, sometimes inhibits people's participation.

This issue of formalism as an element that influences the intention to denounce was also found in the work of Natan, Hanukayev and Fares(2011) which stated that nurses were more likely to verbally report the aggression suffered because it was easier and it took less time than written reports. These, in turn, require the specific form search and the need to explain the problem clearly and appropriately, which demands time and effort. One possible explanation is that people with disabilities believe that procedures in the Public Administration are time-consuming and ineffective. In this way, people end up opting for other faster solutions, such as third-party help or complaints on social networks, for example.

## CONCLUSION

This article is relevant in that it seeks to present society with the problem of lack of accessibility in government websites and the lack of surveillance, which is harmful for people with disabilities. It proposes that people with disabilities should be more active in order to enjoy their rights of accessibility to government sites. As shown, there is preliminary evidence that people with disabilities do not report problems with web accessibility on governmental websites. In this sense, this article sought to understand the factors that influence the denunciation behaviour of people with disabilities and to assist in the promotion of policies that change this scenario.

The research found that the main causes for people with disabilities not denouncing accessibility problems in government portals are: people with disabilities scarcely access government portals, so it is uncommon to deal with accessibility issues at these sites, or when/if they encounter these problems, they prefer to take the help of others (close people, like family and friends) as it is faster and less laborious; lack of combative culture, in which people prefer not to express dissatisfaction in official bodies; disbelief that the complaint promotes changes or improvements in the reported problem; opinions and attitudes of the people close to them; lack of knowledge about legislation that dictates that government sites should be

accessible; lack of knowledge that the difficulty of navigating is an accessibility problem or a lack of technical knowledge to report the problem in a complaint; lack of awareness that problems of accessibility to information and communication technologies are as serious as any other accessibility problem; lack of knowledge of the people in relation to the attributions of the Public Prosecution Service; and the perception that denunciation involves a time-consuming, labour-intensive and unsuccessful process.

Given the above-mentioned, there is a need for change in this scenario, by encouraging the population with disabilities to be more active in denouncing the problems of accessibility in government portals. For this, it is necessary to propose the discussion of this theme and bring this problem to the knowledge of society. Society should also be made aware of the role played by Ombudsmen and the role of the Public Prosecutor's Office in defending the rights of persons with disabilities. However, it is fundamental to restore the confidence of society in the effectiveness of the performance of public administration. It is also relevant to give training courses on the issue of web accessibility to the prosecutors, the members of the Municipal Councils of People with Disabilities as well as to public servants, especially those who work in the Ombudsman's offices.

The authors of the current article suggest that future research - both quantitative and qualitative studies - focusing on the denunciation behaviour of people with disabilities are needed. It is worth mentioning that the authors are already researching this subject further by distributing questionnaires to people with disabilities, to understand the interaction between the factors from the Theory of Planned Behaviour.

Results from this research will hopefully confirm and complement the results of this article.

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# The Impact of Leprosy and Physical Disability on Marital and Sexual Relationships of Married Nepali Men

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## ABSTRACT

**Purpose:** Both leprosy and disability can have a negative impact on a person's relationships. This study aimed to gain insight into the impact of leprosy and disability on marital and sexual relationships of married Nepali men.

**Method:** The study used a cross-sectional design with a qualitative approach. Thirty participants were selected using purposive sampling and put in 3 groups (10 in each group):

(1) men with impairments due to leprosy, (2) men without leprosy but with physical disabilities, and (3) men without leprosy or disabilities (control group). Data were collected during semi-structured interviews and two focus group discussions, and analysed with the software programme NVivo using structured coding.

**Results:** The majority of the men indicated they were satisfied with their marital and sexual relationships. However, some leprosy-affected men and some men with disabilities experienced friction in their marital relationships. Fighting between husband and wife was reported by half of the men affected by leprosy. Leprosy and disability had a negative influence on the sexual relationships of some of the men, because of physical limitations, pain, or decreased sex drive. Furthermore, many participants appeared to lack knowledge about the cause of leprosy and about sexual health.

**Conclusion and Implications:** Men affected by leprosy or disabilities seemed to face more problems in their marital relationships than men from the control group. This was primarily related to physical limitations which resulted in the inability to work; this threatened their personal and social identity. Findings

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*show that there may be a problem in accessibility or availability of sex education. In addition, some marital problems could be related to lack of knowledge of leprosy. These point to the importance of providing education on leprosy and sexual health at the time of diagnosis.*

**Key words:** *marriage, sex education, physical limitations, identity, friction, qualitative*

## INTRODUCTION

Leprosy, or Hansen's disease, is an infectious disease (Han et al., 2008; Suzuki et al., 2012) that is closely associated with health inequalities and poverty (Bhutta, Sommerfeld, Lassi, Salam & Das, 2014). Common impairments caused by leprosy are impairments of hands and feet, and visual impairments (Pannikar, 2009). Leprosy is a stigmatised disease (Sermrittirong & van Brakel, 2014) Leprosy-related stigma and disabilities may result in participation restrictions and social exclusion of persons affected by the disease (van Brakel et al., 2006). The areas of life that are affected by stigmatisation include interpersonal relationships, marriage, mobility, and social participation (including education and employment) (van Brakel, 2003). Stigma and its consequences may also lead to reduced self-esteem (Brouwers, van Brakel & Cornieljeet al, 2011), lower (family) quality of life (van't Noordende, Aycheh & Schippers, 2020; van't Noordende, Aycheh & Schippers, 2020) and poor mental well-being (Somar, Waltz & van Brakel, 2020).

The areas of life that are affected by stigma are related, for example, loss of employment may lead to inability to support one's family (Brouwers et al., 2011) and to lower self-esteem (Rao, Rao & Palande, 2000). The areas of life that may be affected by leprosy are marital relationships and the sexual relationship that is embedded in a marriage (Christopher & Sprecher, 2000; Scott, 2000; Heijnders, 2004; Try, 2006). The quality of marital and sexual relationships is a major predictor of a person's psychological well-being (Tepper, 2000; Kim & McKenry, 2002). Research has shown that for women affected by leprosy, marriage prospects decline as a result of the stigmatisation related to leprosy (Heijnders, 2004). A recent study in Nigeria showed that leprosy can also influence marriage prospects of men affected by leprosy (Dahiru, Iliyasu, Mande, van't Noordende & Aliyu, 2021).

Both existing and future marriages may fail because spouses or (future) in-laws do not accept a person with leprosy in their family (Try, 2006; Dahiru et al., 2021). In addition, some studies have found that leprosy may be a reason for divorce



(Scott, 2000; van't Noordende et al., 2020; Dahiru et al., 2021). A study in Nepal found that women affected by leprosy experienced violence and abuse from their spouse (van't Noordende et al., 2016). In addition, a study among women in Indonesia found that leprosy can negatively impact sexual health (Susanto, van 't Noordende, van Brakel, Peters & Irwanto, n.d.). No other studies were found on experiences of persons with leprosy regarding their sexual relationships. However, there are studies on the impact of disability on marriage (Tepper, 2000). Tepper (2000) found that persons with disabilities are excluded from sexual relationships because they are viewed as asexual, childlike, and in need of protection. They found that persons with disabilities are excluded because the main objective for having sex is thought to be reproduction, and persons with disabilities are regarded as unsuitable for reproduction and therefore thought not to be in need of sex.

Several studies have shown that both leprosy and disabilities may influence people's marital and sexual relationships. However, no study has specifically looked at the impact of leprosy on the marital life of men. The current study aimed to gain insight into the impact of leprosy and disability on the marital and sexual relationships of married Nepali men. This was done by comparing the experiences regarding marital and sexual relationships of married men with impairments due to leprosy, married men with disabilities not due to leprosy, and married men without leprosy or disabilities.

## **METHOD**

### *Study Design*

This study used a cross-sectional design with a qualitative approach, in order to gain an in-depth understanding of the experiences of Nepali men regarding their marital and sexual relationship.

### *Study Site*

The study was conducted in Morang district, Nepal. A total of 3,054 new cases were detected in Nepal in 2016 (WHO, 2018). In 2016, Mahottari, Jhapa and Banke districts had the highest case detection rates, 4.7 in 10,000 population respectively (Health Management Information System report 2016). There are still sixteen districts that are considered high endemic for leprosy.

## Study Population

There were three groups of participants in this study:

(1) Men with impairments due to leprosy, (2) men without leprosy but with physical disabilities, and (3) men without leprosy or disabilities (control group). These three groups of men were included in the study to be able to distinguish the effect of leprosy from that of disabilities in general and from other cultural factors.

Inclusion criteria:

- All participants had to be married men or men who had been married.
- All participants had to live in Morang district.
- Men affected by leprosy were included only if they had a Grade 1 disability (G1D, loss of sensation without visible impairments) or Grade 2 disability (G2D, visible impairments or disabilities) based on the WHO's leprosy disability grading system (WHO, 1988).

The study defined impairment as 'problems in body function or structure such as a significant deviation or loss' and disability as 'an umbrella term for impairments, activity limitations and participation restrictions'(WHO, 2001). Men were considered to have a physical disability if the disability was obvious to the community, based on appearance and/or if the disability caused limited functioning.

Exclusion criteria:

- Men below the age of 18.
- Men unwilling or unable to give informed consent.

## Sampling Procedure

Participants were selected using purposive sampling. The participants affected by leprosy were reached through Morang district's local health clinics that provided extensive lists of men affected by leprosy. Men with disabilities were reached through local disability organisations and contacts of NLR Nepal in Biratnagar, Morang district. Men from the control group were recruited in the same villages as the other participants, based on their similarity to the men affected by leprosy and the men with disabilities, in terms of marital status, age and living area. Participants were included until data saturation was reached.

## Data Collection

Data were collected through semi-structured interviews and focus group discussions (FGDs) that were conducted in May and June 2016. Interview guides were prepared based on previous research conducted among Nepali women (van't Noordende et al., 2016) and discussions with leprosy specialists. The interview guides were translated from English to Nepali. Back translation to English was done by another interpreter and checked to ensure the Nepali translation was accurate. The data were collected by two local male interviewers who were trained before conducting the interviews. Two pilot interviews were held before conducting the actual interviews in the home or in a private space in the village of the participants. All men affected by leprosy and men with disabilities who participated in the in-depth interviews were invited to participate in a focus group discussion (FGD) also.

Two FGDs were conducted - one with men affected by leprosy and one with men with disabilities. One facilitator (who also conducted the in-depth interviews) led the discussion, while another researcher wrote down the key information that was discussed. The main topics for the FGDs were the same as for the interviews and were complemented by key topics emerging from the interviews. Due to the sensitive nature of the study topic, the (female) first author (MJM) was not present during the interviews. Each in-depth interview and FGD lasted approximately one hour.

## Data Analysis

The in-depth interviews and FGDs were audio-recorded, the recordings were transcribed verbatim and then translated into English by the two interviewers. The data were analysed through a structured coding that was based on the predefined topics of the interview guide. The coding of the transcripts was discussed with another researcher to determine that the coding was appropriate. In the coding process, first of all the translated interview transcripts and notes were read to get a feel for the data. Afterwards, initial codes were given to the experiences of the Nepali men. The next step was to try and identify the pre-defined themes of marital and sexual relationships in the codes which formed the coding scheme. Furthermore, the different experiences were categorised according to the three participant groups and the disability grade for the men affected by leprosy. The software programme NVivo was used to analyse the data. The findings of the FGDs were coded in a similar fashion and added to the information from the interviews.

## Ethical Considerations

Ethical approval was obtained from the Nepal Health Research Council (approval number 97/2016) before this research was begun. Participants had to first sign an informed consent and, if they were not able to do so, verbal consent was voice recorded.

## RESULTS

### Demographic Information

Thirty men were included in this study: 10 affected by leprosy, 10 with disabilities and 10 in the control group (see Table 1). All participants were married at the time of the interview. The mean age of the participants was 35 years. Of the total sample, 17 men had an arranged marriage and 13 men had a love marriage. The majority of the participants were Hindu (n=26) and the majority (n=25) had at least one child or more. Seventeen participants lived in a single household consisting of only one family, whereas 13 were part of an extended family, which included grandparents and/or sisters and brothers. Of the men affected by leprosy, 5 had a G1D and 5 had a G2D.

**Table 1: Demographic Information of the Participants**

	Men affected by Leprosy (n = 10)	Men with Disabilities (n = 10)	Men from the Control Group (n = 10)
<b>Age</b> , mean (range)	32 (21-42)	38 (27-48)	35 (23-50)
<b>Highest education completed</b>			
No education	4	2	0
Primary	4	2	1
Secondary or higher	2	6	9
<b>Employed</b>			
Yes	7	8	10
No	3	2	0
<b>Religion</b>			
Hinduism	10	6	10
Other <sup>a</sup>	0	4	0
<b>Living area</b>			
Rural	5	5	8
Urban	5	5	2
<b>Type of marriage</b>			
Arranged marriage	7	3	7
Love marriage	3	7	3

<sup>a</sup>This includes Christianity (n=2), Islam (n=1) and Kirat (n=1)

Of the 9 men who indicated that they had received sex education, 6 were without leprosy and disabilities. One man with leprosy received sex education via school, and 2 men with a disability received sex education via an NGO. Other ways in which information on sexual health was obtained were via television, radio, books and relatives. All men affected by leprosy were diagnosed with the disease during their marriage. The median time since diagnosis was four years. However, 9 men with disabilities already had a disability before getting married. Five out of 10 men affected by leprosy were open about their leprosy status. Among the remaining men, only the wife and/or close family knew about their leprosy status.

Four men affected by leprosy and 8 men with disabilities (see Table 1) participated in FGDs. One FGD was held for men affected by leprosy and there was one FGD for men with disabilities.

## **Experiences regarding the Marital Relationship**

### **Men affected by Leprosy**

The men affected by leprosy indicated that they were satisfied with their marital relationship and that they considered their marriage very important. All of them were diagnosed with leprosy after marriage and most of them said their wives supported them after the diagnosis. One participant said:

*“No, I wasn’t treated differently. In fact, my wife helped me a lot. She helped me to follow the doctor’s advice and there was a gradual improvement in me”* (man affected by leprosy, 34 years old, G1D).

All the men affected by leprosy explained that they still went to the temple and attended marriage ceremonies and other social activities regardless of their disease. In addition, 8 men indicated that their community did not discriminate against them, while 2 men said they did not know how their community members felt. However, in the FGD, some men indicated that they had heard that other persons affected by leprosy were discriminated against by their community members. Most men were satisfied with their role in their household, as most were still guardians of their families because they could still earn money.

However, some men experienced problems (e.g., friction and shifting of family roles) in their marital relationships because of leprosy. These problems were said to occur because their spouses did not know about leprosy and distanced themselves. In addition, inability to work because of physical limitations was

mentioned as a cause for marital problems. This created friction in households because the wife or other family members became primary breadwinners, which meant they were also guardians of the house and in charge of making decisions. In Nepal, the men are traditionally seen as the head of their household. One man explained:

*"I can't go to my work due to my leg. Neither can I pull a rickshaw. I am living on my wife's income. It's almost eight or nine years she is working. Now she is frustrated too. She tells me to get well soon and do some work. Many people offer me jobs, but I can't accept them. I am a man, but I can't do my duty, play my role. I can't take care of my family. Other people say that I live on wife's earnings"* (man affected by leprosy, 42 years old, G2D).

Participants indicated that physical disabilities and (negative) community perceptions about leprosy could cause problems in marriage. Almost half of the men affected by leprosy told us they were afraid of getting (additional) disabilities in the future, which could cause marital problems because of possible unemployment and negative perceptions from the community or their in-laws. Participants indicated that negative attitudes of the family-in-law would have a more severe impact on the marital relationship than negative attitudes from the community. For example, in some cases participants indicated that the wife would be excluded from her family if she would not divorce her husband. One man, who already had a disability, explained:

*"My mother-in-law had told me to divorce her daughter and she told her daughter that she would arrange another boy to marry her. My wife says, 'before his physical condition it was good but it is bad now. How can I leave him alone now, I will stay with my husband.' Now we live together and we have a good relationship"* (FGD with men affected by leprosy).

Four men affected by leprosy (and one man with a disability) spoke about fights between husband and wife. Most of these men (three out of four) indicated that they do not drink alcohol. However, one man indicated that *'small violence'* occurred within his marriage; this was related to alcohol.

*"I don't have much money so I don't drink usually. When I meet my friends and when I have money, I drink. I consume alcohol two to three times a week. (...) There is small violence, not big. But it's not for a long period (...) the reason (for the violence) was alcohol"* (man affected by leprosy, 42 years old, G2D).

During the focus group discussion, one more man affected by leprosy (and one more man with disability) admitted he was sometimes violent towards his wife and that this was related to drinking alcohol.

### **Men with Disabilities**

Nine of the men with disabilities said they were satisfied with their relationship with wife and children. All except one already had a disability before getting married. Most men said they were content with their household situation as they were still able to earn money and were still guardians of the family. Furthermore, except for one participant in the FGD, all participants said there was no violence in their marriage. Many participants said that they drink alcohol regularly.

Even though the men were happy with their relationship with their wives, negative attitudes from the families-in-law or the community caused difficulties in three of the marriages. One man explained:

*“Her parents did not agree and we did not get family support from her family, so now she also has difficulties with her family. If a person has good physical condition and just passed class 8 and has not got a good reputation in society, and another person is physically weak and is educated and has got a good image in society, even then they will prefer to give their daughter to the (man with a) good physical condition” (man with disability, 38 years old).*

Two men with disabilities indicated that negative attitudes from others do not only influence marriage prospects, but also have an impact on daily activities with their wives.

*“Yes, we will go together to social and cultural activities. However, our society is still narrow-minded regarding disability. They indirectly take notice of us, but when they know me then they regard me positively” (man with disability, 38 years old).*

In addition to negative attitudes causing problems in the marital relationships, half of the men were unable to work or had difficulties in working because of their physical limitations; this was said to cause problems in the household. Some participants mentioned that they were afraid of being unable to work in the future because of possible disabilities later on. One man explained that his wife handled all finances because he could not work and thus did not earn any money; he was unhappy with his role in the household because of his disability.

*“At present, I do not do anything for my family due to my disability. I can't earn, walk, work like others. I want to talk with others, but they won't come and talk with me. Actually I can't do anything so there is no reason to be happy. I am very unhappy. My wife brings food from her father's house”* (man with disability, 46 years old).

Another man underlined the traditional role division in Nepali households and how his role was different from other men because of his disability.

*“Yes, there is much difference with others. A son has to go out of the home and do different kinds of physical work. There is a lot of difference between a mobile person and an immobilised person. If I were a normal person then I might go to Korea and earn 100,000 per month”* (man with disability, 38 years old).

### **Men from the Control Group**

All men without leprosy or disabilities said they were satisfied with their marital relationships and underlined the importance of marriage. They experienced no problems in their households. However, 4 men did mention problems that they heard were common in other households, namely extramarital relationships and alcohol abuse.

*“Yes, I am happy. Some people go with another girl and ignore their family, but I am not like them”* (man from the control group, 23 years old).

Three men mentioned that they drank alcohol. All of them said they were not physically violent towards their wives. However, 2 men did elaborate on being aggressive or having intense verbal fights with their wives. One man explained:

*“No, there is no violence, but sometimes there will be an intense fight due to a financial problem. But I don't drink or smoke”* (man from the control group, 25 years old).

In addition, one participant indicated that he is sometimes violent towards other people, but not to his wife.

## **Experiences regarding the Sexual Relationship**

### **Men affected by Leprosy**

All men indicated that they were satisfied with the sexual relationship with their wife. Nine men mentioned that their wife shows empathy regarding leprosy and



their sexual relationship. Though all men developed leprosy after getting married, 7 indicated that they experience no difference in their sexual relationship because of leprosy. In addition, the reported frequency of having sex was similar to the reported frequency of the other participants in the study; having sex once or twice a week was reported most often.

All men indicated that they themselves and their spouses were sexually satisfied, and that there was no sexual violence. However, despite mentioning that they were satisfied, some participants indicated that leprosy did influence their sexual relationship. For some men, leprosy was said to have decreased their sexual desire.

*“She shows empathy and she never pressures me to have sex with her. The desire to have sex might be less after leprosy. So there is a difference. Before I had leprosy I was fresh and I had more desire for sex, but after taking medicine I feel that I have less interest in sex and less desire. My wife requests me not to have sex because I am weak, so sometimes I don’t feel good”* (man affected by leprosy, 27 years old, G2D).

Eight of the men affected by leprosy did not know the cause of leprosy. It was unclear how much their wives knew about leprosy. One participant said he experienced difficulties with his wife because she did not know about leprosy:

*“At first she did not know about leprosy. After I told her the effect of leprosy and its treatment, she understood all and now there are no problems. Before she was scared as she didn’t know about leprosy, but I told her that it won’t transfer after the treatment. Slowly there is positive change”* (man affected by leprosy, 38 years old, G2D).

Participants indicated that personal problems were only discussed with their wife or the doctor. Seven men said they did not talk about sex at all with friends.

*“If a problem arises relating to sex, then I will consult with a doctor in the health post. If I consult with friends then my problem will not be solved, so I have to consult with a doctor. If I have a mood of having sex, then in that situation only I talk to my wife, in other cases we do not talk (about sexual problems). With friends I talk about other people’s sexual relations, but we do not talk about our own sexual relation”* (man affected by leprosy, 37 years old, G1D).

One participant with leprosy had received formal sex education. While 2 men said sex education was not of importance to them, 8 men did find sex education important because of disease transmission and because sex is seen as an important factor in marriage.

*“Yes, all men and women have to take sex education; if we fail to take sex education we may be unsuccessful in our marital life”* (man affected by leprosy, 33 years old, G1D).

### **Men with Disabilities**

Though all men said their wives showed affection and empathy regarding their sexual relationship and their disability, several problems were mentioned which were all directly related to their physical disability. Common problems were being limited in acting on sexual desires or having no sex at all, and feeling pain or feeling no pleasure. One man said:

*“Yes, there are lots of difficulties, we can have sex in natural way, but we cannot have sex using different methods that normal people do nowadays to satisfy their wife. We cannot do a different style”* (FGD with men with disabilities).

One man, who acquired the disability after being married, mentioned he did not have sex anymore due to his disability. Another man explained that he does not experience pleasure from sex:

*“No, I don’t experience pleasure. My wife has to make my leg straight after having sex. There is pain, it is difficult to have sex as (my body) below the hip is not working. My wife used to say ‘this disability should be for me, not for you’ but she is happy”* (man with disability, 43 years old).

Participants said they mainly discussed these sexual problems with their wife and the doctor. Some did talk to friends about sex in general. In addition, all men underlined the importance of sex education. Reasons mentioned were to raise awareness about diseases and contraceptives and because many men had extramarital sex. One man said:

*“Sex education is important because many people have sexual intercourse with many girls. It teaches us about how to have sex with other girls (safely). Many diseases are caused by sex and protection from it is necessary”* (FGD with men with disabilities).

Furthermore, all men denied there was sexual violence in their marriage. However, during the FGD, 3 men did talk about sexual violence towards women with disabilities. One man said:

*“There are many women suffering from sexual violence due to the speech problem. Some years ago there was a woman who could not speak and a boy convinced her and took her to a place where no one came. He had sex with her and killed her there”* (FGD with men with disabilities).

## Men from the Control Group

The men without leprosy or disabilities were overall satisfied with the sexual relationship they had with their wife. All thought that a sexual relationship was very important in a marriage and that mutual understanding was needed in order to have a good sexual relationship. One man elaborated on his sex life, confirming he had extramarital sex:

*“I have sex two or three times in a week. We can live without getting married but we cannot live without sex. I have had sex for the first time when I was 15 and till now I have had sex with a lot of girls. If I get the opportunity to have sex with a girl, I will. Why not?”* (man from the control group, 38 years old).

Most men indicated that they talked to their wife or doctor in case they experienced any sexual problems. In addition, all men said they also talked to friends about sex. Topics that were discussed included sex methods, contraceptives and the number of sexual partners. Eight participants thought sex education was important, of whom 6 had received formal sex education themselves. Sex education was said to be important given the increase in sexual violence and extramarital sex, and to get knowledge about sexually transmitted diseases. One man elaborated on the importance of sex education:

*“Yes, sex education is important, because nowadays there are many diseases that can be transmitted through sex. Many people are interested to have sex with another girl other than their wife and they may suffer from such diseases”* (man from the control group, 45 years old).

Sexual violence was not mentioned by any of the men in this group. However, 2 men did talk about the decision-making regarding sexual intercourse.

*“Until now there is no sexual violence, because she is my wife. Why do I have to force her to have sex, I can have it next time also if she does not have desire. Firstly the male decides about having sex and only then the female makes a decision about it”* (man from the control group, 26 years old).

## DISCUSSION

### Similarities among the Three Participant Groups

This is the first study specifically addressing the influence of leprosy and disability on marital and sexual relationships of married men in Nepal. As in other studies conducted in Nepal, marriage was considered to be of utmost importance by all

men, and embedded in their culture (Sharan & Valente, 2002). The majority of the men in this study indicated that they were satisfied with their marital and sexual relationships. All men indicated that sexual relationships were of importance in a marriage. The majority of the men in this study had not received sex education; however, many considered this important. Finally, some men in each participant group said they drank alcohol regularly.

## **The Impact of Leprosy and Disability on Marital Life**

The majority of the men in this study said they were satisfied with their marital relationships despite having had leprosy or having a disability, and that they still participated in social events. However, some men experienced difficulties in their marriage (e.g., friction and shifting of family roles) because of negative attitudes from either their wife or community members towards their condition or associated physical impairments. This is similar to findings from a review by one of the authors (van Brakel, 2003). While most men affected by leprosy had not experienced discrimination, negative attitudes from the community did have an impact on men with (visible) disabilities, because they would be recognised and stared at in public. Indeed, visible impairments are often linked to negative perceptions and stigma (Zeldenryk, Gray, Speare, Gordon & Melrose, 2011; van Brakel et al., 2012; van't Noordende et al., 2019; van't Noordende et al., 2021).

In some instances, the family-in-law would not accept a man affected by leprosy or disability and would ask their daughter to leave him. Though several studies mention that existing or future marriages may fail because (future) in-laws do not accept the person with leprosy or disabilities, this was rare in the present study (Scott, 2000; Try, 2006; van't Noordende et al., 2020; Dahiru et al., 2021). It could be that divorce occurs more often when women have leprosy or disabilities (Try, 2006; Brouwers et al., 2011; Dijkstra, van Brakel & van Elteren, 2017). However, it should be noted that most likely divorce due to leprosy or disability was not found in the present study because only married men were included as participants. In addition, all but one of the men with disabilities already had their disability when they got married. This is an important difference between the men with disabilities and the men affected by leprosy in this study, because a condition that is already there at the time of marriage may be less likely to cause changes and friction than a condition that develops during marriage. At the same time, the diagnosis of leprosy can be a traumatic experience which occurs at a given point in time, and therefore the impact on people's marriage may be different from, for example, people who have a disability since birth.

Some men affected by leprosy or disability had difficulties working or providing for their family, or were afraid of being unable to work because of their physical limitations. This is similar to findings from other studies (van't Noordende et al., 2020). Inability to work resulted in a division of tasks in the households – the role of the man as guardian was taken over by other family members. Although this is not something that has been explored in-depth, perhaps this may have threatened the personal and social identity and self-esteem of the men, as has been found in other studies (Major & O'Brien, 2005; Goffman, 2009; Scambler, 2009). From other studies it is known that being able to work increases people's social value, and promotes dignity, independence and engagement in daily (social) life (Ebenso et al., 2007; Dadun et al., 2017; van't Noordende et al., 2021). Being able to work again after loss of a job can also increase the acceptability of persons affected by leprosy by their family and community members (Rao et al., 2000).

### **The Impact of Leprosy and Disability on Sexual Relationships**

In the present study, men said that they were satisfied with their sexual relationships and the frequency of having sex was similar in all participant groups. These findings appear to contradict the conclusion of Tepper (2000), who found that people with disabilities are excluded from sexual relationships because they are seen as childlike or asexual. This may be because of sampling bias in the present study: only married men were included, and most men with disabilities already had their disability when they got married. However, the study did find that leprosy and disability had a negative influence on the sexual relationships of some of the men because of physical limitations, pain or a decreased sex drive.

Fighting between husband and wife was reportedly common among the married men affected by leprosy. Two men affected by leprosy admitted they were sometimes violent towards their wives. In another study by one of the authors (van't Noordende et al., 2016), married women affected by leprosy indicated that their husbands were violent towards them, which was often related to alcohol abuse and their leprosy status. In the present study, participants indicated that violence was linked to drinking alcohol but given that this was mentioned by only two participants, there is no clear indication that alcohol abuse resulted in violence towards the spouse. In addition, it should be noted that verbal fights with the wife were also mentioned by participants in the group of men without leprosy or disabilities.

A study among women affected by leprosy in Nepal found that a lack of knowledge about leprosy, insufficient access to sex education and the negative perception of leprosy can negatively influence marital and sexual relationships of persons affected by leprosy (van't Noordende et al., 2016). This is similar to the findings in the present study. In addition, poor knowledge of leprosy is associated with negative attitudes towards persons affected by leprosy in general (Seshadri, Khaitan, Khanna & Sagar, 2014; Singh, Singh & Mahato, 2019; van't Noordende et al., 2019). In the present study, insufficient access to sex education was not unique among men affected by leprosy or men with disabilities; it was something found in all participant groups. However, given that a lack of knowledge about leprosy likely had a negative influence on marital and sexual relationships of affected persons, persons affected by leprosy (and persons with disabilities) would benefit from specific sex education focusing on what they can (and sometimes cannot) do and addressing misconceptions about their condition (e.g., that leprosy is not sexually transmitted).

## **Limitations**

The authors believe that the use of both individual interviews and FGDs increased the validity of this research. Future research on leprosy and sexual health should make use of the advantages of FGDs when addressing personal issues. A limitation of this study is that some answers were superficial and needed follow-up questions for more in-depth insights, but sometimes these questions were not asked.

Finally, a limitation of this study is that the sampling was not random and therefore the results of this research specifically apply to this study sample and cannot be generalised. There were differences in demographic information between the participants in the study. For example, men from the control group had, on average, received more education and all were employed. In addition, in contrast to the men affected by leprosy, most men with disabilities already had their disability when they married. For this reason, it is not possible to draw firm conclusions regarding the differences and similarities experienced by the men affected by leprosy and the men with disabilities on the basis of the data. It is unclear how much of the experiences of participants were determined by the fact they had leprosy or disabilities – it cannot be ruled out that some differences may have been caused by other factors. A larger follow-up study using random sampling will need to clarify how much of the impact on marital and sexual

relationships can be attributed to leprosy or disability; this is an important topic for future research.

## CONCLUSION

Findings from this study confirm that marriage is an important aspect in the lives of Nepali men. The results of this study indicate that men affected by leprosy and men with disabilities face more problems (friction and shifting of family roles) in their marital relationships than men without leprosy and disabilities. The negative impact on their lives was primarily related to physical limitations, which resulted in an inability to work and threatened their personal and social identity. Furthermore, there was a lack of knowledge about leprosy as well as a lack of sex education, despite the fact that almost all men considered the latter important. This shows that there may be a problem in accessibility or availability of sex education. Some marital problems are possibly related to lack of knowledge of leprosy, which illustrates the importance of providing education on leprosy and sexual health at the time of diagnosis. An important topic for future research is a quantitative study which addresses both the frequency of marital and sexual problems among married men affected by leprosy and disability, and the risk factors for such problems.

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The data that supports the findings of this study are available on request from the corresponding author (AvtN).

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# The Dynamics of Social Inclusion of People with Spinal Cord Injury

Ashok Kumar Sar\*

## ABSTRACT

**Purpose:** Social inclusion of people with disability is critical for maintaining social equity. The goal of this paper was to examine the dynamics of social inclusion of persons with spinal cord injury.

**Method:** A cross-sectional research design was adopted to study the impact of individual, interpersonal, organisational, community and socio-political conditions on interpersonal relationships and community participation. Confirmatory factor analysis was used to validate the measurement models. Structural equation modelling (SEM) in AMOS was used to derive results.

**Results:** The individual, interpersonal, organisational, community and socio-political conditions strongly influence social inclusion of persons with spinal cord injury. The strongest influencer of community participation is socio-political conditions ( $\beta=0.692$  and  $p=0.001$ ) and the strongest influencer of interpersonal relationships is organisational conditions ( $\beta=0.677$  and  $p=0.001$ ).

**Conclusion:** Social inclusion, measured by interpersonal relationships and community participation, can be enhanced by improving the individual, interpersonal, organisational, community and socio-political conditions, thereby contributing to social equity and sustainable performance.

**Key words:** personal conditions, interpersonal conditions, organisational conditions, community conditions, social and political condition, interpersonal relationship, community participation

## INTRODUCTION

As per the World Bank, “social inclusion is the process of improving the terms on which individuals and groups take part in society — improving the ability, opportunity, and dignity of those disadvantaged on the basis of their identity”. As

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per the United Nations, “social inclusion is the process by which efforts are made to ensure equal opportunities – that everyone, regardless of their background, can achieve their full potential in life”. Social inclusion is recognised as a general principle (Article 3), a general obligation (Article 4) and a right (Articles 29 and 30) in the United Nations Convention on the Rights of Persons with Disabilities. Social inclusion is a multidimensional concept with three facets, i.e., a) “markets - land, housing labour and credit”, b) “spaces - political, cultural, social and physical” and c) “services - social protection, information, electricity, transport, education, health and water”. These three facets interface with the ability, dignity and opportunity of people who are disadvantaged.

Clement and Bigby (2009) used the community inclusion framework with adults with severe disability and found that a pattern of service delivery with community presence best describes social inclusion. Cobigo et al (2012) conducted a literature review on social inclusion and suggested that “social inclusion speaks of the full and fair access to community-based resources and activities, having relationships with family, friends and acquaintances, and having a sense of belonging to a group”. Bates and Davis (2004) studied services for people with learning disability and suggested that “social inclusion means ensuring that people with disabilities have full and fair access to activities, social roles and relationships directly alongside non-disabled citizens”. Duggan and Linehan (2013) reviewed thirty-five papers on social inclusion and suggested that social inclusion can be understood as natural supports to promote independent living by people with disability. Forrester-Jones et al (2006) studied 213 people with disability, resettled after long stay in hospitals, over a 12-years follow-up and found that social networks and social support are considered to be key aspects concerning social inclusion. Hall (2009) articulated social inclusion to be associated with formal and informal supports, appropriate living accommodations, gainful employment, involvement in activities, significant reciprocal relationships and acceptance as individuals beyond disability.

Social inclusion is an integral part of social equity which constitutes the triple bottom line approach to sustainability. If social equity is questionable, it can lead to serious adverse impacts on ecology and the economic system, thereby rendering other efforts of individuals and institutions ineffective. In the United Nations’ Sustainability Development Goals for 2030 agenda, Goal-3 includes seven targets and eleven indicators explicitly referencing persons with disabilities, covering inclusion and empowerment of persons with disabilities among other aspects.

The global reporting initiative (GRE framework) provides comprehensive objective measures of social equity, which are being used worldwide for reporting sustainability performance by companies. Social inclusion benefits all people: a) individuals with physical or intellectual/ developmental disability, b) community, c) society and the nation.

Two domains of social inclusion can be inferred from the aforementioned review of literature:

- a) interpersonal relationships, and b) community participation. Within each domain, there are three aspects, namely, kind of people in the social network; structure - length, origin, frequency and mode on interaction; and, function - kinds of support.

The desirability of social inclusion can be seen in aspects such as: a) happiness, self-esteem, confidence and mental health (Forrester-Jones et al., 2006); b) general well-being (Johnson, Douglas, Bigby, & Iacono, 2012); c) adding value and respect (Johnson, Douglas, Bigby, & Iacono, 2009); d) decreasing negative attitudes, stereotypes, stigma and discrimination (Mahar, Cobigo, & Stuart, 2013; Power, 2013); f)e) promoting uniqueness and decision-making capability (Johnson et al, 2009); f) improving lives (Mahar et al., 2013) ; g) enabling people with disabilities to contribute to society (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014); h) combating poverty, unemployment and poor access to healthcare (McConkey, 2007); and, i) enhancing community safety and protection against abuse (Quinn & Doyle, 2012).

## Objective

Spinal Cord Injury (SCI) is a truly shattering injury, with grave consequences for the injured individual, his/ her family and society. The WHO recognises it as a major musculoskeletal condition that presents a serious disease burden. People with spinal cord injuries face specific challenges owing to locomotive as well as bowel and bladder management issues restricting their movements and community activities. One of the principles for empowerment of persons with disabilities under the Rights of Persons with Disabilities Act, 2016, in India, is full and effective participation and inclusion in society. While studies done in the past have focused on intellectual disabilities and social inclusion, there are no studies on social inclusion of persons with spinal cord injury.

With the number of persons with spinal cord injury increasing steadily, this study aimed to examine how individual, interpersonal, organisational, community and socio-political conditions influence interpersonal relationships and community participation among a sample of persons with spinal cord injury in India.

Five sets of hypothesis are proposed, to examine the dynamics of social inclusion:

- 1 a.) Individual conditions have a significant impact on interpersonal relationships.
- 1 b.) Individual conditions have a significant impact on community participation.
- 2 a.) Interpersonal conditions have a significant impact on interpersonal relationships.
- 2 b.) Interpersonal conditions have a significant impact on community participation.
- 3 a.) Organisational conditions have a significant impact on interpersonal relationships.
- 3 b.) Organisational conditions have a significant impact on community participation.
- 4 a.) Community conditions have a significant impact on interpersonal relationships.
- 4 b.) Community conditions have a significant impact on community participation.
- 5 a.) Socio-political conditions have a significant impact on interpersonal relationships.
- 5 b.) Socio-political conditions have a significant impact on community participation.

## **METHOD**

### **Study Design**

A cross-sectional research design was adopted to study the impact of individual, interpersonal, organisational, community and socio-political conditions on interpersonal relationships and community participation.

## Sample

A convenient sampling method was used to select 410 persons with spinal cord injury. The respondents were from all parts of India.

## Inclusion Criteria

- Those with spinal cord injury, either traumatic or due to other causes such as infection;
- Those with injury since at least three years; and,
- Those who were at least wheelchair mobile.

## Exclusion Criteria

- Newly-injured persons; and,
- Persons confined to bed.

## Measures

The constructs were developed through an extensive review of literature. A seven-point Likert scale was used to measure the observable variables that represent the latent variables. The measures developed by Simplican et al (2015) with contextual modifications were used for this study. Details of construct-wise measures are described in the next section.

## Individual Conditions

At an individual level, enabling conditions comprise the use of goal-setting, awareness about feasible activities, level of functioning, confidence and self-motivation (Cobigo et al., 2012; E. Hall, 2005). A sense of belongingness, improved self-esteem and increased happiness are some of the important individual outcomes of social inclusion. To measure individual conditions, the aforementioned measures were modified into a five-item and seven-point Likert scale.

## Interpersonal Conditions

The family and peers/ superiors/ subordinates at the workplace are the relevant entities for the interpersonal domain. Relationships with peers/ superiors/ subordinates and their attitudes, and relationship with family members constitute

the interpersonal enabling conditions (Beadle-Brown, Mansell, Cmbridge, Milne, & Whelton, 2010; E. Hall & Wilton, 2011). Increased social capital and respect and trust between people are the key interpersonal outcomes of social inclusion. To measure interpersonal conditions, the aforementioned measures were modified into a five-item and seven-point Likert scale.

### **Organisational Conditions**

The informal networks like families and formal networks like the workplace settings constitute the organisational domain (Chenoweth & Stehlik, 2004). The enabling conditions for families include family cultures, socio-economic status and social capital. Workplace-level enabling conditions include workplace culture and norms, learning and development opportunities, opportunities for career growth and workplace policy framework (Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012). Changes in organisation culture is the most important organisational outcome of social inclusion. To measure organisational conditions, the aforementioned measures were modified into a five-item and seven-point Likert scale.

### **Community Conditions**

The enabling conditions under this domain comprise culture, traditions, civic amenities, accessible transportation, healthcare, access to general services, and types of living accommodation (Duvdevany & Arar, 2004). Community outcomes of social inclusion include decreasing negative attitudes, stereotypes, stigma and discrimination (Robertson et al., 2001). To measure community conditions, the aforementioned measures were modified into a five-item and seven-point Likert scale.

### **Socio-Political Conditions**

Presence of appropriate legislations and enforcement of laws, market forces, track record of service delivery (say, during pandemic and natural disasters) constitute the enabling conditions under the socio-political domain (Quinn & Doyle, 2012). The socio-political outcome on social inclusion is reflected in the changed behaviour of others in the society, as others need to abide by the associated rules/guidelines to support social inclusion (Hermsen, Embregts, Hendriks, & Frielink, 2014). To measure socio-political conditions, the aforementioned measures were modified into a five-item and seven- point Likert scale..



## **Interpersonal Relationships**

The interpersonal relationship is the first integral component of social inclusion. It comprises three kinds of characteristics : a) category, b) structure, and c) function. From the category point of view, interpersonal relationship reflects in bonding and bridging (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Bonding offers the opportunity to build trust, confidence and reciprocity. Bridging on the other hand brings diverse people into contact with potential for improving employment outcomes. Both bonding and bridging are highly valued by people with spinal cord injury. Structural characteristics refer to the structure of the social network, which include who initiates contact, length of relationship, origin of relationship, frequency of contact and location of interaction (Heaney & Israel, 2008). The structure of the social network can be measured along four dimensions, such as, a) geographic dispersion, b) homogeneity, c) density, and d) size. Through the measure of the structural components, it is possible to get a clear picture of a person's level of social inclusion. The functional characteristic reflects the three types of support systems :

a) instrumental (tangible aid and services); b) informational (advice, suggestions and information): and, c) emotional (love, care and trust) (Abbott & McConkey, 2006). Prior research suggests that people with SCI value each kind of support. To measure interpersonal relationships, the aforementioned measures were modified into a five-item and seven-point Likert scale.

## **Community Participation**

Community participation is measured through three characteristics namely, a) category, b) structure, and c) degree of involvement. Categories of community activities include: a) consumption - access to goods and services; b) religious and cultural activities; c) political and civil activities; d) leisure activities- hobbies, arts and sports/ games; and, e) productive activities- employment/ education (McConkey, 2007; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). The structure reflects the setting in the community for the different categories of activities (Clifford, 2013; Perring, 2005). Although people with SCI participate in many settings, true inclusion would relate to the mainstream setting as opposed to segregated settings. In other words, if larger number of activities are conducted in mainstream settings, it will indicate higher level of social inclusion. Based on prior research (O'Brien & Lyle, 1987; Thorn, Pittman, Myers, & Slaughter, 2009), the degree of involvement was conceptualised as presence (being physically present

in a community event, with little contact with other people); encounter (meeting with strangers in the community, that can be fleeting or more sustained); and participation (involvement in community activities that promote interpersonal relationships). While participation reflects a higher order of social inclusion, presence and encounters are necessary precursors to participation. To measure community participation, the aforementioned measures were modified into a five-item and seven- point Likert scale.

### **Data Collection**

An inventory of variables related to conditions - individual, interpersonal, organisational, community, socio-political, and social inclusion - interpersonal relationships and community participation was established from the review of literature. Data was then collected using a two-stage approach suggested by Bourque and Fielder (2003). A draft/pre-test questionnaire was first administered to twenty-six respondents and based on the input from the pre-test survey, changes were made in varying extent to six questions. The final survey instrument was sent to 562 respondents through WhatsApp peer groups, individual emails and WhatsApp messages, while limited printed forms were administered through field investigators. In all 410 completed forms were received (a response rate of 73%).

### **Statistical Analysis**

Structural equation modelling (SEM) in AMOS was used to get the results from the survey data. The results include descriptive statistics covering the frequencies of the respective distribution from the socio-demographic information. The results also include confirmatory factor analysis, correlation between the constructs and regression.

### **Ethics**

The study confirms to the scientific and ethical standards of Kalinga Institute of Industrial Technology, Deemed to be University.

## **RESULTS**

The demographic characteristics of the participants are shown in Table 1.

**Table 1. Demographic Characteristics**

Variable	N	%
Gender		
Male	312	76.1
Female	98	23.9
Age (years)		
Below 20	9	2.2
21-30	100	24.4
31-40	189	46.1
41-50	102	24.9
Above 51	10	2.4
Education		
Less than High School	1	0.2
High School pass	28	6.8
Graduate	285	69.5
Post-graduate	79	19.3
Ph.D.	2	0.5
Professional	15	3.7
Location Type		
Rural	25	6.1
Sub-urban	171	41.7
Urban	214	52.2
State/ Union Territory		
Andhra Pradesh	8	2.0
Punjab	14	3.4
National Capital Region (NCR)	19	4.6
Telangana	65	15.9
Tamil Nadu	105	25.6
Odisha	199	48.5
Annual Family Income		
Less than 2 lakhs	48	11.7
2-5 lakhs	282	68.8
5-10 lakhs	49	12.0
Above 10 lakhs	31	7.6

## Measurement Model

The measurement models are validated to ensure that the instruments (questionnaire) “measure the aspect (“construct”) that they aim to measure (validity), and that they do this in a reliable way (reliability)”. Using AMOS 20, “confirmatory factor analysis (CFA) was conducted to assess the reliability of the composition of the constructs and validate the scale used”. “Correlation coefficients among the constructs were analysed to find out conceptual and empirical distinctiveness”. Correlation coefficients, standard deviation and mean, are presented in Table 2. The data presented in Table 2 reflects that the constructs used in the study are distinct. In the CFA, Chi-Square test and other goodness of fit statistics like normal “fit index (NFI), comparative fit index (CFI), goodness of fit index (GFI), adjusted goodness of fit index (AGFI), root mean square residual (RMR) and root mean square error of approximation (RMSEA) were used for model validity”. The associated values are presented in Table 3, which meet the respective standards.

**Table 2: Descriptive Statistics and Correlation**

Constructs	Mean	SD	Correlation between constructs						
			INDC	IPRC	ORGC	COMC	SPC	IPR	COMP
INDC	3.59	1.23	1						
IPRC	3.48	1.21	0.361*	1					
ORGC	3.82	0.94	0.424**	0.342*	1				
COMC	5.45	1.52	0.366**	0.276**	0.417*	1			
SPC	3.64	1.13	0.291*	0.411*	0.328*	0.428*	1		
IPR	4.94	1.55	0.668**	0.562**	0.489**	0.519**	0.489**	1	
COMP	4.71	1.67	0.406**	0.462**	0.582**	0.682**	0.562**	0.328*	1

Notes: INDC - individual conditions; IPRC - interpersonal conditions; ORGC - organisational conditions; COMC - community conditions; SPC - social and political condition; IPR - interpersonal relationships; COMP - community participation.

\*\*\*Correlation is significant at the 0.01 level (2-tailed) and \*Correlation is significant at the 0.05 level (2-tailed)“.

**Table 3: Assessment of the Measurement Model of each Construct**

Construct	$\chi^2$	df	<i>p</i>	NFI	CFI	GFI	AGFI	RMR	RMSEA
INDC	13.88	2	0.01	0.988	0.992	0.978	0.931	0.20	0.02
IPRC	53.11	3	0.00	0.947	0.952	0.913	0.738	0.05	0.04
ORGC	6.48	2	0.00	0.992	0.993	0.986	0.936	0.012	0.05
COMC	8.32	2	0.03	0.958	0.961	0.971	0.851	0.014	0.07
SPC	2.68	2	0.05	0.996	0.997	0.995	0.944	0.009	0.01

IPR	3.29	2	0.00	0.992	0.996	0.992	0.968	0.38	0.05
COMP	68.2	20	0.00	0.964	0.976	0.938	0.889	0.076	0.06

Notes:  $\chi^2$  - Chi square; df - degree of freedom;  $p$  - significance; NFI - normal fit index; CFI - comparative fit index; GFI - goodness of fit index; AGFI - adjusted goodness of fit index; RMR - root mean square residual; RMSEA - root mean square error of approximation"; INDC- individual conditions; IPRC - interpersonal conditions; ORGC - organisational conditions; COMC - community conditions; SPC - social and political condition; IPR - interpersonal relationships; COMP - community participation.

## Construct Reliability

Statistical reliability of the scale was established by comparing values of "composite reliability index ( $CR \geq 0.6$ ) and Cronbach's coefficient ( $C\alpha \geq 0.6$ )". The determined values from analysis of the survey data exceed the threshold values suggested by Fornell and Larcker (1981), Anderson and Gerbing (1988), and Hair et al (1998). Cronbach's coefficient are in the range of 0.831 and 0.953 and the composite reliability index are in the range of 0.836 and 0.954.

## Construct Validity

Content, face, discriminant and convergent validity were used to establish statistical validity of the scale. Content and face validity were established considering identification of the variable based on extensive review of literature.

"Convergent validity is a subtype of construct validity that verifies whether the scores of the instrument under study make sense in relation to the scores of other, related instruments. Scores should correlate with scores of other instruments to the degree that one would expect" (Schanz, Equit, Schäfer, & Michael, 2021). "Assessing convergent validity is an iterative process: the more hypotheses are tested, the stronger the evidence towards the instrument being valid. Convergent validity is generally considered adequate if  $>75\%$  of hypotheses are correct, or if a correlation with an instrument measuring the same construct is  $>0.50$ " (Sar, 2020). "The exact values of these cut-off points may be arbitrary, but they provide guidance when judging whether convergent validity is adequate" (Fornell & Larcker, 1981). "Furthermore, correlations with related constructs should be higher than with unrelated constructs" (Anderson & Gerbing, 1988). In the study, convergent validity was established through assessing the average variance extracted ( $AVE = \text{Sum of square of standardised loadings} \div \text{Number of indicators}$ ). Most of the test values are higher than the threshold value, i.e., 0.4 suggested by Anderson and Gerbing (1988). Hence, the constructs are considered valid from the convergent validity point of view.

“Discriminant validity is demonstrated by evidence that measures of constructs that theoretically should not be highly related to each other are, in fact, not found to be highly correlated to each other” (Baumgartner & Homburg, 1996). “Discriminant validity coefficients should be noticeably smaller in magnitude than convergent validity coefficients. To establish discriminant validity, three approaches are used” (Hu & Bentler, 1995). First, square root of average variance extracted is calculated and compared with the correlation coefficients. The constructs will be considered valid with reference to discriminant validity if the “square root of AVE is greater than the correlation coefficient” (Sar, 2020). Second, AVE is compared with maximum shared variance (MSV) and average shared variance (ASV). A construct is valid if AVE is greater than both MSV and ASV (Hair, J.F., Anderson, R.E., Tatham, R.L. and Black, 1998). Third, correlation among the investigated constructs should be less than 0.7 in absolute terms. Finally, to test the fit of the measurement model, goodness of fit measures were computed based on the suggestion of Bagozzi and Yi (1988). Results from the analysis of data show discriminant validity of the constructs on all three approaches. The associated data are presented in Table 4.

**Table 4: Reliability and Validity of Constructs**

Constructs	CR	Range of FL	C- $\alpha$	AVE	MSV	ASV
INDC	0.952	0.749-0.903	0.951	0.821	0.386	0.186
IPRC	0.935	0.782-0.817	0.931	0.741	0.315	0.125
ORGC	0.926	0.799-0.852	0.921	0.762	0.388	0.138
COMC	0.836	0.894-0.913	0.833	0.562	0.386	0.125
SPC	0.951	0.851-0.891	0.952	0.831	0.159	0.059
IPR	0.847	0.812-0.846	0.841	0.586	0.386	0.093
COMP	0.954	0.801-0.902	0.953	0.713	0.075	0.029

Notes: “CR - composite reliability; FL - factor loadings; C- $\alpha$  - Cronbach’s alpha; AVE - average variance extracted; MSV - maximum shared variance; ASV - average shared variance”; INDC - individual conditions; IPRC - interpersonal conditions; ORGC - organisational conditions; COMC - community conditions; SPC - social and political condition; IPR - interpersonal relationships; COMP - community participation.

### Structural Model: Estimation of Causal Model

“Structural equation modelling (SEM)” was used to evaluate the research model and test the hypothesised relationships between the constructs. The values of GFI, AGFI, NFI, CFI and RMSEA derived from the data analysis were found to be higher than the threshold values, establishing that the model fit is satisfactory. The hypothesis testing results covering hypothesis- wise beta values and p values

indicating operational linkages among the constructs are presented in Table 5.

The results established significant relationship of individual conditions on social inclusion in the first cluster of hypothesis, such as individual condition with interpersonal relationship ( $\beta=-0.244$  and  $p=0.001$ ); and community participation ( $\beta=0.189$  and  $p=0.002$ ).

In the next set of hypothesis (H2a and H2b) the results established significant relationship of interpersonal condition with social inclusion, such as, interpersonal condition with interpersonal relationship ( $\beta=0.176$  and  $p=0.001$ ); and interpersonal condition with community participation ( $\beta=0.107$  and  $p=0.023$ ).

In the third set of hypothesis (H3a and H3b), the results established significant relationship of organisational conditions with interpersonal relationship ( $\beta=0.677$  and  $p=0.001$ ) and community participation ( $\beta=0.164$  and  $p=0.004$ ).

In the fourth set of hypothesis (H4a and H4b), the results established significant relationship of community conditions with interpersonal relationship ( $\beta=0.157$  and  $p=0.001$ ) and community participation ( $\beta=0.122$  and  $p=0.007$ ).

In the fifth set of hypothesis (H5a and H5b), the results established significant relationship of socio-political conditions with interpersonal relationship ( $\beta=0.237$  and  $p=0.001$ ) and community participation ( $\beta=0.692$  and  $p=0.001$ ).

**Table 5: Hypothesis Testing Results**

Hypothesis	$\beta$	p	Remarks
H1a	0.244	0.001	"Supported"
H1b	0.189	0.002	"Supported"
H2a	0.176	0.001	"Supported"
H2b	0.107	0.023	"Supported"
H3a	0.677	0.001	"Supported"
H3b	0.164	0.004	"Supported"
H4a	0.157	0.001	"Supported"
H4b	0.122	0.007	"Supported"
H5a	0.237	0.001	"Supported"
H5b	0.692	0.001	"Supported"

Notes: " $\beta$  - estimates; p - significance value"

## DISCUSSION

The findings from the study help in gaining several insights into the impact of disabling conditions on social inclusion. The data supports all the hypotheses. This finding is consistent with the result of a systematic review of literature by Barclay et al (2015) using twenty-three studies.

First, the personal conditions of persons with spinal cord injury significantly impact the interpersonal relationships and community participation. Persons with severe mobility constraints and poor ability to manage bowel and bladder were found to be low in both interpersonal relationships and community participation. The finding is consistent with the result of the study by Carr et al (2017) concerning persons with spinal cord injury in Queensland, Australia.

Second, interpersonal relationships and community participation were strongly influenced by conditions such as relationship with family members, peers, and relationship between peers and family members. This finding is consistent with the result of a longitudinal study on social participation and well-being of persons with spinal cord injury (Fekete, Brinkhof, Tough, & Siegrist, 2017).

Third, organisational conditions such as socio-economic conditions; learning and development opportunities; access to common services and civic amenities; and, shared beliefs and values, strongly influence community participation and interpersonal relationships. The finding is consistent with the result of a systematic review of literature by Müller et al (2012), using seventy papers from six databases.

Fourth, community conditions, such as formal membership in community bodies; general attitude of members towards people with disability; physical support system; and, presence of a sense of sharing and caring, strongly influenced interpersonal relationships and community participation. The result is consistent with the finding of a study by Ahmed et al (2018) concerning community integration and life satisfaction of persons with spinal cord injury in Bangladesh.

Fifth, community participation and interpersonal relationships were strongly influenced by socio-political conditions such as awareness about the rights of people with disability; legal mechanism to protect the rights of people with disability; the availability of an affordable caregiver; and, the presence of activists/NGOs to support the cause of people with disabilities. The finding is consistent with the result of the "German part of the International Spinal Cord Survey" with participation of 1479 persons with spinal cord injury (Sturm et al., 2020).



## CONCLUSION

Building on the Millennium Development Goals of the UN to promote social equity, the Sustainable Development Goal – 10 of the UN aims to promote “imagine the world in 2030, fully inclusive of persons with disabilities”, besides promoting equality on other dimensions. The current study helps to gain meaningful insights into the dynamics of social inclusion of persons with spinal cord injury by deriving the drivers and reflections of social inclusion from a review of the literature, testing for validity and reliability of the constructs as presented in Table 4 and coefficients of correlation and regression presented in Table 2 and Table 5. The study can help policy-makers and civil society to objectively assess the current reality concerning community participation and interpersonal relationships, and work towards improving the same by addressing the personal, interpersonal, organisational, community and socio-political conditions, as the results show a strong impact of the drivers of social inclusion on the reflections of social inclusion.

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# Measuring Access to Assistive Technology using the WHO rapid Assistive Technology Assessment (rATA) questionnaire in Guatemala: Results from a Population-based Survey

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## ABSTRACT

**Purpose:** *Using the World Health Organisation (WHO) rapid Assistive Technology Assessment (rATA) tool, this study aimed to estimate the population level self-reported Assistive Technology use and unmet need in the province of Sololá in Western Guatemala.*

**Method:** *Sixty-one clusters of 50 people, 2+ years of age, were selected using probability proportional to size sampling. Households within clusters were selected using adapted compact segment sampling. Participants were interviewed using the standardised WHO rATA questionnaire.*

**Results:** *A total of 2874 persons were interviewed (response rate 94%). The prevalence of self-reported unmet need for at least one assistive product (AP) was 17.1% (95% CI 14.7-19.8), use was 7.4% (95% CI 5.9-9.3) and overall need was 20.3% (95% CI 17.6-23.2). These indicators all increased significantly with increasing age and level of functional difficulty. The three most common APs used in Guatemala were spectacles (5.8%), canes/sticks/tripods/quadrupods (0.8%) and pill organisers (0.3%). The most common APs reported as unmet need were spectacles (13.4%), canes/sticks/tripods/quadrupods (3.1%) and hearing aids (2.6%). Among assistive product users, most of them (53%) sourced their APs from private providers and paid out of pocket (58%) and the majority (93%) were quite satisfied/very satisfied with their APs. Cost was the*

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*most commonly reported barrier to AP use.*

**Conclusion and Implications:** *There was a high total need and unmet need for APs in the province of Sololá in Guatemala, and lower use of APs. These findings highlight an urgent need to strengthen Assistive Technology provision to improve access in this setting, particularly for older people, and to address cost-related barriers and increase public provision. The findings can be used to raise awareness of the AT needs in the population in Guatemala, including for older people and people with functional difficulties, and to advocate and plan at local and national levels to make APs more accessible.*

**Key words:** *surveys, access, self-report, assistive products, Guatemala*

## INTRODUCTION

Assistive Technology (AT) is defined by the World Health Organisation (WHO) as ‘the application of organised knowledge and skills related to Assistive Products (APs), including systems and services’ (World Health Organisation, 2018). Access to AT (e.g., walking aids, hearing aids, prostheses) can be vital for facilitating people to live productive, inclusive and dignified lives (World Health Organisation, 2016, 2018). However, many people do not have access to the AT they need; the WHO estimates that 1 billion people are in need of an AP but only 1 in 10 people have access to them (World Health Organisation, 2018).

A key factor hindering the planning and strengthening of AT is the lack of data on the population-level need and unmet need. To address the AT data gap, WHO’s Global Cooperation on Assistive Technology (GATE) developed a new self-reported AT tool, the rapid Assistive Technology Assessment (rATA) (World Health Organisation, 2021b; Zhang, Eide, Pryor, Khasnabis & Borg, 2021). The rATA is an interview-administered population-based survey tool for collecting standardised data on AT in different contexts in six self-reported areas: use, source, payer, satisfaction, unmet need, and barriers (World Health Organisation, 2021b; Zhang et al, 2021). In addition to contributing to global data, the rATA is also designed to inform AT programme development and monitoring at country or sub-country levels. Following the development of the tool in October 2020, WHO launched a global call for measuring access to AT using the rATA. This will inform the development of the WHO-UNICEF Global Report on Assistive Technology (GReAT) - a report which aims to provide a baseline for the current situation on AT and strengthen support of Member States in achieving better

access and availability of AT at national and community levels.

A National Survey of Disability conducted in Guatemala in 2016, using the self-reported Washington Group question sets for both adults and children, found that 10.2% of people reported severe functional limitations (International Centre for Evidence in Disability, 2016). People with functional limitations faced significantly more challenges in participation in key life areas compared to people without disabilities, including in self-care, livelihoods, education, and social inclusion (International Centre for Evidence in Disability, 2016; Kuper et al, 2018; Pinilla-Roncancio et al, 2020). Approximately 10% of the population reported using glasses, hearing aids or walking aids, although, in general, awareness of rehabilitation services and AT were low. However, detailed data on AT use, unmet need, satisfaction and barriers to use among different populations in Guatemala are lacking, and hinder the planning, strengthening and advocacy for relevant services and programmes.

In response to the WHO call for global rATA survey implementation, a rATA survey was undertaken to estimate the population-level AT use and unmet need in Sololá province, Guatemala. The specific survey objectives, among people aged 2+ years in Sololá province, were:

1. To estimate of the prevalence of self-reported functional difficulties.
2. To estimate the prevalence of self-reported Assistive Product (AP) access indicators (use, unmet need and total need).
3. To identify AP use, access and experiences with APs.
4. To identify barriers to accessing APs.

## **METHOD**

### **Study Design**

A population-based survey was conducted from April to May 2021 in Sololá province, Guatemala. The survey was conducted by a research consortium coordinated by the Liliane Foundation, including local, national and international partners (see Appendix 1).



## Setting

Sololá is located in the western highlands of Guatemala, is predominately rural and the majority (96%) of the population are indigenous.

## Sample

A sample size of 3,050 people aged 2 years and above was required, based on an estimated prevalence of AP use (of at least one AP) of 7% (Pryor, Nguyen, Islam, Jalal & Marella, 2018), a precision of 20% around the estimate, 95% confidence, a design effect of 2, and 15% non-response. Based on previous evidence, it was assumed there was a lower prevalence of AP use compared to unmet need (Pryor et al, 2018). Therefore, the study was powered to estimate the following three AP indicators: use, unmet need and total need of at least one AP.

Two cluster stage sampling was used. Using the Instituto Nacional de Estadística's 2018 census as the sampling frame, 61 clusters were selected through probability proportionate to size sampling. Within each cluster, 50 people (aged 2+ years) were selected using an adapted compact segment sampling (Turner, Magnani & Shuaib, 1996). Maps of each cluster were created, using either the open-access mapping platform Infraestructura de Datos Espaciales de Guatemala (IDEG) Geoportal (Infraestructura de Datos Espaciales de Guatemala), or through consultation with the local health centre and/or community leaders. Using these maps in discussions with local representatives, clusters were divided into segments, each including approximately 50 people. One segment was selected at random and all households in that segment were visited door-to-door until 50 people were included. Where segments included fewer than 40 people, another segment was chosen at random to achieve the target sample size; where they included 41-49 people sampling continued in the adjacent segment. All eligible participants were recorded on a paper-based enumeration form. Participants who were unavailable after two repeat visits to the household were recorded as non-responders.

Five of the originally selected clusters were reselected due to safety concerns; two because of ongoing conflict and three because of high COVID-19 prevalence at the time of the survey.

## Data Collection

Each of the two survey teams included four interviewers, who were all local community workers. Interviewers worked together in pairs to maximise safety. Data collection was regularly monitored by a field supervisor for quality control. The teams underwent three days of training, including a half-day fieldwork practise in a community.

At each eligible household, interviewers asked to speak to the household head or another appropriate adult, to provide information about the study and obtain consent for the household to participate. Participants who had lived in that household for at least 6 months of the past year were eligible for inclusion. Participants aged 15 years and above were interviewed directly. Proxy interviews with a parent, caregiver or other appropriate household member, were conducted for participants aged below 15 years and for people unable to communicate independently.

## Data Collection Tools

The WHO rATA questionnaire was used, programmed on a survey123 mobile app, to collect data on the following:

- Age, sex, urban/rural location.
- Self-reported functioning, using questions adapted from the WG-Short Set of Questions (Washington Group on Disability Statistics Secretariat, 2020) which ask about level of difficulty (none/ some/ a lot / cannot do) with seeing, hearing, mobility (all ages) and communication, cognition, self-care (5+ years only). In contrast to the original WG questions, for rATA the respondents are asked to report on their difficulty **without** the use of AT or other assistance.
- AP access - current use of any APs and types used. Images and descriptions of approximately 50 APs from the WHO AP priority list (World Health Organisation, 2016) were provided to participants, initially on enlarged laminated showcards with WHO images and subsequently in digital form on the Tablet. Participants were also asked to report on APs they need but do not currently use, or use but that are in need of replacement.
- AP use information - AP users were asked about the source, payment, distance travelled to obtain APs and satisfaction with APs and associated services. This information was collected for up to three APs considered most

important to the participant.

- Barriers - Participants with unmet AP needs were asked about reasons for not seeking services from a pre-coded response list.

A Spanish version of the rATA questionnaire was adapted to Guatemalan Spanish for this survey. Members of local Organisations of Persons with a Disability (OPDs) and AT programme staff reviewed the tool to assess language for cultural relevance and appropriateness, and identify relevant terms for different APs. Three Mayan languages (k'iche', kaqchikel, y 'tz'utujil) are commonly used in Sololá province and each of these was represented amongst the study team. Based upon previous survey experience (International Centre for Evidence in Disability, 2016) and lack of widespread familiarity with reading/writing this language in the population, verbal real-time translation was conducted by the relevant interviewer. Accuracy of verbal translation into Mayan languages was covered in detail during training, and a local guide/interpreter was identified in the communities, particularly in those where an indigenous language was predominant. The questionnaire was pilot-tested with 15 people (including different age, sex and language groups) to assess comprehension and equivalence, with adaptations made accordingly.

## Data Analysis

Data was recorded on Tablets using WHO rATA's mobile app and uploaded daily to a secure, password-protected cloud-based server on the Survey123 web-based platform.

Analysis was conducted using Stata Version 16. The svy command function was used to account for the cluster sampling. Prevalence estimates were calculated for self-reported functional difficulty stratified by age, sex and location. Functional difficulty was calculated at two levels: i) some or worse difficulty in at least one domain (referred to herein as 'some difficulty/worse') and, ii) a lot of difficulty or cannot do at least one domain (referred to as 'a lot of difficulty/worse').

The prevalence of AP access indicators were calculated as follows : i) use (proportion of study participants currently using at least one AP), ii) unmet need (proportion of study participants reporting needing a new or replacing an existing AP), and iii) total need (proportion of study participants using and/or having an unmet need for at least one AP). Logistic regression analyses were conducted to assess the association between these three AP access indicators (need, unmet need and use) with sociodemographic characteristics collected in rATA (age,

sex, urban/rural location) and level of functional difficulty, based on previous evidence of relationship between these characteristics and access to AP and related services (Pryor et al, 2018). Calculations were first made for unadjusted Odds Ratios (OR), secondly the OR was adjusted for age, sex and location, and thirdly OR was adjusted for age, sex, location and functional difficulty.

### **Ethical Considerations**

Ethics approval was obtained from ethics committees at the London School of Hygiene and Tropical Medicine and the Instituto de Nutrición de Centro América y Panamá (INCAP).

Informed verbal consent was obtained from all participants in the preferred local language. This method of consent was preferred (and approved by the ethics committees) to maintain infection control measures (e.g., keeping a 2-metre distance). There were no invasive procedures, and names, date of birth and global positioning system points were not recorded in the app. An explanation of the aims, processes, possible consequences and voluntary nature of participation in the study was provided to all participants. For participants under 18 years or adults with profound difficulty in communicating, verbal consent was obtained from parents/caregiver and verbal assent was obtained from the participant using a simplified information sheet.

Since this survey took place during the COVID-19 pandemic, the following precautions were adopted: regular monitoring of official national and regional Ministry of Health statistics for each survey area, following local and international guidance to assess whether appropriate to proceed with research activities, asking all participants COVID-19 screening questions, strict adoption of infection and protection control measures by team members (e.g., use of Personal Protection Equipment, following hygiene/sanitation guidelines, regular testing) and conducting interviews outdoors while maintaining a 2-metre distance.

Mapping of key AT and rehabilitation services was undertaken prior to the survey and participants identified as having unmet needs were informed about available services.

## RESULTS

### Study Population

Data was collected on 2874 people (response rate 94%), while 141 people (5%) refused to participate and 35 (1%) were unavailable. Overall, 55% of the sample was female and the majority (75%) lived in urban areas. The survey sample was broadly similar to the 2018 census in terms of age and sex distribution (see Table 1), although there was slight underrepresentation of 0-9 year-olds.

**Table 1: Age and Sex Distribution of Study Sample and Census (2018)**

	2018 Census		Study Sample	
	N	%	N	%
<b>Age</b>				
0-9	90,358	21%	430	15%
10-19	99,454	24%	656	23%
20-29	79,502	19%	596	21%
30-39	56,126	13%	383	13%
40-49	39,197	9%	274	10%
50-59	25,921	6%	227	8%
60-69	17,087	4%	148	5%
70+	13,938	3%	160	5%
<b>Sex*</b>				
Female	220,318	52%	1577	55%
Male	201,265	48%	1294	45%

\*Sex was not reported for 3 people in the study sample.

Age, sex and location data could only be collected on 53% of non-responders. Based on those with data, non-responders were, on average, significantly older (35.8 years versus 29.6 years  $p=0.003$ ), and the responders were more likely to live in urban areas (43% versus 25%,  $p<0.001$ ) compared to non-responders. There was no significant difference in sex distribution.

### Functional Difficulty

Overall the prevalence of 'some difficulty or worse' in at least one functional domain (without the use of AP/other assistance) was 27.2% (95% CI 24.1-30.6) and 'a lot of difficulty or worse' was reportedly 12.5% (95% CI 10.4-14.9). The prevalence of functional difficulty increased substantially with age (see Table 2). The prevalence of 'some difficulty or worse' was slightly higher among women, though this was borderline significance ( $p=0.05$ ).

In terms of the functional domain, among adults (18+ years) difficulty was most commonly reported with vision, followed by mobility. For children (2-17 years) it was vision, followed by communication (see Table 3).

**Table 2: Prevalence of Functional Difficulty by Age, Sex and Location**

	Total N	Some difficulty or worse in at least one domain			A lot of difficulty or worse in at least one domain		
		N	% (95% CI)	Adjusted p-value <sup>a</sup>	N	% (95% CI)	Adjusted p-value <sup>a</sup>
<b>Overall</b>	2874	782	27.2 (24.1-30.6)		358	12.5 (10.4-14.9)	
<b>Age group</b>							
2-17	964	106	10.9 (8.5-14.1)	Reference	41	4.3 (3.0-6.0)	Reference
18-64	1693	507	29.9 (26.2-34.0)	<0.001	204	12.5 (9.7-14.9)	<0.001
65+	217	169	77.9 (71.1-83.3)	<0.001	113	52.1 (44.8-59.2)	<0.001
<b>Sex</b>							
Male	1294	320	24.7 (21.3-28.5)	Reference	152	11.7 (9.4-14.5)	Reference
Female	1577	462	29.2 (25.8-33.0)	0.05	206	13.1 (10.9-15.6)	0.41
<b>Location</b>							
Rural	2150	565	26.3 (22.6-30.3)	Reference	265	12.3 (9.9-15.3)	Reference
Urban	724	217	30.0 (24.5-36.1)	0.13	93	12.9 (9.7-16.8)	0.44

<sup>a</sup>P-value from logistic regression analysis adjusted for all variables in the Table.

**Table 3: Proportion reporting Difficulty by Domain**

Functional Domain	Child (2-17) n=964	Adult (18+) n=1910
<b>Some difficulty/worse</b>		
Mobility	20 (2.1%)	351 (18.4%)
Vision	55 (5.7%)	483 (25.3%)
Hearing	17 (1.8%)	187 (9.8%)
Communication	15 (1.9%)	63 (3.3%)
Cognition	26 (3.3%)	249 (13.0%)
Self-care	12 (1.5%)	58 (3%)
<b>A lot of difficulty/worse</b>		
Mobility	5 (0.5)	159 (8.3)
Vision	22 (2.3%)	194 (10.2%)
Hearing	8 (0.8%)	81 (4.2%)
Communication	9 (1.2%)*	35 (1.8%)*
Cognition	6 (0.8%)*	61 (3.2%)*
Self-care	6 (0.8%)*	28 (1.5%)*

\*Restricted to children aged 5-17 years only (n=778).

### **Assistive Product Access**

The overall prevalence of use of at least one AP was 7.4% (95% CI 5.9-9.3) and unmet need was 17.1% (95% CI 14.7-19.8). The total population with AP need (uses and / or has unmet need for at least one AP) was 20.3% (95% CI 17.6-23.2).

In terms of use, 214 participants reported using a total of 231 APs; the majority used one device (n=198), 15 people used two devices and 1 person used three devices. Unmet need was reported by 491 participants for a total of 704 APs; 351 people reported an unmet need for one AP, 87 for two APs, 40 for three APs and 13 for four to six APs.

Increasing age and level of functional difficulty were significantly associated with increased use, unmet need and total AP need ( $p < 0.001$ ) (see Table 4). Compared to males, females were slightly more likely to report unmet need (adjusted Odds Ratio (aOR) 1.3, 95% CI 1.1-1.7), and slightly less likely to use APs (aOR 0.7, 95% CI 0.5-1.0) although the latter was of borderline significance. AP use was more common in urban compared to rural locations (2.4 95% CI 1.5-3.7), but unmet need and total need were similar by location. With additional adjustment for functional difficulty, the effect sizes for older adults (65+ years) were reduced but remained large (OR at least 4.0) and statistically significant. Findings for the other socio-demographic variables remained similar with multivariate adjustment.

**Table 4: Relationship between AP Access and Age, Sex, Location and Level of Functional Difficulty**

	Use of at least one AP			Unmet need for at least one AP			Total Need <sup>a</sup> for at least one AP		
	Total N	N (%)	Adjusted Odds Ratio (95% CI) <sup>d</sup>	N (%)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI) <sup>d</sup>	N (%)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI) <sup>d</sup>
<b>Age group</b>									
2-17	964	23 (2.3%)	Reference	69 (7.2%)	Reference	Reference	81 (8.4%)	Reference	Reference
18-64	1693	144 (8.5%)	3.8 (2.4-6.1)	304 (18.0%)	2.8 (2.1-3.9)	2.2 (1.5-3.0)	371 (21.9%)	3.1 (2.5-4.2)	2.5 (1.8-3.5)
65+	217	47 (21.7%)	11.3 (5.9-21.4)	118 (54.4%)	15.4 (9.8-24.4)	5.1 (2.9-8.8)	130 (59.9%)	16.3 (10.5-25.2)	5.6 (3.0-10.4)
<b>Sex</b>									
Male	1294	104 (8.0%)	Reference	192 (14.8%)	Reference	Reference	238 (18.3%)	Reference	Reference
Female	1577	110 (6.9%)	0.9 (0.6-1.1)	299 (18.9%)	1.3 (1.1-1.6)	1.3 (1.1-1.7)	344 (21.8%)	1.2 (1.1-1.4)	1.2 (1.0-1.5)
<b>Location</b>									
Rural	2150	129 (6.0%)	Reference	374 (17.4%)	Reference	Reference	423 (19.7%)	Reference	Reference
Urban	724	85 (11.7%)	2.1 (1.3-3.2)	117 (16.2%)	0.9 (0.6-1.4)	0.9 (0.5-1.4)	159 (21.7%)	1.1 (0.8-1.6)	1.3 (0.8-1.9)
<b>Functional difficulty</b>									
No difficulty	2092	7 (0.03%)	Reference*	18 (0.9%)	Reference*	Reference*	23 (1.1%)	Reference*	Reference*
Some difficulty <sup>b</sup>	424	207 (23.3%)	9.8 (7.0-13.7)	216 (51.0%)	24.8 (16.5-37.3)	18.6 (12.4-28.0)	257 (60.6%)	43.1 (28.2-65.8)	33.1 (21.3-51.5)
A lot/ cannot do <sup>c</sup>	358	108 (30.2%)	7.9 (5.3-11.6)	257 (71.8%)	-	-	302 (84.4%)	-	-
Full sample	2974	214 (7.4%)	-	491 (17.1%)	-	-	582 (20.3%)	-	-

<sup>a</sup> Total Need = participants reporting using and/or needing at least one AP; <sup>b</sup>Some difficulty, but not a lot or cannot do, in at least one domain;

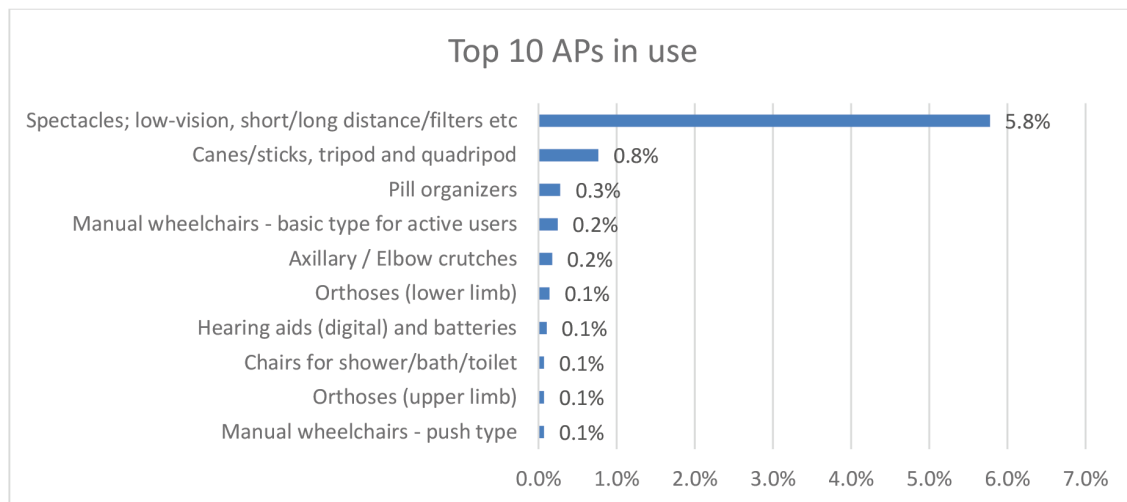
<sup>c</sup> A lot of difficulty or cannot do in at least one domain; <sup>d</sup> Odds Ratio from logistic regression analysis adjusted for all variables in the Table.

\*Due to small cell size for 'no difficulty', 'none' and 'some difficulty' are combined as the reference value.

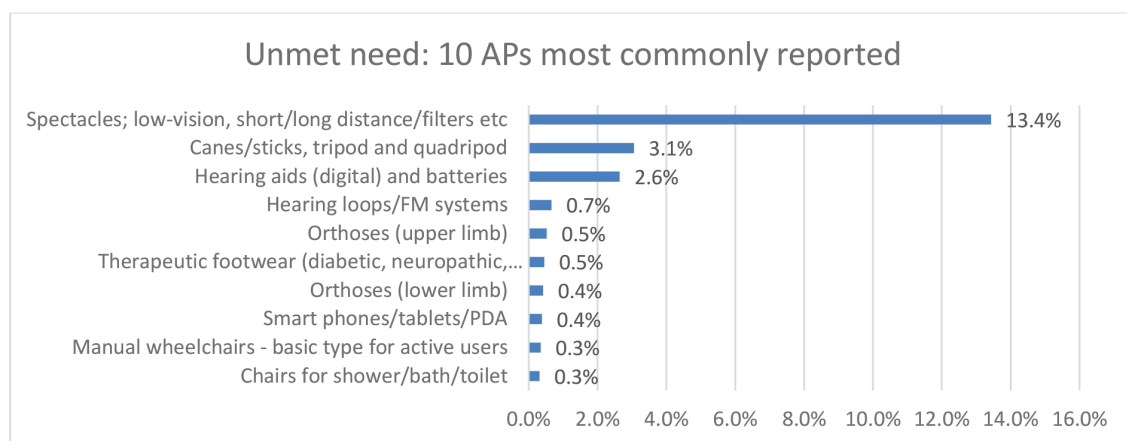


Spectacles were the most commonly used APs (5.8% of total study population), followed by canes/sticks/tripods/quadripods (0.8%), pill organisers (0.3%) and manual wheelchairs (0.2%; Figure 1a). In terms of unmet need (Figure 1b), spectacles were most commonly reported (13.4%), followed by canes/sticks/tripods/quadripods (3.1%) and hearing aids (2.6%).

**Figure 1a: The 10 APs most commonly reported to be used (% out of study population)**



**Figure 1b: The 10 APs that people most commonly reported needing, but did not have/needs replacing (% out of study population)**



### Assistive Product Use: Access and Experience

AP users were asked to report about access and experience with the three APs they considered most important. In total, 214 AP users reported on 231 APs. The APs were most commonly obtained from the private sector (e.g., private health facilities/hospitals or shops/stores; 53% of AP users) followed by the non-government organisation (NGO) sector sources (i.e., non-profit facilities; 22%), while only 6% used public sector sources (e.g., government facilities or public hospitals; see Table 5). The majority (58%) paid out-of-pocket for their AP(s) or relied on family/friends (22%) and only 2% used government funding or health insurance. Most AP users travelled less than 5km (39%) or 6-25km (32%) to obtain their AP(s).

More than 90% of AP users reported being quite/very satisfied with their AP over the past month, and with the associated assessment/training they received. Of the 123 participants who had accessed repair/maintenance and/or follow up services, 83% were quite/very satisfied with services received.

Just over three-quarters (76%) felt their AP was 'mostly'/'completely' suitable for their home environment and that their AP(s) 'mostly'/'completely' helped them do what they wanted to in terms of common daily activities. Most AP users (68%) reported they could use their AP 'a lot'/'completely' as much as they liked in environments they wanted or needed to visit, while 20% responded 'not at all'/'not much'.

**Table 5: Assistive Product use Information**

	N%
<b>Source of AP<sup>a</sup></b>	
Private Sector	114 (53%)
NGO Sector	47 (22%)
Friends/family	34 (16%)
Self-made	14 (7%)
Public Sector	12 (6%)
<b>Source of funding<sup>a</sup></b>	
Out-of-pocket payment	125 (58%)
Family/friends	48 (22%)
NGO/Charity	40 (19%)
Insurance	3 (1%)
Government	2 (1%)
<b>Distance travelled<sup>a</sup></b>	

<5km	83 (39%)
6-25km	68 (32%)
26-50km	29 (14%)
51-100km	15 (11%)
>100km	24 (2%)
<b>Satisfaction with AP<sup>a</sup></b>	
Very dissatisfied	6 (3%)
Dissatisfied	13 (6%)
Neither satisfied/dissatisfied	4 (2%)
Quite satisfied	48 (22%)
Very satisfied	152 (71%)
<b>Satisfaction with AP assessment/training<sup>b</sup></b>	
Very dissatisfied	3 (3%)
Dissatisfied	1 (1%)
Neither satisfied/dissatisfied	8 (7%)
Quite satisfied	19 (17%)
Very satisfied	85 (75%)
<b>Satisfaction: repair, maintenance, follow-up services<sup>c</sup></b>	
Very dissatisfied	9 (7%)
Dissatisfied	12 (10%)
Neither satisfied/dissatisfied	5 (4%)
Quite satisfied	20 (16%)
Very satisfied	82 (67%)
<b>Suitability of AP to home surroundings<sup>a,d</sup></b>	
Not at all	5 (2%)
Not much	21 (10%)
Moderately	33 (15%)
Mostly	75 (35%)
Completely	87 (41%)
<b>Extent AP helps persons do what they want<sup>a,e</sup></b>	
Not at all	2 (1%)
Not much	20 (9%)
Moderately	36 (17%)
Mostly	78 (37%)
Completely	83 (39%)
<b>Extent AP is used in different environments/places<sup>a,e</sup></b>	
Not at all	15 (7%)
Not much	27 (13%)
Moderately	28 (13%)
Mostly	35 (16%)
Completely	112 (52%)

<sup>a</sup>Denominator is all AP users (n=214); information was recorded for up to three APs (considered most important to the participant; n=231 APs) therefore column totals add up to >100%. If one participant reported the same source/funding for >1 AP, this source was counted only once. NB: Three AP users did not know the source of their AP and six did not know the distance.

<sup>b</sup>Denominator is all AP users who reported accessing assessment/training for at least one AP (n=113).

<sup>c</sup>Denominator is all AP users who had accessed repair, maintenance and/or follow-up services for at least one AP (n=123).

<sup>d</sup>Extent AP helps persons do what they want in terms of: doing household activities, self-care, going to school, college or work, visiting friends or neighbours or going for leisure and recreation).

<sup>e</sup>Different environments/places such as schools, workplaces, public spaces.

## Barriers to Assistive Product Access

Among the 491 participants reporting an unmet need for at least one AP, the most commonly reported reason was 'cannot afford' (87%), followed by lack of support (35%), lack of time (16%), AP unavailable (8%), transport lacking/too far (7%), stigma/shyness (3%), and AP not suitable (2%).

## DISCUSSION

### Overall Findings

Using the WHO rATA in the province of Sololá in Guatemala, self-reported need and unmet need for at least one AP was high (20.3% and 17.1% respectively), while only 7.4% reported using at least one AP. Overall, these findings highlight limited access and availability of APs among people reporting need for them, especially among older populations and those who experience functional difficulties. Also, females had a higher reported unmet need, and use was over two times higher in urban areas compared to rural areas ( $p=0.001$ ). These findings suggest a need to specifically target older, rural and female populations in efforts to improve AP access. Additionally, satisfaction with AP and related services was reasonably high, which points to the perceived positive value of APs in the lives of people in this area.

The higher use and unmet need of vision- and mobility-related APs (spectacles 5.8% and 13.4%, canes/sticks/tripods/quadrupods 0.8% and 3.1% respectively), compared to other functional domains, is similar to other studies in low- and middle-income country studies (Matter, Harniss, Oderud, Borg & Eide, 2017). These findings could be due to a few factors including availability of these services in Sololá and greater awareness/understanding of vision and mobility needs in the population compared to the other domains, given these functional difficulties are often more well-known and visible.

The study findings also highlighted cost-related factors influencing AP access. For example, among AP users, APs were most commonly sourced from private providers and paid for out of pocket, and cost was the most commonly reported barrier to AP use. This suggests a gap in public provision of AP in this setting, which is congruent with other findings (Borg and Östergren, 2015; World Health Organisation, 2018) and indicates that low/no cost AP provision is still limited despite the presence of 15 Non-Governmental Organisations (NGOs) and OPDs in Sololá province that provide AP services. This may reflect constrained resources and capacity of these organisations to deliver at scale and/or lack of community awareness of these services. Further research is needed to explore this in more detail.

There is limited population-based data from Guatemala or other Latin American countries, with which to compare the study findings. In the 2018 Guatemalan census, 10.4% of the overall population and 9.1% of the population in Sololá reported 'some difficulty or worse' (Instituto Nacional de Estadística Guatemala & UNFPA, 2019) which is much lower than the study's estimate of 27.2%. In the 2016 Guatemala National Disability Survey, 7.3% reported 'a lot of difficulty or worse' using the WG short set of questions, which is slightly lower than the 12.5% in the current study, although similar trends of increasing prevalence by age and among women were found (International Centre for Evidence in Disability, 2016). The differences in functional difficulty prevalence, in part, likely reflect modifications made to the WG questions for the rATA. The standard WG questions ask people to report on their functioning **with** equipment, devices, products or assistance from others (if they use them), while in rATA people are asked to consider their functioning without these supports. Considering glasses are the most commonly used AP, this different WG administration also likely explains why, in the current study, difficulties were most commonly reported for vision, in contrast to other studies using the WG short set (including the Guatemala national disability survey) where difficulty with mobility is most commonly reported (International Centre for Evidence in Disability, 2016; Pryor et al, 2018). The modified version of WG is used to assess levels of functioning without AT; however it limits comparison to other WG data.

Comparable data specifically on AP access is lacking. For example, in the Guatemala national survey 10% of the population reported using equipment, devices or products or assistance from others for vision, hearing or mobility. However, rATA asks about use of AP only and not assistance from others, which

may explain the lower prevalence estimate (7.4%). A survey in Bangladesh, using an earlier version of the rATA, estimated AP use at 7.1% among people aged 18+ years, which is slightly lower than in the current study (11.0% among 18+ years) (Pryor et al, 2018). The reasons for this are unclear, though they may reflect different economic and service provision contexts. The trends of higher AP use and unmet need associated with increasing age and functional difficulty observed in the current study, were also found in Bangladesh (Pryor et al, 2018).

### **Strengths and Limitations of the Survey Tool**

The rATA relies only on participant self-report for assessing AP needs. Self-report assessment is typically lower cost, quicker and requires fewer human resources compared to clinical assessment (Boggs et al, 2019, 2020). It also, importantly, incorporates consumer choice, and individuals' understanding of their need, uptake and benefit from AT which is crucial for developing AT services (Zhang et al, 2021). However, there are limitations of this approach, with evidence suggesting it can both under- and over-estimate AT need (Mactaggart, Kuper, Murthy, Oye & Polack, 2016; Boggs et al, 2019, 2020, 2021b; Boggs, Polack, Kuper & Foster, 2021c). Consumer choice and participation are undeniably important. However, assessing AT need is complex, and self-assessment can be difficult for several reasons. First, the appropriate intervention is often dependent on understanding the clinical cause, diagnosis and prognosis of the functional impairment. A study in India found that among 60 people who self-reported needing distance glasses, 75% actually either required a different intervention (e.g., cataract surgery) or did not have a vision impairment based on clinical assessment (Boggs et al, 2020). Second, awareness of different APs and what they can do is generally limited. For example, a study in The Gambia found that among those participants who self-reported "some difficulty or worse" with hearing, 62% were unaware of hearing APs (Boggs et al, 2021b). Third, assessing appropriateness of APs is also dependent on personal and environmental factors, such as home environment and different types of terrain. These factors are typically assessed during clinical functional assessments by rehabilitation professionals, for example, to determine which referral services and APs are appropriate. When clinical information and problem solving are lacking, and AP awareness is limited, it may be challenging for people to know which factors to consider in self-assessing for APs. The rATA does recommend use of an AP image booklet to enhance participants' understanding of specific APs (Zhang et al, 2021). However, self-assessment of AT need is still challenging and particularly for less familiar APs (e.g., Hearing

loops/ frequency modulation systems) and more complex functional difficulties/ impairments (Boggs et al, 2021a). A hybrid approach which integrates self-report assessment alongside clinical assessments of impairment, functioning and AT needs, should therefore be considered where resources allow (Boggs et al, 2021c).

### **Strengths and Limitations of the Study**

This study contributes to efforts in addressing the AT data gap in Guatemala and globally. The response rate was high (94%), and the finding about prevalence of use of at least one AP was similar to the predicted estimate by the researchers (7%). The age and sex distribution of the study population was well-aligned to the recent census. The rATA survey123 mobile data collection app with an accompanying web platform enabled data monitoring throughout.

There were also limitations. First, although the overall survey response rate was 94%, the response rate in the three clusters was relatively low. These clusters were urban, with many people out at work when the teams visited, and there were some initial challenges in engaging with the communities. The researchers responded to this through better engagement with community leaders and by adjusting data collection times to include weekends and out of typical work hours. This greatly improved the response rate throughout the remainder of the survey. Second, despite efforts made prior to and during the training to ensure appropriate translation into Guatemalan Spanish (written) and Mayan languages (verbal), some language challenges were still faced in the communities. This resulted in increased time spent with participants to ensure understanding. It is recommended that these language and interpretation issues are discussed with the WHO team so they are better addressed in the rATA guidelines during recruitment and translation processes. Third, this study did not include children <2 years old as per rATA methodology. The low prevalence of AT use and needs in that age group would possibly not substantially affect prevalence estimates. However, additional research to identify appropriate tools to assess AT needs for this younger age group is recommended. Fourth, results from this study cannot necessarily be generalised to other settings in Guatemala. In particular, it is noted that the presence of the 15 NGOs and OPDs in Sololá province that provide APs may result in better AT access compared to other provinces. Therefore, it is recommended that future surveys be conducted in other areas of the country. Finally, although data on barriers was collected, in-depth qualitative studies are required for fully understanding reasons for unmet needs and appropriate strategies to address them.

## Implications

Key recommendations for strengthening AT service/programme in Sololá include:

- Develop an AT action plan with relevant stakeholders, including people with functional difficulties and AP users, to improve access and availability of relevant affordable AP services.
- Work with national stakeholders on WHO's AT actions to develop a national Guatemalan priority AP list (World Health Organisation, 2016).
- Scale-up public provision of AP services focusing on vision and mobility; the AP services which were the highest reported functional difficulties and most needed APs.
- Advocate for increased human resources, especially in the public sector, for both training and paid employment positions for AP manufacturing, assessment, provision and repairs.
- Raise awareness amongst potential and current AP users, caregivers and various service providers on the types and purposes of various APs.
- Strengthen appropriate AP service provision specifically addressing the access needs for women, older adults, and those in rural areas.

The findings also highlight areas where additional research is needed. A modified WHO Assistive Technology Capacity Assessment could be conducted using the system-level tool to better understand and assess the capacity for all-age AT provision in Sololá (World Health Organisation, 2021a). For example, this could provide contextual service information about the types of APs available through different providers (e.g., government health services and NGOs). Qualitative research is also needed to further explore the heavy reliance on private sources and how personal and environmental factors of people with functional limitations and/or caregivers influence AP awareness, access, barriers and satisfaction. Additionally, a hybrid assessment survey integrating self-report alongside clinical AP assessment is recommended to further understand AP need and unmet need in this setting.

Finally, the rATA is a new survey tool and there were two lessons learnt that could help inform future rATA surveys. First, it was challenging to track participants who were unavailable when the survey team first visited (and therefore needed revisiting) as this information could not be recorded in



the survey123 app. A paper-based enumeration form was used to track this; however, it is recommended that this option is included in future versions of the app. Second, the researchers initially trialled a handheld AP image booklet to enhance participants' understanding of specific APs; however due to difficulty in administering this in the field, they switched to showing digital AP images on a Tablet while maintaining safe COVID-19 distance from people. It is recommended that this method is reviewed, alongside the use of a large poster with images, to ensure APs are well explained.

## CONCLUSION

There is high self-reported need and unmet need for APs in the province of Sololá in Guatemala. Efforts are needed to improve AP access in this setting, including addressing cost-related barriers and increasing public provision of AP and related services. These findings can be used by policy-makers and service providers (including NGOs) to inform programme/service planning and by OPDs to advocate for improved AT access and provision at local and national levels. The findings also contribute to the WHO data collection efforts for the forthcoming WHO-UNICEF Global Report on Assistive Technology and will inform current and future research, policies and services/programming to ensure no one is left behind, with all AT needs met.

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The data presented in this study is available on request from the corresponding author. The data is not publicly available due to ongoing analyses by World Health Organisation for the WHO-UNICEF Global Report on Assistive Technology (GReAT).

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## **Appendix 1: Guatemala rapid Assessment of Assistive Technology (rATA) research consortium organisations**

<b>Role</b>	<b>Organisation name</b>
Research consortium coordinator	Liliane Foundation
Technical research consortium coordinator	International Centre for Evidence on Disability, London School of Hygiene & Tropical Medicine
Technical and training coordinator	Range of Motion Project
Research consortium logistic and administrative coordinator	Asociación de Padres y Amigos de Personas con Discapacidad de Santiago Atitlán (ADISA)

## BRIEF REPORTS

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# Creating an Inclusive Ecosystem through Healthcare in Disability Management: Malaysians' Experience

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### ABSTRACT

**Purpose:** *MyRehabMaker is a community initiative project utilising technology as an innovative platform to solve the challenges of people with disabilities specifically, and of society as a whole.*

**Method:** *Providing an Assistive and Adaptive Device (AAD) is one of the interventions to assist people with disabilities in improving their functional level. The AAD prescription work process was enhanced by forming an expert multidisciplinary team and introducing 3D printing technology into practice.*

**Results:** *This project has been recognised and has won a few awards in innovation exhibitions and competitions. The project later expanded into the community to encourage community involvement and contribution.*

**Conclusion:** *The project framework aims to address the needs and interests of participating bodies and promotes inclusivity by adopting community-based rehabilitation and social innovation principles on the IR 4.0 healthcare platform.*

**Keywords:** *rehabilitation medicine, assistive technology, disability, Malaysia*

## INTRODUCTION

A good community programme should identify and address the existing issues within the community in a holistic manner. Innovation plays a vital role in empowering communities and sustaining the community programmes. Appropriate technology can be positioned as the bridge leading to the empowerment

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of marginalised communities. The objective is to create an innovative platform to provide solutions for addressing problems at every community level. This programme also encourages the partnership and collaboration of stakeholders across government, academic institutions and the nonprofit sector. It should lead to benefits for the specifically targeted community as well as fulfil the interests of every participating body.

The authors of the current article demonstrate this with their community initiative project that adopts an affordable and adaptable 3D printing technology in the prescription of Adaptive and Assistive Devices (AADs) for people living with disabilities. This project was first started as a research practice and later translated to benefit society by capitalising on the available resources and maximising the community potential to develop a sustainable project that provides solutions for people with disabilities specifically, as well as for society as a whole.

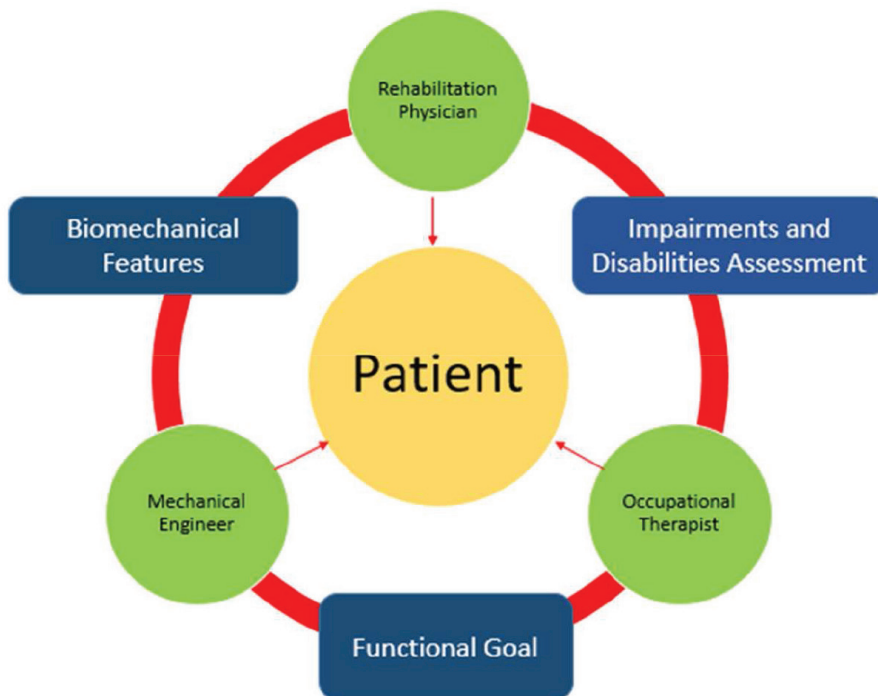
### **Upgrading AAD Prescription Service in Disabilities Management**

An Assistive and Adaptive Device is any form of device or technology which has the primary function of maintaining or improving an individual's functional and independence level by addressing impairments, facilitating participation, and enhancing overall well-being (Yeung et al, 2016). According to the World Health Organisation survey (WHO, 2016), globally, more than 1 billion people require one or more assistive products. However, in many low- and middle-income countries access to these adaptive devices is limited, with only 5% to 15% of the population of people with disabilities having access to such devices (WHO, 2015). The Convention on the Rights of Persons with Disabilities has now recognised access to assistive technology as a human right and has called for international cooperation to improve its accessibility (WHO, 2015). In Malaysia, the total reported number of people with disabilities registered at the Department of Social Welfare in 2017 was about 453,258 persons. The majority are people with physical disabilities (35.2%), followed by those with learning disability (34.8%) and visual disabilities (8.9%) (Department of Social Welfare, 2018). Acknowledging the increasing number of people with disabilities and their need for AADs, the United Nations resolutions recently included the importance of access to assistive technology in realising the targets set in the Sustainable Development Goals relating to universal health coverage (WHO, 2016).

## METHOD

Assistive and Adaptive Device prescription in the local clinical setting is dependent on and limited to what is available in the market or produced by occupational therapists via conventional methods. The complex design of ADDs in Malaysia is difficult to develop due to outdated technology, lack of required technical skills, materials, and multidisciplinary involvement and collaboration. Acknowledging this problem, an expert multidisciplinary team was created, consisting of a rehabilitation physician and technical experts to allow crossover of knowledge and utilisation of existing 3D printing technology to develop customised AADs specific to a diverse set of disabilities. This framework allows a suitable and conformable AAD to be prescribed to effectively address impairment, hence helping to achieve the optimum functional level and reduce the dependency level. Figure 1 and Figure 2 depict the framework and work process of this AAD prescription service.

**Figure 1: Multidisciplinary Framework in AAD Prescription**



**Figure 2: Work Process of AAD Assessment, Prescription and Development**



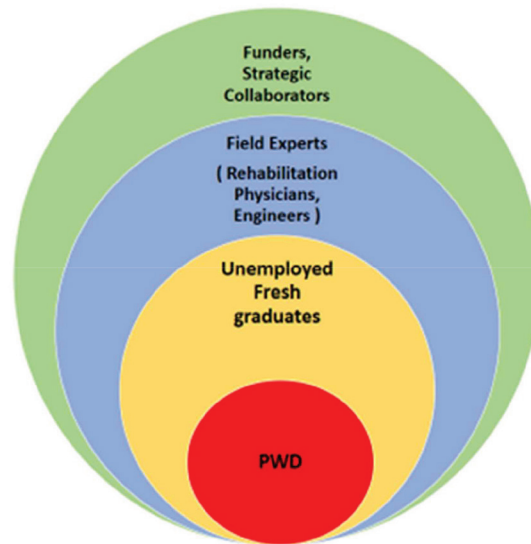
### **AAD Prescription: Towards Promoting Community Involvement**

This project was inspired by the concept of community-based rehabilitation (CBR). Historically, CBR provides rehabilitation services to people living in low- and middle-income countries through local community resources (Khasnabis et al, 2010). The CBR concept outlook has evolved into a broader development strategy, varying in practices and contexts depending on the available resources (Khasnabis et al, 2010; Chung, 2019). In the reported project the same goal and aspiration of CBR was adopted, i.e., ensuring that people with disabilities can access rehabilitation services that contribute to their overall well-being, inclusion, and participation (Khasnabis et al, 2010). Sustainable CBR programmes are dependent on several factors, which are: (i) the availability of well-equipped human resources; (ii) appropriate and practical training, monitoring, and evaluation; and, (iii) collaboration, commitment, and the necessary financing of programmes (Thomas, 2011). This project too was driven by the social innovation concept that was broadly described as a process of deploying solutions to overcome challenges in systemic society in support of social progress (Van der Have & Rubalcaba, 2016). The solutions may consist of ideas or strategies to address deeply-rooted societal problems in education, employment, healthcare, community development, and livelihood (Van der Have & Rubalcaba, 2016). The



researchers combined the understanding of both concepts to develop a viable framework that attempts to fit the local society's needs. Ideally the framework should address issues of people with disabilities specifically, but it aimed at solving problems or meeting the interests of other participating members in society as well. Therefore, it was expected and hoped that this would be a sustainable project.

**Figure 3: Project that Encourages every Community Level Involvement**



### **Unemployment: From a Problem to a Window of Opportunity**

The rate of unemployment in Malaysia has demonstrated a rising trend to 4.7% in August 2020 from 3.3% in the corresponding month of the previous year, amid the severe implications of the COVID-19 pandemic. The number of unemployed people surged from 42.6% a year earlier to 741.6 thousand, while employment declined by 0.2% to 15.15 million (Department of Social Statistics Malaysia, 2020). A report on the second quarter of the year 2020 demonstrated a decreasing number of total job availability in the private sector with 236 thousand year-on-year to 8.383 million (Department of Social Statistics Malaysia, 2020). In the meantime, job vacancies dropped to 170 thousand, with a vacancy rate of 2.0% (Department of Social Statistics Malaysia, 2020). Job markets have become very competitive, and only small numbers of fresh graduates can land jobs that match their educational backgrounds within the local industries. This scenario provides a window of opportunity to use local talent with technical expertise

and skills as a problem-solving strategy to assist in developing and innovating in the AAD prescription service. The researchers recruited them to be part of the technical team in developing AADs by training, monitoring, and providing some financial support. The objectives of this recruitment were: (i) to increase the marketability of the graduates by providing them an avenue to apply their knowledge to practice, (ii) to improve their economic status by helping them to earn an income, (iii) to educate them on the needs of people with disabilities and their possible challenges with function, and (iv) show how they can contribute to use their newly-learned skills in a way that would best serve the needs of people with disabilities.

### **Translation of a Research Practice into a Community Project**

This project was first started as a research exercise to establish a framework integrating multidisciplinary expertise in upgrading current rehabilitation service in AAD prescription in an institutional setting (Mazlan et al, 2021; Othman et al, 2021). It was realised that this project could potentially be expanded, involving other community members at different levels as well. The lessons from the research project are fundamental in providing training and consultations to ensure that recruited graduates receive adequate training in developing AAD products that serve the intended function and meet certain quality standards. The training, monitoring and evaluation allow: (i) knowledge transfer from academic and industrial experts to the community, (ii) continuity of the academic exercise and continuous contribution to the body of knowledge pertaining to product development and innovation, and (iii) demonstrate a good academic research exercise to translate the research output into the community in a practical viable way.

### **Diversify Corporate Social Responsibility Performance**

Financial support remains important and plays a significant role in ensuring sustainable and successful developments in any community programme. A viable framework and proper planning by the anchoring body in the reported project is the University, which is crucial in attracting funds from those who finance research grants, as well as governmental or non-governmental organisations. The project must demonstrate: (i) a proof of concept, (ii) a viable and workable process, (iii) value of the scientific output, (iv) the impact of the project towards current practice, and most importantly, v) how and to what extent the community will benefit from such a project. This project will not only attract monetary contributions but

also knowledge, skills and technology sharing, thereby strengthening academic and industrial strategic partnerships. The resources are well shared at every level of the community, thus making the investment worthwhile for the whole society.

## RESULTS

### Project Outcomes

This project is expected to generate a few impactful outcomes: (i) innovative functional AAD products, (ii) additional value-added skills for a marketable graduate, (iii) upgrading the current state of rehabilitation services, and (iv) promoting the inclusion of people with disabilities in the community. Figure 4 depicts how this project can be beneficial to participating communities. To date, there are several ongoing and completed projects. Examples are the Tenodesis Grip Enhancer Orthosis, the Writing Finger Orthosis, the Forearm Wheeler Writing Orthosis, the Cosmetic Transfemoral Prosthesis, the Large Handle Gripper, the Plate Based Rotator, the Customised Wheelchair Mounted Table, and the Upper Limb Writing Orthosis, to name a few. Funding was received from a research grant and a few strategic collaborations with industrial partners. Five graduates who were successfully recruited and trained were actively involved in developing the AADs. Recently an association was registered under the name PINTAS (Malaysia Association of Technological Assistive Devices) as an official platform to recruit more technologists and attract more funders to engage in the AAD development activities. This project has been recognised and has won a few awards in innovation exhibitions and competitions.

**Figure 4: Project Output impacting at every level of Participating Communities**



## DISCUSSION

To establish a successful programme, the researchers believe that a community project must address the needs of a specific community and address the community interests as a whole. The adopted strategies should be directed towards people with disabilities specifically and indirectly benefit the other group of communities in addressing their specific problem or specific interest as much as possible. This project provides an excellent avenue to assist Malaysia in fulfilling the agenda of globalisation in areas of the sustainable development goals (SDG) by actively embracing and adopting IR4.0 in delivering the rehabilitation services. The project outcomes will help reduce the rate of unemployment and encourage the inclusion of people with disabilities in society by connecting people without disabilities with the people with disabilities, instead of the other way round. Ideally, a community project has to be universal and not exclusive. It should be inclusive by encouraging participation of all community members.

Consequently, the reported project helps in providing an in-depth understanding of the issue of people with disabilities in society at large. These strategies may successfully build interest and maintain enthusiasm, as well as attract collaboration and financing opportunities for similar projects. It is hoped that this project will be sustainable in the long run for its clinical applications, availability of required skills and talents, ongoing collaborations, and cost-effective operational costs that are yet to be determined. It is envisioned that this initiative may evolve into a community-driven project and run independently to ensure the inclusion of all society members.

## CONCLUSION

It is believed that this project can encourage and promote good collaboration at and between every community level, maximise potentials, and deliver impactful outcomes in driving Malaysia towards achieving the agenda of the Sustainable Development Goals.

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## EXPERIENTIAL ACCOUNT

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# Lessons from a Women-led Livelihood Pilot in a Neglected Tropical Diseases endemic area in Southern India

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### ABSTRACT

**Purpose:** This study was conducted in a Neglected Tropical Diseases (NTD) endemic location in South India. It aimed to determine whether income-generating opportunities for members of low-income households would help in reducing their vulnerability to NTDs.

**Method:** Eleven women participated in the 'Jagruti' livelihood project. A baseline survey captured their demographic details, economic situation, and perspectives of the future. An end-of-project survey recorded the impact. The marketing strategy used Behaviour Change Communication through product and menstrual hygiene awareness among Self-Help Group (SHG) women, one-on-one peer education for women at home, and counselling for adolescent schoolgirls.

**Results:** All participating women had changed their own and their daughters' menstrual hygiene behaviour. They felt that their entrepreneurial and communication skills had improved. The maximum and minimum individual earnings from sanitary napkin sales had been USD 54 and USD 8 per month respectively. This additional income had met pressing household needs, toilet repairs, and medical treatment of family members with COVID-19. In May 2021 the COVID-19 second wave and lockdown, as well as the state government initiative to sell sanitary napkins at subsidised rates to rural women, and free of cost to adolescent school-going girls, led to the termination of the livelihood project earlier than scheduled.

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**Conclusion and Implications:** Sustainable livelihoods for women from low-income households can bring in additional income to be utilised for medical treatment, improving household sanitation and nutrition, etc. This may reduce household members' risk of contracting or transmitting NTDs. The government initiative will be routed through selected SHGs with proven efficiency. Four of the trained women entrepreneurs are confident that their SHGs will be selected and look forward to using the knowledge and experience they have gained from the livelihood project. Investment in empowering and developing the business skills of enterprising women is a worthy cause.

**Key words:** lean experiment, entrepreneurship, menstrual hygiene, lockdown, risk

## INRODUCTION

Neglected Tropical Diseases (NTDs) are diseases of poverty. They have devastating human and socio-economic consequences for more than one billion people globally, predominantly among vulnerable and marginalised populations in low- and middle-income countries, who have poor access to basic health, water and sanitation services (WHO, 2020).

The 'Jagruti' livelihood project was an innovative, one-year lean experiment model to study the impact of a women-led sanitary napkin marketing and sales livelihood project on economically poor households in 78 NTD endemic villages in Vizianagaram District of Andhra Pradesh, South India. The American Leprosy Missions and LEPRO Society had earlier implemented a women-led integrated Water, Sanitation and Hygiene (WASH) and NTDs project in this area.

None of the self-help groups (SHGs) in the Block had implemented a livelihood initiative in the previous two years. This project was designed as a social enterprise intended to address menstrual hygiene, a neglected aspect of WASH, while also addressing household poverty, a key risk factor associated with NTDs (Aagaard-Hansen and Chaignat, 2010). However, an unforeseen event resulted in irreversible closure of the livelihood project after only eight months. This was four months before the project could complete its planned exit strategy which involved phased handing over of the enterprise to the women who would manage it independently. This report briefly outlines the lessons learnt and describes the project's impact on the women who participated in it.

## **Objective**

The aim of the project was to study whether increasing the income of economically poor households in an NTD endemic location in India would contribute to reducing the household members' vulnerability to NTDs.

## **METHOD**

### **Study Design**

Initially a baseline survey was conducted regarding the demographic details, household economic situations, and future perspectives of the eleven women entrepreneurs. An end-of- project survey was done to capture the impact on the participating women and their households.

### **Project Initiation**

Eleven women, from different SHGs and with some basic leadership and management experience, were selected from communities at risk for NTDs. None of the women themselves suffered from a NTD. One woman had a household member with lymphatic filariasis. The selection of a sanitary napkin marketing and sales enterprise was made after several rounds of participatory discussions with the members of the SHGs and district authorities. The decision to focus on the neglected issue of menstrual hygiene was raised by the women themselves, with consensus that this would be a relevant and potentially sustainable women-led enterprise. The women entrepreneurs received training in behaviour change communication (BCC), peer education on menstrual health and hygiene, and were made aware of affordable and safer options to the traditional absorbent materials and practices of their communities. The project also developed their business and management skills to equip them to scale and run their enterprise profitably and independently by the end of one year, the time-frame by which this lean experimentation model project would have completed its exit strategy of phased handing over of the entire management to the participating women.

The products and packaging were designed with inputs from the women and delivered to the project site by the vendor. The enterprise was officially launched in the third week of January 2021, with assured cooperation from the district Rural Livelihoods and Health Departments. After completion of the training in early February 2021, product and menstrual hygiene awareness began for the



SHGs, door-to-door marketing was done through one-on-one peer education for women at their homes, and counselling was done for adolescent girls in schools and hostels. The women sold the product at a small margin which they retained, returning the cost price to their business savings account. With its innovative marketing strategy, the enterprise was the first of its kind in this Block.

### **A Series of Unexpected Events**

Sales started in the second week of February 2021 and showed a small but steady increase until April 2021. The second wave of COVID-19 resulted in the sudden imposition of a rigorous lockdown in May 2021. All activities were abruptly halted by a government order. The women accepted this situation, and looked forward to sales picking up after the lockdown. However, towards the end of May the project suffered a major setback with the announcement of a state government initiative. Tenders were invited from multi-national companies for mass production of sanitary napkins which would be sold at highly subsidised rates to rural women, and provided free of cost to all adolescent schoolgirls. In fact, the government had begun supplying free sanitary napkins through schools in April itself (DC correspondent, 2021). This had affected the enterprise's sales of sanitary napkins as adolescent girls were the enterprise's largest market, adult women being reluctant to change from cloth to disposable napkins.

The women were dismayed, as they surmised that their small enterprise would not be able to compete with the scale of the government initiative and pricing of the subsidised product. While sustainability of this livelihood now seemed unlikely, the government initiative was nonetheless welcomed as it would make menstrual sanitary products available and accessible in their area. A decision was reached by all key stakeholders to cut their losses and exit the project.

## **RESULTS and DISCUSSION**

This WASH-linked livelihood project was taken up by eleven women from households living below the poverty line. The women entrepreneurs had an average age of 34 years and were married. Most of them had completed their secondary school education, and all were members or leaders of different SHGs. Their average monthly household incomes ranged from USD 140 to USD 250. Around two-thirds of them were homemakers, while the rest were working as Accredited Social Health Activists (government frontline workers) in their villages.

According to the baseline survey, their primary reason for joining this enterprise was to improve the financial condition of their families. The women also mentioned their aspirations of providing better education for their children, being able to maintain and repair their houses, and having a stable livelihood. Other expectations from the enterprise were job satisfaction and earning recognition at home and from society. They felt that increasing awareness on menstrual health and providing a needs-based service to women in their community along with proper marketing strategies, could facilitate the fulfilment of their aspirations.

At closure of the project, a modified end line survey captured the impact of the project on the women. It was not possible to conduct a comparative survey for a project that was closed before schedule and had only partly achieved its objectives. In addition, it was necessary to be sensitive to the women who were unprepared for the abrupt termination of their enterprise. However their responses, despite their obvious disappointment, were unexpectedly positive. Some of the responses are as follows:

- 1) Their maximum and minimum individual earnings from sales, during the two months when the livelihood activities were unimpeded, had been USD 54 and USD 8 respectively. The women had welcomed the additional income which was used to meet pressing household needs, pending toilet repairs, and treatment costs of family members with COVID-19.
- 2) The women said that the marketing strategy of raising menstrual health and product awareness among the women in their SHGs helped sales of the product in the community. Marginalised households in India have at least one female family member in a SHG. Therefore, generating awareness during meetings of all the SHGs in the Block was a quick and effective way to convey information to every marginalised household in the Block, and boost sales. The women were confident that the awareness generated would continue to encourage the women in their communities to adopt safer menstrual hygiene practices. They had themselves changed their own and their daughters' menstrual hygiene behaviour.
- 3) All the women felt that their entrepreneurial and communication skills had improved and, had this enterprise been sustainable, their experience and income would have increased. One of the women specifically said that her own negotiation skills and the marketing skills of the whole group had improved with the training provided by the project. Nine of the eleven

women expressed interest in joining a livelihood initiative if an opportunity presented itself in future.

### **Implications**

According to the Block District Rural Development Agency authorities, the government initiative is expected to start within six months. The initiative is planned to be routed through select SHGs with proven efficiency and strong systems of regular meetings, regular savings, internal loans, timely repayment, and proper book-keeping. The government initiative expects the SHG women to sell the product in their communities at a small margin, returning the cost price to the government and keeping the profits from their sales. Four of the trained women are confident that their SHGs will be selected and look forward to using their newly-acquired knowledge and skills. The menstrual health and hygiene awareness raised among all the SHGs in the Block, and their own experience with BCC as a key element for sales, will be an added advantage.

### **CONCLUSION**

This paper shares the authors' experiences with a lean experimentation model livelihood project that was prematurely terminated due to unforeseen circumstances. It highlights the early yet positive impact that such women's empowerment initiatives can have on the participants. It is hoped that these experiences and learning will benefit others involved in similar initiatives.

### **Lessons Learnt**

In NTD endemic areas, involving women from low-income households in sustainable livelihoods is one way to bring in additional household income that could be prioritised for medical treatment and for improving household sanitation, nutrition, etc. This may reduce their family members' risk of contracting or transmitting NTDs.

All business ventures can be risky, but investment in empowering and developing the business and subject matter (in this case, menstrual health) skills of enterprising women from economically poor households is never a loss. Though the sample was small, these women demonstrated surprising resilience and determination in the face of unexpected obstacles and disappointments.

Relevant livelihood projects for SHG women can be piloted and scaled up during the COVID-19 pandemic, along with preparedness for setbacks such as unexpected restrictions or lockdowns. However, in small business ventures such as this marketing and sales enterprise, it is important to recognise unforeseen but potentially insurmountable risks early on and take quick, decisive action to mitigate unnecessary loss.

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