



# DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

Volume 34 ■ No. 2 ■ 2023

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Published by



Website:  
<https://dcidj.uog.edu.et>

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## Editorial

Dear readers,

This is a very challenging year for the Journal.

The year started on a promising note, in anticipation of the University of Gondar stepping in to host and take over responsibility for the Journal. Who would have thought that this script would be altered due to the events currently (August 2023) taking place in the country of Ethiopia? The nightmare of civil war has spread from the Tigray region to impact the lives of the staff of the University of Gondar, their relatives and so many people in the Amhara region.

One of the walls of my living room showcases a beautiful painting bought many years ago in Ethiopia. It portrays a number of priests attempting to resolve a community dispute. A rising sun in the background symbolises hope in times of trouble and despair. I hope and wish that the resilience, pride and power of the Ethiopian people will conquer the evil that is afflicting the country at this time. This wish holds true not only for Ethiopia, but also for all the places on our planet. Let goodness and respect for everyone prevail, most of all for those who are vulnerable.

On the subject of evil, it is increasingly apparent that in many societies there exist high levels of stigma towards certain groups of people with disabilities. I notice in my work that people in various countries are urgently calling for laws and policies to curtail or prevent stigma due to disability. It is a call for changes in systems and structures. While this is very important, I am however afraid that it will prove a useless exercise until we examine the roots of stigma and understand its very nature. Only then will we be able to build structures to support the mechanisms that alleviate stigma.

Stigma towards people with disability is a behaviour that has very serious impact upon fair and equal opportunities in society. What causes people to stigmatise others? What causes people not to challenge or change stigmatising behaviour, even when information is widely available about the causes of disability? Why is stigma still so widespread in many societies? In many cultures where I work(ed) in Africa (and Asia) – for longer or shorter periods – there is still a widespread belief that *“If you get a child with disability, you must have done something wrong”*. A child born with a disability is often seen as worthless and a burden. Fathers blame the mothers for conceiving a child with a disability and often run away; and mothers

either decide to stay strong, love and care for their child, or run away fearing the opinions of the community in which they live. In the worst cases, mothers – in despair – leave their child to die in the forest; at best, they find a grandmother or grandfather willing to take care of the child. I noticed this in Kyrgyzstan and Bangladesh, as well as in Congo, Burundi and Ghana. The grandmother and, at times, the grandfather ask themselves the cruel question, “*What will happen to the child when I / when we die?*”. This is the reality in many cultures. These behaviours are based upon old traditional beliefs referring to divine punishment, including witchcraft, which are most often widespread in situations where resources are limited. I have heard this expressed in subtle or harsh ways by different people, including parents of children with disabilities, religious leaders, politicians, and the public at large.

How to fight such widespread beliefs that cause serious harm to so many people? While many would say that we simply need to inform people about the *actual* causes of disability, I increasingly believe that we need to consider whom to inform and how to inform them. For decades, parallel to the disability emancipation movement, we have informed – usually in a western way and with western methods – society at large and rehabilitation professionals, about disability and stigma. We train and educate; we motivate and get frustrated about people rejecting children (and adults) with disabilities on ‘irrational’ grounds. Is it not time to study the existing cultural methods of influencing ideas and practices in the countries we work in? The coffee ceremony in Ethiopia may be a more effective way to spread messages than by attending a workshop with a PowerPoint presentation at an expensive hotel.

I also think that we are reaching the wrong people. We should target the ones whom others listen to, those who are influential and those who have power. On the one hand there are people with formal – legitimate – authority in the countries’ hierarchical systems (i.e., governments), and on the other hand there are traditional and religious leaders. It is the last groups that have captured my interest in the past decade or so, for the simple reason that we need to counter (traditional) beliefs that are often perpetuated by traditional or religious leaders. If the existing beliefs related to religious scriptures may give the(wrong) idea that it is God or the Gods who punish people with disabilities for sins committed (in a previous life), one cannot and *should not* ignore this.

In my current work I continuously question people about what they hold true in their cultures: something I ask(ed) myself as well about my own culture! It is

time that we challenge people's core beliefs because it is these very beliefs that are creating the problem. If this is done in a respectful way, we can then make a much bigger impact on stigma, discrimination, inequity, and a range of other social issues. We need to challenge religion to not only examine the emphasis on blame-shame-punishment (versus compassion), but also to do so actively and publicly. Religions and religious leaders have a fundamental and profound influence on the understanding of what causes 'bad' things to happen (read the almost classical publication on this issue from Harold Kushner, a Jewish rabbi) and how we should respond to this. It matters because people want to go to Heaven. For many people, peace, joy, and fulfilment are not potentially possible in their physical circumstances, so instead of 'here', they seek it in the future, in Heaven. And, in their minds, it is the religious/moral authorities who '*control the keys to Heaven*'; the very same leaders who, at times, say disability is proof of sin.

In working towards a disability-inclusive society, we should concentrate on the root causes of stigma, namely fear (of being worthy enough to be accepted and loved). This applies not only to the relationship of people (with disabilities) with God or the Gods, but also to other people. We cannot ignore the reality that most people in the world (85%)<sup>1</sup> have strong religious value systems, whether this is Islam, Christianity, Hinduism, Buddhism or traditional animism. We also cannot ignore the fact that religion may have a very powerful influence on stigma, including self-stigma by those affected. We cannot therefore ignore an entry point to dealing with stigma, nor can we forget the widespread resource infrastructures in dealing with the consequences of disability, such as home-based care, community-based care, rehabilitation, caring for abandoned children (with a disability), prevention of infanticide, and numerous other issues. Protecting old negative ideas and/or practices will not lead to the necessary change with regard to the acceptance of people with disabilities and their families. It is high time we stop the simplistic methods of awareness-raising. Awareness does not come from statistics or posters. Awareness comes from a deep internalised consciousness that what we always believed is wrong. It requires more than a radio jingle or the celebration of World Disability Day.

Your Editor-in-Chief,  
Huib Cornielje

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1 <https://worldpopulationreview.com/country-rankings/religion-by-country>



# Universal Design: an Embedded Case Study on the Approach towards the Inclusion of Students with Physical Disabilities in Higher Education in India

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## ABSTRACT

**Purpose:** Research on students with physical disabilities in higher educational institutions (HEIs) often focuses on students' abilities rather than on environmental barriers. Architectural barriers are notably the major roadblock for students with physical disabilities. This study explored the architectural barriers faced by students with physical disabilities in India, and the environmental requirements for social participation and inclusion.

**Method:** Using a qualitative approach, an instrumental embedded case study was employed to explore the need for Universal Design to promote the inclusion of students with physical disabilities in higher educational institutions. The study participants were 6 students with physical disabilities, between 22 and 30 years of age, and their teachers (n=5). Data was collected through semi-structured interviews and a participatory observational accessibility assessment. It was analysed using categorical aggregation followed by cross-case analysis through constant comparisons of similarities and differences of themes.

**Results:** Two-thirds of the participants reportedly experienced barriers to participation in the built and social environments. Most barriers originated from the institute's built environment design and from activities conducted on the premises. Students using wheelchairs or walking frames experienced significantly more participation barriers than those using crutches or sticks. The areas that need the most improvement are the indoor spaces (such as corridors and classrooms) and opportunities for vertical movement.

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**Conclusion:** *Failure to make adequate modifications in the built environment for students with physical disabilities results in restricted participation or exclusion from opportunities to participate in and out of the classroom. The study findings can have implications across future research, architectural design practices, higher educational institutes, and policies to promote inclusion, optimal participation, and social interaction of students with physical disabilities within higher educational institutions.*

**Key words:** *architectural barriers, built environment, participation, universal design, physical impairment, accessibility, India*

## INTRODUCTION

India has one of the world's largest higher education systems (Ramprasad & Subbaiyan, 2017), with over 30 million students (Federation of Indian Chambers of Commerce and Industry, 2012). Nevertheless, the scope needs to be raised to a higher level to meet the global demand. In the last decade, the Indian government has attempted to address barriers to higher education (Ministry of Human Resource and Development –MHRD, 2018) including making higher educational institutions accessible for students with disabilities. India has been a signatory member of the United Nations Convention on Rights of Persons with Disability since 2007 (Ministry of Social Justice and Empowerment, 2020) and is mandated to facilitate inclusive infrastructure at all levels of education (UNCRPD, 1995). Soon after the inception of the Rights of Persons with Disability (RPWD) Act (2016), the process was fast-tracked. Persons with disabilities have a right to accessible infrastructure and information (RPWD, 2016). The Indian government envisions accessibility as the key to inclusion and equal access for persons with disabilities, and considers a barrier-free environment the first step towards fulfilling their right to participate in all areas of community life (Accessible India Campaign, 2017). Although the Accessible India Campaign promotes accessibility for all, it is limited to the accessibility of public buildings, transport, and information (Accessible India Campaign, 2017), overlooking higher educational institutions (higher education colleges and universities). Consequently the infrastructure of these institutions often remains the same - with inaccessible built environments for students with physical disabilities (Ali, 2020).

Disability is a socially constructed phenomenon based on prevailing misconceptions and stigma (Shakespeare, 2006). Social norms are often constructed by able-bodied, higher-class people who overlook the need of

persons with disabilities and can create a barrier (Garbutt & Saltiel, 2020). Such societal perspectives may reinforce higher education authorities' and institutions' attitudes towards providing limited services and infrastructural support for students with physical disabilities. Although Indian higher educational institutions have an affirmative policy of reservation for enrolment of students with physical disabilities, most built environments are not disability-friendly (Ali, 2020). So, while students with physical disabilities are enrolled in higher educational institutions, access and use of these institutions' built environment such as classrooms, library, hostel, and dining hall, are challenging. This inaccessibility could be the main reason behind the drop-out of students with physical disabilities before completing higher education (Lippman, 2015). Thus, there is an urgent need to make higher educational institutions accessible and inclusive. Although higher educational institutions in India are making architectural modifications (e.g., accessible ramps and washrooms), creating a conducive built environment that supports meaningful participation of students with physical disabilities seems a distant dream. There is still a massive gap in making the built environment accessible.

### **Higher Education and Infrastructural Barriers**

Research on students with physical disabilities in higher educational institutions often focuses on students' abilities rather than the institution's infrastructural support (Jamieson, 2003). Each student should avail of these facilities equally and easily, irrespective of their abilities (RPWD, 2016).

In India, several advocacy groups are working to improve school education for students with physical disabilities. However, these efforts have not translated to effect change by removal of barriers to higher education for students with physical disabilities (Jameel, 2011). The barriers, notably, are inaccessible infrastructural facilities, limited accessible transportation facilities, negative attitudes towards persons with disabilities, and lack of required support services (RPWD, 2016).

Design professionals, such as architects, planners, and developers, can unintentionally create a disabling environment with infrastructural barriers because they lack awareness about students with physical disabilities' accessibility design needs (Imrie & Hall, 2003). Barriers in the built environment include inappropriate stair heights, slippery surfaces, sharp edges, and the absence of ramps, handrails, and textured/guiding surfaces of lifts. These barriers restrict the mobility of students with physical disabilities and affect their cognition and

social and emotional well-being. Ultimately, this negatively impacts students with physical disabilities' enrolment, performance, and timely completion of academic degrees in higher education, thus limiting their prospects for employment, social participation, and improved quality of life (Mutanga, 2018).

As per the RPWD (2016), government and local authorities shall endeavour that all their funded educational institutions provide inclusive education to students with physical disabilities, including:

- Admit them without discrimination and provide equal education and opportunities for sports and recreation activities;
- Make buildings, campus, and various facilities accessible, providing reasonable individual accommodations;
- Provide the necessary support, individualised or otherwise, in environments that maximise academic and social development consistent with the goal of full inclusion.

The statements above affirm that infrastructural accessibility and supports are critical to promoting students with physical disabilities' full inclusion in higher educational institutions. The academic and social development of students with physical disabilities must be maximised by the institutions providing physical environments that promote inclusion. This inclusion could be made possible by following the Universal Design principles that aim to optimise the use of the diversity of human needs and the plurality (age, gender, height, abilities)(Centre for Universal Design, 2020).

### **Theoretical Understanding of Universal Design**

Universal Design (UD) and its principles address exclusion from infrastructure (Iwarsson & Stahl, 2003). Universal Design promotes diversity, maximises use, and enhances usability, space functionality, and physical environment (Centre for Universal Design, 1997). Globally, Universal Design has seven principles: UD1) Equitable use; UD2) Flexibility in use; UD3) Simple and intuitive; UD4) Perceptible information; UD5) Tolerance for error; UD6) Low physical effort; and, UD7) Size and space for approach and use (Centre for Universal Design, 1997). These principles mandate that infrastructures are usable by people of all ages and abilities, to the greatest extent possible, without needing adaptation or specialised design (Centre for Universal Design, 2020).

In India, Universal Design has five principles based on the design need and country context (see Table 1).

**Table 1: Universal Design India Principles with description (Khare & Mullick, 2012)**

S. No.	Principles	Description
1	Equitable	The design is fair and non-discriminating to diverse users in the Indian context.
2	Usable	The design is operable by all users in the Indian context.
3	Cultural	The design respects the cultural past, and the changing present assists all users in the Indian context.
4	Economic	The design respects affordability and cost considerations for diverse users in the Indian context.
5	Aesthetics	The design employs aesthetics to promote social integration among users in the Indian context.

Agarwal and Steele (2016) argue that a commitment to universal access is needed at every level of the project - planning, design, implementation, and operation - with the concepts institutionalised in the same way as health and safety. This theoretical understanding supported the findings and discussions to achieve the current study's objectives.

## Objectives

- To explore the environmental requirements for participation of students with physical disabilities to promote inclusion.
- To explore the architectural barriers faced by students with physical disabilities in higher educational institutions.

## METHOD

### Study Setting

The research site was an architectural institute in Central India.

The site is divided into five zones- 1) Academic (lecture halls, library, and labs), 2) Administration (administrative offices), 3) Residential (hostels, residential accommodation for staff and faculty), 4) Recreational (outdoor and indoor play area, gymnasium), and, 5) Movement (horizontal and vertical).

## Study Design

This qualitative study employed an instrumental embedded case study of an architectural institution, as the instrumental case allowed for exploring barriers associated with the institute's built environment (Stake, 1995). Moreover, the instrumental case provided insights into the students with physical disabilities' participation experience in the built environment (Stake, 2006). An interpretative paradigm was used, including participants in the co-creation of meaning associated with the data because it allowed for the capture of participants' perspectives on their participation experiences and focus on the meaning that illuminates the case (Stake, 2006).

## Study Sample

A sample must be selected purposefully to ensure the richness of information collected from the case (Flyvbjerg, 2006). Using purposive sampling, participants (6 students with physical disabilities and 5 teachers) were recruited from different departments, based on pre-determined eligibility criteria, to explore their interaction with the institute's built environment (see Table 2).

**Table 2: Eligibility Criteria**

Inclusion criteria	Exclusion criteria
<b>Students with physical disabilities</b>	
Types of impairment: physical (congenital)	Acquired temporary impairment due to accidents or other
Age: 22-32 years	
Must be enrolled in the institution during data collection	
<b>Teachers</b>	
Must be teaching in any of the departments within the institute	Visiting faculty or guest faculty were excluded because of their limited interaction and teaching experience with students
Must have taught in the institute for more than five years	

## Data Collection

Multiple measures were used to collect data as it is suitable for instrumental cases (Yin, 2018). Data was collected by the primary researcher using the following methods:

- Interviews - Face-to-face, audio-recorded semi-structured interviews with open-ended questions were conducted with the research participants.

Interviews were in English (participants' preferred language) and lasted for an hour. Interview questions mainly focused on experiences of students with physical disabilities in interacting with the built environment and spaces inside the campus. Tables 3 and 4 provide the full interview protocol.

**Table 3: Interview Protocol 1**

<b>Interview Protocol: Students with Physical Disabilities</b>
<ul style="list-style-type: none"> <li>• Could you please tell me about yourself?</li> <li>• Could you tell me about your experience in accessing:               <ul style="list-style-type: none"> <li>i) Classrooms?</li> <li>ii) Library?</li> <li>iii) Hostel (Students' residence)?</li> </ul> </li> <li>• What are the challenges you face in your daily movement within the campus? (Probe: please elaborate)</li> <li>• Is there any physical barrier that, according to you, mainly hampers your learning process in the institute? If yes, what is it? Kindly elaborate.</li> <li>• What may ease your accessibility in different important buildings on the campus?</li> <li>• What difference to your life will it make if the buildings are modified and accessible?</li> <li>• Have you spoken to the authorities in the institute about it? If yes, what was their response? If no, why?</li> <li>• What are your thoughts on the modifications done (ramps, handrail, textured guiding path, elevators, or lifts) helping you? If yes, how? If not, why?</li> </ul> <p><b>Exams and Curriculum:</b></p> <ul style="list-style-type: none"> <li>• What has been your experience inside the classroom?</li> <li>• How has been your experience with the course curriculum?</li> <li>• How has your experience been while appearing for the exams? Has there been any concern? If yes, please elaborate.</li> </ul> <p><b>Social Life:</b></p> <ul style="list-style-type: none"> <li>• What games do you play and how do you participate in the sports activities on campus?</li> <li>• What are your talents and hobbies? Do you showcase it and participate in cultural activities, and what challenges did you face?</li> <li>• How has your socialisation been with:               <ul style="list-style-type: none"> <li>a) Peers?</li> <li>b) Teachers?</li> <li>c) Staff?</li> </ul> </li> <li>• What are the attitudes of teachers towards you?</li> <li>• What are the attitudes of peers towards you?</li> <li>• How do they solve your issues/problems?</li> <li>• What are the attitudes of academic staff towards you?</li> <li>• Your final thoughts or do you wish to share something else that we missed? Kindly share.</li> </ul>

**Table 4: Interview Protocol 2**

<b>Interview Protocol: Teachers</b>
<ul style="list-style-type: none"> <li>• Could you please tell me about yourself?</li> <li>• Are you aware of the students with physical disabilities in the institute?</li> <li>• How has your experience been so far in teaching students with physical disabilities?</li> <li>• Do you think students with physical disabilities face any challenges within the campus? Kindly elaborate.</li> <li>• How much did these challenges affect students with physical disabilities' learning?</li> <li>• What challenges do you face in teaching students with physical disabilities? (Probe: modification adopted or done by you, if any)</li> <li>• How do you make students with physical disabilities comfortable or accepted by the teachers? (Probe: so that their learning process is not affected).</li> <li>• Have you shifted any classes due to students with physical disabilities' accessibility issues?</li> <li>• Have you made any modifications to the students with physical disabilities' curriculum? Please specify.</li> <li>• Have you made any modifications and adaptations to the exam?</li> <li>• Do you follow UGC and MHRD rules for students with physical disabilities?</li> <li>• Your last thoughts or if you want to share something we missed while discussing.</li> </ul>

Field notes - Field notes are an important data source to corroborate the research findings and improve the data's credibility (Phillippi & Lauderdale, 2018). The primary researcher made field notes after each interview, categorising them with respective interview transcripts and then referring to them while coding, analysing, and interpreting data.

- Participatory observational accessibility assessment - A participatory accessibility assessment of the buildings was conducted using 'Harmonised Guidelines and Space Standards for Barrier-Free Built Environments for Persons with Disabilities and Elderly Persons' (Ministry of Urban Development –MoUD, 2016)

Along with the students with physical disabilities, the primary researcher conducted accessibility assessments of buildings frequently visited by students with physical disabilities. The students participated actively in the process and used their walking aids during a month-long evaluation to highlight the barriers they faced while navigating university spaces. They shared their personal stories, and observational assessment notes were taken on-site by the researcher.



## **Data Analysis**

Data was analysed by substantiating the findings from multiple sources and theoretical frameworks using the following three steps:

Data management - Interviews were transcribed verbatim using Microsoft Word and managed in Atlas-Ti. Field notes from each interview were also embedded as comments throughout the transcripts during further analysis and triangulation (Larsen, 2018).

Primary categorical aggregation of data by participants - Participants were involved in primary categorical data aggregation (similarities and differences of categories) from the interview transcripts suitable for instrumental cases as it allows for exploring meaning closely (Stake, 2006). The observational accessibility assessment allowed the primary researcher and participants to co-create meanings related to architectural barriers.

Categorical aggregation of data by the researcher - After primary categorical aggregation, the researcher looked for the similarity and differences of categories across and within cases, reflecting on the main categories from each case to explore how different architectural barriers and ease of movement vary across the cases (Lauckner et al, 2012). Furthermore, discussions with team members helped to group all the categories pertinent to the research questions.

Cross-case analysis through constant comparisons allowed the researchers to draw meaning from interpreting the data (Stake, 1995, 2006). Furthermore, each case's key issues were identified (through the UD and UDIP – Universal Design India Principles) and re-examined to extract common problems that may be addressed differently across the embedded cases (Lauckner et al,2012). Data triangulation was conducted from interviews, field notes, and accessibility assessment notes to reduce the likelihood of misinterpretation and improve credibility (Stake, 2006; Yin, 2018). To achieve confirmability and dependability, an audit trail was maintained and member checks conducted with the participants (Lauckner et al, 2012).

## **Ethical Considerations**

Ethical approval was obtained from the Social Work Research Ethics Board, Tata Institute of Social Sciences, Mumbai, and from the institute participating in the research. Written informed consent was obtained from participants.

## RESULTS

### Characteristics of the Participants

This study had 11 participants (6 students with physical disabilities and 5 teachers). The median age for students with physical disabilities and teachers was 28.5 and 46 years respectively. Sixty percent of the teachers were female, but there were no female students with disabilities. Table 5 describes the participants' characteristics.

**Table 5: Characteristics of the Participants**

Characteristics	Value
Number of participants, n	11
Students with physical disabilities (n)	6
Teachers (n)	5
Median age in years (range)	31 (24-54)
Students with physical disabilities (n)	28.5 (24-31)
Teachers (n)	46 (37-54)
Gender, female n (%)	
Students with physical disabilities (n)	0%
Teachers (n)	60%
<b>Type of impairment</b>	<b>Physical</b>
Type of assistive device user (n)	5
Wheelchair (n)	1
Walking frame (n)	2
Walking stick (n)	1
Crutches (n)	1
*One of the students with a physical disability was not using any assistive device	

Analysed data produced four key categories of architectural barriers that limited ease of movement and participation for students with physical disabilities, and provided insights about the environmental requirements to promote their participation. They were:

- 1) Seasonal barriers in infrastructure,
- 2) Limited vertical movement inside the building,
- 3) The designed built environment as a barrier, and,
- 4) Absence of inclusive space for participation and recreation.

## Seasonal Barriers in Infrastructure

The research participants reported specific seasonal barriers that limit their participation in academic and recreational activities. Eight out of eleven participants mentioned that there is rainwater on the floor during monsoon, making the surface dangerously slippery and accident-prone, and making the space unusable by students with physical disabilities and others.

*“The flooring surface is slippery, and during monsoon, the corridor has water, and it is difficult to walk over it. Often, even people without disabilities have fallen and got hurt”* (Student using a walking frame).

UD5 emphasises creating a safe and secure built environment for users (Ormerod & Newton, 2005). Additionally, the research participants reported falling in the corridor because of errors in the flooring design, such as a slight difference in flooring level, with the same colour material making the difference unnoticeable and therefore an accident hazard. To deal with this, Ormerod and Newton (2005) emphasised incorporating safety aspects into design as it provides a cue for inclusive design dimensions, alerting the designer to incorporate warnings for potential hazards.

Additionally, the choice of flooring material is not anti-skid, creating a safety hazard every morning after cleaning. Others without disabilities have reportedly also slipped on the floor. Although the authorities are aware, it is costly to change the entire flooring. The current study found that integrating accessibility provisions from the outset increases the total cost by 0.93%. This finding resonates with the United Nations (2019) suggestion that incorporating full-access features from the beginning is estimated to increase the total construction cost by 1%, while design adaptation after project completion can increase it by 5% or more.

Another barrier is the ramp in front of the library which has a ratio of 1:9 (accessible ramp slope should be 1:12) (MoUD, 2016), making it an accident zone. Participants have reported incidents of falling while using it.

*“Even the ramp nearby the library has a steep slope, and I fear using it very often. I do not go to the library”* (Student using a walking frame).

In this case, the built environment’s effect on user operation was not considered (Lundstrom et al, 2016). Similarly, according to Imrie and Hall (2003), due to the design professionals’ insensitivity to disability and disability-related needs, they may create an environment that limits participation of students with physical disabilities.

## Limited Vertical Movement inside the Building

Vertical movement is limited as the building has no provision for a lift or ramp. The building has two floors, and building legislation does not permit installing a lift in buildings with fewer than four floors. However, this should not be an excuse to keep buildings inaccessible; a ramp could connect the lower and upper levels. Design professionals' lack of awareness about disability and disability-related needs is a significant reason behind this.

*“The authorities made the buildings considering the immediate user’s need, except us; they missed the opportunity of creating an inclusive and encouraging learning environment. Constructing a ramp costs almost equal to constructing a staircase, and the ramp is not only used by us but all”* (Student using a walking frame).

Due to this limitation in vertical movement, students with physical disabilities miss opportunities for equal participation and learning. The limited vertical movement contradicts the Equality and Usable principle of UD and UDIP, increasing dependency on others and leading to self-isolation by students with physical disabilities, as well as lowering self-esteem.

*“The printing shop is on the first floor and not accessible to us. We need bulk printing of design sheets and reports. Even though my assignments are ready, I depend on my friends for printing and submission. Mostly, I delay my submission waiting for my friend to complete his assignments and get print”* (Student using a wheelchair).

Apart from forced dependency, these architectural barriers create a compromised learning environment for students with physical disabilities, denying their equal participation in the institute.

## The Designed Built Environment is a Barrier

Apart from their design studios, the areas most used by the students were the library, Graphics lab, and Geographic Information System (GIS) labs. However, the research participants highlighted the space limitations inside these designed spaces. The design and layout of the furniture inside these areas do not cater to all users. They are inaccessible to those using a wheelchair, walking frame, crutches, or even walking sticks, forcing the students with physical disabilities to remain in their respective hostel rooms and study. This situation contradicts the

principles of equitable use (UD1), flexibility in use (UD2), and size and space for approach and use (UD7) (Centre for Universal Design, 1997).

In higher educational institutions, students spend significant time in formal learning environments such as classrooms and laboratories (Ramprasad & Subbaiyan, 2017). There are crucial software classes inside Graphics or GIS labs, and students with physical disabilities are often forced to sit in front, with no space to use the computers inside the studio.

*“Initially, I thought they were making sitting arrangements for me inside the labs, but it continued. I have reported it several times to the authorities, but no development has occurred. I prefer learning software online. I feel excluded sitting in front of a chair as the space is not enough to move with ease. I believe they have designed these spaces as a barrier”* (Student using crutches).

Studies have established the relationship between indoor classroom environments and student outcomes (Puteh et al, 2012). In the case of furniture arrangement inside the Graphics or GIS labs, participants indicated that the layout does not allow the same means of use for all users, impacting students with physical disabilities’ academic performance. Choi et al (2014) highlight the crucial role of classroom furniture in meeting students’ various pedagogical requirements and learning styles. Other studies also highlight the influence of comfortable classroom conditions on students’ academic achievement or learning performance (Waldrip & Fisher, 2003). Hutchinson (2003) also highlights that seating arrangement and postural comfort impact the learning processes because they have a bearing on concentration and motivation. In the current study, students using a wheelchair or walker could not use the labs like their peers. It is interesting to note how participants experience and explain the built environment as a designed architectural barrier. Students with physical disabilities feel excluded, and they see the facilities provided to them as ambiguous. Education is non-negotiable, and the institute should provide access to education on an equal basis to all (UNCRPD, 1995).

### **Absence of Inclusive Space for Participation and Recreation**

The campus lacks spaces that encourage social interaction and recreation among the students. Although there are certain areas like canteens, corridors, and common rooms (for reading and working together in small groups) inside hostels, these spaces are sporadically planned, and some are not accessible to an

individual using a wheelchair or even a walking frame.

*“Once you meet socially, automatically everybody becomes like a family, and then you don’t need any forced conversation. Inclusive spaces where community life can happen do not require effort from a single person. It can happen effortlessly, and it should happen effortlessly” (A teacher).*

These narratives indicate that such inclusive spaces within the campus may encourage students with physical disabilities to participate, interact, and promote healthy community life. The results of the current study mirror other research on how the physical environment influences the way people feel, see, and interact with one another, and these factors influence an individual’s performance (Jensen, 2005). Another study highlights that spatial design influences how people interact and participate (Lippman, 2015). Therefore, campus developers must understand how learning principles can guide space design (Jamieson, 2003) through the Universal Design approach, supporting community life and social interaction.

## DISCUSSION

This study adds to the existing knowledge about higher education learning environments, mainly regarding barriers in the built environment, from the perspectives of students with physical disabilities. Through the Universal Design approach, the study assesses the existing architectural barriers within an institution of architecture and planning in India. This study can change the planning and design perspective of the design professionals, faculty, staff, and peers within an architectural institute (Imrie & Hall, 2003). It focuses not only on the classroom’s indoor environment and participation of students with physical disabilities (Puteh et al, 2012) but also extends the existing research to the built environmental factors influencing participation outside classrooms.

Globally, equitable educational access is a characteristic of international universities and higher education institutions (Patricia et al, 2003); however, attending to equity issues in higher education is challenging (Mutanga, 2018). Research suggests that globally, students with disabilities are less likely to progress to higher education (Mutanga, 2018) because of the barriers they face from primary education onwards. Even those few students who make it to higher education continue to face challenges (Mutanga, 2018); one major challenge is access to higher educational institutions’ built environments (Ali, 2020; Gupta,



2022). These challenges arise because of the improper conceptualisation of inclusion and limited understanding of disability and related design needs within higher education institutions (de Haan, 2001; Gupta, 2022; Gaurav et al, 2023). Design professionals often conceptualise inclusion as 'one size fits all.' With this thinking, the designers and service providers assume that inequalities can be overcome by providing the same opportunities to the excluded population without considering their diverse needs. People are different, and their needs differ regarding age and ability. Designers who fail to recognise this human diversity eventually create disabling environments (Imrie & Hall, 2003). Disabling the environment impacts the participation of students with physical disabilities by imposing barriers that other students do not face.

Accessible infrastructure is a precondition for independent living, and full and equal participation in higher education by persons with disabilities (Agarwal & Steele, 2016). The Indian higher education sector has experienced tremendous growth, and the enrolment rates have been high (Federation of Indian Chambers of Commerce and Industry, 2012). With a need to have more higher education institutions to accommodate students, and particularly students with physical disabilities, educational administrators and architects should focus on designing built environments of these institutions while keeping in mind disability needs and involving students with physical disabilities (Ramprasad & Subbaiyan, 2017; Gupta, 2022; Gaurav et al, 2023).

Over the past decade in India, evolving building legislations show that a lack of awareness, combined with traditional stereotypes, continue to pose significant hurdles in effectively enforcing an accessible built environment. A Universal Design approach can maximise the use of space and products respective to an individual's diverse needs (Centre for Universal Design, 1997); this approach can also bridge the gap between students with physical disabilities and inaccessible university spaces. Universal Design is the ultimate balance of aesthetics and usability (Imrie & Hall, 2003). Steinfeld and Danford (1999) indicate that environmental factors and perceiving accessibility as an association between a person and the environment are crucial in determining an individual's degree of independent living and the status and identity in society of individuals with disabilities. Universal Design has been able to replace the term 'accessibility' with the term 'usability' by introducing an activity component in design (Steinfeld, 1994). Usability is the efficient, effective, and comfortable use of the design, product, or environment (Iwarsson & Stahl, 2003). With an emphasis on the



usability of the environment, Universal Design maximises the use to all, to the greatest extent possible, without any adaptations to the product or environment (Centre for Universal Design, 1997). Through this approach of maximising use to a broader spectrum of people, Universal Design also promotes democracy and equity.

## Implications

The study findings can have implications across future research, architectural design practices, higher educational institutions, and policies to promote inclusion, optimal participation, and social interaction of students with physical disabilities within higher education institutions. Table 6 highlights the potential implications of the research findings.

**Table 6: Implications of Research Findings**

Domain	The implication of research findings
<b>Future research</b>	<ul style="list-style-type: none"> <li>• Research could explore perspectives of students with disabilities (other than physical ones) for a broader understanding of participation restrictions due to architectural barriers.</li> <li>• Research can explore the participation experiences of students with disabilities pre- and post-built environment modification.</li> <li>• Research could investigate the potential of UD within the building bylaws governing built environment modifications in low- and middle-income countries. Article 04 of CRPD (2016) also highlights promoting Universal Design in developing standards and guidelines.</li> </ul>
<b>Practice</b>	<ul style="list-style-type: none"> <li>• Findings of the current research can scientifically inform the college authorities about the inherent challenges in the institute's built environment.</li> <li>• Findings of the current research highlight the hazardous built environment characteristics in HEIs resulting from design professionals' negligence towards disability-related design needs. Hence, a capacity-building or disability awareness programme for the designers could be developed.</li> </ul>
<b>Policy</b>	<p>Building on the research findings, the authors conducted accessibility assessments of fourteen government-funded universities in Maharashtra, India, and prepared and submitted a report to the government. The research-informed results successfully brought policy-level changes, and the fourteen universities reserved 3% of their entire budget to make their campuses disability-friendly (I-Access Rights Mission, 2020).</p>

## Limitations

The study had some limitations as well. Representation of female students with physical disabilities is low, so their voices and perspectives are missing regarding participation restriction due to architectural barriers. Since this study was limited

to architectural barriers, gathering perspectives on attitudinal and social barriers would provide a thorough understanding of factors influencing the participation of students with physical disabilities in higher educational institutions. Also, the study participants' fear of answering specific questions about the university administration's response to their design needs limits the understanding of how these issues are addressed by the administrations.

## CONCLUSION

Disability and architecture are closely related where the built environment can perpetuate the exclusion of persons with disabilities. Failure to provide adequate built environmental modifications results in students with physical disabilities' restricted participation or exclusion from the participation opportunities in higher educational institutions. The situation demands an understanding that supports inclusion. While individual cases and experiences can be unique, the root of exclusion lies in the societal and organisational structures which perpetuate a disabling environment in higher education institutions. Additionally, understanding disability plays a crucial role in shaping the attitudes of architects, designers, engineers, teachers, staff, and friends within the university setting. There is an urgent need to modify the existing built environment of higher education institutions with a Universal Design approach, provide supportive services to accommodate all, and nurture a healthy, inclusive teaching and learning environment within higher educational institutions.

## ACKNOWLEDGMENT

The authors would like to thank all the students with physical disabilities and faculty members who participated and helped in pursuing the research objectives. They also thank the architectural institute authorities for allowing them to conduct the study.

The authors declare there is no conflict of interest.

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# Perceptions of Youth with Disabilities in Bhutan on Family Support, Attitudes, and Encouragement towards Meaningful Community Engagement: Implications for Parental Self-Efficacy

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## ABSTRACT

**Purpose:** Awareness and attention towards disability-inclusion in Bhutan has steadily increased over the last few years. However, there are still many challenges that remain to support meaningful employment and community engagement for youth with disabilities such as inequity, discrimination, stigma, inaccessible physical environments, and bullying that seems to impact the self-efficacy of the youth with disabilities themselves. In this article, we explore how youth with disabilities in Bhutan perceive their family's level of support, attitudes, and encouragement in order to explore the implications of parental self-efficacy.

**Method:** This article reports on a national-level survey in Bhutan on the perceptions of youth with disabilities ( $n = 216$ ; Male = 127 & Female = 87) about family attitudes, support systems, and family encouragement towards their employment and the role of parental self-efficacy beliefs. The participants in the survey were recruited through purposeful sampling procedures that provides representation and generalizability across multiple characteristics and factors. Data were analysed using descriptive and inferential statistics.

**Results:** Findings from this study suggest that youth with disabilities were supported and encouraged to contribute to the family livelihood within the home, but less so out in the community, indicating lower parental self-efficacy beliefs about their child with a disability's capabilities to contribute in the community and their own ability to facilitate and ensure that contribution.

**Conclusion:** Negative family attitudes and lower self-efficacy can be detrimental

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*as it limits the ability of youth with disabilities to fulfil and achieve their life goals. Equally, youth with a disability's perception of their negative family attitudes and low self-efficacy can also be detrimental to their development. This article recommends further research into the self-efficacy beliefs of parents of children with disabilities. Furthermore, engagement, awareness raising, and training parents on ways to support their child with a disability to engage in meaningful employment and community activities.*

**Key Words:** *Bhutan, Family support, Attitudes, Support, Self-Efficacy, Disability, Inclusion*

## INTRODUCTION

In Bhutan, awareness and attention towards disability-inclusion has been steadily increasing. Bhutan ratified the UN Convention on the Rights of the Child (CRC) in 1990 followed by signing the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2010. These commitments demonstrate that the Bhutanese Royal Government is committed to protecting the rights of children, including youth with disabilities. A two-stage child disability study focusing on the ages of two to nine reported 21.7% of the sample (n = 11,370) as having some form of disability at varying degrees (NSB & UNICEF, 2012). This study was conducted using a functional multi-indicator methodology. The national census of Bhutan reports a much lower disability population prevalence of 2.1% (NSB, 2020), suggesting that the disability prevalence rate is somewhere between 2% and 21% – although ‘disability’ is relative and a socio-culturally constructed phenomenon (Schuelka, 2018).

Bhutan has embraced at least a segregated ‘special educational needs’ model since 1973 with the establishment of a school for the blind in eastern Bhutan (Rinchen Dorji & Schuelka, 2016). Since 2009, in order to enhance social support and provision of education of children with disabilities, the Ministry of Education (MoE) and UNICEF established ‘Special Education Needs (SEN)’ units within ‘mainstream’ schools with a somewhat push-in inclusive model (Rinchen Dorji & Schuelka, 2016). At the time of the writing of this article, there are a total of 26 schools that are fully accepting of students with disabilities – including two vocational centres run by a non-governmental organization (NGO); and the Muenselling Institute for the Blind and the Wangsel Institute for the Deaf, which are nominally supported by the Royal Government but mostly funded through international donation – with a total of 997 students (MoE, 2020). While the MoE

and Royal Government has been involved in supporting these initiatives, many local NGOs and some international development organizations have arisen to fill in the gaps to provide necessary support and education to the persons with disabilities. Despite these developments, there are continuing issues related to a lack of teacher preparedness and training, resources, cultural and religious beliefs, social stigma, and a lack of awareness amongst the general public in supporting education for persons with disabilities (Grimes, et al., 2021; Kezang Sherab, et al., 2015; Rinchen Dorji & Schuelka, 2016).

Most recently, the current Royal Government has approved the SEN policy document (GNHCS, 2019). This policy seeks to improve the lives of persons with disabilities Persons with disabilities through empowering them to participate in the socio-economic development process; mainstreaming disability initiatives in plans, policies, and programs; improving access to education, and other opportunities and services; promoting healthy living; and promoting positive attitudes and behaviour amongst the general public (GNHCS, 2019). To address the issue of teacher preparedness, the Paro College of Education started offering a two-year Master's in Inclusive Education program to in-service teachers since the 2020 academic session. Over the last few years, inclusive education and disabilities has also received increasing attention from scholars. There have been numerous research projects carried out to understand inclusion and disabilities, such as on teachers' perspectives on inclusion, disability, Gross National Happiness, and Buddhism (Dawa Dukpa, et al., 2022); the effects of school leadership towards inclusion (Rinchen Dorji, et al., 2022; Subba, et al., 2019); implementation of inclusive education policy and practices (Kezang Sherab, et al., 2015); parental communication and collaboration in schools with a SEN program (Karma Jigyel, et al., 2018); and the cultural production 'disability' in Bhutanese schools (Schuelka, 2018).

In spite of these efforts and development, there is still social stigma and beliefs related to culture and religion that seems to impact the upbringing of the persons with disabilities. The registration of people with disabilities in Bhutan conducted in 2015 found that an overwhelming majority (84.4%) of the children with disabilities did not attend a school (Kezang Sherab, et al., 2015 ). Research has shown that these children were "marginalized and excluded" (Schuelka, 2013, p. 67), which was attributable to the unwillingness of the parents to send their children with disabilities to school because of low expectations; an unfriendly school environment such as a lack of individualized and accommodative

curriculum and the presence of bullying; a lack of trained teachers; and inaccessible infrastructure (Kezang Sherab, et al., 2015).

There are many challenges to the Bhutanese school system that need to be addressed at the systemic and policy levels, but this article will specifically focus on parental support for their children with disabilities. While there could be various reasons for the lack of parental support, anecdotal evidence suggests that some of the plausible reasons could be due to the lack of parental awareness and skills to parent children with disabilities, parental attitude, and attitude of persons with disabilities themselves. Research conducted in non-Bhutanese contexts has shown that low parenting self-efficacy is directly associated with reduced parenting effectiveness, insecure attachment, increased susceptibility to helplessness, and negative attitudes (Aral, et al. 2019; García-López, et al., 2016; Young, 2011). Therefore, this article is aimed at exploring the perceptions of youth with disabilities in Bhutan about family attitudes, support systems, and family encouragement towards their employment.

In this article, we first look at the importance of family attitudes and self-efficacy, particularly as it is related to youth with disabilities, and how this theoretical framework informs our research questions. Next, we explain the methodology that was employed to answer our research questions and give the context of the larger study and project that this article derives from. Findings are presented that demonstrate that perceptions of youth with disabilities are that their families give them some support and encouragement, but not that significantly and much less outside of the home environment. In the discussion, we argue that this shows that self-efficacy of parents of youth with disabilities in Bhutan needs more support and resources in order to help them see and realize a future for their child beyond the home environment.

## **Background Literature**

### *Family Attitude*

Family is the first important contact point for any child with or without disabilities. It is crucial that family members exhibit positive attitude towards their children with disabilities because of additional development challenges and social stigma. Existing literature suggests that the negative attitudes of family, friends, and society in general have limited the ability of persons with disabilities to fulfil and achieve their life goals (Antonak & Livneh, 2000; Morris, 2000). Knowledge

of attitudes of persons without disabilities towards persons with disabilities helps to understand nature of the interaction between the two groups (Antonak & Livneh, 2000). Li-Tsang, et al. (2001) found that negative attitudes “may lead parents to adopt maladaptive coping skills including feelings of guilt, pessimism, hostility, aggression and avoidance” (p. 61).

In the context of Bhutan, family attitude is something that has not been fully explored. While there have been some improvements to family and community behaviours and attitudes regarding persons with disabilities, there are still many challenges that remain such as unfairness, inequity, discrimination, stigma, inaccessible physical environments, dissatisfaction, bullying, and name-calling (Schuelka, 2015, 2018; UNICEF & MoE, 2017). For instance, UNICEF and MoE (2017) found that almost 20% of the heads of households who responded to their survey believed that children with disabilities did not contribute positively to their family. Furthermore, 24% of the respondents stated that children with disabilities did not contribute positively to society. However, more highly educated respondents were positive that children with disabilities make positive contribution to family and society. This is in line with the findings around the world (Morin et al., 2013 as cited in UNICEF & MoE, 2017). This suggests that there should be more attention to education with a focus on attitudinal change.

Efforts have been reported across many countries to include persons with disabilities in the community at large. Improvement in the quality of life for persons with disabilities will remain a challenge until the society they live in espouses the value of equity and inclusion and multiple elements are aligned in order to support this value (Schuelka & Kezang Sherab, 2022). Attitudinal barriers, products of fear, and negative societal perceptions of disability hinder full integration of persons with disabilities into their communities (Smart, 2008). Research has shown that exclusion of persons with disabilities from employment opportunities, being shunned from the pursuit of romantic relationships, and a prohibition from engaging in the self-determination process can adversely impact their psychological and physical well-beings (Livneh, 2001). While family attitude and the attitude of youth with disabilities play important role in terms of the employment and their overall well-being, not much is known about family attitude and attitude of the youth with disabilities themselves in Bhutan. We will explore these phenomena through the lens of self-efficacy.

### *Perceived Self-Efficacy*

A perceived sense of self-efficacy refers to future beliefs of one's capabilities to organize and execute a particular task in a specific situation (Bandura, 1997). The efficacy theory of Bandura has been widely used to predict effort exertion, behaviour, motivation, persistence, actions, and coping in a wide variety of situations (Ellis, 2019; ([Anonymized], 2013). According to Bandura (1997), efficacious individuals envisage successful outcomes while inefficacious individuals are preoccupied with negative outcomes. Fundamentally, self-efficacy portrays individual's beliefs about themselves as competent or incompetent to perform the given task in a specific situation. In other words, self-efficacy is task and context specific. For instance, a person's self-efficacy to swim would be different from his or her self-efficacy to play basketball, and self-efficacy to swim at the age of eight would be different from at the age of 15. Furthermore, self-efficacy of Bhutanese parents to raise their children with disabilities would be different from that of other contexts such as in India or the United States. Essentially, there are four key sources from where human beings judge and estimate their sense of self-efficacy: Enactive mastery experiences (assessment of their own past experiences), vicarious experiences (observing and learning from their models performing the task), verbal persuasion (motivation and praise from significant others), and physiological/emotional states (positive or negative experiences which leads to confidence or lack of confidence) (Bandura, 1997; Wittkowski, et al., 2017).

### *Parental Self-Efficacy*

Parental self-efficacy (PSE) refers to a belief about their ability to parent a child successfully (Jones & Prinz, 2005; Meunier & Roskam, 2009). The important role parents play in the growth and development of children in general, and even more so of children with disabilities, has been widely researched (Hohlfeld, et al., 2018; Meunier & Roskam, 2009; National Academies of Sciences, Engineering and Medicine, 2016). Much of the literature suggests that parenting a child with disabilities is much more stressful and challenging with a wide range of difficulties compared to parenting a child without disabilities (Ellis, 2019). Therefore, it is crucial that parents of children with disabilities are motivated, resilient, persistent, capable, and efficacious of raising their children and fulfilling the demanding social role. Existing literature indicates that parents with higher self-efficacy are able to take proper care of their children leading to healthy development processes, whereas the parents with lower self-efficacy negatively impact the development

of their children leading to psychiatric symptoms, emotional problems, and behavioural problems (Aral, et al. 2019; García-López, et al., 2016; Young, 2011). The literature also suggests that PSE has been one of the crucial determinants of positive parenting (Bryanton, et al., 2008; Wittkowski, et al., 2017). A meta-analysis of some 34 PSE measures concluded that “PSE has been demonstrated to be a strong predictor of parenting functioning” and recommended that “parents with lower levels of PSE are better identified and supported to improve their skills in parenting” (Wittkowski, et al. 2017, p. 2975). Short training programs have been found to be a significant contributor of increased self-efficacy among parents (García-López, et al., 2016). Studies have also confirmed that parents of children with disabilities participating in behavioural change training programs have positive correlation to PSE (Benedetto & Ingrassia, 2018). Thus, the take-away from this article should not be one of ‘blaming’ parents for the outcomes of their children. Rather, this research highlights the importance and collective societal responsibility of developing, supporting, and increasing PSE.

## Objective

Although there is a strong amount of global literature on PSE and children with disabilities, less is known about Bhutanese parents’ attitude and self-efficacy to raise their children with disabilities. Therefore, this study focused on addressing the following research questions:

What are the perceptions of youth with disabilities about family attitudes, support systems, and encouragement towards their employment?

Sub-questions:

- a. What is the level of perceptions of youth with disabilities about family attitudes in terms of belief, support systems, and encouragement towards their employment?
- b. Is there a statistically significant difference in terms of gender and role in the perceptions of youth with disabilities about family attitudes, support systems, and encouragement towards their employment or finding meaningful community activities?
- c. Is there a statistically significant relationship between family attitudes towards belief about disability, support systems, and encouragement of the employment of persons with disabilities?



- d. What kinds of meaningful activities did the family encourage them to do in the community?

## METHOD

The research and findings in this article are original but part of a larger project that investigated multiple strands of understanding pertaining to youth with disabilities in Bhutan. *The Comprehensive Survey of Transition and Employment of Youth with Disabilities in Bhutan* (see Schuelka, et al., 2022; Tichá, et al. 2023) was conducted in 2019 and 2020 as part of a project titled “Understanding, Developing, and Supporting Meaningful Work for Youth with Disabilities in Bhutan: Networks, Communities, and Transitions,” funded by the United Kingdom Foreign, Commonwealth, and Development Office (FCDO) Global Challenges Fund and managed by the University of Minnesota’s Institute on Community Integration, Royal Thimphu College, and the University of Birmingham (UK). The survey was Phase One of the project and included 216 youth with disabilities aged 16 to 24 across 17 out of 20 *dzongkhags* [districts] in Bhutan. Fieldwork surveys and interviews were conducted in person, using Geographic Information Systems [GIS]-enabled technology (‘Survey123’ and ‘Collector’ by ESRI). Ethical clearance for the survey was given by the Bhutanese National Statistics Bureau (NSB/SDPD/Survey/2019-20/4870), as well as the University of Birmingham Research Ethics Office (ERN\_18-1601). The survey was administered by trained project staff (five research assistants that were academic faculty members from Royal Thimphu College, and two Bhutanese co-investigators from the project staff). The distribution of participants across Bhutan can be observed in Figure 1 below. While a wide range of research questions and objectives were being addressed through this Phase One survey and not presented in this article (see Schuelka, et al., 2022; Tichá, et al. 2023), the questions specific to self-efficacy and youth with disability perceptions of family support are the focus of this article.



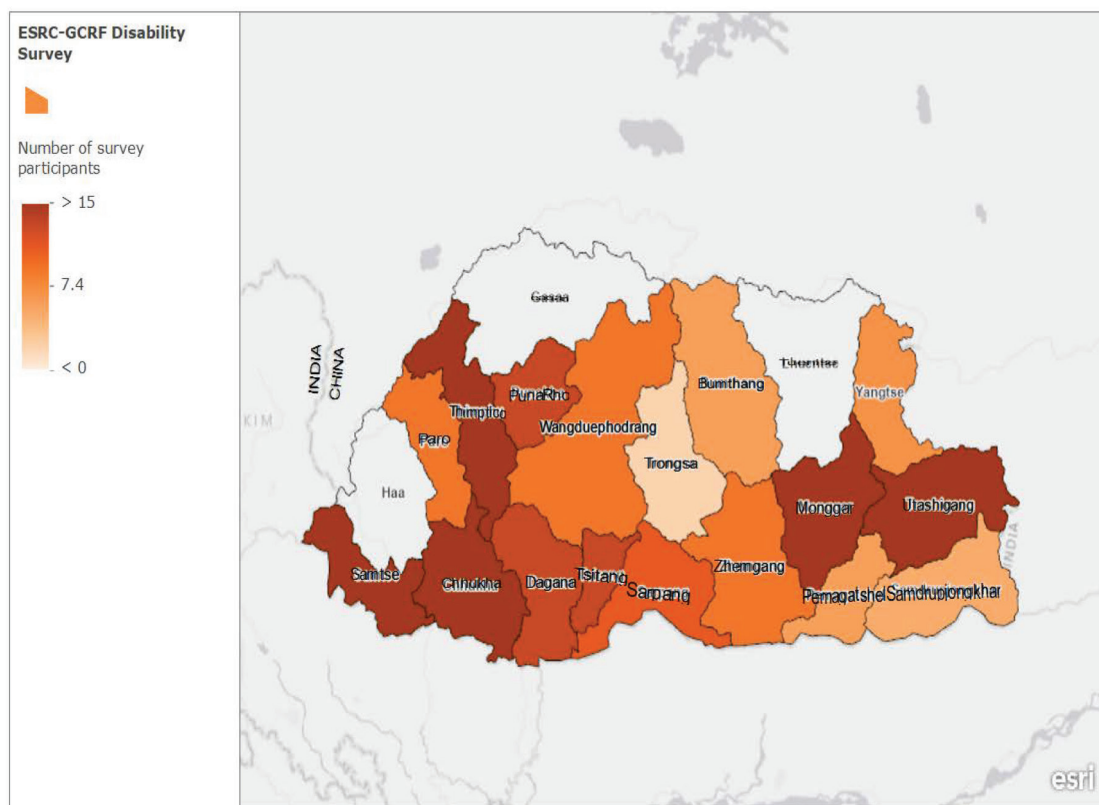


Figure 1. Map of Bhutan with Number of Survey Participants per Dzongkhag (n = 216).

The distribution of participants from different Dzongkhags is roughly equivalent to the population of that Dzongkhag. Of the three Dzongkhags that we were unable to reach, Gasa, Lhuentse, and Haa are among the smallest and most remote Dzongkhags in Bhutan, with elevations of 5,000 to 7,000m (16,400 to 23,000ft). Reaching these during the monsoon season was not possible. Survey participants included youth with disabilities and proxy respondents who were mainly their family members (see Table 1). Proxy respondents – those who were unable to answer the survey directly but had a designated family or community member answer the survey questions – made up less than 20% of our survey.

**Table 1. Survey Participant Composition**

Characteristic	Category	n*	%
Gender	Male	127	58.8
	Female	87	40.3
Role	Proxy	43	19.9
	Individual	173	80.1

Currently working for money	Yes	45	20.8
	No	142	65.7
	NA (Student)	23	10.6

Total Number of Respondents = 216 (\*totals do not add up to 216 due to missing values)

The respondents in this survey were categorized by experienced difficulties based on the Washington Group (2021) functioning classification system to determine disability characteristics. This is now the established methodology used by the National Statistics Bureau in Bhutan, and we support this methodological approach as it avoids the medical pathologisation of disability and embraces a more socio-cultural constructed approach. Table 2 below expresses these difficulty and disability characteristics.

**Table 2. Functional Difficulties Experienced by Survey Participants**

Sl. No.	Difficulties in...	n	%
1	Seeing	82	38.0
2	Hearing	136	30.1
3	Walking or climbing	101	46.8
4	Remembering or concentrating	116	53.7
5	Self-care (washing, dressing)	87	40.3
6	Using hands	79	36.6
7	Understanding directions	83	38.4
8	Interacting with others	128	59.2
9	Learning at the same rate as others	155	71.7

Total Number of Respondents = 216

Participants in the survey were located and sampled through a process of purposive sampling – working through various governmental and non-governmental organizations to locate persons with disabilities across the country.

Within the comprehensive survey, seven four-point Likert type survey items related to perceptions of youth with disabilities in terms of family attitudes (3 items), support systems (2 items), and encouragement (2 items). More detail on methodology and the survey itself can be found in the full survey report published online (Schuelka, et al., 2022; Tichá, et al. 2023).

In order to answer the research questions through the survey data collected, we analysed survey data using both descriptive and inferential statistical methods. For example, for sub-question A, we used descriptive statistics to derive mean and standard-distribution information from four-point Likert-scale items. For sub-

question B, we used multivariate analysis to observe correlational significance. Chi-squared tests were also performed. Descriptive analysis of all the seven items showed no substantive non-normality in terms of skewness, kurtosis, and outliers. The cases of missing values were also observed to be minimal and without any form of pattern.

There are some limitations to the findings that should be acknowledged. While the surveys were conducted by field staff in multiple local languages and dialects – primarily in Dzongkha, Tsangla/Sarchop, and Nepali – there could be some challenges in terms of understanding and communication. Some surveys were conducted in Dzongkha sign language, but proficiency is limited. We believe that the number of participants is representative and with a sufficient number that is able to be generalizable. If we are to use the statistics from the national census (NSB, 2020), we surveyed about 1 in every 4 persons with disabilities in Bhutan. The results of this study should be addressed with caution. In this study, youth with disabilities were asked about their parents' attitude, belief, support system and encouragement. Indeed, self-perceptions are important when examining self-efficacy. However, in order to receive a more adequate picture, especially for intervention needs, further research should explore not only adolescents' perceptions but also parental perceptions as well.

## RESULTS

### Level of Perceptions of Youth with Disabilities about Family Attitudes in Terms of Belief, Support Systems, and Encouragement Towards their Employment

The perceptions of youth with disabilities in terms of their family belief, encouragement, and support system were measured by a four-point Likert type scale beginning with not much (1); little (2); much (3); and a great deal (4). The mean and standard deviation for each item were computed using SPSS (see Table 3).

**Table 3. Level of perceptions of youth with disabilities**

Items	n	M	SD
Does your (their) family <i>believe</i> that you (they) can meaningfully contribute by working at home?	203	2.34	.99
Does your (their) family <i>believe</i> that you (they) can meaningfully contribute by working in the community (in office, business, etc.)?	209	2.11	.95

Does your (their) family <i>believe</i> that you (they) can meaningfully contribute to nation building?	208	2.02	.84
Does your (their) family <i>encourage</i> you (them) to contribute to home activities?	207	2.53	.92
Does your (their) family <i>encourage</i> you (them) to work in the community (in office, business, etc.)?	208	1.99	.98
Has your (their) family <i>supported</i> the employment goals you (they) have for yourself (themselves)?	205	2.30	1.11
Has your (their) family <i>supported</i> you (them) in working outside of the home (e.g., getting ready for work, providing transportation, etc.)?	207	2.31	1.10

As shown in table 3 above, the highest mean is 2.53 and the lowest is 1.99. This is an indication that the youth with disabilities have the perceptions that their family somewhat encourage them to work and contribute *at home* – which would often include a family farm for subsistence – while they are not encouraged to work in the community such as in an office or private retail business. This suggests that family members are not confident or prepared to send their children with disabilities outside of the home to work and contribute to the larger community. Furthermore, there is a similar pattern that the perceptions of youth with disabilities dwindle in terms of their family belief that they can contribute from home to community and then to the national level. Meanwhile, in terms of support systems, the perceptions of youth with disabilities seem to vary as shown by higher standard deviations, but not correlated with their level of functioning

### **Influence of Gender and Role (Proxy and Individual) on Perceptions of Youth with Disabilities**

A multivariate analysis was conducted to answer if there were gender and role differences in youth with disabilities' perceptions of family belief, support system, and encouragement both for employment and meaningful community participation. Inspection of multivariate Box's M test and Levene's test did not show any significance ( $p > .05$ ), indicating that homogeneity of covariance matrices of all the dependent variables were equal across groups and that variances for the grouping variables were homogeneous, respectively.

The overall multivariate F-tests (see Table 4) showed significant result for only role.

**Table 4. Multivariate tests to compare family believe, support, and encouragement by gender and role**

Effect		Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared
Role	Wilks' Lambda	.903	2.808 <sup>b</sup>	7.000	184.000	.008	.097
Gender	Wilks' Lambda	.932	1.884 <sup>b</sup>	7.000	182.000	.074	.068

For all seven dependent variables, the mean for the Proxy is significantly lower than the mean for the individuals (see Table 5). This is an indication that Proxy (who were mainly family members) had much lower attitude towards youth with disabilities compared to the youth's perception of belief, support, and encouragement.

**Table 5. Mean differences for the significant multivariate tests**

	Item	Role	M	SD	n
1.	Does your (their) family believe that you (they) can meaningfully contribute by working at home?	Proxy	1.97	1.03	40
		Individual	2.45	0.98	152
2.	Does your (their) family believe that you (they) can meaningfully contribute by working in the community (in office, business, etc.)?	Proxy	1.78	0.86	40
		Individual	2.19	0.96	152
3.	Does your (their) family believe that you (they) can meaningfully contribute to nation building?	Proxy	1.57	0.68	40
		Individual	2.14	0.84	152
4.	Does your (their) family encourage you (them) to contribute to home activities?	Proxy	2.23	1.03	40
		Individual	2.59	0.91	152
5.	Does your (their) family encourage you (them) to work in the community (in office, business, etc.)?	Proxy	1.63	0.81	40
		Individual	2.09	1.01	152
6.	Has your (their) family supported the employment goals you (they) have for yourself (themselves)?	Proxy	1.83	1.08	40
		Individual	2.45	1.09	152
7.	Has your (their) family supported you (them) in working outside of the home (e.g., getting ready for work, providing transportation, etc.)?	Proxy	1.97	1.12	40
		Individual	2.38	1.09	152

Chi-Square tests were performed to inspect gender and role (individual or proxy) on another question from the survey: *Does your (their) family encourage you (them)*

to spend time in the community doing activities you enjoy/find meaningful? The Chi-Square tests revealed that there were no statistically significant relationships ( $p > .05$ ) both in terms of gender and whether the survey respondent was a proxy or the individual youth with a disability (see Table 6).

**Table 6. Chi-Square tests for family encouragement for meaningful community participation**

Categorical variable	Item	n	Value	df	Asymptotic Significance (2-sided)
Gender	Does your (their) family encourage you (them) to spend time in the community doing activities you enjoy/find meaningful?	206	2.808 <sup>a</sup>	1	.094
Role		206	.758 <sup>a</sup>	1	.384

### Correlation Between Family Attitudes Towards Belief, Support Systems, and Encouragement of Employment for Persons with Disabilities

Using multivariate analysis, there are significant relationships between belief, support systems, and encouragement of employment for persons with disabilities. See Table 7 below. This finding suggests that the perception of youth with disabilities about their family attitudes and beliefs towards their youth with a disability go hand-in-hand with their perceptions of active support and active encouragement for community participation and employment.

**Table 7. Correlation between family belief, support, and encouragement**

		Belief	Support	Encourage
<b>Belief</b>	Pearson Correlation	1	.607**	.812**
	Sig. (2-tailed)		.000	.000
	N	210	209	209
<b>Support</b>	Pearson Correlation	.607**	1	.644**
	Sig. (2-tailed)	.000		.000
	N	209	209	209
<b>Encourage</b>	Pearson Correlation	.812**	.644**	1
	Sig. (2-tailed)	.000	.000	
	N	209	209	210

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

### Community Activities Encouraged by Family

Youth with disabilities in Bhutan are most encouraged to engage in religious

activities, and secondly encouraged to make and meet friends in the community, as seen in Table 8. This is not surprising to us given the socio-cultural context of Bhutan, which we will discuss in the next section of this article.

**Table 8. What kind of activities does your (their) family encourage you (them) to do in the community?**

Sl. No.	Activity	Proxy (n=43)	Individual (n=173)	Male (n=127)	Female (n=87)
1	Meeting friends	11 (25.6%)	76 (43.9%)	50 (39.4%)	36 (41.4%)
2	Religious	21 (48.8%)	82 (47.4%)	55 (43.3%)	47 (54.0%)
3	Shopping	6 (14.0%)	32 (18.5%)	20 (15.7%)	18 (20.7%)
4	Sports	4 (9.3%)	35 (20.2%)	29 (22.8%)	10 (11.5%)
5	Others	6 (14.0%)	24 (13.9%)	20 (15.7%)	10 (11.5%)

## DISCUSSION AND CONCLUSION

To summarize the findings above, the perception of youth with disabilities towards family attitudes, support, and encouragement is that they are somewhat supported and encouraged to contribute to the family livelihood within the home, but less so out in the community. There is a difference between the attitudes of youth with disabilities (more positive) and the proxy responses to the survey (more negative) in terms of support and encouragement. Such negative family attitude can be risky as it limits the ability of persons with disabilities to fulfil and achieve their life goals (Antonak & Livneh, 2000; Morris, 2000). There was no difference in gender. Beliefs, attitudes, support, and encouragement are strongly correlated together, and the most common community activities that are encouraged for youth with disabilities are religious activities and meeting friends.

The finding from this study on keeping youth with disabilities at home, versus employment and other forms of economic engagement in the community, is supported by the literature. Previous research shows that parents of children with disabilities in Bhutan tended to want to keep their children at home and away from school and work responsibilities. This practice was primarily as a form of protection from bullying and being overburdened with tasks that the parents believed that their children could not perform. In other words, it had more to



do with low expectations than it did with socio-cultural stigma (Schuelka, 2015; 2018). In other cases, youth with disabilities themselves felt that they could best support their families by being as small of a 'burden' as possible (Johnstone, et al., 2023). Parents of children with disabilities in Bhutan do generally support inclusive schooling and the development of skills (Karma Jigyel, et al., 2020), but are worried about their child's experience and sense of belonging while they are in school as well as sceptical about the utility of their child's school experience.

It is worth noting that the proxy responses to our survey were often performed because the youth with a disability had more significant difficulties with communicating through speech and language. This will no doubt skew this finding in that these family members taking the survey for their child would perhaps have less expectations for this youth because of more significant challenges. Those youths with disabilities that took the survey themselves had at least the basic skills necessary to communicate through speech and language.

In this regard, parental self-efficacy (PSE) as seen from this research can be ascertained through the perception of youth with disabilities about their family attitudes, support, and encouragement. This can primarily be understood through the findings located on Table 3 above, which show that there is some belief in youth with disabilities to contribute and engage meaningfully, but much less so when these contributions and engagement move beyond the home itself. As suggested by other literature on PSE, particularly when it comes to having a child with a disability (Ellis, 2019), we argue that what the findings from this research suggest that parents of children with disabilities continue to need further support and resources to help them understand what opportunities for meaningful engagement and employment look like and how they can have the confidence and skills to help their child reach those higher expectations.

The lack of statistically significant differences between genders in terms of attitudes and perceptions is also supported by literature. In general, Bhutan has gender parity and equality across most sectors, which is in stark contrast to its immediate neighbours in South Asia (ADB, 2014). While Bhutan has a strong tradition of matrilinearity and strong policies that promote gender equality of access, there does still remain issues of subtler gender discrimination and inequalities when it comes to socio-economic outcomes (Roder, 2012; Tashi Dema, 2017). In the case of youth with disabilities in Bhutan, we believe that low expectations and attitudes extend to both genders equally.

The meaningful activities that are encouraged and available to youth with disabilities in Bhutan is appropriate to the socio-cultural context. Bhutan is a very rural and agrarian country, with the majority of the population engaging in subsistence agriculture. In the comprehensive survey data, there was a significant correlation between meaningful economic and social opportunities and whether the respondent lived in an urban area (more opportunities) or a rural area (less opportunities) (Schuelka, et al., 2022). The majority of respondents in both urban and rural areas also indicated that there were very few activities in the community in general that matched their interests. Traditionally, village life in Bhutan centred around farming activities and religious activities such as *tshechu* [religious festivals]. There would also be some opportunity to play sports and games such as archery and *kuru* [dart throwing]. Buddhism and culture are so intertwined in Bhutan that religious activities are the majority of community activities available.

The findings from this research demonstrate that youth with disabilities in Bhutan desire their families to be supportive and encouraging when it comes to creating opportunities for meaningful community engagement and employment. Parental self-efficacy is about creating confidence, setting high expectations, and seeing those goals through to a positive outcome. In this regard, this research shows that parents of children with disabilities in Bhutan need further support and resources in order to increase their self-efficacy. As shown by earlier research in the international contexts, short training programs focused on parental behavioural change would be crucial to raise the self-efficacy of Bhutanese parents (Benedetto & Ingrassia, 2018; García-López, et al., 2016). Parents need to see and understand what is possible for their children with disabilities beyond the home and be given the skills and tools that can support them. While this study was specific to Bhutan, we believe that the findings can speak to other countries and contexts that are remote and agrarian in nature. We do not mean to suggest that meaningful activities and engagement can take place only outside of the home, as that would be culturally insensitive to suggest for the Bhutanese context. Rather, what we argue is that youth with disabilities should be supported and encouraged by parents with high expectations that their youth can participate both at home and in the larger community, regardless of what functional challenges inform their lived experience.

## ACKNOWLEDGEMENT

We are very appreciative of Renáta Tichá and Brian Abery from the University of Minnesota's Institute on Community Integration for their support on the survey and data analysis. We also acknowledge our Royal Thimphu College fieldwork team of Ura Sonam Tshewang (Coordinator), Vanlallawmkimi, Dip Raj Pradhan, Dago Palden, Jamyang Pelmo, and Tshering Wangchuk. Thanks also to our other project co-investigators Christopher Johnstone, Paul Lynch, Sarah Benson, and Luca Mannocchi.

This research was funded by a Global Challenges Research Grant from UK FCDO, administered by the Economic and Social Research Council (ESRC ES/S004319/1).

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# Linkage between International Classification of Functioning, Disability and Health Qualifiers and Functional Levels of the Functional Independence Measure: a Proposal for Applicability in Clinical Practice

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## ABSTRACT

**Purpose:** *This study aimed to propose a link between Functional Independence Measure (FIM) levels and International Classification of Functioning, Disability and Health (ICF) qualifiers for use in low- or middle-income countries such as Brazil.*

**Method:** *A multidisciplinary committee was formed to discuss the need for standardisation of the classification so that different professionals could accurately record the functioning and for the standardisation to be meaningful for the individual and his /her support group, allowing observation and participation in the rehabilitation process. The proposed steps to adapt linking ICF qualifiers with FIM scores and functional levels were: 1. Inversion, 2. Parity, 3. Transposition, and 4. Adaptation.*

**Results:** *FIM's seven levels of functioning have been linked to the five ICF qualifiers. FIM levels "7 (independent)" and "6 (modified independence)" have been linked to qualifiers*

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*“0 (no problem)” and “1 (mild problem)”, respectively. FIM levels “4” and “5” have been grouped and linked to ICF qualifier “2 (moderate)”. FIM levels “3” and “2” have been related to qualifier “3 (severe)”. FIM level “1” which indicates complete dependence has been linked to qualifier “4 (complete)”.*

**Conclusion:** *This methodology allows for the creation of a link between the FIM and ICF, preserving clinically important information and having a description and clear relationship. It is thus able to facilitate clinical use of the ICF.*

**Key words:** *International Classification of Functioning, Disability and Health, Patient-reported outcome measures, Functional Independence Measure.*

## INTRODUCTION

Functional status information is used in the rehabilitation of people with disabilities and in care facilities for older adults as a way to measure the outcomes of interventions and to organise care. It is also needed in order to understand the population’s health (Üstün et al, 2003; Giacomini et al, 2008). The health system’s routine and consistent collection of this information and making it available in administrative records permits management of the quality of care and the development of health research and public policies (World Health Organisation, 2001; Iezzoni & Greenberg, 2003; Üstün et al, 2003). To this end, the World Health Organisation (WHO) created the International Classification of Functioning, Disability and Health (ICF), which incorporates the biopsychosocial model of health to create indicators of functioning and health.

The ICF was developed to provide a standardised language that promotes consistency and facilitates communication among professionals and countries (Cieza et al, 2002; Üstün et al, 2003; Jette, 2009; World Health Organisation, 2001, 2020). The ICF utilises alphanumeric codes, allowing for the statistical analysis of data and the organisation of health components, thus supporting clinical and epidemiological studies. Moreover, it promotes the sharing of information in professional practice and research, and provides the necessary indicators for evidence-based policy making.

Routine collection of data with consistent quantification is crucial for capturing the levels of difficulty and support needed by individuals entering the healthcare system (World Health Organisation, 2001; Üstün et al, 2003). Functioning encompasses not only body functions but also physical and social environmental factors that impact overall well-being (World Health Organisation, 2001; Üstün

et al, 2003). Therefore, analysing the influence of personal and environmental factors on functioning is essential, even in countries with lower socioeconomic conditions. Studies have highlighted disparities in the prevalence of physical disabilities among vulnerable groups, including older adults, individuals with chronic diseases, and those with other disabilities (Barreto et al, 2022). These populations also experience negative effects on their quality of life and level of social participation (Giacomin et al, 2008; Neves-Silva & Álvarez-Martín, 2014; Cruz et al, 2019; Silva et al, 2021). Hence, examining the impact of personal and environmental factors on functioning is vital for comprehensive healthcare planning and addressing health inequalities.

Due to the lack of resources and infrastructure, low- and middle-income countries (LMICs) often have worse accessibility conditions in both private and public environments. This can make it difficult for individuals to acquire the necessary resources to face these barriers, which ultimately impacts their health and degree of activity and participation, leading to increased disability and impairment (Neves-Silva & Álvarez-Martín, 2014). Although Brazilian legislation is advanced, the lack of details about functional status information (FSI) makes it difficult to analyse and develop policies for people with different degrees of dependence (Giacomin et al, 2008; Barreto et al, 2022).

Among the strategies used to initiate the process of health data and information collection using the ICF is the possibility of linking the instruments now used in clinical practice with the ICF's codes and categories. This systematic process of linking was developed by Cieza et al and is based on specific, updated rules for linking the ICF and measuring instruments (Cieza et al, 2002, 2005, 2019). This process is necessary to convert data from different measurement instruments into universal language, allowing the information to be utilised by individuals who are unfamiliar with the specific instrument. This process not only facilitates the comparison of functioning measured with different instruments but also enables the comparison of information in various research, clinical, epidemiological, and social contexts. Such comparisons are essential for developing more targeted and effective public policies (Üstün et al, 2003; Cieza et al, 2005). One of the instruments most linked to the ICF and widely used in rehabilitation centres is the Functional Independence Measure (FIM) (Cohen & Marino, 2000; Silva et al, 2020). This scale was developed by the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation (Cohen & Marino, 2000).

In order to incorporate the FIM into the biopsychosocial model effectively, it is necessary to establish a connection to the ICF model. This connection will facilitate the identification of concepts measured by the FIM that are associated with the categories of the ICF, including body functions, activities, participation, and environmental factors (Ovando et al, 2016; Ballert et al, 2019; Silva et al, 2020; Silva et al, 2021).

However, existing literature only highlights the content-based linkage between the FIM and ICF, without establishing a clear relationship between the scoring levels of the FIM and the qualifiers of the ICF (Silva et al, 2020). Following assessment, these categories are assigned severity grades using ICF qualifiers, which range from “0” to “4”. Here, “0” represents no problem, and “4” indicates a complete problem. Nevertheless, consensus has not been reached regarding the appropriate coding for linking the ICF qualifiers with the FIM score.

Only in the study conducted by Fréz et al (2013) is there a proposed linkage between the FIM and the ICF through the identification of the relationship between qualifiers and categories. However, the authors did not provide a detailed description of the criteria adopted for the grouping of FIM scores and only reported the inversion of values. This limitation in the study disregards significant clinical aspects, thereby reducing its practical relevance. Furthermore, the authors did not consider information regarding the impact of environmental factors on functioning, which holds crucial importance for clinical professionals and the formulation of public policies pertaining to accessibility, inclusion, and equity, particularly in low- and middle-income countries. Furthermore, the FIM is a reliable and valid rehabilitation tool that requires administration by trained professionals to ensure accurate results. Additionally, expertise is necessary when using the ICF to qualify categories, and the qualification process involves evaluating functioning using existing clinical practice tests and instruments. The results of these measures will determine the qualification.

Both the FIM and the ICF can be used based on an individual’s perception, following the same measuring criterion. Therefore, the linking of the ICF with the FIM facilitates precise information dissemination and improves the identification of environmental factors. This integration allows for the integration of data from diverse sources, leading to a comprehensive understanding of an individual’s functioning. Examples include identifying architectural barriers in domestic environments, such as a lack of accessibility, and identifying environmental factors that influence participation in community activities, such as inaccessible

transportation. This information can guide interventions and environmental modifications to enhance functioning and improve individuals' quality of life.

## **Objective**

The universal applicability and simplicity of the ICF make it particularly valuable, especially in low- and middle-income countries, where standardised and comprehensive frameworks are crucial for effective healthcare delivery and research. Hence, the objective of this proposed linkage is to establish a correlation between FIM levels and ICF qualifiers, specifically designed for implementation in contexts, such as in Brazil.

## **METHOD**

### **Instruments**

#### **Functional Independence Measure (FIM)**

The Functional Independence Measure (FIM) is a widely used and extensively studied tool in rehabilitation, known for its validity, relevance, sensitivity, and reliability, which justify its use in clinical practice. Although it has been validated in Brazil in a self-reported questionnaire format (Riberto et al, 2004), it is important to ensure that it is administered correctly by qualified professionals to ensure accurate and consistent results (Cohen and Marino, 2000).

The FIM is a quantitative measurement scale used to assess functional limitations. It evaluates 18 tasks encompassing the subcategories of self-care, sphincter control, transfer, locomotion, communication, and social cognition. Each item assessed in the FIM receives a score ranging from "1" to "7", with "1" indicating total dependence and "7" indicating complete independence. The following scores are possible for each item of the FIM:

- 7 - Total independence,
- 6 - Modified independence,
- 5 - Dependence with supervision,
- 4 - Dependence with minimal assistance (client performs 75% of the task independently),
- 3 - Dependence with moderate assistance (client performs 74-50% of the task),

2 - Dependence with maximal assistance (client performs less than 49% of the task but contributes at least 25% of the effort),

1 - Complete dependence (client performs less than 24% of the task).

The total score of the FIM ranges from 18 to 126 points, with higher scores indicating greater independence (Riberto et al, 2004).

### **International Classification of Functioning, Disability and Health (ICF)**

The ICF taxonomy is divided into two main parts, each consisting of two components: Functioning and Disability, which includes body functions (b), body structures (s), and activities and participation (d); and Contextual Factors, which encompasses environmental factors (e) and personal factors (not classified by the ICF). Each letter is followed by a numeric code that starts with the chapter number (one digit), followed by the second level (two digits), and the third and fourth levels (one digit each). The example below was presented by Pereira et al (2022) and can help to better understand this taxonomy.

d4	Mobility	(first level code)
d450	Walking	(second level code)
d4501	Walking long distances	(third level code)

Subsequently, each ICF category should be accompanied by a qualifier, which is used to grade the client's level of functioning in each ICF category, indicating the client's overall level of impairment, the level of assistance required, and the extent of participation restrictions.

The qualifier is a numerical scale ranging from "0" to "4", with higher scores indicating more severe impairments or restrictions. The five levels of the ICF qualifier are as follows:

Qualifier .0: No problem, limitation, or restriction (0 to 4% problem)

Qualifier .1: Mild problem, limitation, or restriction (5 to 24% problem)

Qualifier .2: Moderate problem, limitation, or restriction (25 to 49% problem)

Qualifier .3: Severe problem, limitation, or restriction (50 to 95% problem)

Qualifier .4: Complete problem, limitation, or restriction (96 to 100% problem)

The ICF qualifier provides a standardised way to evaluate a client's disability and provides a common language for healthcare professionals to communicate

the client's level of impairment or restriction. It helps healthcare providers to assess the effectiveness of interventions, monitor changes in the client's condition over time, and communicate the client's level of functioning to other healthcare providers.

Overall, the ICF qualifier is an essential tool for evaluating the functioning status of clients and developing effective interventions to improve their quality of life.

### **Linking Procedures and Rules**

The linkage between the concepts measured by FIM and the ICF is well-discussed in the literature, and there is a consensus on this relationship published in a systematic review (Silva et al, 2020). However, this study aimed to relate the scoring options of FIM with the qualifiers of ICF, following a clear, consistent, and standardised methodology (Cieza et al, 2002, 2005, 2019). The aforementioned rules underwent a refinement process (Cieza et al, 2019), in response to the need for updating them to enable more consistent information in relation to the linking process between ICF categories and the concepts measured by outcome measures. Among the ten rules originally proposed by Cieza et al (2016), only five were applied to link the qualifiers to the scoring of the FIM (Chart 1).

### **Chart 1: The Application of Five out of Ten Linkage Rules to Establish Connection with the International Classification of Functioning, Disability, and Health (ICF)**

- 1 Acquire good knowledge of ICF's conceptual and taxonomic concepts, as well as its chapters, domains, and categories of classification, including definitions, before beginning to link significant concepts to ICF categories;
- 2 Identify the purpose of the information to be linked and the most relevant concept(s) to be linked to the ICF;
- 3 Identify any additional concept contained in the information, beyond the principal concept(s) identified in the previous step;
- 4 Identify and document the perspective adopted in given information upon linking it to the ICF;
- 5 The description undertaken for each level allows for adequate classification of the answer.

(Adapted from Cieza et al, 2019)



## Committee of Experts

A committee of experts consisted of a work group comprised of three physiotherapists, one speech therapist, one psychologist, and one occupational therapist, all with ample experience in assisting adults and seniors with physical disabilities. The committee analysed and discussed levels of functioning to establish a relationship between the scales and the qualifiers the ICF.

This expert committee discussed the need for standardisation of the classification (ICF) to ensure that different professionals can accurately and consistently record functioning. There was a concern that the classification should be easily understood by the individuals being classified, allowing for their observation and participation in the rehabilitation process. Due the discrepancy between the levels of functioning in the ICF and the scoring of the FIM, it was important to consider the need to group similar conditions within the FIM levels. To address this, it was necessary to highlight the assistance required for task completion, the time involved during activities, and the necessary adaptations in order to discern the degree of an individual's independence. This involves evaluating the level of support needed and organising the environment and support network. Although the ICF allows for classifications considering functioning with and without assistance, in the Brazilian context the FIM is primarily applied through interviews where information about the required assistance is gathered based on individuals' perceptions, as described in the FIM application manual (Riberto et al, 2004).

To organise the proposed linkage between the qualifiers of the ICF and the functional levels of the FIM, the expert committee conducted virtual meetings to discuss the classification of activities assessed in the FIM. These activities had been previously evaluated by the multidisciplinary team at different points in time and by different professionals considering important aspects of functioning. Subsequently, the expert committee proposed organisational phases to standardise the linkage process:

1. **INVERSION:** Inversion of the numeric order of classification, since the FIM measures the degree of independence and considers its highest number "7" to indicate greater independence and "1" for totally dependent, while the ICF has a negative scale which measures the magnitude of the problem/difficulty, considering the minimum value "0" as being totally functional/having no difficulties and "4" non-functional/with great difficulty.



2. **PARITY:** Due to the discrepancy between the scoring options of the FIM and the qualifiers of the ICF, it was necessary to adapt the scoring options during the linkage process. To do so, some FIM levels were grouped to match the number of options in the ICF qualifiers. Thus, the FIM score “3” was linked to ICF qualifier “3”, as it indicates the need for assistance from another person to complete the activity, which suggests a severe difficulty and an important reference for assistance. FIM levels “4” and “5” were then grouped together as they indicate a mild to moderate problem, meaning that the person needs assistance from another person for specific interventions, environment preparation, or less intense monitoring.
3. **TRANSPOSITION:** Adaptation of the generic and numeric scale of the ICF qualifiers for the qualitative description of the FIM score, distinguishing a person’s difficulty and need for external help to carry out the activity. However, the quantification of the FIM refers only to the caregiver’s assistance and does not consider the percentage of help provided by environmental factors. Consequently, the first and last ICF qualifiers have little percentage variation, making it impossible to group more than one FIM functional level for each qualifier.
4. **ADAPTATION:** Adaptation of the description to contemplate the different categories following the same concepts.

### **Application of the Linking**

After the above cited stages of inversion, parity, transposition and adaptation, the committee of experts met to discuss relevant categories of all chapters of the activity and participation component. All discussions were conducted by an interdisciplinary team based on clinical cases found in a physical rehabilitation centre to confirm the presence of consensus and applicability of the link established.

## **RESULTS**

Table 1 provides a summary of the consensus reached by the expert committee regarding the conversion of FIM scores into ICF qualifiers, encompassing the inversion, parity and transposition phases. The committee agreed to maintain three distinct levels of functioning, corresponding to scores “7”, “6”, and “1” on the FIM, as they are highly specific and crucial for differentiation. The level

indicating the need for total assistance was kept separate to represent a severe and specific condition, reflecting a high degree of dependence. This level, FIM level “1”, is associated with the ICF qualifier “4 (complete problem)”.

Furthermore, the FIM levels of functioning “7 (complete independence)” and “6 (modified independence)” are linked to the qualifiers “0 (no problem)” and “1 (mild problem)” respectively. These qualifiers distinguish the need for additional time to perform an activity, the presence of resources in the physical environment, and the presence of risk.

**Table 1: Suggested Relationship between ICF Qualifiers and FIM Functional Levels**

Qualifier	ICF			FIM	
	Quantitative descriptor	Qualitative descriptor	Level	Quantitative descriptor	Qualitative descriptor
0	0-4%	No problem	7	-	Complete independence
1	5-24%	Mild problem	6	-	Modified independence
2	25-49%	Moderate problem	5 - 4	+75%	Modified dependence
3	50-95%	Severe Problem	3 - 2	74-50%	Modified dependence and Complete dependence
4	100%	Complete Problem	1	25%	Total dependence

ICF: International Classification of Functioning, Disability and Health; FIM: Functional Independence Measure

The Adaptation phase encompassed proposing a qualitative description for each item of the ICF to facilitate the identification of individuals’ needs and functioning. The multidisciplinary team conducted a comprehensive review of the instrument to ensure clarity and to identify clinically significant differences in interpretation. This process involved observing and discussing each item until a consensus was reached among the professionals, resulting in an appropriate qualitative description for all domains.

The entire process consisted of six meetings, each lasting at least 180 minutes. The concept of assistance provided was given paramount consideration during these discussions. The outcome of this process is presented in Table 2.

**Table 2: Description of Levels of Functioning proposed after linking ICF Qualifiers with FIM Functional Levels**

<b>LEVELS OF FUNCTIONING</b>
<p><b>FIM Level 7 (Complete Independence) - ICF Qualifier: 0 (No Problem)</b></p> <p>When activity is done safely, autonomously, and independently, under any condition or in any situation, in a reasonable amount of time, with no modifications or need for interference in environmental factors.</p>
<p><b>FIM Level 6 (Modified Independence) - ICF Qualifier: 1 (Mild Problem)</b></p> <p>When done independently, less safely, taking longer than reasonable or with some modification, with the presence of some environmental factor, which may be an assistive device or the need for occasional repetition.</p>
<p><b>FIM Level 5 (Moderate Assistance) - ICF Qualifier: 2 (Moderate Problem)</b></p> <p><b>FIM Level 4 (Moderate Assistance) - ICF Qualifier: 2 (Moderate Problem)</b></p> <p>When mediation from a third party is needed, possibly for supervision, offering a verbal command or guidance simply to motivate/suggest, and/or preparing the environment and/or helping in the setup. The participation of a third party can be done by people with little training and intermittently.</p>
<p><b>FIM Level 3 (Moderate Assistance) - ICF Qualifier: 3 (Severe Problem)</b></p> <p><b>FIM Level 2 (Maximal Assistance) - ICF Qualifier: 3 (Severe Problem)</b></p> <p>When the intense help of others is called for, as the individual only executes part of the task and needs help to complete it, which requires a caretaker who is better trained and who can dedicate more time.</p>
<p><b>FIM Level 1 (Total Assistance) - ICF Qualifier: 4 (Complete Problem)</b></p> <p>When maximal assistance is needed to conduct the activity, with practically no participation by the individual.</p>

FIM: Functional Independence Measure; ICF: International Classification of Functioning, Disability and Health

## DISCUSSION

The expert committee consisted of a multidisciplinary team that was already integrated due to their clinical practice, facilitating alignment and discussions and enabling consensus on the linkage between the functional levels of the FIM and the qualifiers of the ICF. The committee's final proposal involved linking the seven levels of functioning in the FIM to the five ICF qualifiers. FIM levels "7" (independent) and "6" (modified independence) were linked to qualifiers "0 = no problem" and "1 = mild problem," respectively. FIM levels "4" and "5" were grouped and linked to the ICF qualifier "2 = moderate". FIM levels "3" and "2" were associated with the qualifier "3 = severe". FIM level 1, indicating complete dependence, was linked to the qualifier "4 = complete".

Most studies linking the ICF and FIM instruments only map the instrument items to ICF categories and conduct agreement tests on the evaluator's qualifier choices. In this study, similar to Frez et al (2013), magnitude linking was performed to establish correspondence between the FIM instrument score and ICF qualifiers. This process considered new health concepts that seek to value the influence of environmental factors and strategies that allow conversion to the ICF language, even when not performed in the study, facilitating the production of Functional Status Index (FSI).

The expert committee established a connection between FIM level "1 (total dependence)" and ICF qualifier "4 (complete problem)". In the context of eating, for instance, it indicates the individual's inability to receive food by mouth, necessitating tube feeding. Conversely, FIM levels of functioning "7 (complete independence)" and "6 (modified independence)" were associated with qualifiers "0 (no problem)" and "1 (mild problem)" respectively.

The committee deemed it crucial to differentiate the levels of independence in order to discern the need for environmental modifications or accessibility. For example, even though individuals at level "6 (modified independence - 1 mild problem)" are considered independent, they may require minor environmental adjustments, adaptations, assistive technology, or more time than usual to perform a task. By maintaining these distinct levels of functioning and linking them to specific qualifiers, the assessment process captures significant variations in functional abilities, encompassing the level of dependence, environmental support, and potential risks. This approach enhances the clarity and precision of evaluating individuals' functioning status, thereby facilitating appropriate interventions and support.

In contrast, Fréz et al (2013) grouped levels "7 (complete independence)" and "6 (modified independence)" and linked them to the qualifier "0 - no problem." However, this grouping underestimates the effect of environmental factors on levels of independence, ignoring the fact that clients often do not become completely independent due to environmental barriers which make them take longer or spend more energy to complete the task. For this reason, in the present study, the authors chose to differentiate levels of independence, linking them to different qualifiers to estimate the impact of the environment on functioning. They also chose to group FIM levels "3" and "2" which refer to moderate and maximum dependence respectively, and linked them to the ICF qualifier "3 – severe problem." This is because in these cases there is a need for assistance in more than 50% of the task.

Similar to the linking rules used in Fréz et al (2013), the grouping of FIM scores “5 (supervision)” and “4 (moderate assistance)” was maintained in this study but associated with a different qualifier. While Fréz et al (2013) linked these scores to the qualifier “.1 - mild problem,” the current authors chose to link them to the qualifier “.2 - moderate problem.” This is because both levels “5” and “4” indicate the need for slight support and supervision with minimal effort required from the caregiver. Therefore, following the criteria adopted in this study, this could not be classified as a mild problem.

Differentiating between various levels of functioning enables one to identify whether an individual maintains independence in other probable environmental situations of regular life, as described by Okawa et al (2008). The instrument also allows one to determine the need for environmental facilitators to complete tasks safely and efficiently. The need for support from another person to perform tasks was categorised into three levels of functioning: total assistance, moderate assistance requiring the presence and effort of others at the time of completion, and light or intermittent assistance. The results were similar to those of Okawa et al (2008) who aimed to operationalise the qualifiers for social security in Japan.

Low- and middle- income countries can benefit from this methodology as it provides a simple form of compiling health information and analysing the impact of environmental barriers or facilitators on functioning after a disabling health condition. This proposed linking between the FIM score and ICF qualifiers aims to facilitate the coding of clinical information for the FSI through direct conversion, enabling analysis of environmental contexts for decision-making in therapeutic planning. The publication of these data can be important for the development of public policies for individuals with disabilities.

The strategy used to link the ICF with the FIM proved effective in preserving clinically relevant information and establishing clear relationships between support needs and environmental factors. This approach facilitates the clinical use of the ICF, fosters interdisciplinary discussions with the multidisciplinary team, and enables productive conversations with relatives (Rauch et al, 2006). Additionally, this strategy supports the production of health indicators that highlight important information about support needs, particularly regarding caregivers who assist with functioning, as identified by Okawa et al (2008).

Although the benefits of the proposed linkage between the ICF and the FIM are evident and it has been validated by a committee of experts, it is important to note

that this proposal has not yet been analysed in psychometric terms. The conversion to the ICF reduces the number of responses and alters some characteristics of the instrument which needs to be further studied to understand possible differences in the information produced by the instrument with and without linkage and to discuss the impact on clinical information.

Another limitation of the study is related to the fact that in the Brazilian context the FIM is predominantly administered through interviews, where information regarding the required assistance is collected based on individuals' perceptions, as described in the FIM application manual (Riberto et al, 2004). This approach gathers data on performance. To evaluate capacity and establish contrasts between the constructs of capacity and performance, as recommended by the ICF, it would be necessary to include an analysis of task execution in a standardised environment. Therefore, the proposed linkage in this study provides relevant data for performance evaluation by linking the ICF qualifiers to the functional levels of the FIM; however, they are not suitable for assessing capacity.

It is important to emphasise that the process of establishing the linkage is complex. In this study, the relationship between the FIM functional levels and the ICF qualifiers were explicitly identified, following the rules proposed by Cieza et al (2019). Out of the ten rules, only five were utilised as they were originally proposed to link the concepts of the instruments to the categories of the ICF, rather than specifically linking to the qualifiers. Therefore, the five rules (as shown in Chart 1) were employed that could be replicated to standardise the linkage process and make it clear and reproducible.

In conclusion, the use of ICF has changed the way of thinking, measuring, projecting, collecting, and analysing data about functionality and disability (Madden & Bundy, 2019). This is why the WHO has encouraged collecting information relevant to rehabilitation by using ICF; however, the WHO recognises that there is still a long way to go for this to be implemented worldwide (World Health Organisation, 2020). Therefore, studies like this one, which propose a way to use the precepts of the ICF in an easy and inexpensive way and that can be used in low- and middle- income countries, may represent great relevance, mainly, for proposing an equitable use of the ICF. Future studies and practical application by work groups are still needed to verify the benefits and acceptance by professionals and to facilitate understanding of the biopsychosocial model and the guidance of public policies.



## Acknowledgement

This study was conducted with a scholarship supported by CAPES/PROSUP – Brazilian Federal Agency for Support and Evaluation of Graduate Education of the Ministry of Education.

The authors declare no conflict of interest.

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# Higher Education of Persons with Disabilities in India: Past, Present and Future

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## ABSTRACT

**Purpose:** *The article aimed at providing glimpses of the status of higher education for persons with disabilities in India, starting with the distant past and moving on to present day developments. It describes the impact of legislations and policies on the educational support systems through the years.*

**Method:** *Desk review of relevant documents was undertaken and data was presented in the conventional narrative review style. Research questions address the status of higher education of persons with disabilities in India, the impact of Acts and policies and the support systems in place in the past and in the current educational systems. The main focus is on factors that lead to successful completion of higher education and challenges in accessing higher education by persons with disabilities in the country.*

**Results:** *In ancient India, during the Vedic period, there were no special arrangements for higher education of persons with disabilities. During the Mughal and British periods as well the education of persons with disabilities was not addressed. After Independence, although the provisions mandated by the Acts have increased the support systems in universities and colleges, higher education requires more streamlining to meet the needs of persons with disabilities. Universities that have made innovative arrangements for the education of persons with disabilities have been mentioned.*

**Conclusion:** *India has made giant strides in facilitating higher education for all, yet there are gaps in the educational system. The article puts forward some recommendations for achieving equitable higher education for persons with disabilities.*

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*Key words: models in higher education, Acts and policies on education, Indian education, educational administration, university education, students with disabilities*

## INTRODUCTION

The Indian educational system has a rich heritage that dates back to the Vedic period - 1500 to 500 BCE (New World Encyclopaedia, 2020) – a time when students lived with their teachers for a number of years and received education. During the Mughal regime education was propagated in *Madradas*, while the British regime introduced their higher education system to India in the 19<sup>th</sup> century (Krishnamoorthy, 2019). Since then, a considerable number of reforms have been made in the education system, with accreditation and regulatory bodies in place to ensure quality in higher education.

Special schools for persons with disabilities were established in the early 1900s, either by missionaries or by parents whose children were rejected from regular schools because of their disabilities. Those who managed to complete high school attended higher education institutions without having any special provisions made for them. In recent years the status of higher education for persons with disabilities has improved with the enactment of specific legislations that have empowered them with rights, equal opportunities and entitlements. The Right to Education Act (2009) has made education a fundamental right, thus ensuring that all persons, including those with disabilities, have access to appropriate education at all stages in life. The recent National Education Policy (NEP, 2020) has strengthened higher education for everyone, including persons with disabilities.

### Objective

India has come a long way in terms of providing access to education for persons with disabilities. The present article aims to analyse the status of higher education for persons with disabilities in the past as well as in the current system with its strengths and challenges, and tries to assess what further needs to be done for ensuring equity and quality in higher education for persons with disabilities.

The specific research questions include:

1. What was the status of higher education for persons with disabilities in India in the past?

2. What is the current status of higher education for persons with disabilities in India?
3. What are the merits and challenges in the system of higher education?
4. What can be the way forward?

## **METHOD**

### **Study Design**

Desk review of relevant documents and literature was performed.

### **Data Collection**

Data was gathered predominantly through focussing on the following content areas:

- Documents on constitutional obligations, Acts and policies, government schemes, and university regulation systems.
- Research, review articles and published information on higher education in India.
- Websites of specific higher education institutions that showcase specific arrangements made to facilitate education for persons with disabilities.

### **Data Analysis**

The collected data was classified into past and current day content, and analysed to answer the research questions. The findings are presented as a conventional narrative review.

## **RESULTS and DISCUSSION**

Initially the status of education in the past and in present day India is narrated in order to provide a background to the Indian educational system. Subsequently, the merits and challenges with regard to accessing education by persons with disabilities are discussed.

### **Higher Education for Persons with Disabilities in the Past**

In ancient India, all students received education by staying with their teacher for a specific number of years. Such a system was called '*Gurukula*' (*Guru* in Sanskrit



language refers to teacher, *kula* refers to abode). The Guru was highly respected and was responsible for assessing the aptitude and abilities of his students and teaching them suitably, evaluating them for their proficiency and declaring them to have mastered the respective discipline (Pareek, 2021). In popular Indian epics such as the Ramayana and Mahabharata, the teachers were highly revered and respected by everyone, including by emperors. *Gurukula* was also regarded as an institution of higher education (Chandi, 2021).

The University of Takshashila (currently in Pakistan) was established near the banks of the Indus River in 700 BCE during the Buddhist period, and is on record as the world's first higher education institute (Sanskrit Magazine, 2022). In addition to Takshashila / Taxila, India had world-class higher education institutes such as Nalanda and Vikramshila that set the highest standards of multidisciplinary teaching and research, and were reputed as they hosted scholars across different countries (Krishnamoorthy, 2019). The country was home to great scholars such as Charaka the physician, Sushruta the surgeon, Aryabhata the mathematician/astronomer, and Chanakya the statesman and philosopher, to name a few. These scholars made seminal contributions to the world knowledge in diverse fields such as mathematics, astronomy, Ayurveda (the medical science), yoga, architecture, fine arts, shipbuilding and navigation (Gopal, 1990a).

The literature sources from tenth century A.D. onwards give reasonable knowledge on the policies of education, the prominent sources being the Rigveda, the Aranyaka, the Upanishads, the Epics and the Puranas (Scharfe, 2002). It is documented that in the post- Vedic period, the teachers would instruct their students in metaphysics and its branches, and also on special secular subjects such as astronomy, mathematics and literature (Basham, 2004). With Buddhism and Jainism gaining popularity, education was imparted in the monasteries rather than in the teachers' homes. In the middle ages, these monasteries developed into true universities, the most popular one being Nalanda.

Education of persons with disabilities in the early years was not a formal system; however a few of them were geniuses. Ashtavakra, whose name literally means eight deformities (*ashta* -eight, *vakra* – deformities) that were congenital, was considered a born genius who studied in the ancient Mithila University (called Uddalaka Aruni Ashram) and was the wise advisor to king Janaka (Dalal, 2002). He has authored the book 'Ashtavakra Gita' (Gopal, 1990b). In *Gurukulas*, the teachers had a way of classifying students on the basis of their abilities and potential, and would teach them at the level of their understanding. In some cases,

special methods of teaching existed for the 'dullards' (Mookerji, 1951). Those who learnt did so by their own efforts or with some Gurus taking an interest in them. Chandragupta Maurya was the first emperor in the archaeologically recorded history to rule the entire Indian Subcontinent during 322 to 298 BCE. He had strategies to train persons with disabilities to receive on-the-job training, and established vocational training workshops for them so that they could earn their livelihood (Shekar, 2021).

Such episodic content is recorded in the literature as evidence of support to the education of person with disabilities. Not much authentic evidence is found in the literature on educational policies, if any, for persons with disabilities in ancient India. During the Mughal period, through the *Madrasas* and *Maktabas*, the Islamic tradition of education was introduced. Later, during the British regime, the higher education system underwent significant change with the introduction of British systems and no special provisions were made for higher education of persons with disabilities. Whoever managed to get educated in the mainstream systems of higher education, in spite of their disabilities, completed their education facing considerable challenges. The monograph by Miles (1997) is a detailed document on the history of care and education for persons with disabilities in the 19<sup>th</sup> and early 20<sup>th</sup> centuries in India. The document discusses informal and formal education in the early years, with anecdotal records. In ancient India, the attitude towards disability was more one of charity and compassion. Education was focussed on preparing these persons for a vocation or job skill, to earn a living to the extent possible.

### **Present Day Higher Education System**

This subsection has been classified into two parts:

1. Focussing on the Government policies and legislations, and
2. Provisions made by various universities.

### **Government Policies and Legislations**

The Constitution of India was framed in 1950, and refers to 'Education for all' (Article 45) and Right to Education, Work and Public Assistance for persons with disabilities (Article 41). However, a specific plan of action with focus on persons with disabilities emerged only in the 1990s with relevant legislations. The recent National Education Policy (NEP, 2020) has taken higher education a

step further with equitable and quality education of persons with disability. The Government and universities have brought about considerable changes in the system to facilitate higher education for persons with disabilities.

### **Rights of Persons with Disabilities Act (2016)**

This replaced the earlier Act of 1995, to align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). As noted by Raub et al (2006), the UNCRPD outlines the legal duties of States to ensure full enjoyment of a wide range of economic, social, civil, and political rights specifically by individuals with disabilities, and education is one of the key commitments. UNCRPD's commitment to higher education is geared towards '...ensuring that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others...' (Art.24.5, UNCRPD). The Rights of Persons with Disabilities Act (2016) covers 21 disabilities and is in line with UNCRPD, ensuring the right to higher education and lifelong learning. The Act, 47.1 (b) emphasises disability related studies in all higher education, stating : 'induct disability as a component for all education courses for schools, colleges and University teachers, doctors, nurses, paramedical personnel, social welfare officers, rural development officers, Asha workers (health workers), *anganwadi* workers (early childhood workers), engineers, architects, other professionals and community workers. Focussing on research, Rights of Persons with Disabilities Act, 2016 (47. 2.) further states: 'All Universities shall promote teaching and research in disability studies including establishment of study centres for such studies and to take steps to include disabilities and research in higher education'.

Welfare and education of persons with disabilities have been integral aspects of planning by the Government of India. The Ministry of Education and Ministry of Social Justice and Empowerment (MSJ&E) have schemes for persons with disabilities. For instance, inclusive education is implemented by the Ministry of Education while special education is the responsibility of the Department of Disability Affairs of the MSJ&E. Though higher education is regulated by the Ministry of Education, the accessibility to academic material, barrier-free environment and such other supports are stipulated by the MSJ&E. The launching of Rashtriya Uchcharat Siksha Abhiyan (RUSA, 2013), a scheme sponsored by the Central Government, has one of its noteworthy objectives in the context of education of persons with disabilities.

## **Higher Education System in India**

A brief picture of higher education in India is provided to help in understanding how the education system reaches those with a disability.

Universities in India are classified into five types based on their management:

Central University, State University, Private University, Institutions-deemed-to-be-a-University and Institute of National Importance (Centre for Civil Societies, 2015). Colleges affiliated to a particular University award their degrees under the aegis of the respective University. The University Grants Commission (UGC) acts as the regulatory body to establish standards in higher education throughout the country. Furthermore, there are a number of professional councils such as the Medical Council of India, All India Council of Technical Education, National Council of Teacher Education, and Rehabilitation Council of India that regulate courses that are carried out by the respective Universities. All the Councils have made special provisions and reasonable accommodations for persons with disabilities, facilitating access and support for instructions and assessment procedures. The All India Council for Technical Education(AICTE) has developed guidelines for accessibility, promoting inclusive practices in higher education for persons with disabilities to be adhered to by all AICTE approved institutions of higher education (AICTE, 2022).

## **Rehabilitation Council of India**

The Rehabilitation Council of India (RCI) was established by an Act of Parliament in 1992 to regulate professional education programmes in the area of disability rehabilitation (RCI Act, 1992). All the higher education and professional courses aiming at rehabilitation, such as special education, rehabilitation psychology, speech pathology and audiology etc., are regulated by the RCI. The curriculum, infrastructural facilities, conduct of the course by the Universities and other professional institutions are regulated and monitored by the RCI throughout the country, and the qualifying professionals are certified by the Council. In addition, the RCI also carries out continuing rehabilitation education programmes to update the professionals and to renew their certification to practice rehabilitation. This effort by the Government aims to maintain professional standards in higher education related to rehabilitation, which in turn leads to competent professionals working with persons with disabilities. Most of these courses are open to persons with disabilities, with specific accommodations and adaptations made.

## **Government Schemes for Higher Education of Persons with Disabilities**

In the tenth Five Year Plan (2002 – 2007) and eleventh Five Year Plan (2008 – 2012) the focus on higher education for persons with disability led to specific plans and budget allocation in the name of 'component plan for the disabled' in various government departments, and scholarships were provided to pursue higher education (Tenth Five Year Plan, 2002). Barrier-free environment and other accessibility related issues received focus, leading to better awareness and support systems. Furthermore, the Rights of Persons with Disabilities Act (2016) 32(1) states that all government institutions of higher education and other higher education institutions receiving aid from the Government shall reserve not less than 5% seats for persons with benchmark disabilities.

A noteworthy scheme implemented during the tenth Five Year plan was the Higher Education for Persons with Special Needs (HEPSN) scheme for students with disabilities pursuing higher education (Disability Law Initiative, 2002). It focussed on:

1) The establishment of special units for students with disabilities in various universities and colleges that would facilitate admission of student with disabilities; 2) To provide them with guidance and counselling, ensure accessibility with barrier-free environment; and 3) To provide assistive devices, special equipment to augment educational services for students with disabilities (Dawn, 2016a).

A number of universities and colleges have implemented the HEPSN scheme in the country. Pondicherry University took advantage of this scheme and established a disability friendly campus; the University then won the national award for the 'best training institution for the empowerment of persons with disabilities' in the year 2011. The facilities provided include free education including boarding and lodging for students with disabilities, accessible library with state-of-the-art facilities with hardware and software, all the buildings were made barrier-free buildings, single rooms for the persons with disabilities in the dormitories with accessible bathrooms, free transport for the day scholars with seats reserved in the buses, reading and scribe services for those who need, and well- informed faculty members to help the students meet their learning needs (Bharti, 2013; Pondicherry University website).

The Teacher Preparation in Special Education (TEPSE) scheme from the University Grants Commission provides financial assistance to higher education institutions

offering special education courses. There are also schemes by the UGC that provide financial assistance to teachers who are blind and National Fellowships for persons with disabilities (UGC, 2023).

These are some schemes available to a few students with disabilities, but India is yet to develop a national plan with clear guidelines so that every person with disability who wishes to pursue higher education has smooth access to those educational institutes that practice inclusion. A noteworthy point here is that every higher education institution is given guidelines to be followed for accessibility. Some of the practices are discussed in detail later.

### **NITI Aayog**

NITI Aayog is a state-of-the-art resource centre of the Government, which is supposed to act with speed, promote research and innovation, provide strategic policy vision for the government, and deal with contingent issues. The scheme aims to set up dedicated institutes for technical education for persons with disabilities that would have direct impact on the job opportunities (NITI Aayog, 2017).

### **National Policies on Education**

Considering the needs, changing trends and developments, the National Policies on Education have been brought out in 1968, 1986 and 2020 (NPE, 1968; NPE, 1986; NEP, 2020). The National Policy on Education 1986 included for the first time an exclusive subsection on education of students with disabilities. The major focus on inclusive education and specific programmes in higher education are given significant importance in the National Education Policy 2020.

### **National Assessment and Accreditation Council (NAAC)**

NAAC is set up by the UGC to conduct periodic assessment and accreditation of higher educational institutions to ensure quality of the institution. In addition to standards for barrier-free and accessible learning environments for persons with disabilities, it also has guidelines for the promotion of greater participation of persons with disabilities.



## **Efforts of Specific Universities in promoting Higher Education for Persons with Disabilities**

With the Acts and policies in place, many universities have established special cells to address the specific needs of enrolled persons with disabilities. These cells, in addition to ensuring that the environment is barrier free, also address specific academic-related issues that the students with disabilities may face, ranging from organising books in accessible form, technological supports, examination related issues such as arranging for a scribe, and counselling support on any emotional issues, in short, being sensitive to the needs of the students. Some of the universities and institutes have made innovative efforts to accommodate persons with disabilities, a few of which are discussed here.

### **Indian Institute of Management, Bangalore (IIMB)**

In IIMB, one of the prestigious business schools in India, an office of disability services was set up in the year 2010. At the time of admission, the specific needs of the persons with disability are assessed to determine the extent of support needed, and the information is passed on to faculty and facilities providers, so that these are available to the student without having to seek them each time. To name a few support systems: students with visual disabilities receive a copy of the PowerPoint file of their classes so that they can load it on a personal computer which has JAWS installed; students with hearing disabilities have a note-taker assigned in advance, who is present in every class; students with locomotor disabilities attend classes in rooms that are accessible without having to ask for them (Krishnan, n.d).

### **Indian Institutes of Technology (IITs)**

There are several IITs in India and they enrol students with disabilities. IIT Madras (IIT M) has specific 'Support Services for Students with Disabilities' (3SD). At the time of admission, the specific needs of the students are taken into account. IIT Madras also encourages the development of innovative projects related to disability and accessibility by the students, thus promoting indigenous development of products and programmes for persons with disabilities. (Think Change India, 2019; Outlook, 2021). All IITs in India promote technological innovations towards independent living of persons with disabilities. IIT Roorkee (IIT R) has established a school 'Anushruti Academy for the Deaf' (Anushruti, 2014) that lays the foundation for higher education of students who are deaf.

## **National Institutes**

The Department of Empowerment of Persons with Disabilities has an exclusive programme on disability rehabilitation and has set up National Institutes in different parts of the country, each with a focus on a specific disability, namely, visual impairment, hearing impairment, locomotor/physical disability, intellectual disability, and multiple disability. These institutes and their regional centres aim at developing service models, innovate on aids and appliances, generate human resources in the field of the respective disability and carry out research and dissemination (Department of Empowerment of Persons with Disabilities, 2022). All these institutes are affiliated to the universities in their region for conducting higher education programmes at Bachelor, Masters, M.Phil. and Doctoral levels. These courses have a certain percentage of seats reserved for persons with disabilities so as to enable them to become professionals in the area of disability rehabilitation if they wish. The Rehabilitation Council of India regulates the courses to ensure quality in the programmes.

## **Open University**

At National and State levels there are a number of Open Universities that allow the students to enrol and study at their own pace. Indira Gandhi National Open University (IGNOU) is one such national university where a large number of persons with disability enrol to receive higher education. This university has a national centre for disability studies to cater to the educational, vocational and rehabilitation needs of persons with disabilities through a wide range of activities (IGNOU, 2022). Other Open Universities too have initiated efforts to make the university accessible to persons with disabilities. For instance, Tamil Nadu Open University has established a 'Centre for multimodal material production for differently abled' with the aim of making it a barrier-free university. Some of the efforts include production of Braille books, closed caption videos, computer assisted instructions and prosthetic and orthotic supports where needed (TNOU, 2012).

## **Skill Training**

The Ministry of Labour and Employment also plays a role in the higher education of persons with disabilities by providing opportunities for skill training. This Ministry has established Vocational Rehabilitation Centres (VRC, n.d.), currently renamed as National Career Service Centre for the differently abled (NCSC-DA)

with 24 centres spread out in different parts of the country to provide training in specific skills for persons with varied disabilities. There are jobs reserved by the government for persons with disabilities and, typically, these centres aim at preparing the enrolled persons for these jobs. In addition, the Scheme for Implementation of the Rights of Persons with Disabilities Act, (SIPDA,1995) a scheme by the Department of Empowerment of Persons with Disabilities, focusses on skills training for persons with disabilities by establishing the Skill Council for Persons with Disability. This Council's objective is to create a robust and vibrant ecosystem for quality education and skill development for persons with disability in the country and to ensure barrier-free and accessible environments.

### **Universities dedicated to the Education of Persons with Disabilities**

A few universities in India are dedicated to the education of persons with disabilities.

The Jagadguru Rambhadracharya Divyanga University (2001) was established in Chitrakoot, Uttar Pradesh, to provide higher and professional education to persons with disabilities. The core aim of the university is to facilitate socioeconomic development by providing higher education to persons with disabilities. The university offers a disability-friendly campus, classrooms and courses enriched with traditional and modern knowledge. Besides providing boarding, lodging and essential requirements to the students, it also supports suitable job placement to persons with disabilities in public and private sector enterprises.

Dr. Shakuntala Misra National Rehabilitation University (2008) is the first State-funded university committed to providing needs-based higher education to persons with disabilities in an accessible and barrier-free environment. The university reserves 50% seats for students with disabilities in all courses. It promotes skill development and has job-oriented vocational / technical courses suitable to students with different disabilities, thus aiming at their social, educational and economic rehabilitation.

### **Dedicated Schemes and Institutions for the Deaf**

The Department of Empowerment of Persons with Disabilities (DEPwD, 2015) has established the Indian Sign Language and Research Institute that conducts two programmes - DISLI (Diploma in Indian Sign Language Interpretation) and DTISL (Diploma in Teaching Indian Sign Language) - to develop professionals

competent in Sign Language. The DTISL is exclusively designed for deaf individuals to develop as teachers to teach Indian Sign Language (ISL). The Department of Empowerment of Persons with Disabilities (DEPwD, 2018) has also implemented a scheme for financial assistance for establishing colleges for deaf students in five zones of India. It provides financial supports for sustaining the existing special colleges for people who are deaf, with the objective of providing equal opportunities to students with hearing impairment for pursuing higher education.

### **Higher Education for Persons with Intellectual and Developmental Disabilities**

Higher education for persons with intellectual and developmental disabilities is a challenge. In the past, typically, the special schools established by non-governmental organisations (NGOs) expanded to have vocational training units and/or exclusive vocational training units/sheltered workshops.

One such institute of higher education for persons with intellectual disabilities in India is

Manovikas Institute of Higher Education (n.d). This NGO, established at New Delhi, offers job oriented certificate and diploma level programmes to persons with intellectual and developmental disabilities in particular. The college also focuses on life skill training leading towards independent living by persons with intellectual disabilities. One of the major achievements of this organisation is helping students with intellectual and developmental disabilities to enrol in higher education by preparing them for courses offered by the IGNOU. As these courses are offered by distance mode, the students are supported to learn and appear for the examination at their own pace. Manovikas Institute enrolls and supports these students with limited capacity for self-learning because it is an essential skill for distance education. This enables a number of students with intellectual and developmental disability to successfully complete graduation.

### **Technological Institutes supporting Education for Persons with Disabilities**

Higher technological education is available for persons with disabilities as well.

The Kalasalingam University (KLU, 1984) offers inclusive technical education courses both at Diploma and Bachelor levels, such as a Bachelor of Technology (B.Tech). Students with and without disabilities can enrol in such programmes. The Dr. Ambedkar Institute of Technology for Handicapped (1997) was established in

Kanpur with a barrier-free campus which offers undergraduate /B. Tech courses. Diploma courses with an intake of 40 students each are offered exclusively for persons with disabilities, whereas 60 % seats are reserved in the B.Tech courses.

As can be seen from the examples cited, there are efforts by the Government, universities and civil societies to promote higher education for persons with different disabilities. The Government of India, through the University Grants Commission, has specified rules and regulations to enable quality and equitable education for persons with disabilities. Efforts at offering higher education for persons with disabilities are made by various government Ministries including the Ministry of Education, the Ministry of Social Justice and Empowerment and the Ministry of Labour and Employment. In addition, universities, colleges and the private sector too reach out to enrol and educate persons with disabilities in the country. As a result, access to higher education for persons with disabilities is promoted.

### **Strengths in the Higher Education System**

Acts and policies in the past three decades have ensured inclusive equitable education promoting lifelong learning for 'All' learners. Hence the needs of persons with disabilities are mandated to be met at all levels.

India has a dedicated Ministry and departments at the State and national levels for the empowerment of persons with disabilities, with provision for grievance redressal so that their voices are heard. The education policies in India are aligned to national priorities and global trends in early intervention, foundational literacy, inclusive education and higher education. India has regulatory bodies at more than one ministerial level, i.e., the Ministry of Education (MOE) and Ministry of Social Justice and Empowerment (MSJ&E) which monitor human resource development in higher education. The Rehabilitation Council of India monitors human resource development exclusively in the area of capacity building related to rehabilitation of person with disabilities. Higher and technical education for persons with disabilities is greatly subsidised and sponsored by the Government through various schemes and policies apart from the reserved seats. Some Universities have offices specially to address the higher education needs of persons with disabilities.

Unless provisions are monitored, implementation is not ensured. In 2017, a year after the Rights of Persons with Disabilities Act was enacted, in response to a plea

regarding non-implementation of reservation of seats for persons with disabilities and the environment not being accessible in the college, the Supreme Court of India directed the higher education institutions to comply with the provisions of the Act while admitting students in courses of higher education and to ensure accessible facilities. The Court directed UGC to form a committee to monitor the implementation of the provisions for persons with disabilities (Hindustan Times, Dec 15, 2017.)

These support and legal systems have resulted in an increase in the enrolment of persons with disabilities in higher education. A survey conducted by the National Centre for Promotion of Employment for People with Disability (NCPEDP, 2005) reported 0.1% of the total number of students in universities had a disability. Dawn (2016b) reported that 8,449 students with disabilities were enrolled in higher education. In comparison to the 2005 NCPEDP figures and Dawn's data of 2016, the number of persons with disabilities enrolled in 2020-21 was 79,035 (Lakshman, 2023). Though there has been an increase in enrolment, it is not adequate considering the right to education and the support systems provided in the country.

### **Challenges Faced by the Students with Disabilities**

While Government mandates and support systems to promote higher education for persons with disabilities are in place, poor enrolment is a cause of concern. Kunnath and Mathew (2019) carried out a qualitative study in six metropolitan areas of India, involving adults with disabilities who have had higher education, and found that poor planning and implementation of disability policies, lack of disability sensitisation in society and inadequate availability of resources were major challenges for persons with disabilities in pursuing higher education.

Attitudinal barriers are a major challenge to be overcome by persons with disabilities. In the words of the authors' colleague with disability, who works as a teaching faculty,

*"Our ability is generally underestimated and we need to prove ourselves at every stage to exercise our rights".*

Unless this issue is addressed, no amount of efforts towards inclusion will have the expected positive results.

India is a nation with diverse socioeconomic, religious, linguistic and geographical variations. These differences contribute to difficulties in imparting



education uniformly to all. Though some colleges and universities are made accessible and barrier-free, roads and transportation facilities to these colleges are not particularly disability-friendly, preventing many from accessing higher education. As observed by Zuber and Ramakrishna (2021), a major challenge among students with disabilities is lack of accessible infrastructure, laboratories, libraries, toilets, dining halls and space for sports and games; unsupportive / overcrowded classrooms without appropriate seating facility and poor acoustics. As rightly noted by Kaufman et al (2023), depending on the nature and severity of disabilities, creative thinking about equipment, technology, and sometimes more difficult-to-make accommodations and variation in presentation or participation are required, as in the case, for example, of hearing impairments and deaf-blindness. Specific focus on this aspect is essential for promoting higher education for persons with disabilities.

Another reason for poor enrolment in higher education is a lack of financial resources among persons with disabilities. As noted by Ambati (2009), many persons with disabilities are first-generation learners from poor families and have difficulty in affording higher education. Though there are scholarships provided by the Government, these are not sufficient to sustain them. Therefore, many opt to find jobs rather than go for higher education.

The real challenge in the higher education sector is to reach the unreached persons with disabilities. Research and development have not yet achieved an optimum level in the area of disability rehabilitation. India is an agrarian country with 70% being rural. Technological advances are yet to reach all corners of the country. Lack of awareness about government schemes and about special arrangements in some colleges and facilities regarding higher education are other major causes for poor college enrolment. Efforts have to be geared towards creating awareness on the rights, entitlements and policies related to higher education of persons with disabilities.

### **The Way Forward**

Technological development has been rapid in the past three decades and persons with disabilities have increasingly better modes of communication and mobility, leading them towards independent living. There is a high demand for and focus on the information technology sector supported by policies of the government. Online education and virtual programmes are recent additions in most universities, enabling more students with disabilities to enrol in higher

education. While efforts are made to improve physical access to colleges, online courses by open universities can be a blessing in reaching higher education to persons with disabilities.

For achieving Sustainable Development Goal 4 (UNESCO, 2015), the National Education Policy 2020 accentuates that the entire education system be reconfigured and re-energised to support and foster learning, from early childhood up to higher education. A deadline of 2040 is set, wherein all higher education institutions shall aim to become multidisciplinary institutions and have larger student enrolments for vibrant communities. The Government has laid down certain steps which include, among others, developing and supporting technology tools for better participation and learning outcomes of persons with disabilities.

## **CONCLUSION**

Persons with disabilities in India can benefit from special provisions made in the higher education institutions and access such institutions largely as a result of the enactment of legislations and policies. Regulatory bodies function to ensure quality and equity in education. There are also exclusive higher education universities and colleges established by the Government and private agencies, at central and state levels, dedicated to the education of persons with disabilities. Special support cells are created in many universities and colleges to facilitate the education of persons with disabilities.

In spite of the systems that are in place, the enrolment rate of persons with disabilities is not optimal, though the numbers have increased in the recent past. Distances and lack of accessible transportation add considerably to this situation. The optimal use of technology in online education may contribute to an increase in enrolment.

Raising awareness about the potentials of persons with disabilities can contribute to diminishing the attitudinal barriers in society and can lead to the inclusion of persons with disabilities in all life domains.

### **Declaration**

This is not a funded study.

There is no conflict of interests.

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# Caregiver Perceptions about Factors Impacting their Ability to Carry out Home-Based Therapy Programmes in Central Botswana: A Qualitative Study

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## ABSTRACT

**Purpose:** Home-based programmes, as an aspect of Community-Based Rehabilitation (CBR), are provided as an integral part of remedial programming for children with disabilities in central Botswana. Difficulties with integration of these activities into daily living have been observed. The study therefore aimed to gain an in-depth picture of caregiver and therapist perceptions about the factors that impacted ability to carry out prescribed therapy at home.

**Method:** Purposive sampling was used to recruit therapists and caregivers of children with disabilities, through active occupational therapy and physiotherapy contacts in central Botswana. Caregivers lived in different villages served by CBR and the children had been referred for therapy at the NGO branch office. Semi-structured qualitative interviews were conducted for data collection. Twelve questions for caregivers and 9 for therapists were presented during in-person meetings. Interviews with 5 caregiver family members and 4 therapists were audio-recorded and transcribed by the first author. Thematic analysis combined manual coding and NVivo software.

**Results:** Participant response themes described both direct and indirect influences on adherence to the home programme. Direct influence themes were child characteristics, therapy competence and frequency, competing demands, and other issues. Indirect influence themes, which represented major impediments for carrying out a home programme, were insufficient preparedness of healthcare providers, mismatched social welfare services, support system inadequacies, and language barriers.

**Conclusion:** Although onset of the COVID-19 pandemic interfered with completion of all planned interviews, which was a limitation of the study, the

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*findings underscore the need for understanding the lived experiences of parents and other caregivers who are charged with carrying out home-based therapy programmes for children with disabilities. Given this knowledge, workers in the CBR system can implement solutions in the community that are designed to educate policymakers and workers in the social welfare system, while assisting clients to overcome barriers and advocate for their needs.*

**Key words:** *children with disabilities, Botswana, home programmes, qualitative research, community-based rehabilitation, barriers, effectiveness, social welfare services, caregiver support*

## INTRODUCTION

Botswana, one among many developing African nations, was described as one of the poorest counties in the world at the time it achieved independence in 1966. It has since progressed to becoming a middle-income country, striving to promote social justice and inclusion for children and adults with disabilities. It is an established welfare state, in that social assistance programmes are in place, which are financed primarily by mineral rents (Botlhale et al, 2019). The social assistance and rehabilitation programmes that were developed have been modelled after the 2008 United Nations Convention on the Rights of Persons with Disabilities (CRPD), the National Policy on Care for People with Disabilities (NPCPD), and the Convention on the Rights of the Child, ratified in 1995 (Botswana Institute for Development Policy Analysis, 2013; United Nations Development Programme, 2019). Botswana ratified the CRPD on August 12, 2021 (Southern Africa Litigation Centre, 2022). Community Based Rehabilitation (Helander, 1999; WHO, 2004, 2010) was field-tested in Botswana from 1981 to 1984 (Ingstad, 1997).

This qualitative study was conducted in the central region of Botswana. The first author, a practising occupational therapist in the region, frequently noted in his encounters with caregivers and other therapists that home-based programmes for a child living with a disability were being carried out inconsistently or not at all. Caregivers – either parents or other family members - were facing difficulties with incorporating therapist-prescribed therapeutic exercises, functional activities, play and positioning into daily living. These families received rehabilitation services through a non-governmental organisation (NGO) that worked closely with government agencies and delivered a variety of programmes, including community outreach intended to support rehabilitation and social inclusion for individuals with disabilities. The first author was hired by the NGO to provide

occupational therapy in an outreach project that was termed Community-Based Rehabilitation (CBR) and was supported by the larger healthcare system.

Findings of research conducted in other Southern African countries echoed the first author's observations about challenges faced by caregivers of children with disabilities. Families faced barriers to community participation, access to health services, and educational resources, all of which would compound hindrances to successful home-based programme adherence and compliance (Lundgren-Lindquis & Nordholm, 1996; Chappell & Johannsmeier, 2009; Grut et al, 2012; Hansen et al, 2014; Bongo et al, 2018).

In the current study, the authors aimed to gain an in-depth understanding of the lived experiences of parents and other caregivers charged with providing home-based therapeutic programmes and to corroborate these experiences with the reports of therapy professionals. They anticipated that an interplay of factors - some consistent with published reports of research and others unique to central Botswana - had been influencing caregivers' capacity to incorporate a child's home programme into the daily routine of the household. Ultimately, the knowledge gained could be used to provide a foundation for educating workers within CBR and welfare systems, as well as policymakers, and lead to implementation of solutions for overcoming barriers and advocating for needs in the community.

### **Overview of Social Welfare Services in Botswana**

Among the state-run social welfare services, the ones most relevant to families of children living with a disability are child support grants, destitute persons allowances, vulnerable groups supplemental feeding food baskets, transport allowance for medical check-ups, community home-based care, and other assistance such as emotional or psychological support. These services have been instituted to provide assistance to the most vulnerable, particularly those who are poor and excluded, in adherence to the concept of *kutlwelo botlhoko* or compassion, and guided by the National Poverty Reduction Strategy (NPRS). Social welfare service workers are tasked with assessing the socioeconomic status of families and determining their level of qualification for specific benefits (Maundeni & Mupedziswa, 2017; Botlhale et al, 2017).

Deficiencies in welfare system programmes in Botswana, however, have been described in terms of insufficient clarity and comprehensiveness of policies or operational guidelines, "lack of coordination, poor implementation, and

ineffective utilisation of resources and lack of accountability” (Maundeni & Mupedziswa, 2017). Analysts and researchers have pointed to the need for reforms to optimise social spending (Botlhale et al, 2019), as well as multiple barriers to the exercise of rights, including stigma and discrimination, deficiency of supporting infrastructure and transportation, and poor availability of information and communication technologies that would enhance access to essential knowledge about disability rights and available services (Mukhopadhyay & Moswela, 2019). Philpott (2014) commented on the potential of the CRPD as a lens to identify and transform gaps and limitations in policies for children with disabilities. Clearly, the ongoing work that is essential for identifying and supporting caregivers of children with disabilities is just beginning, and that is why the CBR approach to supporting families that have members with disability is widely advocated.

### **Community-Based Rehabilitation in Central Botswana**

The context for this study was the existing CBR outreach project. According to CBR Guidelines, providing a remedial programme for a child with a disability in the natural home or classroom environment will enhance development of his or her innate abilities and optimise the benefits of therapeutic services (Khasnabis & Motsch, 2010). Bongo and colleagues (2018) studied the effectiveness of the Chipinge World Vision CBR programme for children with a variety of disabilities in a region of Zimbabwe and concluded, “CBR has been successful in reaching some of the poorest families and their children with disabilities by making daily life better with valuable, practical skills, devices, creating integration and lessening discrimination and social integration”. The capacity of the primary caregiver to administer a programme is of key importance, nonetheless. As an illustration, mothers in Zambia reported lack of social acceptance, misunderstanding of disability, travel inaccessibility, financial burdens, experiences of self-doubt and fear, and feeling alone and isolated despite support from the CBR programme and their own resourcefulness (Hansen et al, 2014). These broader patterns, though often undisclosed, are important considerations. What an occupational therapist or physiotherapist in central Botswana might judge as noncompliance and neglect on the part of caregivers might be the result of constraints created by the interaction of individual misfortune and existing medical, social, cultural, and historical influences.

The first author was part of a team of CBR therapists who travelled to a number of remote villages in central Botswana on a daily basis from Monday through

Thursday. Each village was served by a primary care clinic or smaller health post facility within an average radius of one to two kilometres, staffed mainly by nurses and sometimes by doctors. Travelling therapists provided rehabilitation services in these primary care clinics, as well as in homes and schools. It should be noted that service availability varied considerably among villages and not all locations are served by the CBR outreach. When it comes to the attention of a nurse, therapist or volunteer that a child with a disability has medical or rehabilitative needs beyond what CBR can offer, they can be referred for specialised health-related medical or rehabilitative care to a government primary care hospital or the NGO branch office rehabilitation centre, which are both located in a town 30 to 120 kilometres from villages in central Botswana that are served by the outreach project. After being seen, the child may be referred for monthly or bimonthly outpatient visits at either the hospital or NGO branch office. CBR therapists coordinate with the clients, social workers, volunteers and clinics regarding various referrals. The CBR therapy team members are available for outpatient visits at the NGO branch office on Fridays.

Though the outreach programme in which the first author initially provided occupational therapy was called CBR by the NGO, his observations indicated that this service was more consistent with the medical model and health-related specialist rehabilitation. In keeping with a CBR Joint Position Paper (WHO, ILO, UNESCO, 2004), CBR should be “implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services”. In other words, the programme should be ongoing within the village and run by the community, with professionals coming in as consultants. “Because CBR belongs to the community, representatives of the community must be involved in the planning, implementation and evaluation of CBR programmes” (p. 13).

Therefore, the first author set up exploratory wellness programmes via partnership with community members in some of the villages in central Botswana. These addressed chronic health issues in adults as well as the health, function and activity restrictions of children with conditions such as autism and cerebral palsy. CBR volunteers who were residents of the villages were recruited to work with clinic staff, village development committees, village leadership, and the outreach team, on issues of community members with disabilities. He worked with community volunteers who helped check on people with disabilities in their



homes and various environments, and also with social workers, nurses and other community leaders who assisted with highlighting the issues of people with disabilities to the healthcare community in general. The aim was to exemplify the evolving social model of CBR by enhancing community involvement, promoting continuation of care, and increasing awareness of environmental barriers to inclusion and participation. Therapists provided technical support by teaching techniques that could be applied independently in the wellness centres and in the home. Members of the villages expressed a sense of ownership. The first author also helped to organise community groups to deal with some of the challenges related to caring for a child with a disability, offer support and solutions amongst themselves about caregiving, and initiate advocacy channels that included support groups. Nevertheless, this CBR community outreach was apparently not addressing all component factors that would ensure the success of a home-based programme in central Botswana. As failure to carry out home-based programmes for children persisted, the authors determined that this problem should be a key research focus.

## **Objective**

The primary objective for this project was to inform practices in both health-related specialist rehabilitation and in the CBR-affiliated aspects of programme delivery in order to fully understand barriers to effective care for children with disabilities. This required obtaining a comprehensive picture of caregiver and therapist perceptions regarding factors that influenced the lives of these children directly or indirectly. In particular, the authors wished to learn details about caregivers' reports of factors that impacted their ability to carry out home programmes. The perspectives of occupational therapists and physiotherapists, as well as caregivers, were sought to determine the degree to which points of view were consistent. The objective in the long term was to equip CBR therapists and workers with tools they could use to empower parents and caregivers to overcome barriers, and to communicate with various official bodies regarding recurrent issues and needs, particularly governmental and non-governmental departments that provide services to children with disabilities and their families. The research questions were:

- 1) Why are parents and other caregivers of a child with a disability in rural central Botswana not carrying out home-based therapeutic programmes?
- 2) Could barriers be addressed in the context of the CBR outreach project?

## METHOD

### Study Design

A phenomenological qualitative research design was used to gather information about the lived experiences and perceptions of study participants (Vagle, 2018). Qualitative research was selected as a foundational approach for identifying unique issues relevant to this local population and as a basis for improving the effectiveness of care for children with disabilities.

The first author carried out the study, and the second author served as research design and academic writing consultant. Throughout the time of the study, the first author was employed by the NGO in Botswana that oversees a variety of rehabilitation and social inclusion programmes for people with disabilities.

### Study Participants

A purposive sampling method was used, based on familiarity with the population of interest.

Five caregivers from among clients who lived in different villages served by CBR were recruited for semi-structured qualitative interviews by the first author. Children sometimes received alternate therapy sessions in the government hospital and a few caregivers could afford the services of a private physiotherapy clinic in town. Because of the need for special attention, they had been referred for outpatient rehabilitation at the NGO branch office and had attended one or more sessions. Caregivers who participated in the interviews represented a range of backgrounds and experiences, including position on a socioeconomic spectrum that ranged from middle class to destitute, married couples and single parents, employed and unemployed. The caregivers looked after children who were clinically complex - either a child with a physical disability or a condition such as autism or sensory motor deficits - who were ambulatory but presented a high burden of care.

Prospective participants were identified from among caregivers encountered when they brought a child to receive therapy and during home visits or phone calls to book appointments. To qualify for inclusion, the prospective participant needed to be fluent in English or Setswana—which is the local language—and caring for one or more children currently receiving occupational therapy or physiotherapy services or who received one of these therapies in the past one

year but were not being seen currently. During initial contact, the purpose and nature of the research was explained by the author and after obtaining verbal informed consent, an appointment was scheduled for a one-on-one qualitative interview at the clients' preferred location. At the first interview meeting, the clients were provided with a printed copy of the consent information in either English or Setswana that they could keep.

Four therapists were recruited for qualitative interviews through occupational therapy and physiotherapy contacts in the region. Again, the purposive sampling method was used to select participants from a variety of representative backgrounds. The only criterion for inclusion was fluency in English. Of those who participated in the interviews, three therapists worked as part of the CBR outreach and made visits to the villages, in addition to seeing families in the NGO branch office. One was also employed at a government hospital, and one was in private practice. Three were foreign therapists practising in Botswana and one was a native Motswana. The purpose and nature of the research was explained to participants and confidentiality was assured. An interview meeting was scheduled to take place in person. Before commencement of the interview, the participants were asked to read and sign a printed consent form.

### **Data Collection**

The semi-structured in-depth interview sessions with caregivers and with therapists were completed from April through September 2020. Three enrolled caregivers were interviewed at their homes as a couple i.e. with their spouses, while two chose a secluded area at the rehabilitation centre for their sessions. Therapists were interviewed at their places of work in a private office. As the first author understands spoken Setswana, participants were invited to use their native language when they struggled to express themselves in English. During and after each interview, the author made notes on his observations of non-verbal expressions to ensure that emotional nuances were captured. Each participant's name and any personal details were removed from the audio recordings, and a letter-and-number code was used to label all data and findings. The document that linked a participant to his or her code and personal information was stored in the password-protected research computer. Only the first author had access to a participant's identity. Brief background information and the code designation for each participant are provided in Table 1.

**Table 1: Participant Description**

Participant Codes and Case Overviews	
S3.	A couple who cared for a female child with microcephaly and quadriplegia. No response to visual stimulation, mostly smiley. Often had what was described as stomach complications and feeding difficulties, since she could not chew. Excessive crying reported. Father was a primary school teacher and mother was the full-time caregiver. They described that they struggle to maintain the family with the father's salary.
NV7.	A single parent who had a child with cerebral palsy hemiparesis with difficulty in crawling and lower limbs dissociation, born preterm at 6 months. Stayed with her parents, as she was unemployed and dependent on them for support.
MK2.	A mother with an autistic child who was also hyperactive. She was interviewed alone, but both parents were very dedicated to caring for their child. Mother was a primary school teacher and father had a stable good job; reported that they would go all the way in meeting the child's needs.
CC6.	A couple caring for a child with cerebral palsy. Father was an accountant; mother, who was expecting at the time of the interview, was a full-time caregiver. The child had quadriplegia with emotional sensitivity, poor neck control and a major concern of excessive crying.
K1.	A couple caring for a child with cerebral palsy and quadriplegia, who spent time in a wheelchair and had minimal environmental responses. Father worked at a mining company and mother was a full-time caregiver. At the time of the interview, the couple, who were not legally married but living together, were in the process of separation due to what the mother reported as problems with their relationship exacerbated by their child with disability. The author organised a counselling session with a psychologist for both; only the mother attended.
M4.	A foreign physiotherapist working with a non-governmental organisation that was providing Community-Based Rehabilitation. Two years of living and practising in Botswana.
JB9.	A foreign occupational therapist working with a non-governmental organisation with 7 years of practice in Botswana. Was working in both Community-Based Rehabilitation and residential rehabilitation for children.
DM5.	A foreign physiotherapist with over 10 years of practice experience in Botswana, working at the government hospital at the time of the interview. Treated outpatient, inpatient and Community-Based Rehabilitation clients.
TM8.	A physiotherapist who ran her private clinic where she attended to both adults and children. She was a Motswana, or citizen of Botswana, with many years of experience practicing within the country, working in government hospitals before going into private practice, and was also a participant in the Community-Based Rehabilitation outreach.

An instructor at the Psychology Centre in Botswana, with an MA in research psychology, who was also an expert in qualitative analysis and a Botswana native, assisted with translating consent forms and interview questions to ensure

consistency with the intended meaning. The records officer at the rehabilitation centre, whose duties included serving as a Setswana-English translator and who was legally permitted access to client personal information, was called upon on rare occasions to provide assistance with interviews. The role of the records officer included explaining the purpose of the study and gaining consent where needed. Each session was electronically audio-recorded.

A sequence of semi-structured interview questions was read to each participant. The questions were designed to elicit comments on direct and indirect factors that interfered with carrying out a home programme. Direct factors were considered to be embedded in characteristics of the child, the family situation and medical and rehabilitative service provision that would have an immediate impact on the ability of the caregiver to conduct home-programme activities, while indirect factors were anticipated to be secondary issues in the healthcare and social welfare systems that impeded a caregiver's ability to carry out these activities. Verbal prompts were employed to further elicit each participant's expression of views, feelings, and experiences relevant to the interview questions. Sufficient time to answer each question was given, and it was possible to complete each interview within one hour. Interview questions are depicted in Tables 2 and 3.

**Table 2: Caregiver Semi-structured Interview Questions**

Question
1. Tell me about your child with a disability. <i>Probe:</i> Journey since diagnosis, the child's current presentation
2. How supportive is the healthcare system towards your child with a disability? <i>Probe:</i> Accessing healthcare services, understanding of the child by physicians, nurses, and other government service departments
3. Is your child receiving therapy? If so, please describe the therapy and its effectiveness
4. Do you work? <i>Probe:</i> What makes it difficult?
5. Are there therapy activities that you are supposed to do at home with your child?
6. Do you and the therapist discuss and agree on these activities?
7. As there are a number of foreign therapists and other healthcare specialists in Botswana, what role does language barrier play in understanding home programmes and other healthcare instructions?
8. Do you currently engage in home programmes and other healthcare activities with your child?

9. What makes it difficult or easy to carry out these activities? <i>Probe:</i> How the programme fits into their daily lives, support system
10. How can these activities be made better?
11. What would be your advice to the therapists?
12. What would be your advice to the healthcare system and government in general about the needs of children like yours?

**Table 3: Therapist Semi-structured Interview Questions**

Question
1. Does your practice include giving home programme instructions?
2. Do you believe home programmes are important in rehabilitation of a child with disabilities?
3. What have your experiences been with providing home programme instructions to caregivers living with children with disabilities?
4. Do you or any therapists you know place enough emphasis on home programmes?
5. From your experience, what factors determine the success or failure of a home programme?
6. What would be your advice to caregivers about home programmes?
7. What advice would you give to other therapists about giving home programmes?
8. Do you feel that children with disabilities and their families are supported enough by the healthcare system and the government in general? If not, explain your views.
9. Do you base your home programme activities and how to engage the caregiver on available evidence?

## Data Analysis

The audio-recorded interviews were transcribed by the first author in preparation for analysis. The records officer assisted as necessary during transcription where clarification of a spoken phrase in Setswana was needed. The instructor at the Psychology Centre in Botswana was consulted to cross-check themes, but she did not have access to audio recordings. The first author analysed transcribed text to identify recurrent themes using published coding manual guidelines (Saldaña, 2016) and the NVivo computer software. Once text was exported to NVivo, the application helped him to classify, sort and arrange information, and to examine relationships. Zamawe (2015) described the value of NVivo for analysing a qualitative study for theme variations and noted that this software facilitated an accurate and transparent process in which the user always remained in control.



## Ethical Considerations

Prior to initiating qualitative research, Institutional Review Board (IRB) approval was obtained from Boston University in Massachusetts, United States of America, where the investigators were affiliated at the time of data collection. The first author was also granted approval for human research from the Republic of Botswana Ministry of Health.

Each study participant was assured that participation was voluntary and without any consequences should they choose not to participate. They were also assured that any information they provided would be kept strictly confidential.

## RESULTS

By the completion of the final interviews no new themes had emerged, indicating that data saturation was reached. The authors confirmed that participant response themes could be grouped according to whether they represented direct versus indirect influences on adherence to the home-based programme. Details for themes relating to **direct influences** with sample quotes are provided in Table 4. Themes relating to **indirect influences** with sample quotes are provided in Table 5.

**Table 4: Themes relating to Direct Influences**

Theme	Description	Sample Quote
Child Characteristics	<ul style="list-style-type: none"> <li>● One child characteristic reported by caregivers was uncontrollable crying. Some related that they stayed up all night so that he or she would cease crying, unable to comfort the child, while not knowing what was happening. Some spent most of the time during the day trying to stop the crying.</li> <li>● Children with sensory or behavioural challenges were described as often refusing to initiate or maintain engagement in home programme activities.</li> <li>● Caregivers whose child cried while activities were being carried out were concerned about causing pain, and they were reluctant to push the child to continue.</li> </ul>	<p><i>"This child can cry and this child would cry. I am telling you, she would cry uncontrollably from morning up to... during that time there would be no time to do some therapy."</i> S3 (Parents)</p> <p><i>"Sometimes when we didn't sleep the whole night, in the morning it would be difficult to say we have to continue doing therapy."</i> CC6 (Mother)</p>

<b>Therapy Competency and Frequency</b>	<ul style="list-style-type: none"> <li>● All caregivers felt that therapy provided in the clinic once per week, or more typically every two to three months, was not sufficient for their child to make gains.</li> <li>● They expressed the desire to spend more time with the therapist during each visit so they could better learn how to care for the child as they struggled to carry out the home programme.</li> <li>● Some reported that they feared they would do the wrong things and cause injury to the child.</li> </ul>	<p><i>"If I may give you an example, this month is just about physical stretching of the child; then you will take 2 months without going there; when you get there after 2 months, you know there is no continuity with what she was doing obviously."</i> CC6 (Mother)</p>
<b>Competing Demands</b>	<ul style="list-style-type: none"> <li>● Household chores, basic caregiving, and work-related activities made it difficult for the caregivers to incorporate home programmes into their daily activities.</li> <li>● This was also noted by therapists who reported their interactions with the caregivers; they related that home programmes were only partially carried out, and then only when the caregiver had the time.</li> </ul>	<p><i>"In my personal view, because at home we have not applied them much based on the situation, I don't see any problems with these activities, they are fine. The problem is lack of implementation here at home."</i> S3 (Parents)</p>
<b>Other Issues Connected with Beliefs and Understanding</b>	<ul style="list-style-type: none"> <li>● A recurring therapist theme was partial involvement by caregivers during therapy sessions, which was negatively impacting how the home programme was carried out. This seemed to stem from the belief that a parent's duty was simply to bring the child to his or her appointment. While the child was being seen, the caregiver would be engaged on the phone, as opposed to actively participating in the session.</li> <li>● Cultural themes were prominent. One theme was inadequate home programme follow-up because of a cultural misunderstanding about what therapy entailed. <i>Tshidilo</i>, a Setswana word that means therapy to most in this population, was generally interpreted as involving massage and physical stretching, according to therapists. Therefore, providing training on carrying out a home programme of occupation-based activities did not make sense to some caregivers.</li> </ul>	<p><i>"This is an African set-up; you get some clients or people who believe that, 'I am bringing my child to you so that you give them the therapy that they need. I pay for that, therefore I am not obliged to do any other thing outside of that.'" TM 8 (Physiotherapist)</i></p>

	<ul style="list-style-type: none"> <li>• Therapists also reported difficulty with implementing a home programme when the child was brought to therapy by the grandmother, which was often the case. Teaching the grandmother was found to be a challenge, presumably because her level of education was insufficient for understanding the child's condition, therapy needs, and home programme. Belief in traditional healers was found to be highly valued by some caregivers, who incorporated these practices into home programme instructions provided by the therapist and used treatments that could be detrimental to the child.</li> </ul>	
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**Table 5: Themes relating to Indirect Influences**

Theme	Description	Sample Quote
<b>Insufficient Preparedness of Healthcare Providers</b>	<ul style="list-style-type: none"> <li>• Caregivers expressed, with great concern, the theme of unpreparedness of the healthcare system, including lack of knowledge on the child's condition, plus structural and procedural inconsistencies, such that the child's functional deficits could have been mitigated, or even prevented, with better medical care.</li> <li>• Experiences with physicians who attributed symptoms to the child's disability, with minimal to no further exploration conducted, was a recurring theme.</li> <li>• Caregiver experiences led to reluctance to take the child to the hospital, even when they knew he or she was not feeling well and they were certain that something was medically wrong. This in turn affected most other areas of caregiving, including carrying out home programmes and adherence to therapy.</li> </ul>	<p><i>"Almost every day we were at the hospital for the first year, but unfortunately when we get to the hospital...the doctors would say, this is the condition, there is nothing we can do...She is crying because of the condition, she is feeling pain because of the condition, there is nothing that we can do." S3 (Parents)</i></p>

<p><b>Mismatched Social Welfare Services</b></p>	<ul style="list-style-type: none"> <li>● Therapist and caregiver reports included lack of socioeconomic well-being, made worse by delays and denial of social welfare assistance, which interfered with the ability to manage the needs of the child and family. Gaps and inefficiencies in the social welfare system contributed negatively to access to services, and therefore made it difficult or impossible to focus on implementing a therapeutic home programme.</li> <li>● Caregivers who reported moderate economic status struggled to keep the family afloat; one single parent was destitute and unable to provide basic necessities on her own. They were dependent on relatives and any allowed social welfare services.</li> <li>● If one or both partners were working, the mother was the primary caregiver who strained to balance frequent travel for therapy visits or medical check-ups with the demands of family upkeep.</li> <li>● If a child with a disability could not eat regular meals and needed a costly special diet, funds might be diverted from other family subsistence. Despite the sacrifice, the special diet was often unavailable.</li> <li>● Recurring themes were the difficulties connected with obtaining access to any services because of the long wait for assessment and the poor likelihood of qualifying. Caregivers reported that people in the social service offices did not understand their needs adequately. Lack of sensitivity was reported, with caregivers led to believe that benefits were not an authentic entitlement.</li> <li>● Stigma was largely reported by caregivers, while negligence was observed by both caregivers and therapists.</li> <li>● Caregivers experienced misunderstanding of disability and lack of awareness of specific benefits among social welfare service workers, who might perceive the child as not needing sufficient care to qualify the family for disability grants or nutritional assistance based on their status. Food baskets lacked items the child could consume, leading to malnourishment.</li> </ul>	<p><i>“You cannot emphasise on doing home programmes when they do not have food to eat.”</i> DM5 (Physiotherapist)</p> <p><i>“My advice is that they don’t have to give all kids the same thing like when they give to children with disability. They have to look at what K needs. Isn’t it that some other kids can chew, they are with disability but they can eat rice, macaroni and all those kinds of things; as for K she can’t eat those kinds of things so they don’t really go into detail that what does this child really need.”</i> K1 (Parents)</p> <p><i>“We do not know if we are entitled to those services.”</i> CC6 (Mother)</p> <p><i>“Even on that food ration, we use a token; there are some shops where that token is used and most of the times they don’t have the food that she can eat.”</i> S3 (Parents)</p> <p><i>“There are a lot of things that are put in paper but are not really practical, it’s not what is happening on the ground. We can brag about the social welfare office giving disability grants and food baskets and ensuring that there is something but how effective is it? To me I don’t think they are effective.”</i> JB9 (Occupational Therapist)</p>
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<p><b>Support System Inadequacies</b></p>	<ul style="list-style-type: none"> <li>● Caregivers complained that they were not informed about systems for providing emotional or psychological support, given that they went through long periods of stress because of adjustments needed to adequately address the child's condition while meeting challenges inherent to carrying out their daily activities.</li> <li>● Caregivers reported few to no opportunities for respite, where they were able to engage in activities other than caregiving, as well as few sources of emotional support other than the child's treating therapist and the spouse. This was a recurring theme.</li> <li>● Almost all of the caregivers that were interviewed were not comfortable leaving their child with someone other than a spouse or immediate family member. This reluctance was often attributed to the child's delicately balanced care requirements, which in one case meant an extended feeding time using specialised techniques. The busy lives of family members and friends made them reluctant to be involved with the care of a child with disability.</li> <li>● The crucial need for employer support and understanding was another recurring theme. Some caregivers felt well-supported by the employer, while others related that their employer had no idea of the challenges inherent in taking care of a child with a disability.</li> <li>● When an employed caregiver was called upon to assist a family member with the child who was unwell, or to transport the child to a clinic or hospital, permission was typically needed to arrive at the workplace late or to leave before the end of the workday.</li> <li>● If periods of respite or access to persons who could provide psychosocial support were not available which is often the case, caregivers reported sporadic burn-out episodes that affected the way the child's home programme and other daily activities were carried out.</li> </ul>	<p><i>"And sometimes maybe he is not affected; for me, I am really affected to the extent that maybe sometimes the care I am supposed to give the child I cannot do due to stress and worry."</i> K1 (Parents)</p> <p><i>"We feel uncomfortable with leaving him with someone else. It's only the siblings to my husband, who also have their own responsibilities."</i> MK2 (Mother)</p> <p><i>"It's like I am stuck with him for life and I am not progressing in any way and again it's difficult to leave him with someone else."</i> CC6 (Mother)</p> <p><i>"I can say I am very lucky because I am working at a rehabilitation centre which knows about people with disabilities and I am very thankful to my employer because he gives me time whenever the baby needs assistance."</i> CC6 (Father)</p> <p><i>"Even where we work, they know the situation of my child, but I remember a situation a couple of years back when I wanted them to give me a house closer to facilities where my child was being helped, but they never understood my language because they are never taught about the sensitivity of these issues."</i> K1 (Father)</p>
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<p><b>Language Barriers</b></p>	<ul style="list-style-type: none"> <li>● Of the four therapists who were interviewed, one was a Motswana, or citizen of Botswana, and three were natives of another country. A theme common to therapists of foreign extraction was their great concern about the impact the language barrier had on their ability to effectively communicate with clients.</li> <li>● Though each of the three had practiced long enough in Botswana to pick up conversational Setswana, at times they needed translation service to discuss specifics with the caregiver about the child's medical or physical condition and the plan for carrying out a home programme. Not only were translators inconsistently available, they lacked training in medical concepts and terminology and therefore changed the meaning of the therapist's message.</li> <li>● Therapist resorted to demonstration where there was no way to effectively communicate verbally.</li> <li>● The caregivers who were interviewed could speak in English, but still reported that it was not easy for them to express themselves at times when they needed to explain complex experiences or feelings.</li> </ul>	<p><i>"I think for us here because we are still youthful and we have been through to maybe these tertiary schools, I think it's not of a big deal, but if I put myself into the shoes of an ordinary Motswana, I think it's a bit of a burden to them. The language barrier I think is something that is a problem. They might see what is being done but understanding of it through verbal communication I think it's a problem."</i> K1 (Parents)</p> <p><i>"Sometimes these doctors can provide someone to translate English to Setswana because sometimes you might understand, but since we are Botswana you find that it is very difficult for us to express in English."</i> K1 K1 (Parents)</p> <p><i>"Language barrier is just a huge one; a client would tell you, 'I don't', even if they understand; as long as you are not speaking their language they would say I don't understand what you said."</i> JB9 (Occupational Therapist)</p>
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## DISCUSSION

This qualitative investigation was undertaken to gain insight into the reasons behind not carrying out home-based therapeutic programmes by parents and other caregivers of children with disability who were part of the CBR outreach project in rural central Botswana. As participants expressed concerns that were foremost on their minds, problem areas came to light that were consistent with prior descriptions by analysts and researchers concerning barriers embedded



in: the Botswana social welfare system (Maundeni & Mupedziswa, 2017; Mukhopadhyay & Moswela, 2019); health-related rehabilitation services in the Southern African region (Veltman et al, 2001; Iezzoni et al, 2003; McColl et al, 2008; Grut et al, 2012; Hansen et al, 2014); and language incompatibility in healthcare (Ali & Watson, 2018). A notable aspect of findings was the consistency in the lived experiences described by both caregiver and therapist participants, despite the uniqueness of each family group. They painted a picture in which children with disabilities and the families who cared for them were underserved, unsupported and at the mercy of social welfare service workers.

It would appear that participants in this study were encountering medical care and social welfare inequality with detrimental effects on their quality of life and that of their families despite governmental efforts, such that they remained vulnerable and providing a therapeutic home-based programme was an uphill battle. Their lived experiences pointed to the existence of insufficiencies in the larger system. Key practical barriers revealed during the study, that could be mitigated in the context of the CBR outreach project “through the combined efforts of people with disabilities...their families, organisations and communities, and the relevant governmental and non-governmental ...social and other services” (WHO, ILO, UNESCO, 2004) are described in Table 6.

**Table 6: Key Practical Barriers revealed during the Authors’ Research that could be mitigated in the context of the CBR Outreach Project**

<b>Barrier</b>	<b>Goal</b>	<b>Action Plan</b>
<b>Inadequate nutrition because of food baskets that do not meet a child’s nutritional needs or tolerances.</b>	Food basket options suited to the individual child’s nutritional needs, food tolerances, and level of chewing capability are available.	Promote policy change via interaction between the therapist, doctor, dietician and social services as members of the CBR support team. Educate CBR community groups and volunteers in the villages about advocating for appropriate food baskets.
<b>Physician misperceptions and lack of expertise on disability in children.</b>	Physicians take steps to discover and mitigate underlying deficits for caregiver-reported child behaviours, such as crying or refusal of food. They have a grasp of the complexities of caring for a child with a disability.	Inform the Ministry of Health on the need for policy promoting education of doctors on child disabilities, the complexities of care and underlying deficits that require medical intervention. Conduct in-service training of physicians as members of the CBR support team, consistent with developed policy.

<b>Insufficient means to mitigate presence of language incompatibility.</b>	Caregivers understand explanations and instructions for a home-based programme that is provided by therapists and physicians.	Prepare illustrated paper handouts in the caregivers' language. Show prepared instructional videos in the caregivers' language. Recruit informally trained translators from the community to serve on medical or rehabilitation teams. Involve CBR therapists and local community workers as guides.
<b>Need for self-advocacy skills.</b>	Caregivers understand how to communicate with health care, social welfare workers, and the school system regarding qualifications for assistance and needed care for the child.	Empower direct consumers who are the parents and caregivers about navigating the system and how they can self-advocate to access services. Provide teaching in the local villages to individuals and groups.
<b>Denials and delays of social welfare assistance with lack of sensitivity by social welfare workers.</b>	Social welfare workers more fully understand the challenges and complexities connected with caring for a child with a disability, types of handicaps, and special needs of an ambulatory child who may have other impairments affecting cognition or use of the upper extremities. Improved clarity in operational guidelines.	Promote policy change to more fairly connect the child with disability with needed welfare assistance by working with members of the CBR support team. Empower direct consumers who are the parents and caregivers by providing education about navigating the system and how they can self-advocate for appropriate welfare assistance.
<b>Need for respite, insufficient resources for emotional and psychological support and competing demands of duties connected with work and household chores.</b>	Caregivers have opportunities for respite from long periods of stress and the burden of care, where they are able to engage in activities other than caregiving for a child that may be delicate, unwell, and constantly crying. They have sources of emotional and psychological support in the community and a means to leave the child with someone other than an immediate family member.	Village leadership and the CBR outreach team work with volunteers and community groups in the villages to set up a system of mutual emotional and psychological support that includes respite. Parents or other caregivers who understand how to care for a child with a disability are encouraged to come together and share respite by caring for children in the other family.

<p><b>Need for one-to-one support with carrying out the home programme.</b></p>	<p>Parents and other caregivers have sufficient understanding of how the child’s home-based programme is carried out correctly. They also understand the benefits of focused therapeutic intervention and the consequences for not engaging the child in therapeutic activities.</p>	<p>Travelling therapists in the CBR outreach periodically conduct home visits based on a scheduling system. During visits, therapists ask parents or other caregivers to demonstrate the home-based therapeutic programme and they provide feedback. Correct techniques are reinforced, and therapists offer flexibility by teaching alternative approaches. Visits can also take place in the local clinic or wellness centre.</p>
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As seen in Table 6, advocacy for the rights of children with disabilities and their caregivers can and should extend from the direct consumers, who are the parents and caregivers, to the CBR support team, volunteers and community groups in the villages, and to the larger organisational structures. Hansen (2014) notes that “CBR staff might consider teaching advocacy skills to all stakeholders of children with disabilities including families and communities...in an effort to develop policies that are holistic, child-centred and address the challenges experienced by children with disabilities and their families”. Further development of approaches to coordination and collaboration is needed that links the CBR teams and village communities with medical and rehabilitation healthcare providers, social service workers, dieticians, and government officials. This essential next step within the CBR outreach project will ultimately lead to practical solutions for community education approaches to medical exploration and treatment, disability grant qualification criteria, and other social policies that impact children with physical, sensory and intellectual disabilities.

### **Strengths of the Study**

Care was taken to achieve the greatest possible rigour in qualitative data collection and analysis. Purposive selection of participants, based on familiarity with the populations, was used to approximate a representative sample of caregivers and therapy providers as much as possible. The sample was composed of direct consumers from villages in the CBR outreach initiative and 3 therapists on the CBR team. Painstaking attention in the study design was directed to ensuring that wording of the questions posed to participants communicated the desired meanings. Cross-checking of themes that were derived from analysis was carried out using a qualified consultant and both manual and computer-assisted qualitative analyses were employed.

## Limitations

Though the originally planned number of research participants was 6 therapists and 10 caregivers, onset of the COVID-19 pandemic necessitated discontinuation of personal interviews. Despite this unanticipated emergency, the authors were satisfied that the range of characteristics was consistent with the aims of purposive sampling, particularly as data reached saturation. A larger study may nevertheless have given a broader and more complete picture.

## CONCLUSION

The authors' use of qualitative methodology demonstrated an approach of particular value when a situation of service provision is untenable and specific guidelines for change can be learned from the research findings. This study took place within well-intentioned national social welfare and CBR outreach systems whose purpose is to ensure that vulnerable groups with special needs because of poverty and disability would not be excluded from the benefits of rehabilitation programmes. However, there were indicators that the systems might not be working as well as they should.

As a means of enhancing the quality of inclusive care, the authors undertook an investigation to explore the experiences of families in central Botswana who were struggling with the challenges of caring for a child with complex needs because of a disability. The first author experienced the practical advantages inherent in the CBR outreach project, in that therapists, volunteers, and village leadership could try out new approaches on a small scale in the local communities; for example, he spearheaded a new chapter of the International Rotary Club. Their work in the villages to help continue the community programmes and support the needs of parents of children with disabilities has been ongoing. It is hoped that continuing efforts to promote community awareness and improve service delivery will help resolve barriers to home-programme adherence and compliance in this region.

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# Activity Limitations and Life Satisfaction: a Cross-sectional Study among Amputees in an Orthopaedic Rehabilitation Centre in Ghana

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## ABSTRACT

**Purpose:** This study aimed to examine the limitations experienced by amputees in the performance of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), and the impact on their life satisfaction.

**Method:** A quantitative cross-sectional study was conducted among 200 amputees at the Nsawam Orthopaedic Training Centre (OTC) in Ghana. The Groningen Activity Restriction Scale (GARS) and the Life Satisfaction Questionnaire-11 (LISAT-11) were used to collect data from the respondents. All statistical analyses were made using IBM Statistical Package for the Social Sciences (SPSS) software 23.0 and summarised in Tables. A multivariate analysis was used to establish the relationship between activity limitation and life satisfaction.

**Results:** The respondents experienced some limitations in carrying out Activities of Daily Living and Instrumental Activities of Daily Living, with an overall mean activity limitation score of  $(36.57 \pm 10.93)$ . They had moderate life satisfaction with a mean score of  $(3.86 \pm 1.15)$ . A multivariate analysis revealed that there was a strong negative statistically significant relationship between activity limitations and life satisfaction ( $\beta = -0.13, p = 0.000$ ).

**Conclusion:** The government of Ghana must explore these limitations through the Ministry of Health and its agencies who are involved in the management and rehabilitation of amputees. This would help inform decision-making in the planning and preparation of rehabilitation programmes, resource allocation, and policy formulation for amputees, in order to improve their overall satisfaction and well-being.

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*Key words: amputation, amputees, activity limitation, life satisfaction, Ghana, Activities of Daily Living*

## INTRODUCTION

Amputations are done for a multiplicity of reasons, including congenital limb deficiency, vascular insufficiency, burns, cancer, and traumatic injuries (Williamson & Walters, 2010). The prevalence of amputation worldwide is unknown and the little data existing shows a significant difference among countries (Bello et al, 2020). As many as 1.6 million people in the United States were projected to be without limbs by 2005, and this is estimated to increase to 3.6 million people by the year 2050 (Ziegler-Graham et al, 2008). Among these amputations, 90% are of the lower limbs and 75% of the amputees are over 65 years of age (Wetterhahn et al, 2002). The prevalence rates, between and within countries, for acquired amputations differ significantly. The occurrence of lower limb amputation is also greater than that of the upper limb (Ziegler-Graham et al, 2008). It is reported that the prevalence ranges from 1.2 per 10 000 women to 4.4 per 10 000 men in the Navajo nation in the USA (Burger & Marincek, 2007). In the United States, evidence suggests that 30,000-40,000 amputations were performed yearly (Ziegler-Graham et al, 2008). A record of commercially health-insured children under the age of 18, to estimate the rates of major lower extremity limb loss, found a prevalence of 38.5 cases per 100,000 per year from 2009-2015 (McLarney et al, 2020).

In low- and middle-income African countries, very little research has taken place to examine the prevalence and consequences of a limb amputation on clients (Walla et al, 2015). In Nigeria, the incidence of amputation is increasing (Bello et al, 2020) and accounts for 0.38% of all orthopaedic operations. Overall, the estimated incidence of lower limb amputation in Nigeria is 1.6 per 100,000 population (Thanni & Tade, 2007).

In Ghana, it is projected that approximately 145,299 individuals had an amputation and the country is experiencing significant increases in its amputee population (Chalya et al, 2012). At the KomfoAnokye Teaching Hospital in Ghana, the amputation of the lower limb comprised of amputation of the knee (n = 23; 22.1%), amputation of the toe using Rays (n = 15; 14.4%) and de-articulation of the hip (n = 2; 1.9%) (Kyei et al, 2015).

Specialised rehabilitation services for people with amputation in Ghana are insufficient. Lack of these services is among the difficulties associated with rehabilitation, especially in low- and middle-income countries like Ghana (Gallagher & MacLachlan, 2004). The provision of services including orthopaedic devices is mostly done at the national levels in the teaching hospitals and centres located in other regions at regional hospitals (Aduayom-Ahego & Ehara, 2016). There are eight centres providing specialised rehabilitation services for amputees in Ghana. There are four teaching hospitals in Accra, Cape Coast, Kumasi and Tamale offering such services. The Ministry of Health Orthopaedic centre in Accra, the St. Joseph Orthopaedic Hospital and the Nsawam Orthopaedic Rehabilitation Centre serve the Eastern region of Ghana. Duayaw Nkwata St. John of God Hospital serves the people of the Ahafo region. Due to the limited specialised resources, physiotherapy units in some local and primary care facilities also support the rehabilitation of people with amputation. However, there is no data available about the extent to which this is happening. The services available to people with amputation focus mainly on the diagnosis, correction, prevention, and treatment of clients with orthopaedic deformities, including the provision of assistive devices such as orthotics and prosthesis, and in most cases provide wheelchairs for the elderly (Aduayom-Ahego & Ehara, 2016). Wong (2005) stated that limb amputation is frequently done for a diversity of reasons such as removing ischemic, diseased necrotic tissue, or locally unresectable tumours. The World Health Organisation (WHO) has laid emphasis on this problem by designating that amputations are increasing but adds that more than half of these amputations could be prevented with adequate recognition and care (Day, 2011). Amputation conveys a disastrous change and alteration in an individual's life notwithstanding the cause, affecting the quality of life and well-being (Razak et al, 2016). Amputation limits a person's performance of personal, professional, leisure, social and marital activities, including expression of sexual feelings between partners (Geertzen et al, 2009).

The International Classification of Functioning, Disability, and Health (ICF, 2001) described activity limitations as the difficulties an individual may experience in executing activities. Disability in the amputee may arise due to activity limitations and constraints placed upon involvement that emerge due to the interaction between body structure, function limitations, and an unhelpful environment (Bello et al, 2020). People with amputation may face limitations in the performance of daily activities and their social life, such as in relationships, education, and community involvement (ICF, 2001). Bello et al (2020) further

assert that everyday skills to engage in activities of daily living tend to decrease with age for both males and females following amputation, but males generally have better physical function than females and this correlates to improved quality of life and satisfaction. The ICF framework states that many personal factors of individuals with impairments such as amputation, impacts the physical, psychological, and social functioning which are core domains of life satisfaction (WHO[ICF],2001). Participation in cherished activities of clients and satisfaction with life are impacted negatively by major limb amputation (Yilleng & Dapap, 2020). The body must adjust to amputation setbacks to be able to execute activities of daily living, return to work, and other activities concerning his or her roles, responsibilities, and expectations (Sinha et al, 2014). Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) are the basic and essential routine of an individual's everyday life, which has direct impact on quality of life and life satisfaction (Fitzsimmons, 2011; Dyer & Ostwald, 2012; Hamilton, 2012). ADL and IADL are tasks of self-care, functional mobility, functional communication, home management, and community living that enable an individual to accomplish his or her freedom (Pousada et al, 2015). They are the elementary and indispensable routines of an individual for daily life (Fitzsimmons, 2011). IADL are more complex daily activities, cognitively influenced and emphasise community activities like shopping, cooking, transportation and housekeeping (Cahn-Weiner et al, 2007). According to Diego (2019) amputees could show some level of independence in their activities of daily living after rehabilitation which consequently affects their overall satisfaction and well-being. Ability to perform ADLs at discharge after amputation is a very significant reason in predicting future satisfaction and quality of life of clients (Hoshino et al, 2008). Individuals with no limitations in ADL are more likely to report high levels of life satisfaction than those with limitations in ADL or dependence on others in their ADLs. They showed that as clients progress from full ADL independence into ADL limitations to ADL dependence, the proportion of people with high levels of life satisfaction declines (Boccaccio et al, 2021). Several studies reported that as the dependence or limitations in ADLs increase, the quality of life and life satisfaction of individuals, especially the elderly, also decrease (Chokkanathan & Mohanty, 2017; Wang et al, 2017).

Life satisfaction is a multidimensional concept of quality of life (Tate & Forchheimer, 2002). Life satisfaction forms one of the subjective statements of a person's life quality (Rachmat et al, 2020). Life satisfaction is a mental appraisal of one's life according to selected principles and is considered one of the most

significant parts of individual well-being (Hamaideh, 2021). Life satisfaction is another important rehabilitation outcome and is examined as the perceived discrepancy between aspiration and achievement (Wang et al, 2018). Amputation can have a direct or indirect undesirable effect on individuals, resulting in a lower level of life satisfaction or being doubtful when reporting judgement on their life (Addabbo et al, 2015). Mollaoglu et al (2010) focused on the life satisfaction of the elderly with mobility disabilities including amputees and found that disability significantly affects life satisfaction.

Assessments of functional outcomes during the performance of ADLs and IADLs of amputees have gained growing prominence to support evidence-based practice (Frossard et al, 2011). Limitations in ADLs and IADLs can be described as needing help in at least one of the following activities: walking, taking a shower, toileting, getting out of bed, getting up from a chair, using the toilet, dressing, and eating (Zunzunegui et al, 2006). Hommel et al (2004) concluded in their work that clients' experiences of dependence may be lessened over time when executing activities of daily living that are perceived as important, and performance of such ADLs has been established to be a relevant gauge of client outcome and improvement in satisfaction. Dependence for activities of daily living is linked with poorer quality and satisfaction of life (Millán-Calenti et al, 2010). Arling and Williams (2003) reported that the more dependent clients may experience lower satisfaction and quality of life than those who are Activities of Daily Living independent. After six months of rehabilitation in persons with lower-extremity amputation, independence in ADLs/IADLs is significantly linked with higher satisfaction of life (De-Rosende Celeiro et al, 2017). In a study of the ADLs of middle-aged clients who suffered lower limb amputation from sarcoma, it was found that they could retain their quality of life and satisfaction of life (Pardasaney, 2006). The adverse consequence of amputation on life satisfaction can lead to a lower level of life satisfaction (Addabbo et al, 2015).

## **Objective**

Ghana is experiencing significant increases in its amputee population (Chalya et al, 2012), yet research on the limitations in daily living activities and its impact on their life satisfaction is limited. Adequate attention has not yet been given to these very important determinants of functional independence during rehabilitation (Kyei et al, 2016). The lack of data on the health and well-being of amputees makes it difficult to monitor their health status during rehabilitation and the

impact of social policies on their health and satisfaction. Since Ghana is a country which aspires to focus on implementing rehabilitation programmes, a study of this nature is needed to realise the full effect of amputations on the lives of the amputees and to provide essential data for policy formulation, rehabilitation programme implementation, evidence-based practice and to make adaptations to their needs and perspectives. This study aimed to examine the limitations experienced by amputees in the performance of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living.

## **METHOD**

### **Study Design**

The study utilised a quantitative approach and a cross-sectional study design.

### **Study Setting**

This study was conducted at the Nsawam Orthopaedic Training Centre (OTC) in the Nsawam-Adoagyiri Municipality of the Eastern region of Ghana. The primary purpose of the centre is the rehabilitation of persons with physical disability in Ghana and West Africa. This centre was chosen because a significant percentage of amputees live or visit the centre for rehabilitation and other interventions on a regular basis. A purposive sampling technique was used to select the study setting.

### **Study Sample**

Purposive and simple random sampling methods were used to recruit respondents. It provided an opportunity for each member of the population to have an equal chance of being selected. This not only enhanced the selection of suitable respondents for the study, but also facilitated data collection within a short duration of time. A total of 200 respondents were recruited for the study.

Inclusion criteria:

- All amputee men and women, with bilateral or unilateral limb amputation,
- Amputees who were 18 years of age or older,
- Those who were attending post-amputation rehabilitation programmes, with or without prosthesis,



- Those who were temporary residents of the Nsawam Orthopaedic Training Centre or had been visiting the centre at least for over 3 months for rehabilitation and treatment.

The aim was to obtain information about the variables under investigation from different gender perspectives. It was felt that those above 18 years of age would give appropriate responses to the variables under study. The clients visiting the centre for treatment for over three months were included on the basis that they had been stabilised and were gradually adjusting to life post-amputation.

### **Study Tools**

Standardised data collection tools were used. The questionnaires were self-administered, in-person in paper-and-pen formats, under the supervision and guidance of the researchers.

The Groningen Activity Restriction Scale (GARS) is a non-disease-specific instrument to measure limitations or difficulties in ADLs and IADLs. It has 18 items based on a 5-point Likert scale which measures the level of disability or limitation encountered in the performance of daily activities, ranging from '1' as independent to '5' as dependent or needing help to be able to perform that activity. The response is based on what the client can do with that activity. The scale provides a minimum score of 18 and a maximum score of 72. The higher the score, the greater the disability or limitation (Suurmeijer et al, 1994). The GARS was selected because the psychometric characteristics, which measures disability in ADL and IADL simultaneously, make this instrument very useful for comparative research. It can be administered by the researcher or by the clients if they are able to read and write. Details of the questionnaire were explained to the respondents.

The second questionnaire was the Life Satisfaction Questionnaire-11 (LISAT-11) for measuring the satisfaction with life. The Life Satisfaction Questionnaire-11 (LISAT -11), which can be client or researcher administered, assesses different aspects of life satisfaction rated on an ordinal scale ranging from '1' (very dissatisfying) to '6' (very satisfying). Summing of the scores is not recommended; it seems more appropriate to use mean domain scores rather than a total score to keep the information on each domain available for clinical interventions. The LISAT-11 was selected because it provides meaningful information on quality of life for clinical and research purposes (Fugl-Meyer et al, 2002).

A pre-test of the questionnaires was carried out at the orthopaedic unit of the Korle-bu Teaching Hospital (KBTH) among the amputees who had been visiting for rehabilitation. The orthopaedic unit of the Korle-bu Teaching Hospital (KBTH) was selected for the pre-test because the respondents have characteristics similar to those of the respondents of the study setting. It was done to check accuracy, to estimate time and any inconsistency, and corrections were made based on responses from pre-test. Feedback from the pre-test was incorporated into the final version of questionnaire design.

### **Data Collection**

Protocols and questionnaire instructions were explained in detail to the respondents and their written consent was obtained. The questionnaires were administered by the researchers to all those who consented to participate. When respondents had difficulties understanding an item on the questionnaire, they requested and received further clarification and explanations. A translator was hired to interpret and translate information on the questionnaires to respondents who had difficulty reading and understanding the English language. Since the researchers spent several days with the respondents to get the sample size of 200, those who enrolled in the study were given a unique number for easy identification on subsequent visits. The researchers checked and reviewed all the filled-out questionnaires to ensure completeness and consistency of the information collected. The complete data can be accessed from the research repository of the Department of Health Promotion and Disability Studies, at the Kwame Nkrumah University of Science and Technology.

### **Data Analysis**

Statistical analysis was performed using SPSS version 23.0 statistical software package to generate descriptive statistics such as frequency, mean, standard deviation (SD), and cross-tabulations. The results are presented in Tables. The measure of the impact of the activity limitations on the satisfaction of life was determined using logistic regression and correlation analysis.

### **Ethical Considerations**

Ethical approval (Approval number: CHRPE/AP/360/21; Date: 9<sup>th</sup> August 2021) was sought from the Committee on Human Research, Publication, and Ethics, Kwame Nkrumah University of Science and Technology (KNUST). All ethical issues regarding the study's population were adhered to.

An amputee was deemed eligible for this study if he/she provided signed informed consent. The respondents signed or, where necessary, thumb-printed consent forms indicating their willingness to participate. To avoid the invasion of privacy and possible recruitment against their will, they were given the assurance of adhering to routine study schedules, study procedures, and other recommendations throughout the study period. Those who communicated their unwillingness to proceed were allowed to withdraw from participation.

## RESULTS

### Demographic Characteristics of Respondents

A total of 200 upper and lower limb amputees were recruited for the study. Among them, 107 (54%) were males, 102 (51%) were married, and about 49 (24%) were between 31-40 years of age. The majority of the respondents - a total of 78 (39%) - had completed high school. One hundred and twenty people (60%) had prosthesis as part of their rehabilitation programme. Furthermore, a high proportion of the study respondents - 174 (87%) - were lower limb amputees and the majority - 179 (89%) - had unilateral amputation. The findings are summarised in Table 1.

**Table 1: Demographic Characteristics of the Respondents**

Variable	Frequency [n=200]	Percentage (100%)
<b>Age (years)</b>		
18-30	28	14
31-40	49	24
41-50	45	23
51-60	47	24
60+	31	15
<b>Sex</b>		
Male	107	54
Female	93	46
<b>Marital status</b>		
Single/divorced	82	41
Married	102	51
Widow/widower	16	8
<b>Education</b>		
No formal education	25	13
Basic	48	24
Second cycle	78	39

Tertiary	49	24
<b>Type of amputation</b>		
Upper limb amputation	26	13
Lower limb amputation	174	87
<b>Form of amputation</b>		
Unilateral	179	89
Bilateral	21	11
<b>Prosthesis Status</b>		
Prosthesis Non-User	80	40
Prosthesis User	120	60

Source: Author's fieldwork, 2022

### Activity Limitations experienced by Amputees in the Performance of ADLs and IADLs

Generally, the respondents could perform ADLs and IADLs with some difficulty, with an overall mean activity limitation score of  $36.57 \pm 10.93$ . For ADLs, the respondents indicated they could get around in the house ( $2.07 \pm 0.89$ ) and walk outdoors ( $2.28 \pm 0.91$ ) with some difficulty. However, they were able to go up and down the stairs ( $2.69 \pm 0.98$ ) with great difficulty. On IADLs, the respondents revealed that they had some difficulty in preparing breakfast or lunch ( $2.24 \pm 0.93$ ), washing and ironing clothes ( $2.24 \pm 0.94$ ), and doing shopping ( $2.05 \pm 1.18$ ). They also had great difficulty in preparing dinner ( $2.58 \pm 0.92$ ) and doing "light" household activities ( $2.71 \pm 0.76$ ). It is significant to note that most of the respondents said they could not do "heavy" household activities and then only with someone's help ( $3.53 \pm 0.57$ ). Activity limitation scores for the respondents are summarised in Table 2.

**Table 2: Activity Limitation Scores of Respondents**

Groningen Scale	Mean $\pm$ SD	Range (Min-Max)
Overall score	$36.57 \pm 10.93$	18-72
<b>Activity of Daily Living (ADL)</b>		
Dress yourself	$1.29 \pm 0.86$	1-4
Get in and out of bed	$1.61 \pm 0.86$	1-4
Stand up from sitting in a chair	$1.72 \pm 0.96$	1-4
Wash your face and hands	$1.38 \pm 0.78$	1-4
Wash and dry your whole body	$1.63 \pm 0.78$	1-4
Get on and off the toilet	$1.81 \pm 0.84$	1-4

Feed yourself	1.11±0.46	1-4
Get around in the house	2.07±0.89	1-4
Go up and down the stairs	2.69±0.98	1-4
Walk outdoors	2.28±0.91	1-4
Take care of your feet and toenails	1.73±1.01	1-4
<b>Instrumental Activity of Daily Living (IADL)</b>		
Prepare breakfast or lunch	2.24±0.93	1-4
Prepare dinner	2.58±0.92	1-4
Do "light" household activities	2.71±0.76	1-4
Do "heavy" household activities	3.53±0.57	1-4
Wash and iron your clothes	2.24±0.94	1-4
Make the beds	1.96±1.10	1-4
Do the shopping	2.05±1.18	1-4

Source: Author's fieldwork, 2021

### Life satisfaction among Respondents

The respondents indicated moderate life satisfaction with a mean score of  $3.86 \pm 1.15$ . However, vocational situation ( $2.87 \pm 0.96$ ), sexual life ( $2.87 \pm 1.11$ ), financial situation ( $3.31 \pm 1.06$ ), and psychological health ( $2.97 \pm 1.09$ ) of the respondents were shown to be rather dissatisfying. Ability to manage self-care ( $3.75 \pm 0.90$ ), partner relationship ( $3.76 \pm 1.47$ ), physical health ( $3.74 \pm 0.94$ ), and family life ( $4.21 \pm 1.0$ ) were moderately satisfying among the respondents. The level of life satisfaction among the respondents is illustrated in Table 3.

**Table 3: Life Satisfaction among Respondents**

	Mean ±SD	Range (Min-Max)
Life as a whole	3.86±1.15	1-6
My vocational situation	2.87±0.96	1-5
My financial situation	3.31±1.06	1-6
My leisure situation	3.31±1.03	1-6
Contacts with friends and acquaintances	3.57±0.98	1-6
My sexual life	2.87±1.11	1-6
My ability to manage self-care	3.75±0.90	1-6
My family life	4.21±1.0	1-6
My partner relationship	3.76±1.47	1-6
My physical health	3.74±0.94	1-6
My psychological health	2.97±1.09	1-5
Overall	38.22±6.82	23-61

Source: Author's fieldwork, 2021

## Relationship between Activity Limitation and Life Satisfaction among Amputees

A multivariate analysis was used to establish the relationship between activity limitation and life satisfaction. The multivariate analysis revealed that there was a strong negative statistically significant relationship between activity limitations and life satisfaction ( $\beta = -0.13$ ,  $p=0.000$ ) when all variables were held constant. The findings are summarised in Table 4.

**Table 4: Crude and Adjusted Linear Regression Model for the Effects of Activity Limitation on Life Satisfaction (adjusting for essential cofounding variables)**

Variable	N	Univariate Analysis			Multivariate Analysis		
		Crude $\beta$	95% CI	p-value	Adjusted $\beta$	95% CI	p-value
<b>Age (years)</b>							
18-30	28	Ref.					
31-40	49	-2.45	-5.1-0.61	0.116	-2.66	-5.43-0.11	0.06
41-50	45	1.05	-2.05-4.17	0.505	-0.32	-3.22-2.57	0.825
51-60	47	-1.12	-4.21-1.96	0.473	-3.32	-6.26-(-0.37)	<b>0.027*</b>
60+	31	-5.39	-8.7-(-2.02)	<b>0.002*</b>	-5.37	-8.84-(-1.92)	<b>0.003*</b>
<b>Sex</b>							
Male	107	Ref.					
Female	93	.72	-1.19-2.63	0.456			
<b>Marital status</b>							
Single/divorced	82	Ref.					
Married	102	4.18	2.28-6.1	<b>0.000*</b>	4.82	2.99-6.66	<b>0.000*</b>
Widow/widower	16	-0.09	-3.60-3.43	0.962	1.9	-1.54-5.52	0.268
<b>Education</b>							
No formal education	25	Ref.					
Basic	48	2.91	-0.38-6.20	0.083			
Second cycle	78	0.34	-2.72-3.41	0.828			
Tertiary	49	2.22	-1.06-5.50	0.183			
<b>Location</b>							
Upper Limb Amputation	26	Ref.					
Lower Limb Amputation	174	0.11	-2.72-2.95	0.08			
<b>Form</b>							
Unilateral	179	Ref.					
Bilateral	21	-8.91	-11.76-(-6.06)	<b>0.000*</b>	-5.97	-9.05-(-2.90)	<b>0.000*</b>
<b>Groningen score</b>							
Activity limitation	200	-0.21	-0.29-(-0.13)	<b>0.000*</b>	-0.13	-0.211-(-0.04)	<b>0.003*</b>

$\beta$ =beta coefficient, \*Significant, CI=Confidence Interval



## DISCUSSION

A total of 200 upper and lower limb amputees participated in the study. Most of them - 120(60%) - had a prosthesis and most of them were using their device. There were 93 (46.5%) female amputees as compared to 107 (53.5%) male amputees. Most of the respondents were in the age bracket of 31-40 years (24.5%). A similar study conducted in Ghana reported that more males were part of the study as compared to females, but reported an older amputee population group of 41–60 years (60%) (Amoah et al, 2018), as compared to the findings in the current study. Also, a recent study conducted in Nigeria showed that males constitute the greatest percentage of amputees in Kano (Bello et al, 2020). Furthermore, a similar finding in a study of Asians showed that the incidence of amputation is 1.2 per 10, 000 women to 4.4 per 10 000 men in the Navajo nation in the USA (Burger & Marincek, 2007). A higher proportion of the study respondents were lower limb amputees (87.0%), and the majority (89.5%) had unilateral amputation. This means that lower limb amputees in this study were more than upper limb amputees, with majority of the amputations affecting a single limb. A study among amputee population in Nigeria reported similar findings; that about 90% of all amputations were lower limb amputations and involved only one of the lower limbs (Bello et al, 2020). This finding is also reported in the work by Rachmat et al (2019), that amputation more often happens in men than in women and that amputation in the lower limbs comprises the majority (85-90%) of all amputations.

On activity limitations, generally, the respondents could perform ADLs and IADLS with some difficulty and limitations. A similar study conducted among older amputees in Nigeria, within the age group of 40-60 and >60 years, revealed higher levels of activity limitations (Bello et al, 2020). This suggests that higher age and amputation reinforce the level of activity limitation and difficulty. For Activities of Daily Living (ADLs), it was evident that the respondents experienced limitations in mobility-related activities. The respondents indicated they could manage getting around in the house and walking outdoors with some difficulty, while they could go up and down the stairs with great difficulty. This limitation was expected, since lower limb amputation impacts negatively on physical activity and function, and general health, compared to the general population. Several studies have postulated that compared to the population without disability, amputees walk slower and with a larger energetic penalty (Paysant et al, 2006; Gates et al, 2012), with about 60% of the affected population citing an inability to walk on uneven terrain as a major limitation (Hagberg &

Branemark, 2001). Also, it is reported in the literature that amputation has a great influence on many activities and has resulted in participation restriction in various activities that people used to do (Kakooza et al, 2020). The respondents experienced limitations in almost all the Instrumental Activities of Daily Living (IADLs). They revealed that they experience limitations in preparing breakfast or lunch, washing and ironing clothes, and doing shopping. They however experienced great difficulty in preparing dinner and doing “light” household activities respectively. It is worth mentioning that the respondents indicated that doing “heavy” household activities was almost impossible and required help or assistance. This can be attributed to the fact that the activities listed above require higher physical energy and exertion to complete, as the literature reports that amputation leads to threefold loss of function in the individual (Razak et al, 2016). A similar study reported that major limb amputees typically have reduced mobility which affects their ability to perform daily tasks and to successfully reintegrate into community life (Cox et al, 2011). This finding further agrees with a study conducted among upper limb amputees which reported that the simple task of cutting a tomato to make a sandwich becomes difficult as there is no way to keep the tomato stable to cut it. Pouring a glass of water can also be difficult as the other hand is not able to stabilise the cup to stop the water from spilling (Sproats et al, 2013). The respondents reported a moderate life satisfaction score. This finding agrees with the findings of Dias (2006) who, in a Portuguese sample, found that amputees were moderately satisfied with life, but it contradicts the work of Pereira et al (2018) which revealed that individuals were dissatisfied with their life. The respondents in the current study generally showed moderate satisfaction in the areas of management of self-care, relationship with partners, physical health, and family life. This could be attributed to the fact that most of the respondents were receiving caregiving support from their relatives (family) who help with self-care management most of the time. The satisfaction with physical health could also be attributed to the fact that the respondents were receiving rehabilitation from the facility. The services they were receiving were medical, physical, and occupational therapy services, which focus primarily on the diagnosis, correction, and treatment including the provision of assistive devices such as orthotics and prosthesis as well as wheelchairs, and training on the use of these devices. Majority of the amputees recruited for the study were back at the facility for a review of previous rehabilitation interventions they had already received. These findings agree with the views and experiences that were reported by Rachmat et al (2019) wherein it was stated that the most affected

attributes of amputees are their reduced physical capacity, poor general health, and pain, for which rehabilitation services are sought. The findings of the current study concerning the moderate satisfaction of lower limb amputees on partner relationships and family life, complements the findings by Geertzen and Dijkstra (2009) who reported that lower limb amputation limits a person's performance of marital activities, including expression of sexual feelings between partners.

On the subject of life satisfaction, the respondents reported that their vocational situation, sexual life, financial situation, and psychological health were rather dissatisfying. This could probably be due to the rehabilitation centre primarily focussing on the physical limitations of the respondents, but not on their economic, emotional and psychological needs. This finding agrees with a study that investigated the experiences of amputees and reported that due to the traumatic events, amputated victims go through psychological torture and loss of employment (Kakooza et al, 2020). Furthermore, another study reported that peoples' lifestyles are forced to change due to disability caused by amputation, and sources of earning a living partially or badly affected (Mugo, 2010). Also, evidence suggests that in addition to lowering lifestyle quality, limb amputations are financially taxing to both clients and healthcare systems (Jindeel & Narahara, 2012; Joret et al, 2016). On sexual life, these findings agree with Williamson and Walters (2010) who stated that for some people with amputation, achieving the desired sexual position with a partner can be troublesome. Research also suggests that individuals with physical disabilities experience problems in forming and maintaining intimate, romantic, and sexual relationships (Taleporos & McCabe, 2001). In determining whether activity limitations have direct impact on life satisfaction, it was revealed that there was a strong statistical relationship between activity limitations and life satisfaction. This means that the more a person is limited in the execution of ADLs and IADLs, the more dissatisfied the person is with various life domains. It thus means that activity limitation is a predictor or determinant of life satisfaction. Dias (2006) found similar results and reported a significant and positive relationship between life satisfaction and the health status domain, such as physical functioning in amputees. A study conducted among an aged population with physical disabilities including amputations reported contradictory results and stated that there was no significant association between activity limitations and life satisfaction (Jørgensen et al, 2017). However, Blace (2012) reported that individuals with higher mobility impairment are more likely to report lower life satisfaction. In a study of life satisfaction among amputees by Pereira et al (2018) similar findings were reported that the experience of mobility

difficulties in amputees may predispose individuals to be less satisfied with their life.

## **Limitations**

Due to its cross-sectional nature, this study failed to establish the relationship between the demographic characteristics and activity limitations as well as life satisfaction. The researchers believe this could have directly influenced respondents' responses. However, a longitudinal study would be required to establish this. Another limitation is that the study population is not representative of the general population of amputees.

## **CONCLUSION**

Amputation has a significant impact on activity limitations and life satisfaction. The amputees experienced some limitations when performing ADLs and IADLs. Most of the activities with which they had difficulty and limitations are mobility-related activities for ADLs and the more complex activities of IADLs, such as preparing breakfast and dinner, doing light and heavy household activities, washing and ironing, making beds and shopping. The life satisfaction of respondents was moderately satisfying. The amputees showed dissatisfaction in their vocational situation, sexual life, financial situation, and psychological health, as compared to family life, partner relationship, and physical health that were very satisfying. There was a statistically significant relationship between activity limitations and life satisfaction; therefore, the more an amputee experiences limitations in ADLs and IADLs, the less satisfied he/she is with life.

## **Implications**

The loss of a limb has severe implications for a person's mobility and ability to perform activities of daily living. This negatively impacts their participation, integration into society and quality of life. The goal of rehabilitation after amputation is to train the individual to ambulate successfully, return to a high level of activity performance and social reintegration. It is therefore recommended that the Ministry of Health and its agencies such as the Ghana Health Service (GHS), and stakeholders such as the medical and rehabilitation professionals who are involved in the management of amputees, must explore the amputees' limitations and difficulties in engaging and performing activities; this is required to inform the planning and preparation of a comprehensive

rehabilitation programme. This can be done through a transdisciplinary team of various rehabilitation professionals and stakeholders. The country must adopt a comprehensive rehabilitation programme which clearly focuses on pre-operative preparation, amputation surgery and acute post-surgical management, prosthetic assessments, prescription and training, community integration, vocational rehabilitation and follow-up. It is highly recommended that throughout all these phases, rehabilitation professionals ensure that a rehabilitation treatment plan is well utilised together with service users to guide the care of an individual who has undergone an amputation and to adapt to their needs and perspectives. It is further recommended that rehabilitation interventions start from the date of admission to the hospital or rehabilitation centre, through to discharge and integration into the community, with a focus on addressing disabilities or activity limitations as a consequence of amputations, to improve the overall satisfaction and quality of life of the amputee population. Furthermore, practitioners such as doctors, rehabilitation nurses, occupational therapists, physiotherapists and social workers who extend care to the amputee population need to seek training programmes that will improve their skills, if they are to contribute significantly to the lives of the amputee population. This can be done in the form of workshops, seminars, CPD programmes and attending further studies.

## ACKNOWLEDGEMENT

The authors thank the study's participants and the staff of Nsawam Orthopaedic Training Centre for their support and cooperation.

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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# Assessment of Demographic Variables affecting Teacher Attitudes towards Inclusive Education in Ghana

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## ABSTRACT

**Purpose:** *This study examined teachers' attitudes towards the inclusion of learners with special educational needs in three schools in the Central Region of Ghana.*

**Method:** *The study adopted a cross-sectional survey involving 142 teachers (68 female teachers and 74 male teachers) selected from two special schools and one inclusive school in the Central Region of Ghana. Independent T-test and one-way ANOVA measures were used for data analysis.*

**Results:** *Age was found to be the most influential factor in determining teacher attitudes towards inclusion. Female teachers (48%) were more positive in overall attitudes than male teachers (52%). Younger teachers, who were between 20-30 years old and classroom teachers, were associated with positive attitudes towards learners with special educational needs. However, the level of education and length of professional service did not affect teacher attitudes towards these students.*

**Conclusion:** *The study concluded that, in general, educators in special schools and inclusive schools in the Central Region of Ghana have a positive attitude towards learners with special educational needs. Further in-service training for these teachers is recommended, as a means of improving teacher attitudes towards inclusion in Ghana.*

**Key words:** *attitudes, inclusive education, Ghana, special needs, developing countries*

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## INTRODUCTION

Inclusive education is a multi-faceted concept that seeks to appreciate the differences and diversity of learners while considering human rights, social justice, and equity, which are based on the social model and human rights models of disability (Artiles et al, 2006; Forlin et al, 2011). Inclusive education considers the needs of all learners and offers support by modifying the learning environment including the curriculum, physical classroom environment, pedagogy, and assessment techniques (Murdaca et al, 2018). Therefore, attitudes of teachers towards learners with special educational needs and children with disabilities should focus on how accessible and acceptable the learning environment is. Research on attitudes towards inclusive education and attitudes towards learners with special educational needs are abundant globally (Avramidis and Norwich, 2010; Mwaimba, 2014; Randiki, 2015; Deku & Vanderpuye, 2017; Ofor & Akinlosotu, 2017) but are scarce in sub-Saharan Africa. Meanwhile, teacher attitudes have been identified as decisive in successfully implementing inclusive education (Dulčić & Bakota, 2008; De Boer et al, 2011; Schmidt & Vrhovnik, 2015) because teacher attitudes affect how teachers readily accept the concept of inclusion and adapt teaching methods, strategies, and teaching environments to assist learners with special educational needs (Ryan, 2009). Positive teacher attitudes towards learners with special educational needs have been reported to positively impact teaching and learning in mainstreamed and inclusive educational settings, while negative attitudes have also been linked with ineffective teaching and learning which largely is associated with teacher apathy towards implementing inclusive educational practices (Avramidis and Norwich, 2010). Murdaca et al (2018) have noted that the successful implementation of inclusion requires a range of changes in the methods of teaching, pedagogy, and assessment, which rely not only on effective collaboration between the home, teachers, school, and the community, but also on teachers' attitudes and educational backgrounds. This study thus examined teacher attitudes at various periods of their professional service to determine whether their age, gender, and teacher designation affected their attitudes towards learners with special educational needs in Ghana.

The explanations for negative teacher attitudes have been extensively studied and it is reported that they are not only typically related to personal variables such as teachers' sex, age, training, length of professional service, or perceptions of disabilities (Scruggs & Mastropieri, 1996; Avramidis and Norwich, 2010; De Boer et al, 2011; Vanderpuye et al, 2018), but also to the severity of a



student's disability (Avramidis & Kalyva, 2007) and the teacher's role or designation (Moberg, 2003; Hernandez et al, 2016). Other studies have also reported relationships between teacher attitudes (Dupoux et al, 2005) and gender of teachers (Alghazo & Naggar Gaad, 2004), the severity of the learner's disability (Langdon & Vesper, 2000), values and beliefs of teachers (Dupoux et al, 2005), and training and teaching skills of teachers (Alghazo & Naggar Gaad, 2004; Haq & Mundia, 2012).

It has been generally reported that female teachers are more sensitive and positive about learners with special educational needs than their male counterparts. In a survey with 138 participants, AlMahdi and Bukamal (2019) reported that female teachers showed better attitudes towards learners with special educational needs than their male colleagues (Avramidis et al, 2000; Hodge & Jansma, 2000; Opdal et al, 2001; Ellins & Porter, 2005; Forlin et al, 2009). In a study with 122 teachers, Alghazo and Naggar Gaad (2004) found that male teachers used more negative terms such as "handicapped" or "stupid" in describing learners with special educational needs, compared to female teachers who used milder and more positive words like "less able" or "children with disabilities". Also, in a study involving 1155 participants, Romi and Leyser (2006) analysed pre-service teachers' attitudes and reported that female teachers were more positive towards learners with special educational needs than their male counterparts. Similarly, Saloviita (2020), in a survey of 4567 classroom teachers, reported that female teachers showed better attitudes toward learners with special educational needs than male teachers. Other studies (Avramidis et al, 2000; Hodge & Jansma, 2000; Opdal et al, 2001; Ellins & Porter, 2005) have also described female teachers' attitudes towards inclusion of learners with special educational needs as more positive than the attitudes of male teachers.

In contrast, Alhassan (2014) has reported no gender differences in attitudes among 108 teachers from two districts in Ghana who participated in a study. Other researchers (Van Reusen et al, 2000; Carroll et al, 2003; Parasuram, 2006; Al-Zyoudi, 2006; Varcoe & Boyle, 2013) have also reported no differences between both male and female teachers' attitudes towards learners with special educational needs. These inconsistencies in the attitudes between male teachers and female teachers towards inclusive education have also been reported by Avramidis et al (2000) and Bailey et al (2015).

The age of a teacher has also been reported to affect teacher attitudes towards the inclusion of learners with special educational needs. Tabakhmelashvili

(2008) indicated that older teachers showed more negative attitudes to inclusion than younger teachers did. Mashiya (2003) explains that ageing teachers and educators did not adapt to modern teaching approaches for learners with special educational needs and this led to their negative attitudes. In contrast, Nyaigoti (2013) has stated that older teachers were found to have better attitudes than younger teachers, possibly due to their experience in teaching learners with special educational needs throughout their careers. Meanwhile reports from other studies have suggested that teachers' age did not in any way influence attitudes in inclusive and special school settings (Tůmová, 2012; Dukmak, 2013). In Ghana, since learners with special educational needs have teachers from different age groupings, knowledge of these characteristics is essential.

The length of professional service has further been reported to influence teacher attitudes towards inclusion. Familiarity with learners with special educational needs affects teachers' behaviour in both inclusive and special schools. Experienced teachers showed better comprehension in their attitudes towards special education needs children; therefore, Avmaridis and Norwich (2010) and Leyser and Tappendorf (2001) have stated that teacher attitudes are not closely linked to any other predictor than the cumulative years of experience in teaching learners with special educational needs. For instance, Schuster (2013) found that older and more experienced teaching staff in Saskatchewan had positive attitudes towards learners with special educational needs. Similarly, in Kenya, teachers with longer teaching experience reported more tolerance and confidence in addressing learners with special educational needs in their classrooms (Mwaimba, 2014; Ofor & Akinlosotu, 2017). Lambe and Bones (2006), on the other hand, claimed that fewer teachers with less experience, such as pre-service teachers who had no contact with learners with special educational needs, were more optimistic about inclusion than teachers with more experience. In support of this, Dukmak (2013) believes that positive teacher attitudes to inclusion are inversely related to the length of professional service.

Schuster (2013) has noted that teachers working in rural areas are more likely to show more positive attitudes towards learners with special educational needs than their counterparts in urban areas, because they are more in contact with and comfortable with the children. In a report on inclusive education in rural schools, nevertheless, Moreno et al (2015) revealed that teachers in rural areas do not take full advantage of the background in which they are situated, thereby portraying negative attitudes towards learners with special educational needs.

Florian (2012) again claims that general classroom teachers viewed inclusion as a hindrance to other children's successful education, so they were more negative in their attitudes than special education teachers. However, Dukmak (2013) explored regular classroom teachers' attitudes towards the inclusion of children with disabilities in the United Arab Emirates and reported that generally all teachers, whether regular, special, or subject teachers, were positive towards inclusion, with male teachers being more positive than female teachers. Saloviita (2020) reported statistically significant variations in attitudes of special education teachers and subject teachers, with special education teachers scoring the highest and subject teachers scoring the lowest in a one-way ANOVA (analysis of variance) test.

## **Objective**

This study examined how different demographic variables (gender, age, level of education, length of professional service, and teacher designation) affect the inclusion of learners with special educational needs in inclusive and special schools in Ghana.

## **METHOD**

### **Study Design**

The study adopted a cross-sectional survey using a modified version of the Teachers' Attitude to the Special Need Students Questionnaire -TASNSQ (Offor & Akinlosotu, 2017) for data collection.

### **Study Sample**

Among the 142 teachers who participated in the study, 68 (48%) were female teachers and 74 (52%) were male teachers. The teachers, aged between 20 years and 59 years, taught in Early grade, Upper Primary or Junior High School. They were sampled using the census sampling technique (see Table 1). Selected schools were stratified, with Schools A and C as special schools for the Deaf/ Blind and School B as an inclusive school.

**Table 1: Demographic Information of Participants**

Variables		N	%	X	SD
Age	20-30	24	16.9	0.5	4.2
	31-40	36	25.4	47.6	4.0
	41-50	42	29.6	48.0	3.2
	51+	40	28.2	46.7	5.7

### Data Collection

The questionnaire was divided into two parts. Part A collected information on the personal data of teachers, such as sex, age, educational level and teaching experience, teacher designation and type of school. Part B contained 21 items which were rated on a 4-point Likert scale as Strongly Agree (SA) - 1, Agree (A) - 2, Disagree (D) - 3, and Strongly Disagree (SD) - 4. The Cronbach alpha ( $\alpha$ ) was used to measure the reliability of the instrument and yielded a reliability coefficient of 0.707.

All questionnaires were self-administered and returned to the researchers on the same day as they were given out. On-site field checks ensured that the participants answered each item on the questionnaire. The questionnaire was completed in about 20 minutes.

### Data Analysis

The independent sample t-test and one-way ANOVA were used to test the relationships between variables in the study and the total teacher attitudes. The total attitude was set as the dependent variable while gender, age, length of professional service and teacher designation were the independent variables in the study.

### Ethical Considerations

Permission to conduct the study and consent was sought from the heads of all institutions and teachers before questionnaires were administered. The teachers who did not agree were excluded from the study.

## RESULTS

### a) Gender

An independent sample t-test was performed to compare the male and female teachers' attitudes and designation of teachers toward inclusion (see Table 2). A

significant difference in male teachers' attitudes ( $M=46.80$ ,  $SD=4.72$ ) and female teachers' attitudes ( $M=49.19$ ,  $SD=4.05$ );  $t(140) = -3.230$ ,  $p = 0.002$ , was recorded. This result suggests that gender affects teachers' attitudes toward inclusion. Specifically, female teachers' attitudes were more positive than their male counterparts.

**Table 2: Independent Sample T-test on Gender Effect on Teachers' Attitudes towards Learners with Special Educational Needs**

Variables	Total n (%)	Attitude of teachers towards inclusion				
		M	SD	F	df	p-value
<b>Gender</b>				0.500	140	.002**
Female	68(47.9)	46.80	4.72			
Male	74(52.1)	49.19	4.05			

\*\*  $p < .01$

### b)Teacher Designation

In terms of the designation of teachers, this study recorded a significant difference between attitudes of subject teachers ( $M=47.19$ ,  $SD=3.92$ ) and classroom teachers ( $M=48.86$ ,  $SD=5.11$ );  $t(140) = -2.199$ ,  $p = 0.030$  (see Table 3). This means that classroom teachers were more positive towards inclusion than subject teachers.

**Table 3: Independent Sample T-test on Effects of Teacher Designation on Teachers' Attitudes towards Learners with Special Educational Needs**

Variables	Total n (%)	Attitude of teachers toward inclusion				
		M	SD	F	df	p-value
<b>Designation of Teacher</b>				1.614	140	.030*
Female	68(47.9)	47.19	3.92			
Male	74(52.1)	48.86	5.11			

\*  $p < .05$

### c) Age

The study used a one-way between subjects ANOVA to compare the effects of age, level of education, and length of professional service on teacher attitudes toward inclusion (see Table 4). The effect of age on teacher attitudes was statistically significant at the  $p < .05$  level for the age ranges [ $F(3, 138) = 3.916$ ,  $p = 0.010$ ]. A Post Hoc comparison using the Turkey HSD test showed that the mean score for the 20-30 age group ( $M=50.50$ ,  $SD=4.220$ ) was significantly different from the

age group above 50 years ( $M=46.65$ ,  $SD=5.75$ ). However, the 31-40 age group ( $M=47.56$ ,  $SD=4.05$ ) did not differ significantly from the 41-50 age group ( $M=48.05$ ,  $SD=3.22$ ). These results suggest that attitudes towards inclusion are influenced by age of the teacher. Specifically, the findings of this study showed that teachers' attitudes towards inclusion are more positive when teachers are younger, and there is a decline when they are older and closer to retiring. It is also revealed that mid-year age groups did not appear to significantly affect teacher attitudes towards inclusion.

**Table 4: One-way ANOVA Results on the Effects of Age on Teacher Attitudes towards Learners with Special Educational Needs**

Variables	Total sample n (%)	Attitude of teachers towards inclusion of Learners with Special Educational Needs				
		M	SD	F	df	p-value
<b>Age</b>				3.916	3	.010*
20-30	24(16.90)	50.50	4.22			
31-40	36(25.35)	47.56	4.05			
41-50	42(29.58)	48.05	3.22			
51+	40(28.17)	46.65	5.75			

\*  $p < .05$

#### d) Level of Education

By comparing the effects of the level of education on teachers' attitudes towards inclusion, the study reported no statistically significant differences at the  $p < .05$  level for the four conditions [ $F(3, 138) = 0.665$ ,  $p = 0.575$ ] (see Table 5). This suggests that the level of education of a teacher does not influence the attitude towards inclusion.

**Table 5: One-way ANOVA Results on the Effects of Level of Education on Teacher Attitudes towards Learners with Special Educational Needs**

Variables	Total sample n (%)	Attitude of teachers towards inclusion of Learners with Special Educational Needs				
		M	SD	F	df	p-value
<b>Level of Education</b>				0.665	3	.575
Teacher's Cert A	2(1.41)	50.50	0.71			
Diploma	30(21.13)	47.23	5.76			
Bachelor's	98 (69.01)	47.98	4.20			
Master's degree	12(8.45)	49.00	4.35			



### e) Length of Professional Service

In addition, this study reported no significant effect of length of professional service on teacher attitudes towards inclusion at  $p < .05$  for four conditions [ $F(3, 138) = 1.481, p = .222$ ] (see Table 6). This suggests that in special schools and inclusive schools in Ghana, the length of professional service does not affect teachers' attitudes towards inclusion.

**Table 6: One-way ANOVA Results on the Effects of Length of Professional Service on Teacher Attitudes towards Learners with Special Educational Needs**

Variables	Total sample n (%)	Attitude of teachers towards inclusion of Learners with Special Educational Needs				
		M	SD	F	df	p-value
<b>Length of Professional Service</b>						
0-5	57(40.14)	47.87	3.97	1.481	3	.222
6-10	25(17.61)	49.60	2.94			
11-15	18(12.68)	47.33	3.76			
16+	42(29.57)	47.33	6.06			

\*  $p < 0.05$

## DISCUSSION

Findings from this study suggest that gender affects teacher attitudes toward inclusion. Analysis from the independent sample t-test performed to compare the teacher attitudes showed a significant difference in favour of female teachers. These findings are consistent with reports by AlMahdi and Bukamal, (2019) and Saloviita (2020) that female teachers' attitudes towards inclusion were better than the attitudes of male teachers. Similarly, Ellins and Porter (2005) confirmed this by reporting that male teachers' attitudes were more negative than those of female teachers. The Index for Inclusion (Booth & Ainscow, 2002) defines inclusion as perceiving student differences as a resource to assist learning rather than as a problem to be solved; however, in this study, findings indicate this was not necessarily the view of male teachers. In the Ghanaian culture, women are more hospitable and accommodating of children with disabilities and learners with special educational needs, than men. For instance, anecdotal evidence suggests that mothers rank higher than fathers in terms of clinical attendance and follow-up services when it involves children with disabilities. It is therefore common for mothers of children with disabilities to take care of their children without support from men, as men generally consider this responsibility a burden. This provides

a plausible explanation as to why the current study reported more positive female teachers' attitudes toward inclusion than that of their male counterparts. In contrast, Alhassan, (2014) reports no gender differences in attitudes among 108 Ghanaian teachers who participated in a study from two districts in Ghana.

The current study reported a significant effect between age and teachers' attitudes towards inclusion at the  $p < .05$  level for the age ranges. To support this finding, Mashiya (2003) and Tabakhmelashvili (2008) reported that older teachers were more negative towards inclusion than younger teachers. For junior teachers a transition from learning to teaching occurs, and this forms an integral part of their life. Junior teachers often try to build their identity based on their beliefs about what an ideal teacher should be, according to Rodgers and Raider-Roth (2006), and thus offer their best to students. Therefore, when teachers are younger, they are more enthusiastic to serve than when they are older and closer to retiring. This could explain the finding of the current study. In contrast, Nyaigoti (2013) found older teachers to have better attitudes than younger teachers, possibly because of the experiences they have gained in teaching learners with special educational needs during their careers. This may explain why the results indicate that the age of the teacher influences attitudes towards inclusion. The findings of the current study are in contrast to the findings of Dukmak (2013) and Tůmová (2012) who have reported that teachers' age did not influence attitudes towards learners with special educational needs in inclusive and special school settings.

Also, the findings of the current study report no significant effect between teachers' attitudes towards inclusion and their level of education [ $F(3, 138) = 0.665, p = 0.575$ ] and cumulative length of professional service [ $F(3, 138) = 1.481, p = 0.222$ ] at the  $p < .05$  level for the four conditions. This puts forward the suggestion that a teacher's educational level does not affect the attitude towards inclusion. The finding is contrary to the report of Parasuram (2006) that teachers who are Master's degree holders showed more positive attitudes than teachers who were Bachelor's degree holders or were Higher Secondary Certificate holders. In Ghana, teachers in inclusive or special schools take a mandatory course in introduction to special education during their training at the diploma level, degree level and Master's level. The current study's finding is consistent with other studies by Villa et al (1996), Hastings and Oakford (2003), and Monsen et al (2014). This finding however contradicts the findings of Leyser and Tappendorf (2001) who reported that there is no other variable closely related to teacher attitudes towards learners with special educational needs than the overall years of teaching experience.

Again, Lambe and Bones (2006) believed teachers with less experience, like pre-service teachers and teachers who had little or no prior interaction with learners with diverse special educational needs, were more optimistic about inclusion than more experienced teachers. Therefore, it is reasonable to assume that participants in this study had previous knowledge of inclusion, and this could explain why the level of education and length of professional service did not affect the teacher attitudes.

It was worth noting the significant difference in the attitudes of subject teachers and classroom teachers, as classroom teachers showed more positive attitudes towards inclusion than subject teachers. This finding is consistent with reports by Saloviita (2020) who found that subject teachers scored the lowest concerning child-centredness and self-efficacy. Classroom teachers spend more time with learners with special educational needs than subject teachers do. They constantly monitor their academic achievements and observe children both in classroom and out-of-class situations, such as during sporting activities. Classroom teachers, therefore, learn about the strengths and weaknesses of children and are constantly looking for ways to improve their performance. It is therefore acceptable for classroom teachers to understand the requirements of learners with special educational needs better than subject teachers do. The development of inclusive teaching and learning methods that respect student differences is essential to inclusion. Regardless of their background or personal characteristics, all educators must create a space where all learners feel supported and included, by valuing and embracing diversity. Additionally, teachers who are knowledgeable about culturally responsive pedagogy can modify their lesson plans to guarantee that all students have access to enriching educational opportunities. However, the current finding differs from the findings of Dukmak (2013) who reports that, in general, all teachers, whether regular, special, or subject teachers, displayed positive attitudes towards inclusion in education.

The average mean score shown in Table 4 above indicates that teachers have a positive view of 20 items at a mean of  $1.85 \pm 0.76$  but disagreed with item 2 ( $1.24 \pm 0.57$ ). The average mean is also higher than the cut-off means ( $1.88 > 1.25$ ). The study, therefore, concluded that educators in special schools and inclusive schools in the central region of Ghana have a positive attitude towards learners with special educational needs.

## CONCLUSION

The assessment of demographic variables affecting teacher attitudes towards learners with special educational needs has increasingly become necessary for modifying inclusive practices in all educational settings in Ghana. Teacher demographic variables can impact the teaching and learning process, especially for learners with special educational needs. On this basis, the authors of the study recommend that teacher training institutions in Ghana can help to demystify biases in teaching such students. The index for inclusion (Booth & Ainscow, 2002) could serve as a good school development guide for schools and educators. Also, training on inclusion should be intensified among pre-service and in-service teachers in Ghana, and the content for training courses should also make room for critical discourse on topics and principles of inclusion and teaching effectiveness. Through in-service training programmes, teachers will be equipped to concentrate on cooperative learning and instructional approaches, knowledge analysis and alternative evaluation strategies for learners with special educational needs. Finally, pre-service training for teachers on the education of learners with special educational needs should begin with a vision of inclusion that stresses that inclusive education does not only contribute to the benefit of students with disabilities but also to the promotion of higher education.

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# Searching for Jobs: Experiences of Persons with Disabilities in the Komenda- Edina- Eguafo - Abirem Municipality of Ghana

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## ABSTRACT

**Purpose:** *This study investigated the job search experiences of persons with disabilities in the Komenda- Edina- Eguafo- Abirem Municipality in central Ghana, in order to identify measures to improve their employability.*

**Method:** *The study was qualitative with a descriptive design. Purposive sampling was used to include people with visual disabilities, people who are deaf and people with physical disabilities who had searched for jobs. Face-to-face interviews were conducted in the local language (Fante) and were audio- and video- recorded. The recorded interviews were then transcribed and translated from Fante to English. Data was analysed using thematic analysis. The transcribed data was coded, grouped into categories, refined, and then organised into various themes based on the study objectives.*

**Results:** *Findings revealed that employers had negative attitudes towards job-seekers with disabilities. They had low expectations of them, feeling pity rather than considering them productive. This resulted in persons with disabilities being pushed into low paid jobs and feeling dissatisfied. The negative attitude of employers deterred many such job-seekers and they opted for self-employment. Inaccessible workplaces and lack of access to information were also reported as major barriers.*

**Conclusion:** *Negative attitudes of employers towards job-seekers with disabilities have not changed despite legal efforts being made to change negative perceptions. It is recommended that stakeholders should intensify public*

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*education on disability issues. The working environment and information on job opportunities and protocols should also be made accessible to persons with disabilities by enforcing provisions in the Persons with Disability Act.*

**Key words:** *accessibility, barriers, employment, attitudes, persons with disabilities*

## INTRODUCTION

Persons with disabilities constitute a substantial component of the population whose needs should be considered in national planning. Around one billion people world-wide have some form of disability (World Bank, 2021) with greater prevalence rates in developing countries (Hanass-Hancock et al, 2017). The 2021 Population and Housing census of Ghana shows that about 8% (2,098,138) of people, 5 years and older, of the population have varying degrees of disability (Ghana Statistical Service, 2023). This is about 3 times the percentage recorded in the 2010 Population and Housing census. Though Ghana's 2021 Population and Housing census report, currently available, is silent on the percentage of persons with disabilities who are unemployed, the 2010 Population and Housing census estimated that 54.1% of persons with disabilities aged 15 years and older are employed (Ghana Statistical Service, 2014). The percentage of unemployed people with disabilities if left unproductive will increase the dependency ratio and place a heavier burden on the working population and society in general. Enhancing the employment of persons with disabilities can help improve their standard of living and reduce the rate of poverty and the number of poor people. Hayes et al (2016) argued that employment does not only help in providing necessities of life, but also gives social recognition and increases the level of social inclusion of persons with disabilities. This view was reiterated by Nota et al (2014) who indicated that work is a crucial issue in the lives of persons with disabilities because it helps them construct their identities and find meaning in life.

The importance of work has been highlighted in the Universal Declaration of Human Rights. Article 23 (1) of the Declaration states that everyone has the right to work, free choice of employment, and favourable conditions and protection against unemployment (United Nations, 2013). However, persons with disabilities hardly have access to the labour market and its economic benefits due to discrimination from employers (Choruma, 2007). The negative attitude of employers, arising from misconceptions about disability and stigma as well as doubts about the capabilities of persons with disabilities, has limited access to

jobs for persons with disabilities. That is, the erroneous perception that a worker with a disability may not be as productive as an employee without a disability has led to employers refusing to employ persons with disabilities (Bamber et al, 2004). This creates unemployment among persons with disabilities.

Despite the fact that persons with disabilities have the right to work and there are several policies and legal provisions backing these rights, little has been achieved regarding the employment of persons with disabilities (International Disability Rights Monitor, 2004). Caswell et al (2003) reported that there are many legislative instruments providing employment quotas for persons with disabilities. Unfortunately, these legislations are underutilised or not enforced, leading to a high unemployment rate among persons with disabilities in society.

For instance, the Washington Times (2005) found that in developing countries 80% - 90% of persons with disabilities of working-age are unemployed, whereas in industrialised countries the figure is between 50% and 70%. Also, a study by the Organisation for Economic Co-operation and Development (OECD) showed that in developing countries, working-age persons with disabilities experienced significant labour market disadvantages and worse labour market outcomes than working-age persons without disabilities (OECD, 2010). Similarly, working-age people with disabilities have been found to have much lower employment rates than people without disabilities in both developed and developing countries (WHO, 2011). This has led to poor living standards among persons with disabilities. For instance, the United Nations (2009) estimated that about 20 % of persons with disabilities live on less than 1US\$ a day due to unemployment. For this reason, Thomas (2005) argued that persons with disabilities would continue to depend on others for survival since it would be difficult for them to benefit from jobs and escape poverty. Previous studies on employability of persons with disabilities have focused on perspectives of employers (Avoke, 2002; Roessler & Rumrill, 2003; Opoku-Boadi, 2015), that is, willingness of employers to employ persons with disabilities. The current study therefore focused on the job search experiences of persons with disabilities, taking into consideration their own perspectives, in the Komenda- Edina- Eguafo- Abirem municipality.

The current study therefore focused on the experiences of persons with disabilities in their job search.

## Objective

The study examined the job search experience of persons with disabilities, from their own perspectives, in the Komenda-Edina-Eguafo-Abirem municipality of Ghana. It focused on the challenges encountered by these job-seekers and how this influenced their search for jobs in the future.

## METHOD

### Study Design

This was a qualitative study, using a descriptive study design. According to Ary et al (2002), this design helps to study humans and their behaviour effectively and also helps to understand how individuals determine and react to their reality. The design was therefore suitable for the study as it helped to investigate the subjective experiences of persons with disabilities during their job search.

### Setting

Komenda-Edina-Eguafo-Abirem Municipality, in the central region of Ghana, has been in existence for over thirty-five years. It comprises four distinct traditional areas which have been carved out of the Cape Coast Municipal Council to constitute a political district. Komenda- Edina- Eguafo- Abirem District was one of the forty-six new districts created in 1988 as part of the decentralisation programme in Ghana. This study setting was chosen because of the large number of persons with disabilities, constituting 6.3% out of the total population (144,705) in the municipality as recorded by the 2010 Housing and Population Census (Ghana Statistical Service, 2010).

### Study Sample

The target population was persons with disabilities (people who are deaf or deaf people. People with a visual disability and those physical disability) of working-age, who had searched for jobs at some time and were residing in the Komenda-Edina- Eguafo- Abirem Municipality.

Twenty participants were purposively recruited for the study, from the street and their homes. The sample size was based on the principle of saturation as espoused by Richards and Morse (2012). Saturation is reached if adding more participants to the sample does not yield any new perspective. The threshold



for this study was reached after the 20th person was interviewed, as responses relating to each of the objectives were being repeated.

### **Data Collection**

Feminist scholars claim that interviews are a very good way to study marginalised groups, such as persons with disabilities, because it allows them to tell their stories in their own words (Reuben et al, 2011). Interviews for 20-30 minutes were conducted, using a semi-structured interview guide, among participants in the study area. Participants were asked various questions relating to their experiences, employers' attitudes, and how those experiences influenced the type of work they were doing as well as their future job search plans, and the challenges they faced while seeking employment.

### **Data Analysis**

Data was analysed using the thematic content analysis. Thematic content analysis is defined by Cho and Lee (2014) as a research method used for the subjective interpretation of the content of text data through a systematic classification process of coding and identifying themes or patterns. This was done by first transcribing the spoken responses as well as observations and videos (deaf participants), then classifying the responses into themes, developing categories and coding schemes for themes, pre-testing the coding scheme on a sample, coding all the text, drawing inferences based on themes considering study objectives, and finally presentation of results.

Pre-tests were conducted earlier in the Cape Coast municipality because it shares boundaries with Komenda- Edina- Eguafo- Abirem municipality. For the pre-test, twelve participants comprising of four from each of the different groups of people with disabilities considered in the study (people who are deaf, people with visual disabilities and those with a physical disability) were employed. The pre-test enabled the researchers to restructure inappropriate questions to suit the study objectives before the actual field work. Also, member checking was done to increase credibility of findings. This involved sharing the summary of the findings with participants to confirm their responses and correct discrepancies.

### **Ethical Considerations**

The study protocol was first approved by the supervisor of the study. An approval letter was sought from the Head of Department (HOD) and an introductory letter

from the Centre for Disability and Rehabilitation Studies (CEDRES). As there was no or low risk to the participants, approval from CEDRES and the HOD was enough for the commencement of this study. Participation in the study was voluntary. Participants provided their oral consent and were at liberty not to answer questions at any stage of the interview. Anonymity was assured by the use of pseudonyms such as, for instance, D1= participant number 1 who is deaf and B2 = participant number 2 who has a visual disability.

## RESULTS

### Demographic Characteristics of Participants

As shown in Table 1, half of the participants (50%) were within the age group of 20 - 30 years and 65% were males. Concerning the employment status, 50% were employed, 20% were self-employed, 15% were retired and 15% were unemployed. In terms of educational level, 35% had basic education while those with vocational education (10%) and those without any education (10%) were equally represented. Twenty percent (20%) had tertiary education, suggesting that the educational attainment of participants was fairly good.

**Table1: Demographic Characteristics of Participants**

Categories	Number of Respondents	Percentage (%)
<b>Age Range (years)</b>		
20–30	10	50
31–40	2	10
41–50	2	10
51–60	2	10
61or above	4	20
<b>Sex</b>		
Male	13	65
Female	7	35
<b>Type of disability</b>		
Deafness	5	25
Visual disability	5	25
Physical disability	10	50
<b>Employment status</b>		
Employed	10	50
Unemployed	3	15
Self-employed	4	20

Retired	3	15
<b>Educational level</b>		
Never been to school	2	10
Basic	7	35
Secondary	5	25
Tertiary	4	20
Vocational	2	10

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Field data, 2018

### **Attitudes of Employers towards Job-seekers with Disabilities**

Attitudes of employers were negative towards persons with disabilities who were searching for jobs. According to the participants, employers expressed pity and surprise when faced with applicants with a disability, and consequently paid more attention to their condition instead of their capacities and qualifications.

*“Immediately when they saw me after reviewing my application, the Head started saying ‘sorry, sorry’, shaking his head. So, I think he didn’t expect the applicant to be a person with disability. He was not talking about my pursuit of work but rather my condition and how I am able to survive. In the end, I believe I was offered the opportunity to work with them based on my condition and not qualification or productiveness” (P7).*

The findings also indicated that some of the participants were badly treated by employers and felt humiliated.

*“The kind of treatment I received makes me feel useless as if for me I am not part of creation. In fact, some of these attitudes are part of people committing suicide because the society does not embrace them. They said if only I was hearing impaired, they could have managed, but visually impaired? They will not employ me and still employ my personal assistant never, they cannot afford, not here” (V3).*

Some participants said they were completely ignored by employers.

*“Immediately I reached there, they did not even offer me a seat, not to talk of asking me of my mission there. I stood there till I was tired because of the long queue and went back home” (P3).*

Another participant with a visual disability added,

*“They said because I cannot see I will be delaying their time and work process and did not offer me the chance” (B4).*

As a result of this negative attitude exhibited by employers, some of the participants said they resorted to online job application procedures.

*“I would rather search online for jobs to avoid the disrespect I will receive in person when I go to drop my job application letter at the job premises” (P6).*

This was supported by another participant.

*“It helped me to know the trends of reception that is given, that it is not welcoming, and how to carry myself, so I have adopted online job search as compared to physically walking and searching for job where someone may exhibit some attitude that is not welcoming towards you; that will not be pleasant and will not let you get the job” (P9).*

### **The Nature of the Physical Environment**

The findings revealed that the physical environment at the workplace was generally not accessible to many of the participants. Some of the participants reported that even with the use of assistive devices, they still struggled a lot in accessing some of the workplaces they visited in search of jobs.

*“I had issues climbing and walking on the stairs, but I had to adjust my assistive device, that is the crutches, which wasn’t comfortable at all and could have caused me to fall” (P8).*

Some participants also complained about the rugged terrain that made movement difficult, and the distance they had to cover over such terrain in search of jobs. As indicated, the physical environment was a major barrier.

*“The environment I went searching for jobs wasn’t accessible, I had difficulty walking, especially whenever I went there alone, but my mother helped me in most instances” (P4).*

*“The working environment was a big problem; I had my white cane but the place was so crooked that I had to go with a guide before I could send my application” (B10).*

### **Communication Barrier**

Communication was an issue for some participants, especially the ones who are deaf. Some participants also had difficulty in accessing information on jobs; they were mostly people with visual impairment.

*"I went through more problems at the places I went to search for the job. For instance, when I asked them questions by signing, no one paid attention to me; they were busily working as if they had not seen me, but even when they came to me after a long time of sitting they could not respond to my questions which I signed and did not understand. But all they say is 'go and come later' in sign language and they always said 'go and come' so I stopped going there again because they only waste my time but cannot talk with me" (D2).*

### **Effects of Negative Attitudes on the Kind of Jobs for Persons with Disabilities**

According to the participants, employers tended to give low paid jobs to persons with disabilities because of pity and doubts about their working abilities. This led to their working at less satisfying jobs.

*"No, I am not satisfied at all because my earnings are not enough, and it is from this same small earning that I will eat from and do other things because am not a child. I am grown, I fend for myself, and as I raise a family in addition to my one child, my expenses will be more and I don't wait for anyone before I eat, meaning I don't wait for people to feed me" (P1).*

*"I have no option and if even am not satisfied, I have to do because my condition will not let me do any other work" (B5).*

These experiences have shaped participants' job-seeking behaviour. For example, most of the participants were unwilling to search for jobs anymore and would prefer establishing their own businesses.

*"Because of the treatment from employers, I want to have my own shop. If you work for someone, the person will always dictate for you what to do and what not to do and can sack you at the least mistake and since I have a difficulty in walking, I walk slowly which may not let me be quick about any task I will do, but establishing my own business will not cause me this 'wahala' (problems)" (P1).*

*"Even before the job, I suffered a lot before getting it, they were always giving me stories, and I was later sacked again because they said I cannot work with them, so I have decided not to work for others again but to establish my own work if even it will earn me little. I started some self petty work and not to search for jobs again" (P1).*

*"As for me, I will never search for jobs again but I will work hard and raise*

*money to establish my own business; if even I will start small, I will get there, because now I cannot work in any school and most workplaces do not know sign language so if even I go they cannot communicate with me and they will waste my time as they did in my former job search” (H6).*

*“I prefer self-established job to avoid maltreatment and disrespect from my boss at a mistake committed. Meanwhile you may even be older than your boss” (P5).*

Some also thought that having their own businesses would enable them to generate enough revenue, be independent and avoid the humiliation they encounter.

*“A self-established business is better because of the profit you will get from it as compared to a public work where someone will abuse you and pay you and is on monthly basis, but your own work will earn you money daily” (D7).*

## DISCUSSION

This study investigated the job search experiences of persons with disabilities in the Komenda- Edina-Eguafo -Abirem Municipality in the central region of Ghana. The findings confirmed findings from previous studies about challenges persons with disabilities encounter when searching for jobs, notably about employers’ attitudes towards persons with disabilities and conventional views that persons with disabilities are unproductive, dependent and need assistance (Dovidio et al, 2011). Burke et al (2013) also reported that employers exhibited negative attitudes towards job-seekers with disabilities because they perceived them to be unproductive which, as such, could lower productivity and profit of their businesses.

A report by the Office of National Statistics (2014) in Tanzania indicated that most people showed negative attitudes towards persons with disabilities and discriminated against them in most sectors including education, health, and employment. These findings suggest that even in the 21<sup>st</sup> century, when the social and human rights models of disability have gained momentum, the charity model is still prevalent and may be responsible for the discrimination of persons with disabilities. Instead of viewing them as productive citizens who can contribute meaningfully to their communities, they are still viewed as victims of circumstances, deserving pity and in need of “help,” “care,” and “protection” from a benevolent society (Amponsah-Bediako, 2013). This means that employers have still not changed their perceptions about the potential benefits of employing persons with disabilities. .



The negative attitude of the employers towards the job-seekers in the study also influenced the kind of jobs they did, confirming previous findings that persons with disabilities were often clustered into sectors offering low-paid jobs and where (low) paid jobs are linked directly to (low) performance (Burchardt,2000). For example, some participants resorted to small-scale self-employment to avoid being maltreated and humiliated by employers. Most of them also preferred part-time to full-time jobs so that they could have more time to rest and manage their condition. This finding is consistent with a study which discovered that persons with disabilities desire flexibility in work arrangement so that they can cope with their disability (Schur, 2002). This is also consistent with findings by Chia and Kee (2013) whose study discovered that because persons with disabilities were treated negatively or unfavourably during job searches, they were discouraged from undertaking future job searches. This implies that negative attitudes of employers towards persons with disabilities, if not changed, will affect Ghana's efforts at poverty reduction and the achievement of its targeted Sustainable Development Goals. Also, with continuing negative attitudes of employers, those who are likely to be employed would not have adequate protection and employers are unlikely to provide them with the necessary reasonable accommodations.

Analysis of the data revealed that the physical environment was generally not accessible to persons with physical disabilities and those with visual disabilities, and this affected them in their search for jobs. This finding corroborates a survey by Schoof (2006) who noted that physical barriers such as inaccessible public transport, information, housing and workplaces were often the main reasons why persons with disabilities were not employed. It was also discovered that persons with disabilities who wanted paid employment were unable to achieve this goal for reasons unrelated to their condition, but rather due to unfriendly workplaces and discriminatory hiring practices (Brown et al, 2010).

For persons who are deaf, communication with prospective employers was the major challenge encountered during their job search. They also complained of not having enough information about job opportunities. This finding is consistent with Thumann-Prezioso's (2005) work which found that people who are deaf lag behind information on a daily basis and always lack up-to-date information on jobs. This finding points to ineffective implementation of the provisions on accessibility issues in Persons with Disability Act 715 of Ghana which requires that public places should be accessible to all persons with disabilities.

## CONCLUSION

The findings indicated that persons with disabilities had unfavourable experiences during their job searches. They encountered negative attitudes from employers, were posted to low-wage positions and faced barriers relating to the physical environment and information. The study therefore recommends intensive sensitisation campaigns to correct employers' negative perceptions about the productive abilities of persons with disabilities, through a collaborative effort between the relevant Government Ministry, the National Commission for Civic Education and Ghana Federation of Disability Organisations. Also, by implementing and enforcing provisions stated in the Persons with Disability Act 715, the Ministry of Gender, Children and Social Protection should ensure that public places, especially workplaces, are accessible to persons with disabilities. Finally, the National Commission for Civic Education, in collaboration with the Labour Commission, the Ministry of Works and Housing and the Ghana Federation of Disability Organisations, should make information available about job opportunities, in appropriate formats such as Braille and sign language videos, so that there is easy access for persons with various disabilities.

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# Exploring Employers' Practices for Persons Living with Disabilities and Employers' Implementation of the Persons with Disability Act in Zambia: A Qualitative Study

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## ABSTRACT

**Purpose:** *The study aimed to explore the employers' practices for persons living with disabilities and employer's implementation post-enactment of the Persons with Disability Act No. 6 of 2012 in the public sector.*

**Material and method:** *A qualitative phenomenological study design was used, and data was gathered through in-depth interviews with human resource directors, managers, and commissioners. A total of eight participants took part in the in-depth interviews. The analysis was performed using Atlas.ti version 7 software. To allow the themes to emerge from the data, thematic analysis using an inductive approach was used.*

**Results:** *Only a few persons living with disabilities were employed at the headquarters in the three government organisations. The study found that employers mainly use the Employment Act and do not take the Persons with Disability Act no. 6 of 2012 into account when recruiting. Furthermore, the majority demonstrated a lack of knowledge of the provisions enabling disability inclusion in workplaces as well as awareness of the Persons with Disability Act no. 6 of 2012.*

**Conclusions:** *The study emphasizes the gap between developing and implementing Disability Act policies. Raising awareness of the Persons with Disability Act No.6 of 2012 and its provisions supporting the inclusion of persons with disabilities in the workforce, as well as strengthening employers' knowledge of these policies, is essential for its successful implementation.*

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*Keywords: employment, disability, public sector, persons living with disability, disability act.*

## BACKGROUND

According to the Bureau of Labour Statistics-United States of America (2022), the unemployment rate for persons with disabilities (10.1%) was nearly twice as high as the rate for persons without disabilities (5.1%). Across all age categories, those with disabilities were significantly less likely to be employed than those without disabilities, and those who were employed were more likely to be self-employed than those who had no disability (United States Bureau of Labor Statistics, 2022). The Australian Bureau of Statistics has also similarly stated that as of 2019, the employment rate for persons of working age with disabilities is lower (48%, or 984,000) than it is for persons without disabilities (80%, or 11.3 million) (Australian Bureau of Statistics, 2020).

Persons living with disabilities face numerous challenges in accessing employment opportunities and experiencing fair treatment in the workplace. In Zambia, there is a growing recognition of the rights of persons with disabilities and the need for inclusive practices in various domains, including employment. The enactment of the Persons with Disability Act in Zambia aimed to promote equal opportunities, non-discrimination, and social integration for individuals with disabilities (Chikwanka & Chiluba, 2020). Zambia, like many members of ILO, has shown great interest in promoting the livelihoods of all persons including persons living with disabilities (Reynaud, 2017). Disability according to the Zambian government is defined as a permanent physical, mental, intellectual, or sensory impairment that alone or in a combination with a social or environmental barrier, hinders the ability of a person to participate in society fully or effectively on an equal basis with others (Disability Act: No. 8 of 2012, 2012).

The Zambia Federation of Disability Organisation, (2017) reported that about 2 million persons were living with disabilities, representing approximately 15% of Zambia's population. The unemployment rate for people with disabilities in Zambia is very high. This is caused by a number of things, such as low skill levels brought on by inadequate education, discriminatory employer attitudes and behaviours, a lack of policies supporting the employment of PWD, unfriendly and inaccessible work environments, insufficient access to information, and ignorance in society (Zambia Agency for Persons with Disabilities, 2016). Banks et al. (2017) found that disability is associated with poverty. This is due to the fact



that few people with disabilities are in active employment. Chilambwe (2013) examined disability and employment from a legal perspective and found evidence of discrimination against individuals with disabilities within the employment sector. The study also shed light on the deficiencies in the implementation of disability-related laws and the under-utilization of monitoring groups such as the Zambia Agency for Persons with Disabilities. Ultimately, the study concluded by emphasizing the importance of self-advocacy among persons living with disabilities and the need to report instances of discrimination, particularly within the employment sector, in Zambia. In 2022, the Government, through the Ministry of Community Development and Social Services, committed to allocating ten percent of the total number of recruitments to people with disabilities, while making efforts to promote entrepreneurship, set up cooperatives and develop skills (Ministry of Community Development and Social Services, 2022).

However, despite the legal framework in place, the actual implementation of the Persons with Disability Act in the context of employment remains relatively unexplored. Understanding the employment of persons living with disabilities and the extent to which employers are implementing the provisions of the Act is essential for identifying gaps, barriers, and opportunities for improvement. By adopting a qualitative approach, the study captured the rich narratives and diverse voices of employers, enabling a deeper understanding of the complexities and nuances surrounding disability and employment in the Zambian context.

## **Objective**

The primary objective was to gain an in-depth understanding of the experiences, perspectives, and challenges faced by individuals with disabilities from the employers' view, as well as practices of employers regarding the implementation of the disability-related legislation.

## **METHOD**

### **Study Setting**

The study was conducted at the headquarters of the Public Service Management Division (PSMD), Ministry of Labour and Social Security, and Ministry of Community Development and Social Services in Lusaka, Zambia. The PSMD is a government institution that manages human resource and recruitment of the civil service for all Ministries in Zambia.

## Study Design

The qualitative study was done on exploring employers' practices in the employment for persons living with disabilities and employers' implementation of the Persons with Disability Act in Zambia. We employed a descriptive and exploratory research design to gain an in-depth understanding of the experiences, perspectives, and challenges faced by individuals with disabilities from the employers' view, as well as practices of employers regarding the implementation of the disability-related legislation, the Persons with Disability Act number 6 of 2012 (Chiluba, 2019; Tenny *et al.*, 2022).

## Study Sample

To recruit study participants, the study used purposeful sampling. This sampling method provided the opportunity to choose the best, most informative, pertinent, extensive, and readily available participants in order to gain insights and a thorough understanding by providing compelling evidence (Staller, 2021). The study included individuals in administrative and decision-making roles directly involved in recruitment of employees who were willing to participate and available for interviews. All administration positions that were not directly related to civil service recruiting and employment were excluded. There was a total of 8 participants in the study, with a maximum of three participants from each of the three government organizations.

## Data Collection

Data was collected from study participants using a semi-structured interview guide. In-depth interviews with human resource directors, managers, and commissioner were conducted to provide in-depth understanding of the employment of persons living with disabilities and implementation of the Persons with Disability Act no.6 of 2012 during recruitment. The interviews covered topics such as employment of persons with disability, strategies to improve the current employment status of persons with disability, awareness of legislation on PLWDs and implementation of the Act. The interviews were conducted both in person as well as by telephone, and they were recorded using a recording device, with notes taken during the session. Throughout the data collection process, all principles of ethics pertaining to confidentiality, privacy, and consent were upheld. The interviews were held at a time and place that was convenient for the participants.

## Data Analysis

The data analysis was conducted using Atlas.ti version 7 software. Thematic analysis, following an inductive approach, was employed to allow the emergence of themes from the collected data. This qualitative analysis method involved a systematic review of the transcribed interviews, where coding and categorization were performed to identify significant themes, patterns, and sub-themes aligned with the research objectives. The analysis process followed an iterative approach, including data immersion, familiarization, coding, and theme development. Through this iterative process, common experiences, challenges, and perceptions among the participants were identified.

## Ethical Issues

Ethical approval was obtained from ERES Converge Research Ethics Committee with a reference No. 2021-may-098. Permission was obtained from the three institutions to conduct the study. To maintain participant confidentiality, no names were utilized, or mentioned in any subsequent writing. Before the interviews, all participants provided informed consent, and the purpose and method for participation were described to them.

## RESULTS

### Socio-demographic characteristics of the participants from the interview

A total of eight participants took part in the in-depth interviews. All participants were part of the employment process in their respective ministries. Table 1 highlights the participants' socio-demographic characteristics.

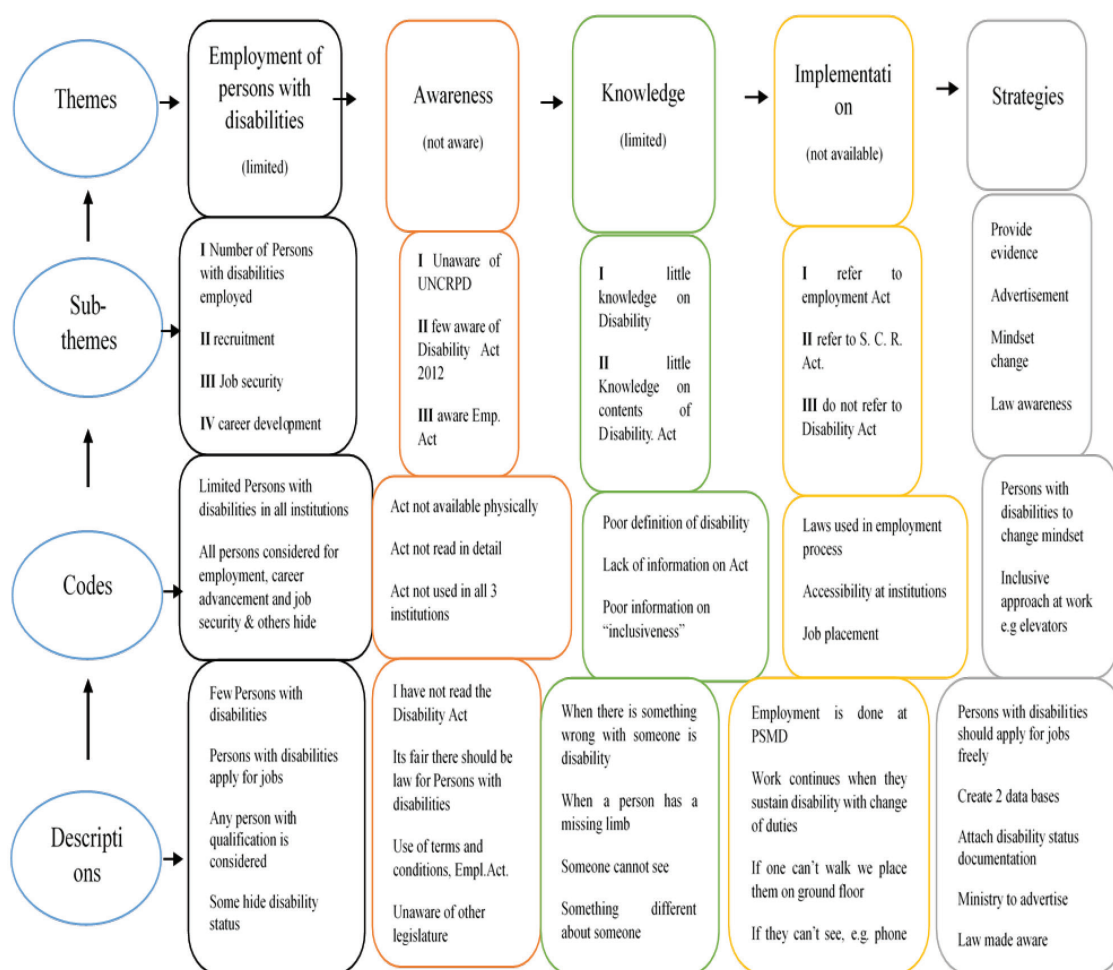
**Table 1: Socio-demographic characteristics of Participants who participated in the IDI**

Variable	Frequency
<b>Sex</b>	
Male	3
Female	5
<b>Age</b>	35 – 63 years
<b>Work experience</b>	10 – 35 years
<b>Position of participants</b>	
Commissioner	1
Human Resource	2
Deputy director	1
Director	4

## Emerging themes from the In-depth interview

Figure 1 shows a summary of the development of themes established in this study. The flow of information is as follows: (i) descriptions, (ii) codes, (iii) sub-themes and finally (iv) themes. The descriptions represent the participants' responses during the in-depth interviews. The descriptions presented were then converted into codes, which helped develop sub-themes and ultimately establish the study's main themes.

**Figure 1. Summary of theme development of qualitative part of the study (adapted from Banda-Chalwe et al., 2014)**



## **Employment of persons living with disability**

### **The number of employed persons living with disabilities**

The research revealed that there were few persons living with disabilities working at the three government ministries headquarters. According to the respondents, only one person with a disability was employed by the Ministry of Labour and Social Security Headquarters, two by the Ministry of Community Development and Social Services Headquarters, and three by the Public Service Management Division. For many years, persons living with disabilities, particularly those who are blind, have filled the position of a telephone operator. However, no specific positions or jobs are specifically reserved for persons living with disabilities, as they can employ anyone in any position if they qualify.

### **Recruitment of qualified applicants with disabilities**

The respondents stated that Directors and human resource personnel tasked with hiring new employees concentrate on finding the best candidate who is qualified, experienced, and competent. They explained that when they are recruiting regardless of whether you have a disability or not, they look at qualifications, merit, competencies, and experience as a basis for appointment. There is no deliberate policy that indicates certain positions should be reserved for someone with a disability, as such persons living with disabilities have to compete with those without a disability for a position and if they are qualified, they will be picked. One of the respondents explained that;

*“They just need to compete fairly like anyone else because there are quite a number that have qualifications and if they compete on a fair platform with anyone else... they can be considered...” ID 1 Director*

### **Job security of persons living with disabilities**

Respondents were asked what happens if an employee suffers an injury that results in impairment or permanent disability while still working with the government. They explained that they usually follow the hospital’s advice or recommendations. If the medical report indicates that the employee requires sick leave, sick leave is granted. If the employee believes they have reached a point where they are unable to come to work, they will apply for medical retirement. Employees who have an impairment and some functional limitations but can still work have their duties changed to something they can manage without changing their salary.

*“Involve the Ministry of Health so that they convene specialists to be able to assess the person’s capacity to continue work. Based on their recommendation the board of specialists depending on the injury, will be able to make a recommendation to say, I think we have assessed the condition; this person can’t continue to work. There is a provision in our Terms and Conditions which is called retirement on medical grounds. They can recommend that or if they feel the person can continue, they can recommend the person can continue. But maybe assign them roles that will be easy to work on given what was found. Even retirement on medical grounds, we give them their full benefits as if they have reached retirement age...”ID 6 Director*

## **Awareness, knowledge and implementation of the Acts relating to persons living with disabilities**

### **Awareness of UNCRPD, Persons with Disability Act number 6 of 2012, and the Employment Act**

The Employment Act was known to all eight of the respondents interviewed for the study, however, two of them were unaware of the provision that references the rights of persons with disabilities. Furthermore, only three of the eight respondents were aware of the UNCRPD and the Persons with Disability Act No. 6 of 2012. For instance, one respondent stated:

*I am aware of the Employment Act, but I am not aware of the part that talks about disabilities...”ID 5 Director*

### **Knowledge of UNCRPD, the Persons with Disability Act number 6 of 2012, and the Employment Act**

Three respondents were knowledgeable of the provision of the Employment Act requiring employers to be inclusive when recruiting. The contents of the UNCRPD and the Persons with Disabilities Act number 6 of 2012 were unknown to all respondents. The reason for this was a lack of time spent reviewing the documents.

*“I think it has a component where I think it urges employers to be able to ensure that we are inclusive in our employment of persons with disabilities. That one I am pretty much aware. The Disability Act, I have never really studied very much. But of course, it’s something that we can always refer to...”ID 8 Director*



## **Implementation of the Acts**

They clarified that in terms of how these Acts are put into practice, they refer to the Employment Act of 2019, which stipulates clearly that employment opportunities are available to all, including persons living with disabilities. The Service Commission Regulation Act, which also outlines the values and principles of public service, is another Act that is utilized. The Act mandates that persons treat persons living with disabilities with respect while they are at work. According to one response, the Employment Act still refers to the Persons with Disability Act, but full details can be obtained from the Persons with Disabilities Act.

*“Ok, when you look at the disability Act, with us we don’t refer to the Disability Act. Our Act is the Employment Act of 2019 and there it is very clear, whatever opportunities are there apply to all including persons with disabilities...”ID 4 Commissioner*

## **Strategies for increasing the employment of persons living with disabilities**

### **Providing evidence of disability**

One respondent recommended that persons with disabilities should seek disability certifications from associations of persons with disability so they can support their applications with the certification or a letter of recommendation from a person with disability organization. As a result, it will be easier to prove that the applicant has a disability when the application is reviewed.

### **Advertisements should encourage persons with disability to apply**

As a government entity (PSMD), they receive a considerable number of voluntary emails from persons applying for employment, which is permitted. Respondents suggested that PSMD might think about inserting a note on the application stating persons with disabilities are invited to apply if they advertise for openings. They believe that making such notice will encourage those with disabilities to apply.

### **Change of mindset**

Some responses underlined the significance of changing one’s perspective. They said that persons with disabilities should start to think of themselves as being like everyone else rather than as being especially unique so they can be granted

employment without being scrutinized like others and that they should be able to compete fairly with everyone else.

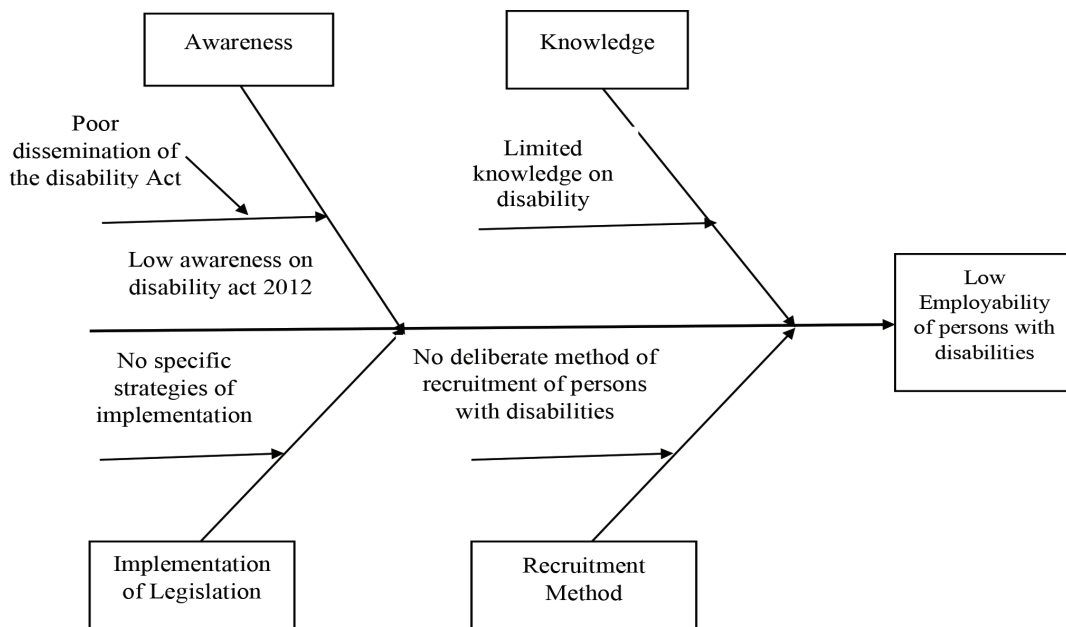
### Sensitization of the Disability Act

One respondent suggested that raising the Persons with Disability Act number 6 of 2012 awareness in the community could encourage more qualified persons with disabilities to apply for jobs.

### Root cause-analysis on the low employment of persons with disabilities

Figure 2 depicts a fishbone diagram or herringbone diagram or cause and effect diagram. The fishbone diagram was first proposed by Kaoro Ishikawa to display the cause and effect to improve processes in the industries (Ishikawa, 1985). The right represents the problem/defect whereas the bones of the fish's face on the left represent the cause (Gartlehner et al., 2017).

**Figure 2. Root cause-analysis diagram based on the themes of respondents on the employability of Persons living with disabilities**



## DISCUSSION

The study findings reveal that only a small number of persons with disabilities were employed at the headquarters of the three government organizations under investigation. This highlights the challenges and barriers faced by individuals with disabilities in accessing employment. The study highlights that employers primarily rely on the Employment Act and do not consider the provisions of the Persons with Disability Act No. 6 of 2012 during the recruitment process. This indicates a lack of awareness or non-compliance with the specific regulations and requirements aimed at promoting disability inclusion in the workforce. A lack of awareness with respect Disability Acts has been noted to be a major problem even by other similar studies, like studies by (Chiluba, 2019; Chikwanda & Chiluba, 2020), which stated a lack of awareness especially on rights of persons with disabilities. This lack of awareness contributes to misconceptions, stereotypes, and discriminatory attitudes towards persons living with disability.

Most employers demonstrated a lack of knowledge regarding the provisions for disability inclusion in workplaces as well as limited awareness of disability Acts. This suggests a need for improved education and awareness programs to ensure employers are adequately informed about their obligations and the benefits of disability inclusion. The study identifies several strategies that could help increase the employment opportunities for persons with disabilities. These strategies include requiring proof of disability during the recruitment process, adopting inclusive advertising practices, fostering a change in mindset among employers, and conducting disability policy sensitization programs.

The study revealed that there were few persons with disabilities working at the ministry headquarters and this may indicate that little progress has been made after the enactment of the persons with Disabilities Act number 6 of 2012 in terms of employment of persons with disabilities. The study highlighted some of the reasons for the low employment rates for persons with disabilities. For example, regardless of their level of disability, all those who meet the requirements for the position are required to compete for the positions because employing authorities in the civil service are focused on selecting the best applicant who is qualified, experienced, and competent. This may not be the case, though, as the amount of effort required varies greatly depending on the disability of the person with a disability to achieve the same level of skill as someone without a disability, if not better (Tinta *et al.*, 2020). Inclusion in the workforce at all levels is crucial. To

ensure that it does not disadvantage the most vulnerable members of our society, an equal opportunity strategy should uphold the highest standards of equity.

Concerning job security for persons with disabilities, the study's findings showed that they are not necessarily dismissed based on acquiring a disability following an injury in the public sector; instead, they could change their workstations within the institution on their request in a similar line of work and still maintain their salary. The study revealed that employers make employees feel comfortable at their workplaces and they are given the necessary support. This finding suggests a sense of consideration for necessary adjustments by the employers to accommodate any employee that might encounter a disability whilst in employment.

The majority of those interviewed in this study were unaware of disability laws and regulations. The few persons who were aware of disability legislation were simply aware that such laws existed but were unfamiliar with their contents. These findings are consistent with the findings of a similar studies on employment and disability which found that employers are frequently unaware of disability and related laws, despite the presence of good laws governing disability matters (Bonaccio et al., 2020; Maja et al., 2011). While some employers have heard of the persons with Disabilities Act number 6 of 2012, they do not utilize it directly. Other Acts, such as the Employment Code and the Service Commissions Regulations Act, as well as other government circulars, are considered during the recruiting process. This is because public-sector employers consider these Acts sufficient for use in the recruiting process and do not need to refer to the Persons with Disabilities Act number 6 of 2012. In a similar study on legislative laws passed in seven Latin countries and their implementation, they found that only one country had been successful in ratifying the disability laws and incorporating them into the national labour laws, which led to their widespread implementation (Pinilla-Roncancio & Rodríguez Caicedo, 2022). Other nations in this study carried out the implementation of their disability laws by providing some incentives for hiring persons with disabilities, and another nation made it necessary to have a certain proportion of persons with disabilities in every workplace (Pinilla-Roncancio & Rodríguez Caicedo, 2022). The findings of this study demonstrate that there are no established implementation strategies for the Act and no stated measures in place to promote inclusion in employment in Zambian civil society.

This study identified some strategies that could be used to improve persons with disabilities' employability. It was stated that to increase the employability

of persons with disabilities, there was a need for proof of the disability in the form of a certificate or reference letter from reputable organisations dealing with disabilities in Zambia. It was believed that doing this would make it simpler for employers to prove a person's disability during the review of their employment application. For applicants who might require special consideration, this could be advantageous. Although it is a good idea for applicants to give documentation of their disability status, it may be argued that doing so could disadvantage persons with disabilities. Persons with disabilities suffer various forms of discrimination and are less likely to be selected on a job application if they indicated their disability status (Kaye et al., 2011). As a result, advertisements should not be discriminatory, and inquiries about disabilities should only be made when necessary (for example, during any necessary interviews) during the hiring process (Bonaccio et al., 2020).

The study found that it is necessary to include a statement on the employment application advertisement that "persons with disabilities are encouraged to apply" to increase the employability of persons with disabilities. This approach was in line with the ILO's recommendations in its report on the promotion of diversity and inclusion through workplace modifications, which outlined the importance of promoting an inclusive employment philosophy (Standing, 2010).

This study also showed that to boost employability, persons with disabilities need to start believing that they are just like everyone else and capable of competing on an equal basis with others. Instead of working hard to be competitive, employers frequently suggest that persons with disabilities would want to be treated in a different way compared to their counterparts without disabilities. In the end, the shift in perspective should be observed from both sides (employers and persons with disabilities) of this employment spectrum. To encourage qualified persons with disabilities to apply for jobs, it is vital to raise community awareness of the Persons with Disabilities Act. The employers who sit on committees for the recruiting process in the public sector should be the first subgroup to be targeted in this sensitization. Employers are required to post advertisements, and if they are unaware of the needs of persons with disabilities, it may be challenging for them to create messages that are relevant to job applicants.

## **Implications**

Employment for persons living with disabilities remains a significant problem despite the enactment of the Persons with Disability Act number 6 of 2012, owing

to the gap between enactment and implementation. The study highlights the need for government and policymakers to increase assessments, monitoring and evaluation of inclusive policies to make sure that such policies are being followed by employing agencies.

The Persons with Disability Act and the specific provisions relating to the employment of persons living with disabilities are not generally known to those involved in recruiting employers. Hence, the results emphasize the importance of holding training, workshops, and seminars with various employment agencies to increase knowledge of the provisions that support the inclusion of persons living with disabilities in the workforce.

### **Limitations**

It is important to acknowledge certain limitations of the study. Firstly, the findings may not be generalizable to the entire population of persons with disabilities and employers in Zambia due to the use of purposive sampling. Secondly, the study relied on self-reported data, which may be subject to biases or recall errors. However, efforts were made to mitigate these limitations by ensuring a diverse sample and employing rigorous data collection and analysis procedures.

Certain gatekeepers (Directors) could not consent to be interviewed and thus some valuable information could have been missed.

Overall, the qualitative study design allowed for an in-depth exploration of the employers practices in the employment process of persons living with disabilities and employers' implementation of the Persons with Disability Act in Zambia. The design enabled capturing the experiences, perspectives, and challenges and provide valuable insights for improving disability-related policies, practices, and support mechanisms in the context of employment.

## **CONCLUSION**

The study findings reveal persistent challenges in the implementation of the Disability Act during the hiring process within government organizations. Despite the enactment of the Persons with Disabilities Act number 6 of 2012, the issue of employment for individuals with disabilities remains a significant problem requiring urgent attention. This study proposes several strategies to enhance the employability of persons with disabilities, including (i) requesting disability documentation during the application process, (ii) framing job advertisements in



an inclusive manner, (iii) promoting a shift in mindset, and (iv) raising awareness of the legal framework pertaining to disability and employment. However, these strategies are primarily theoretical and further research is needed to assess their practical effectiveness. Additionally, the study highlights a gap between the development of Disability Act policies and their actual implementation in practice.

## **ACKNOWLEDGEMENT**

The authors would like to express their gratitude to the participants that took part in this study from different government ministries. The authors express their sincere gratitude to all of the study's supervisors. The author is deeply indebted to Dr. Brian Ng'andwe for his consistency and contribution in this whole research process. The authors also like to express their gratitude to Mrs. Ng'uni.

### **Funding**

N/A

### **Disclosure statement**

The authors declare that there are no conflicting interests.

### **Data availability statement**

The data supporting the findings of this study are available upon request from the corresponding author, [SZ]. Due to restrictions, such as the fact that they may contain information that compromises the privacy of research participants, the data are not publicly available.

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Light for the World is an international NGO and has been so generous to make it possible to give a contribution for the year 2023 in order to facilitate the migration from Ubiquity Press and Liliane Foundation to the University of Gondar.

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**Published by**  
The University of Gondar,  
P.O. Box 196  
Gondar, Ethiopia