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Editorial

Women in the forefront of Support

Due to an accident, I am temporarily disabled. I am sitting on the couch of my living room, trying to write this editorial. For the first time, it feels as a very heavy job; much more difficult to write than all the other editorials I've written in the past. In fact, everything I want to do is difficult; be it activities of daily living or just having a call with the insurance company. I have had to cancel many appointments and am no longer able to travel in December to Ghana and the Czech Republic. The two surgeries carried out in 10 days' time took its toll on me and I am glad I have a strong support network: my wife, children, friends, neighbours. It sounds a bit silly to become so much more aware of the reality of disability at the end of my 'career'. I thought that I knew quite well what the small and not so small struggles of people with disabilities were. When I am now climbing the stairs in our house or when thinking of how to organise transport to give a lecture in 3 weeks' time in a town 20 km from my residence, I far more realise how an impairment, temporary or not, can become disabling for a person. And this coming from a white male living in Europe – far from the worst conditions! I strongly believe that in order to truly understand the life of someone with a disability, one needs to listen, observe, and talk with the person rather about the person.

While reviewing the content of this issue I notice 4 articles that deal with support systems: one from India, one from Thailand, one from the Arab Emirates and one from Sri Lanka. Again, I am asking myself, but also service providers, policymakers, planners, (international) NGOs and multilateral organisations active in the field of disability if they take these support systems well enough into consideration in doing their work and developing realistic policies? My late friend M. Miles stated once at a workshop I organised that "since mankind exists, it is basically mothers and other women who take care of the wellbeing – and of the rehabilitation – of their families". In fact, he was pleading for Community Based Rehabilitation (CBR) to be renamed MBR (Mother Based Rehabilitation) … It is perhaps mothers, sisters, and grandmothers who need to get more attention for their effortless and remarkable contributions to their family as well as society at large. Personally, I am in a luxury position whereby my wife gets some hours (paid) leave to take care of me, but I very much realise the situation in low- and middle-income countries is very different. There, women, on top of their already heavy day tasks, take care of their disabled relatives, without any additional support or schemes to relieve them.

Talking about women, I would like to share a few more thoughts with you. When working in Apartheid South Africa in the nineteen eighties, it was very obvious to me that women with disabilities were at least ‘triple disabled’. First because they had limitations in their activities; second, because they were having more pigment in their skin than the ‘white’ ruling party and third, because they were women who within their own culture were having fewer rights and opportunities and were prone to abuse and stigma. To me, it meant that in all the services that we provided in those days, a special focus had to be placed upon the wellbeing of women. Almost 4 decades later, I notice that INGOs pay a lot of attention to gender and sexual and reproductive health rights and increasingly include women and girls with disabilities in their projects too, as part of intersectionality. While I support such developments in general, I am increasingly becoming worried about the almost ‘obsessive’ drive of western INGOs to reach and convert the ‘ignorant ones’ without considering the existing cultural norms and values, let alone involving those who could truly make a difference in the wellbeing of women[1]. Would it not be wise to work bottom-up with indigenous organisations and leaders and have a dialogue about developments related to and affecting culture, rights, religion, and disability, and doing this on basis of humbleness rather than a position of (hidden) superiority or power? When I was early this year in Bangladesh I was impressed with the work on sexual and reproductive health rights of girls with disabilities; yet I was disappointed that there were no programmes directed at boys (disabled or not) let alone programmes directed at but also with the local leadership. I learned especially the last few years that lobby, and advocacy activities can become far more effective if one works with religious and traditional leaders. These people are often by far more respected and influential than formal authorities. It is high time for western INGOs as well as multilateral organisations to leave their comfort zone and take bold steps in breaking down wrong ideas and harmful practices.

I am very pleased that we have been managing to publish 3 issues of the journal this year. Early next year we hope to publish the last issue of 2023. Thanks to all contributors and supporters of the journal in what was a very challenging year. Wishing you a prosperous and a peaceful 2024 on behalf of the entire DCID editorial team.

Your Editor-in-Chief,

Huib Cornielje

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[1] I mean here those who have influence on society i.e. traditional and religious leaders.

GUEST EDITORIAL

Time to Treat The Climate and Nature Crisis as one Indivisible Global Health Emergency

Over 200 health journals call on the United Nations, political leaders, and health professionals to recognise that climate change and biodiversity loss are one indivisible crisis and must be tackled together to preserve health and avoid catastrophe. This overall environmental crisis is now so severe as to be a global health emergency.

The world is currently responding to the climate crisis and the nature crisis as if they were separate challenges. This is a dangerous mistake. The 28th Conference of the Parties (COP) on climate change is about to be held in Dubai while the 16th COP on biodiversity is due to be held in Turkey in 2024. The research communities that provide the evidence for the two COPs are unfortunately largely separate, but they were brought together for a workshop in 2020 when they concluded that: "Only by considering climate and biodiversity as parts of the same complex problem…can solutions be developed that avoid maladaptation and maximize the beneficial outcomes."[1]

As the health world has recognised with the development of the concept of planetary health, the natural world is made up of one overall interdependent system. Damage to one subsystem can create feedback that damages another—for example, drought, wildfires, floods and the other effects of rising global temperatures destroy plant life, and lead to soil erosion and so inhibit carbon storage, which means more global warming. [2] Climate change is set to overtake deforestation and other land-use change as the primary driver of nature loss. [3]

Nature has a remarkable power to restore. For example, deforested land can revert to forest through natural regeneration, and marine phytoplankton, which act as natural carbon stores, turn over one billion tonnes of photosynthesising biomass every eight days. [4] Indigenous land and sea management has a particularly important role to play in regeneration and continuing care. [5]

Restoring one subsystem can help another—for example, replenishing soil could help remove greenhouse gases from the atmosphere on a vast scale. [6] But actions that may benefit one subsystem can harm another—for example, planting forests with one type of tree can remove carbon dioxide from the air but can damage the biodiversity that is fundamental to healthy ecosystems. [7]

The impacts on health

Human health is damaged directly by both the climate crisis, as the journals have described in previous editorials, [8,9] and by the nature crisis. [10] This indivisible planetary crisis will have major effects on health as a result of the disruption of social and economic systems—shortages of land, shelter, food, and water, exacerbating poverty, which in turn will lead to mass migration and conflict. Rising temperatures, extreme weather events, air pollution, and the spread of infectious diseases are some of the major health threats exacerbated by climate change. [11] "Without nature, we have nothing," was UN Secretary-General António Guterres's blunt summary at the biodiversity COP in Montreal last year. [12] Even if we could keep global warming below an increase of 1.5°C over pre-industrial levels, we could still cause catastrophic harm to health by destroying nature.

Access to clean water is fundamental to human health, and yet pollution has damaged water quality, causing a rise in water-borne diseases. [13] Contamination of water on land can also have far-reaching effects on distant ecosystems when that water runs off into the ocean. [14] Good nutrition is underpinned by diversity in the variety of foods, but there has been a striking loss of genetic diversity in the food system. Globally, about a fifth of people rely on wild species for food and their livelihoods. [15] Declines in wildlife are a major challenge for these populations, particularly in low- and middle-income countries. Fish provide more than half of dietary protein in many African, South Asian and small island nations, but ocean acidification has reduced the quality and quantity of seafood. [16]

Changes in land use have forced tens of thousands of species into closer contact, increasing the exchange of pathogens and the emergence of new diseases and pandemics. [17] People losing contact with the natural environment and the declining loss in biodiversity have both been linked to increases in noncommunicable, autoimmune, and inflammatory diseases and metabolic, allergic and neuropsychiatric disorders. [10,18] For Indigenous people, caring for and connecting with nature is especially important for their health. [19] Nature has also been an important source of medicines, and thus reduced diversity also constrains the discovery of new medicines.

Communities are healthier if they have access to high-quality green spaces that help filter air pollution, reduce air and ground temperatures, and provide opportunities for physical activity. [20] Connection with nature reduces stress, loneliness and depression while promoting social interaction. [21] These benefits are threatened by the continuing rise in urbanisation. [22]

Finally, the health impacts of climate change and biodiversity loss will be experienced unequally between and within countries, with the most vulnerable communities often bearing the highest burden. [10] Linked to this, inequality is also arguably fuelling these environmental crises. Environmental challenges and social/health inequities are challenges that share drivers and there are potential co-benefits of addressing them. [10]

A global health emergency

In December 2022 the biodiversity COP agreed on the effective conservation and management of at least 30% percent of the world's land, coastal areas, and oceans by 2030.[23] Industrialised countries agreed to mobilise $30 billion per year to support developing nations to do so.[23] These agreements echo promises made at climate COPs.

Yet many commitments made at COPs have not been met. This has allowed ecosystems to be pushed further to the brink, greatly increasing the risk of arriving at 'tipping points', abrupt breakdowns in the functioning of nature.[2,24] If these events were to occur, the impacts on health would be globally catastrophic.

This risk, combined with the severe impacts on health already occurring, means that the World Health Organization should declare the indivisible climate and nature crisis as a global health emergency. The three pre-conditions for WHO to declare a situation to be a Public Health Emergency of International Concern [25] are that it: 1) is serious, sudden, unusual or unexpected; 2) carries implications for public health beyond the affected State's national border; and 3) may require immediate international action. Climate change would appear to fulfil all of those conditions. While the accelerating climate change and loss of biodiversity are not sudden or unexpected, they are certainly serious and unusual. Hence we call for WHO to make this declaration before or at the Seventy-seventh World Health Assembly in May 2024.

Tackling this emergency requires the COP processes to be harmonised. As a first step, the respective conventions must push for better integration of national climate plans with biodiversity equivalents. [3] As the 2020 workshop that brought climate and nature scientists together concluded, "Critical leverage points include exploring alternative visions of good quality of life, rethinking consumption and waste, shifting values related to the human-nature relationship, reducing inequalities, and promoting education and learning." [1] All of these would benefit health.

Health professionals must be powerful advocates for both restoring biodiversity and tackling climate change for the good of health. Political leaders must recognise both the severe threats to health from the planetary crisis as well as the benefits that can flow to health from tackling the crisis. [26] But first, we must recognise this crisis for what it is: a global health emergency.

Kamran Abbasi, Editor-in-Chief, *BMJ*; Parveen Ali, Editor-in-Chief, *International Nursing Review*; Virginia Barbour, Editor-in-Chief, *Medical Journal of Australia*; Thomas Benfield, Editor-in-Chief, *Danish Medical Journal*; Kirsten Bibbins-Domingo, Editor-in-Chief, *JAMA*; Stephen Hancocks, Editor-in-Chief, *British Dental Journal*; Richard Horton, Editor-in-Chief, *The Lancet*; Laurie Laybourn-Langton, University of Exeter; Robert Mash, Editor-in-Chief, *African Journal of Primary Health Care & Family Medicine*; Peush Sahni, Editor-in-Chief, *National Medical Journal of India*; Wadeia Mohammad Sharief, Editor-in-Chief, *Dubai Medical Journal*; Paul Yonga, Editor-in-Chief, *East African Medical Journal*; Chris Zielinski, University of Winchester.

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This Comment is being published simultaneously in multiple journals. For the full list of journals see:https://www.bmj.com/content/full-list-authors-and-signatories-climate-nature-emergency-editorial-october-2023

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ORIGINAL RESEARCH ARTICLES

Analysis of Health, Disability, Gender and Disaster Risk Reduction Policies in Nepal using a Human Rights-based Approach

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ABSTRACT

Purpose: *This study assessed the extent to which the issues of vulnerable groups, such as persons with disabilities, women and girls, are incorporated in line with human rights principles in the key policies related to health, disability, gender, and disaster risk reduction in Nepal.*

Method: *A content analysis was carried out using EquiFrame, which analyses policies for the inclusion of vulnerable groups based on the Core Concepts of Human Rights. Fifteen policies were analysed regarding the quality and frequency with which persons with disabilities, women, and girls were included in the documents.*

Results: *Nepal's health policy (n=4) covered 52% of the Human Rights Core Concepts, while policies on disability (n=3), gender (n=2), and DRR (n=6) covered 46%. The overall qualities of those policies were ranked significantly low, with quality index ranging from 8 - 28.*

Conclusion: *The policies inadequately incorporated human rights principles for the inclusion of disability and gender, and were ranked low quality in addressing their health needs and rights. To enhance social inclusion and promote equity in health, it is suggested that the human rights approach guided by EquiFrame be followed while developing policies.*

Key words: *disability, disaster, EquiFrame, gender, health, human rights, policy analysis, Nepal*

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INTRODUCTION

The World Report on Disability 2011 shows that an estimated one billion people comprising 15% of the world population are living with a disability, and 80% of them live in developing countries (World Health Organisation & The World Bank, 2011). It is also estimated that the prevalence of disability among women is higher (60%) than among men (Hosseinpoor et al, 2012). The literature suggests that women with disabilities face multiple disadvantages and exclusions, including disparities in healthcare on account of their gender and disability (Devkota et al, 2018; Mac-Seing et al, 2020). Moreover, women with disabilities are more likely to have unmet healthcare needs than women without disabilities.

Studies in different countries show that persons with disabilities, particularly women and girls, are disproportionately affected by disasters and are at greater risk of injury, death, or long-term negative impacts on their health and wellbeing due to the difficulties in accessing healthcare and life-saving procedures during and after disasters (World Bank Group & GFDRR - Global Facility for Disaster Reduction and Recovery, 2017). A study in Bangladesh revealed the increase in perineal rashes and urinary tract infections in women and girls during floods and starvation post-floods due to the destruction of crops, posing a critical danger to the survivors, particularly to pregnant women, lactating mothers, and children (Ahmed, 2013). At the time of an emergency or in disaster situations, persons with disabilities are less likely to be evacuated, and their possible exposure to the risk of injury and death can be high (UN DESA, n.d.).Moreover, studies also suggest that these vulnerable groups of the population face greater threats to their survival and recovery in the aftermath of disasters (Priestley & Hemingway, 2007).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006, and the Sendai Framework for Disaster Risk Reduction 2015, both ensure the protection of persons with disabilities and lay out expectations regarding the inclusion of the rights of persons with disabilities in situations of risk and humanitarian emergencies (United Nations, 2006, 2015). The Sendai Framework (2015–2030) emphasises the need to integrate gender, age, disability, and cultural perspectives in all policies and practices, and its guiding principles include empowerment and inclusive, accessible, and non-discriminatory participation of vulnerable groups and those disproportionately affected by disasters (United Nations, 2015). Moreover, the importance of promoting inclusive DRR has been progressively articulated in Asia Pacific regional declarations and action plans such as the New Delhi Declaration on Disaster Risk Reduction in Asia and the Pacific – 2016, that emphasises the participation and leadership of women, children and persons with disabilities. In respect of the CRPD and Sendai Framework, the UN calls for all member states to include a disability perspective in their policies and practices. However, it is not known how the policies and health systems in developing countries like Nepal have addressed the needs of these vulnerable populations during disaster situations. It is not known if the key policies and legislations in Nepal incorporate human rights principles or how those policies are translated into practice. To the best of the authors' awareness, the policies in Nepal have not yet been analysed to fill the gaps in knowledge.

Objective

This study aimed to assess the extent to which Nepal's key health, disability, gender, and disaster risk reduction policies cover the core concepts of human rights and the inclusion of persons with disabilities, women, and girls.

METHOD

Study Design

A policy analysis framework, EquiFrame (Mannan et al, 2011), was used to evaluate the selected policies. Initially used in health policy analysis, it follows the human rights approach to policy analysis and is now used in other sectors as well, e.g., disability, economic empowerment, international donor's policies (MacLachlan et al, 2016).

Selection of Policies

The latest policies related to health, disability, gender, and disaster risk reduction formulated by federal and local governments, if any, with the study districts were included for analysis.

The key criteria used for the selection were:

- National Health Policies, Acts, and strategies formulated by the Federal Ministry of Health and Population (MoHP), provincial ministries and local government in the project area. (This policy analysis was one of the activities of 'Gender Responsive Resilience and Intersectionality in Policy and Practice [GRRIPP] South Asia', a study which was implemented in Palungtar and Marsyangdi Municipalities of Gorkha and Lamjung districts respectively.)

- National Disability Policies, Acts, Health Service guidelines, and Periodic plans formulated by the Federal Ministry of Women, Children and Senior Citizens (MoWCSC), provincial ministries and local government in the project area.
- National Gender Policies formulated by the Federal MoHP, MoWCSC, provincial ministries, and local government in the project area.
- National Disaster Risk Reduction Policies, Acts, and guidelines formulated by the Federal Ministry of Home Affairs (MoHA), provincial ministries and local government in the project area.

All these policies were searched using the respective Ministry and local government websites, and the documents were downloaded for analysis.

Table 1 presents the list of policies and Acts related to health, disability, gender, and disaster risk reduction included for analysis.

Table 1: Policies included for Analysis by Sector

Policies
Health Policies
• National Health Policy – 2019 - MoHP
• Public Health Service Act – 2077 [2020]
• National Strategy for Reaching the Unreached – 2073 [2016] - MoHP
• Gandaki Province Health Policy – 2078 [2021]
Disability Policies
• National Guidelines for Disability Inclusive Health Services - 2019
• Disability Related Ten Year National Policy and Plan (2073 – 2082) - 2016
• The Act Relating to Rights of Persons with Disabilities - 2074 [2017]
Gender Policies
• Gender Equality and Social Inclusion Strategy of the Health Sector – 2018-MoHP
• National Gender Equality Policy – 2077 [2020]-MoWCSC
Disaster Risk Reduction Policies
• National Policy for Disaster Risk Reduction – 2018 - MoHA
• DRR National Strategic Plan of Action 2018 – 2030 [2018] - MoHA
• Disaster Risk Reduction and Management Act, 2074 and Rules - 2076 [2019]-MoHA
• DRR Act 2075 [2018], Palungtar Municipality, Gorkha
• DRR Act 2075 [2018], Marsyangdi Rural Municipality, Lamjung
• Disability Related Ten Year National Policy and Plan - DRR (2073 – 2082) [2016]

Data Collection

The study analysed the contents of the policy documents by developing a data extraction matrix that was constructed with the vertical axis listing the 21 predefined Core Concepts of Human Rights mentioned in the EquiFrame (Mannan et al, 2011),and the horizontal axis containing vulnerable groups that were categorised as – persons with disabilities, women/girls. Each policy document was read to identify the vulnerable group mentioned in the document, and the frequencies and score were recorded following the EquiFrame Manual.

EquiFrame

EquiFrame was originally developed by Ahfad University for Women, Sudan, and the Centre for Global Health at Trinity College Dublin, which considers social inclusion and human rights as key components of equity in the context of service provision. It identifies the degree of commitment of the policy to specified vulnerable groups and to the Core Concepts of Human Rights.

Table 2 below presents the EquiFrame's 21 core concepts, alongside the key questions and key language to elucidate the specified core concepts. However, they are not positioned in terms of equivalent importance within the framework, but rather are included with a view to representing a broad range of salient concerns in striving for equitable, accessible, and universal healthcare.

Table 2: EquiFrame's Core Concepts, Key Questions and Key Languages

No.	Core Concept	Key Questions	Key Language
1	Non-discrimination	Does the policy support the rights of people with disabilities and women/girls with equal opportunity in receiving health care?	People with disabilities and women/ girls (Vulnerable groups) are not discriminated against on the basis of their distinguishing characteristics (i.e., Living away from services; Persons with disabilities; Ethnic minority or Aged).
2	Individualised Services	Does the policy support the rights of people with disabilities and women/girls with individually tailored health and rehabilitation services to meet their needs and choices?	People with disabilities and women/ girls receive appropriate, effective, and understandable services.

3	Entitlement	Does the policy indicate how people with disabilities and women/girls may qualify for specific benefits relevant to them?	People with limited resources are entitled to some services free of charge or persons with disabilities may be entitled to respite grants.
4	Capability- based Services	Does the policy recognise the capabilities existing within people with disabilities and women/girls?	For instance, peer to peer support among women-headed households or shared cultural values among ethnic minorities.
5	Participation	Does the policy support the right of people with disabilities and women/girls to participate in the decisions that affect their lives and enhance their empowerment?	People with disabilities and women/girls can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation.
6	Coordination of Services	Does the policy support assistance of people with disabilities and women/girls in accessing services from within a single provider system (intra-agency) or more than one provider system (inter-agency) or more than one sector (inter-sectoral)?	People with disabilities and women/ girls know how services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required.
7	Protection from Harm	Does the policy outline that people with disabilities and women/girls are to be protected from harm during their interaction with health/disaster and related services?	People with disabilities and women/ girls are protected from harm during their interaction with health and related systems.
8	Liberty	Does the policy support the right of people with disabilities and women/girls to be free from unwarranted physical or other confinement?	People with disabilities and women/ girls are protected from unwarranted physical or other confinement while in the custody of the service system/provider.
9	Autonomy	Does the policy support the right of people with disabilities and women/girls to consent or refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to them?	People with disabilities and women/ girls can express “independence” or “self-determination”. For instance, a person with an intellectual disability will have recourse to an independent third-party regarding issues of consent and choice.

10	Privacy	Does the policy address the need for information regarding people with disabilities and women/girls to be kept private and confidential?	Information regarding people with disabilities and women/girls need not be shared among others.
11	Integration	Does the policy promote the use of mainstream services by people with disabilities and women/girls?	People with disabilities and women/ girls are not barred from participation in services that are provided for the general population.
12	Contribution	Does the policy recognise that people with disabilities and women/girls can be productive contributors to society?	People with disabilities and women/girls make a meaningful contribution to society.
13	Family Resource	Does the policy recognise the value of the family members of people with disabilities and women/girls in addressing health needs?	The policy recognises the value of family members of people with disabilities and women/girls as a resource for addressing health needs.
14	Family Support	Does the policy recognise individual members of people with disabilities and women/ girls may have an impact on the family members requiring additional support from health services?	Persons with chronic illness may have mental health effects on other family members, such that these family members themselves require support.
15	Cultural Responsiveness	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic or linguistic aspects of the person, as well as personal safety and dignity?	i) People with disabilities and women/ girls are consulted on the acceptability of the service provided. ii) Health facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e., respectful of the culture of people with disabilities and women/girls.

16	Accountability	Does the policy specify to whom, and for what, services providers are accountable?	People with disabilities and women/girls have access to internal and independent professional evaluation or procedural safeguards.
17	Prevention	Does the policy support people with disabilities and women/girls in seeking primary, secondary, and tertiary prevention of health conditions associated with disaster?	
18	Capacity Building	Does the policy support the capacity building of health/emergency support workers and of the system that they work in addressing health needs of people with disabilities, women/girls?	
19	Access	Does the policy support people with disabilities and/or women/girls—physical, economic, and information access to health services?	People with disabilities and women/girls have accessible health facilities (i.e., transportation; infrastructure; affordability and understandable information in appropriate format).
20	Quality	Does the policy support quality services to people with disabilities and women/girls through evidence-based and professionally skilled practice?	People with disabilities and women/girls are assured of the quality of the clinically appropriate services.
21	Efficiency	Does the policy support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of people with disabilities, women/girls?	

This study assessed the inclusion of two categories of vulnerable groups. They were persons with disabilities and women/girls. In each document, the presence of Core Concepts was assessed for vulnerable groups – persons with disabilities, women, and girls - that were mentioned in the policy. If the policy did not mention vulnerable groups but the concept was found addressing the total population stating "all people", this was categorised as "Universal".

Table 3: Vulnerable Groups and its Definition

Vulnerable Groups	Attributes or Definitions
Persons with Disabilities	Physical, sensory, intellectual or mental health conditions, and including synonyms of disability
Women and Girls	Referring to the female gender

Data Analysis

Measures, Scoring and Procedure

Core concepts (CCs) mentioned individually or collectively were counted by categorising them as disability, gender, or universals. Core Concept frequency, coverage, and the quality of commitment to the Core Concepts were measured and the result of each policy, by sector and in aggregate, is presented quantitatively. Each Core Concept identified in the policy documents listed was scored on a scale ranging from 1 to 4, following the criteria of:

1 = Concept only mentioned,

2 = Concept mentioned and explained,

3 = Specific policy actions identified to address the concept,

4 = Intention to monitor the concept was expressed.

Indices to measure "Core Concept Coverage", "Core Concept Quality" and "Overall Summary Ranking" were developed. **Core Concept Coverage** was measured with respect to the number of Core Concepts mentioned from among the 21 predefined framework concepts, and this ratio is expressed as a percentage. Similarly, **Core Concept Quality** was measured with respect to the number of Core Concepts within it, that were rated as 3 or 4 (as either stating a specific policy action to address a Concept or an intention to monitor a Concept) out of the 21 Core Concepts, and the ratio is expressed as a percentage. When several references to a Core Concept were identified, the mean quality score for the respective concept was recorded. The **Overall Summary Ranking** of the policy document is stated as High, Moderate, and Low, following the criteria:

- High = if the policy achieved ≥50% on all of the three scores above,
- Moderate = if the policy achieved ≥50% on two of the three scores above,
- Low = if the policy achieved <50% on two or three of the three scores above.

Qualitative data was extracted for each of the predefined Core Concepts and vulnerable groups mentioned as person with disability or disability, women/girls or gender, vulnerable group in common, and this was analysed and compared to ensure inter-rater reliability. All policy documents were assessed and rated by two authors independently using EquiFrame Matrix. The total number and scores for the mentioned Core Concepts and vulnerable groups were calculated for each document. In the case of disagreement between two authors in concept extraction and scoring, a consensus decision was reached through discussion with the other team members.

RESULTS

Table 4 reveals that the frequency and average quality scores of Core Concepts of disability, gender, and universal mention of vulnerable groups (stating all populations) in the four health policy documents were 50 (2.6), 34 (3.2) and 19 (1.8) respectively, meaning that there were low frequency references and quality scores. Similarly, the frequencies and average scores for those group concepts in the three disability policies were 175(3), 17(3.4) and 2 (3) respectively, meaning that disability received more frequent coverage, although quality scores were comparable. In the policies related to disaster risk reduction, the frequencies and their average scores were 46 (2.5), 41 (2.6), and 13 (2.3) for disability, gender, and universal coverage respectively, meaning that the policies were less frequently mentioned and poorly explained than the health and disability policies. Two gender policies which made least mention of the concepts, had the frequencies and their average score as 15 (2.9), 28 (3.4), and 16 (2.9) for disability, gender and universal coverage respectively.

Table 4: Reference Frequencies and Average Scores by Sector and Policy Documents

Sectors	Disability		Gender		Universal (All population)	
	Ref. frequencies	Average score	Ref. frequencies	Average score	Ref. frequencies	Average score
Health Policies	**n=50**	**2.6**	**n=34**	**3.2**	**n=19**	**1.8**
• National Health Policy – 2019	4	2	9	3.1	10	2.1
• Public Health Service Act - 2077	6	4	9	4	-	-
• National Strategy for Reaching the Unreached – 2073 MoHP	32	3.1	10	3.9	-	-
• Gandaki Province Health Policy - 2078	8	1.3	6	1.8	9	1.5
Disability Policies	**n=175**	**3**	**n=17**	**3.4**	**n=2**	**3**
• National Guidelines for Disability Inclusive Health Services – 2019	73	2.5	4	4	-	-
• Disability Related Ten Year National Policy and Plan (2073 – 2082)	66	3.7	11	3.2	1	2
• The Act Relating to Rights of Persons with Disabilities - 2074 (2017)	36	3.1	2	4	1	4
Gender Policies	**n=15**	**2.9**	**n=28**	**3.4**	**n=16**	**2.9**
• Gender Equality & Social Inclusion Strategy of Health Sector – 2018 MoHP	15	2.9	21	3.8	16	2.9
• National Gender Equality Policy – 2077 MoWCSC	-	-	7	2.5	-	-
Disaster Risk Reduction	**n= 46**	**2.5**	**n=41**	**2.6**	**n=13**	**2.3**
• National Policy for Disaster Risk Reduction – 2018 MoHA	2	2	3	2	1	2
• DRR National Strategic Plan of Action 2018 – 2030 (2018) – MoHA	22	2.9	26	3	4	3
• Disaster Risk Reduction and Management Act, 2074 & Rules - 2076 MoHA	2	1.5	2	1.5	2	4
• DRR Act 2075, Palungtar Municipality	4	2.3	5	2	3	1
• DRR Act 2075, Marsyangdi Rural Municipality	4	2	5	2	3	1
• Disability Related Ten Year National Policy & Plan (2073 – 2082) - DRR	12	2	-	-	-	-

MoHP: Ministry of Health and Population; MoHA: Ministry of Home Affairs; MoWCSC: Ministry of Women, Children and Senior Citizens

Table 5 shows the sum of frequency counts of disability, gender, and vulnerable groups (universal) commonly mentioned in the reviewed policy documents and their proportion across the 21 EquiFrame concepts. In aggregate, the vulnerable group – disability, gender, and commonly mentioned vulnerable groups - counted 286, 120, and 50, respectively. Altogether, the disability concept covered all 21 Core Concepts mentioned by EquiFrame with a 43% quality score, while gender and commonly mentioned vulnerable group concepts covered 81% and 62%, with 62% and 29% quality scores respectively. The core concepts of "Access" followed by "Non-discrimination" and "Individualised Services" were counted for all categories, while "Liberty" and "Family support" were counted the least.

Table 5: Proportion of References and Average Scores across Concepts in the Policy Documents

#	Concepts	Disability (n=286)		Gender (n=120)		Universal (n=50)	
		% Ref	Av. Score	% Ref	Av. Score	% Ref	Av. Score
1	Non-discrimination	5.9	1.7	14.2	2.3	14.0	1.3
2	Individualised Services	7.7	2.5	16.7	3.1	2.0	1.0
3	Entitlement	3.1	2.8	-	-	-	-
4	Capability- based Services	1.7	2.2	2.5	3.5	2.0	2.0
5	Participation	5.9	3.3	8.3	3.0	6.0	2.0
6	Coordination of Services	7.3	3.2	5.8	3.1	4.0	4.0
7	Protection from Harm	5.9	2.9	14.2	3.2	6.0	3.3
8	Liberty	1.7	2.5	-	-	-	-
9	Autonomy	0.7	2.0	0.8	4.0	2.0	4.0
10	Privacy	0.3	4.0	0.8	4.0	6.0	1.5
11	Integration	5.9	2.2	1.7	4.0	6.0	3.5
12	Contribution	1.4	1.5	0.8	1.0	-	-
13	Family Resource	2.4	3.0	0.8	2.0	-	-
14	Family Support	1.4	3.5	-	-	-	-
15	Cultural Responsiveness	2.4	1.4	0.8	4.0	-	-
16	Accountability	4.9	3.5	4.2	3.7	6.0	3.0
17	Prevention	5.9	3.4	9.2	2.5	-	-
18	Capacity Building	5.9	3.8	-	-	-	-
19	Access	19.2	3.2	15.8	3.2	28.0	2.9
20	Quality	6.3	2.1	1.7	4.0	16.0	1.7
21	Efficiency	3.5	2.8	1.7	3.0	2.0	3.0
		100	**43***	**100**	**62***	**100**	**29***

*N(3+4)/21x100

Table 6 illustrates marked differences in Core Concepts coverage and quality ranking between the policy documents. While analysing the Core Concept coverage by policies, Health policies in aggregate covered the highest proportion (52%) and the other policies – disability, gender and DRR - covered 46% aggregate in each. The overall summary rating was low in all policy documents with the highest rank in gender policies (28) followed by disability (22) and health (13). DRR policies ranked the least (8) in the composite quality index.

Table 6: Core Concepts Coverage and Composite Quality by Policies

Sectors	% Core Concept coverage			Overall Coverage	% Core Concept rated			Overall rating
	Disability	Gender	Universal		Disability	Gender	Universal	
Health Policies	**71**	**48**	**38**	**52**	**17**	**14**	**7**	**13**
• National Health Policy – 2019	14	24	33	24	5	14	14	11
• Public Health Service Act - 2077	10	10	-	10	10	10	-	10
• National Strategy for Reaching the Unreached – 2073 (MoHP)	71	33	-	52	52	33	-	43
• Gandaki Province Health Policy - 2078	29	19	19	22	0	0	0	0
Disability Policies	**95**	**33**	**10**	**46**	**48**	**16**	**3**	**22**
• National Guidelines for Disability Inclusive Health Services - 2019	86	19	-	50	29	19	-	24
• Disability Related Ten Year National Policy and Plan (2073 – 2082)	81	33	5	40	71	24	0	32
• The Act Relating to Rights of Persons with Disabilities - 2074 (2017)	67	5	5	26	43	5	5	18
Gender Policies	**48**	**52**	**38**	**46**	**33**	**27**	**24**	**28**
• Gender Equality & Social Inclusion Strategy of Health Sector 2018(MoHP)	48	48	38	45	33	43	24	33
• National Gender Equality Policy – 2077 (MoWCSC)	◎	29	-	29	-	10	-	10
Disaster Risk Reduction	**52**	**48**	**38**	**46**	**8**	**10**	**5**	**8**
• National Policy for Disaster Risk Reduction – 2018 (MoHA)	10	10	5	8	0	0	0	0
• DRR National Strategic Plan of Action 2018 – 2030 (2018) - MoHA	38	43	19	3	33	38	19	30
• Disaster Risk Reduction & Management Act 2074 & Rules 2076 (MoHA)	10	10	5	8	0	0	5	2
• DRR Act 2075, Palungtar Municipality	14	19	14	16	5	5	0	3
• DRR Act 2075, Marsyangdi Rural Municipality	14	14	14	14	5	5	0	3
• Disability Related Ten Year National Policy & Plan (2073 – 2082) DRR	33	-	-	33	5	-	-	5

DISCUSSION

While analysing the selected policy documents related to health, disability, gender, and DRR, the study found that the policies inadequately incorporated disability and gender issues in line with equity and human rights principles. It was also noted that the policies have not mentioned the Core Concept of disabilities and gender specifically, and most frequently they were mentioned in general and stated as "all people". This indicates that the policies provide limited guidance to include specific vulnerable groups such as persons with disabilities, and women and girls in the planning, system development and services. Moreover, they were all categorised as "low quality" as defined by the EquiFrame criteria. The mentioned concepts were poorly explained and the specific policy actions to address the concepts were barely stated. This finding is consistent with the shadow CRPD report submitted to the "Committee on the Rights of Person with Disabilities" in its 19th session by Nepalese organisations of persons with disabilities, which stated that disability has not been mainstreamed in many of the national health sector policies and plans (Autism Care Nepal Society (ACNS) et.al., 2018). Another study conducted using EquiFrame for the analysis of disability and gender inclusion in the Health, Water and Sanitation policies and strategies of Nepal reported similar results - that disability issues were inadequately covered within the policy documents (Wilbur et al, 2021). Policies in general emerge from government authorities or on their initiatives, and those policies related to gender and disability in particular are contingent upon national laws and international agreements which often are overlooked by omission or commission without proper analysis of potential consequences. Furthermore, a lack of political commitment to the promotion of disability and women's rights, and limited representation and participation of persons with disabilities and women in the policy process are commonly reported as the key reasons for policy insufficiency addressing disability and gender issues in the national policies and strategies (Bhandari, 2018; Nepal Disabled Women Association (NDWA), 2019; Wilbur et al, 2021).

Another important finding of this study is that the disability concept was better covered by the principles of equity and human rights in the policies, as compared to gender. The policies placed emphasis on access, individualised services and coordination of services for persons with disabilities, while the gender inclusion focussed on the individualised services followed by access, non-discrimination and protection from harm for women and girls. It can be explained that access, non-discrimination, and protection have been getting priority in disability and gender advocacy over the past decades, and also these are the most commonly referred concepts in disability and gender-related international policy instruments including UNCRPD and CEDAW (United Nations, 2003, 2006). A number of core concepts appeared infrequently or were absent in the reviewed policy documents. For example, Autonomy and Privacy appeared the least in the policies for persons with disabilities. Liberty, Family Support and Capacity Building for women and girls were not mentioned in any policies included in the analysis.

The Constitution of Nepal 2015, Article 35, states that every citizen shall have the right to free basic health services and no one shall be deprived of emergency health care. It further states that each citizen shall have equal access to health care (GoN/MOLJPA, 2015). In line with the intent of the Constitution, eight sectoral ministries have developed their own gender equality and social inclusion (GESI) policies, and also the Local Government Operation Act (LGOA) 2017 has several provisions for promoting GESI (Asian Development Bank, 2020). Furthermore, Nepal has ratified more than 23 international human rights instruments that include international conventions and covenants on women, ethnic minorities, and persons with disabilities, and against racial discrimination (GoN/MoLJPA, 2018). Despite all these commitments, the policy provisions and legal mandates to improve gender equity and the inclusion of women and people with disabilities have been found to inadequately cover the basic elements of human rights principles in health, disability, gender and DRR policies. Nepal's prolonged political transition, lack of accountability of policymakers, and concentrated efforts and advocacy towards political representation indicate that little attention has been given to policy formulation. This has resulted in poor quality policies that may have ultimately impacted the fulfilment of the state commitments made at the national and international level.

This analysis revealed that the policies offered only weak protection for persons with disabilities and women/girls. However, the authors felt that it is not only a matter of the policies being consistent with human rights instruments such as UNCRPD, but the policies should also be directed to reducing the disproportionate impact that disasters have on vulnerable populations, e.g., persons with disabilities and women/girls in Nepal, which was not found in any of the policies analysed in this study. There is scope for further research on this important issue as this study has generated new findings by looking at national and local policies, thereby indicating a need for broader analysis. Assessment of the national, provincial, and local level policies with a broader perspective in the respective sectors may allow further understanding of the complete scenario of gender and disability inclusion in the policies, their qualities and implementation status. Moreover, the findings of this study suggest that the key policies of related sectors need to be revisited in line with human rights approaches for the realisation of women and disability rights as committed by the state party.

Limitations

This policy analysis was a part of the study on "understanding the intersecting effect of gender, disability, and disaster meeting the healthcare needs and wellbeing of women with disabilities". Policies related to health, disability, gender, and DRR were selected but it was not possible to include all the policies (plan, strategies, acts, or legislations) in a single review; therefore, the complete picture of inclusion in the sectors may not be presented. Moreover, only two categories of vulnerable population/groups – persons with disabilities and women/girls - are included in the assessment and the large section of other vulnerable groups is excluded. Policy contents, structures, and statements in some documents were found to be very general and vague, sometimes creating difficulty to specify or count, and quality scoring. Furthermore, it is important to acknowledge that many of the concepts may have been referenced in the documents without specifying persons with disabilities, or women and girls. For example, concepts may have been included more broadly under the general all-encompassing language that applies to the entire population. Although information pertaining to these concepts should be covered for persons with disabilities, and women and girls specifically, there may be relevant information for these populations that may not have been captured while extracting the data from the documents. Another important limitation to be noted is that while EquiFrame identifies the commitment to social inclusion and human rights included in the policy documents, it does not, however, measure how effectively vulnerable groups are included in the mainstream policy works. Policy development, implementation, and evaluation are all equally important aspects to be assessed.

CONCLUSION

All the policies reviewed were varied but those policies have inadequately covered the core concepts and inclusion of disability and gender as defined in the EquiFrame. Almost all policies are relatively weak and ranked low in terms of quality to address the health needs and rights of the vulnerable groups during disasters in particular. In order to enhance social inclusion and promote the rights and equity in healthcare through equitable policies, it is suggested that the human rights approach, as guided by the EquiFrame, be followed while developing policies in the future.

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Core Concepts of Human Rights and Inclusion of Vulnerable Groups in the National Mental Health Policies of Ireland, Kenya, South Africa, India, and Liberia

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ABSTRACT

Purpose: *Policy analysis is an important tool to ensure that policies are rights-based and socially inclusive. The aim of this study was to assess the level of commitment to core concepts of human rights and the inclusion of vulnerable groups in five national mental health policies across low-, middle- and high-income countries.*

Method: *Policy documents were evaluated using EquiFrame, a systematic policy content analysis framework. Policies were examined with regard to their coverage of 21 core concepts of human rights (Core Concept Coverage), their quality of commitment to these core concepts (Core Concept Quality), and their inclusion of 12 vulnerable groups (Vulnerable Group Coverage). An Overall Summary Ranking was also assigned to each policy with regard to it being of 'high', 'moderate', or 'low' quality.*

Results*: Each of the policies scored 'high' on Vulnerable Group Coverage and Core Concept Coverage, although there were notable omissions. All policies, with the exception of Ireland, scored below EquiFrame's criteria for Core Concept Quality. The Irish policy produced a 'high' Overall Summary Ranking; while the Liberian, Kenyan, South African, and Indian policies each received a 'moderate' Overall Summary Ranking.*

Conclusion: *All policies received their lowest scores for Core Concept Quality, signifying a need for policymakers to ensure specific policy actions and monitoring mechanisms to address human rights in mental health policies. EquiFrame offers a constructive tool for mental health policy analysis in relation to core concepts of human rights and inclusion of vulnerable groups, which are considered key in successfully realising the Sustainable Development Goals.*

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Key words: *human rights, mental health policies, policy analysis, social inclusion, vulnerable groups*

INTRODUCTION

The Constitution of the World Health Organisation (2022a) defines mental health as a state of mental wellbeing that results in the ability to cope with normal life stressors, while realising one's potential, being able to work and learn well, and being able to fruitfully contribute to the community. However, due to the lack of consensus on a mental health definition, the integration of mental health into global healthcare services is often challenging (Whiteford et al, 2013). According to the 2022 World Mental Health Report (WHO, 2022b), approximately one in eight people live with a mental disorder globally.

Despite the prevalence of mental health problems, in low- and middle-income countries (LMICs) approximately 90% of those with mental disorders, such as depression or schizophrenia, do not have access to appropriate healthcare (Carter et al, 2021), despite the availability of effective and low-cost interventions (Patel et al, 2016). Mental health disorders receive as little as 1.05% of government expenditure in low-income countries and 3.8% in high-income countries (WHO, 2021). Mental health problems therefore often remain untreated (Subramaniam et al, 2022). The treatment gap has been used to emphasise the need for governments in LMICs to take action with regard to the provision of mental health services and the social inclusion of such services (Jansen et al, 2015). In response to this treatment gap, the Lancet Commission on Global Mental Health and Sustainable Development has emphasised the need for increased resources to address the mental health of the global population (Patel et al, 2018).

Importantly, a UN report (2017) has argued that "the crisis in mental health should be managed not as a crisis of individual conditions, but as a crisis of social obstacles which hinders individual rights. Mental health policies should address the 'power imbalance' rather than 'chemical imbalance' ". The promotion and protection of human rights in mental health are therefore reliant upon a redistribution of power in the clinical, research and public policy settings (United Nations, 2017). As proposed by Kinderman (2021), a shift from the 'disease model' of mental health to a social and psychological approach will require psychological wellbeing to be addressed in the context of human rights, policy, equity, and social justice. The relationship between mental health and social exclusion is complex, with social exclusion being both a consequential and causal factor of mental health problems (Nasser et al, 2016). Exclusion of disadvantaged groups can be costly at both an individual and societal level (Boardman et al, 2022).

In recent years, there has been an increased focus on mental health and wellbeing, as illustrated by the inclusion of mental health in the Sustainable Development Goals (SDGs) (WHO, 2015). The SDGs emphasise social inclusion and equity by declaring mental health a priority for global human development (United Nations, 2015), underpinned by the ethos of "leaving no one behind". Goal 3 directly focuses on the need for mental healthcare to be included in global health coverage, recognising that investment in mental health globally has the potential to significantly increase the prospects and productivity of persons with mental health problems (Lund et al, 2018). Crucially, the SDGs therefore rely on inclusive and rights-based policy content and policy processes to achieve these goals.

Mental Health Policies

A mental health policy may be defined as an official statement produced by government that describes a vision, with principles, ethics and objectives, and an inclusive action plan to attain this vision and improve the population's overall mental health (WHO, 2021).The WHO has developed a comprehensive Mental Health Action Plan for governments to improve population mental health. This plan identifies active governance and robust leadership as central factors for creating policies and plans to support mental healthcare and services (Thomas, 2013).

However, as outlined in the WHO's 2020 Mental Health Atlas, a total of 146 out of 171countries reported the presence of stand-alone policies/plans (86% of responding countries) for mental health (WHO, 2021). The South-East Asian Region reported the highest percentage, with 100% (*n*=8) of responding countries having a mental health policy, in comparison to the African region which reported the lowest percentage at 76% (*n*=29) of responding countries (WHO, 2021). The number of countries that reported having a stand-alone mental health policy or plan has increased in all regions since the 2014 and 2017 Mental Health Atlas (WHO, 2014, 2017).

Despite progress in the development of policies, plans and laws – including advances in the capacity to record mental health data based on a fixed set of mental health indicators across time-periods – the Mental Health Atlas 2020 reveals significant inequalities in the accessibility of mental health resources and their distribution between high-, middle- and low-income countries. The Mental

Health Atlas also continues to show substantial gaps universally between the existence of policies, plans and laws, and their implementation and monitoring (WHO, 2021).

Policy Analysis

Policy analysis is a powerful tool to address gaps in public policy outcomes and to provide an understanding for how and why governments formulate certain policies (Browne et al, 2018). Policy analysis identifies problems within existing policies and offers practical solutions for policymakers (Cairney, 2021). It typically analyses costs/benefits of public policies using a quantitative, rational approach (Hogan & Murphy, 2021).

However, there has been a recent shift in this approach, urging policymakers to integrate international human rights law for marginalised or disadvantaged groups in accessing healthcare (MacLachlan et al, 2012). Evaluating the extent to which policy content is equitable enables an assessment of vulnerable groups that are not prioritised in comparison with other groups (Amin et al, 2022). Inequitable policy content results in vulnerable groups being socially excluded, living in poverty, suffering from restricted access to resources and employment, and lack of social participation (Tangcharoensathien et al, 2018).

Mental health concerns are more prevalent in some social cohorts and often intersect with other vulnerability factors that can result in double discrimination and multiple disadvantage, such as people living with limited resources (Mannan et al, 2013), with mental health problems compounding poverty for example (Knapp et al, 2006). As proposed by Mannan et al (2013): "Formal recognition and incorporation in…mental health policies of specific mechanisms of exclusion and detailed needs of these populations is required to ensure their equitable access to healthcare". While all-inclusive terminology may be used in policies such as 'all people' or 'all citizens', this fails to recognise the specific needs, barriers to services, opportunities, and aspirations of particular vulnerable groups. Policies that are developed for the general population therefore often fail to support and include the most vulnerable groups (Ivanova et al, 2015). It is therefore critical for policymakers to formulate targeted strategies for all vulnerable groups using a rights-based approach (Eide et al, 2013).

Participation by marginalised groups at each stage of policy and decision-making processes is also crucial, including policy development, implementation, monitoring and appraisal (Kabakian-Khasholian et al, 2020; McVeigh et al, 2021), captured in the slogan of “Nothing About Us Without Us”. However, an inclusive policy process does not always produce an inclusive outcome, and it is therefore important for researchers to analyse the actual content of policies (Chinyama et al, 2018). The content of a policy defines the aims, anticipated beneficiaries, and potential government actions to achieve the goals of the policy (Huss & MacLachlan, 2017).

Objective

EquiFrame is a structured policy content analysis tool, designed to assess the inclusiveness of policy content by evaluating a policy’s level of commitment to 12 vulnerable groups and 21 core concepts of human rights (Disability Action Council Cambodia, 2017).Using *EquiFrame*, the aim of the present study was to assess the level of commitment to core concepts of human rights and the inclusion of vulnerable groups in the national mental health policies of Ireland, Kenya, South Africa, India, and Liberia. This study is relevant to a wide range of stakeholders, including policymakers, service-users, service-providers, and civil society including organisations of persons with disabilities. The overall goal of the study was to identify best-practice mental health policies that support the efforts of the SDGs in promoting right-based and equitable mental health policies and to identify policies that may require urgent revision.

METHOD

Development of EquiFrame

EquiFrame is a validated analytical tool to evaluate the extent to which social inclusion and human rights are prioritised in public policies and policy-related documents (Mannan et al, 2011).*EquiFrame* measures the inclusiveness of a given policy to 12 specified vulnerable groups (see Appendix 1) and its commitment to 21 core concepts of human rights (see Appendix 2) (Disability Action Council Cambodia, 2017). *EquiFrame* is a flexible framework, which allows for the selection and/or addition of vulnerable groups (MacLachlan et al, 2016). However, each of the core concepts and vulnerable groups listed in *EquiFrame* are supported by a significant evidence-base, and therefore any modifications to the framework must be justified by human rights literature and documents (MacLachlan et al, 2016).

EquiFrame was established as part of a work package led by Ahfad University for Women in Sudan, as part of the multi-country EU FP7-funded project *EquitAble*

(Mannan & MacLachlan, 2012). The framework was created at consultation workshops in LMICs, with over 100 participants from various sectors and organisations (Amin et al, 2011). Since the development of *EquiFrame*, it has been used to analyse a range of different policies, including but not limited to health-related policies such as national HIV/AIDS, tuberculosis, and malaria policies (MacLachlan et al, 2016; Chinyama et al, 2018; Amin et al, 2022), national health policies and drug policies (Amin et al, 2011), disability and rehabilitation policies and plans (Mannan et al, 2012; O'Dowd et al, 2014; Disability Action Council Cambodia, 2017), management of childhood illness policy (MacLachlan et al, 2012), and orthopaedic technical services policy (VanRooy et al, 2012), in a broad range of different countries including South Africa, Namibia, Sudan, Scotland, Ireland, Spain, Malawi, India, Cambodia and Ireland.

The Framework

EquiFrame assesses a policy's commitment to 21 core concepts of human rights and inclusion of 12 vulnerable groups, with a particular focus on persons with disabilities. *EquiFrame* focuses on equitable access to healthcare for persons who may be deemed vulnerable (Mannan et al, 2011). It is based on the ethos of accessible, universal, and equitable health service provision. The framework has been developed with a focus on policy content and design, with the intention of producing a systematic, evaluative and comparative analysis of policy content.

A 'core concept' (CC) may be characterised as a "central, often foundational policy component generalised from particular instances (namely, literature reviews, analyses of statutes and judicial opinions, and data from focus groups and interviews)" (Umbarger et al, 2005). *EquiFrame's* 21 CCs encompass a range of salient concerns in human rights in the context of equity in healthcare access (Oliver et al, 2002; Braveman & Gruskin, 2003), enabling health services to be delivered as a basic human right (Gilson et al, 2008). Appendix 1 presents *EquiFrame's* core concepts, with key questions and key language on which the concepts are based.

Vulnerable groups (VGs) may be classified as "social groups who experience limited resources and consequent high relative risk for morbidity and premature mortality" (Flaskerud & Winslow, 1998). Definitions for *EquiFrame's* VGs are presented in Appendix 2. For further details specific to the formulation of *EquiFrame* and the process of identifying core concepts and vulnerable groups, please see the *EquiFrame* manual (Mannan et al, 2011)

Selection of Policies

This study utilised a policy content analysis design. As the study was conducted on freely accessible national policies, there were no direct ethical considerations. Each of the five country's policies that are the focus of this analysis – Liberia, South Africa, India, Kenya, and Ireland – represent distinct challenges with regard to equitable service provision. These five countries show how equitable access to mental health services may be most effectively supported in contexts where more than half of the population lives below the poverty line, particularly in rural areas (Liberia); where irrespective of relative wealth, equitable access to health services has not yet been realised (South Africa); where despite a rapidly growing economy, significant health inequities persist (India); where high rates of poverty exist amidst a high burden of infectious disease (Kenya); and where universal coverage for primary healthcare has not yet been attained, as the only Western European country without a universal healthcare system (Ireland).

Mental health policies were included if they met the following criteria: (1) Mental health policy documents produced by the Ministry of Health; (2) A translated copy of the policy was available; and (3) Strategies that address mental health policies. A search was conducted to find mental health policies on the countries' national government websites. The selected policies contribute to the current body of knowledge on the extent to which national mental health policies are rights-based, equitable and socially inclusive. Each of these policies is briefly described in more detail below.

South African Mental Health Policy

The purpose of the South African 2013–2020 policy is to provide guidance to provinces for the prevention, promotion, treatment and recovery of mental health. The policy aims to address an inclusive scope of all mental disorders across all age ranges. It encompasses the human rights of people with mental health disorders and includes other stakeholders who can influence the improvement of South Africans' mental health status. The reformed Act that informed this policy aims to advance access to mental health services by ensuring the first contact of mental healthcare is through the primary healthcare system, followed by the integration of mental healthcare into general and community health services.

Kenyan Mental Health Policy

The Kenyan Mental Health Policy 2015–2030 was developed by public, private and non-State members through a consultative process, supervised by the

Ministry of Health. The policy is focused on achieving optimal health status and capacity-building of all citizens. The policy's goal is to attain the highest standard of mental health throughout the country, emphasising that all individuals in both the private and public sector are responsible for the fulfilment of this goal. Current mental health interventions in Kenya are wide-ranging and overlap with other sectors, showing the critical need for this policy to have an intersectoral and multidisciplinary approach.

India's Mental Health Policy

This policy was created in 2014 after a Policy Group, constituted by the Government of India in 2011, recommended the need for a national mental health policy. The goal of this policy is to promote inclusivity and de-stigmatisation of mental health, while ensuring that those affected by mental disorders have access to affordable and high-quality social care and healthcare across all age ranges. The Indian government emphasises the importance of having good mental health in order to achieve overall health. Thus, this policy aims to promote mental health awareness and to prevent mental disorders and suicide.

Liberia's Mental Health Policy and Strategic Plan

The reformed Mental Health Policy and Strategic Plan for Liberia (2016–2021) was created based on evidence regarding the need for mental health investments and the profound burden of disease in the country. The policy and strategic plan were published as one document. The strategy and policy aim to expand the accessibility of all mental health clinicians by developing new wellness units in each county and rehabilitation services in all regions. The policy also emphasises the need for regulation in order to supply psychotropic drugs in an effective way. The policy aims to improve Liberia's primary care services to achieve high standards across all mental healthcare services.

Ireland's Mental Health Policy

Ireland's most recent national mental health policy, 'Sharing the Vision' (2020–2030), encompasses several aspects of the original policy 'A Vision for Change' (2006), including guidance on the effective delivery of mental healthcare services. The policy promotes a holistic view of mental health, while acknowledging the multifaceted interplay of factors that may influence mental health. The policy adopts a person-centred approach, emphasising personal decision-making within recovery, supported by best clinical practice and lived mental health experiences.

The goal of this reformed policy is to develop a mental health system that focuses on the specific requirements of individuals and the needs of the population. The national Irish mental health policy aims to ensure that this system can deliver inclusive services (to service users and their families) to promote positive mental health within communities, prevent mental disorders and ensure appropriate and effective treatment.

Within the policy, various additional vulnerable groups are discussed, including the Traveller community and LGBTQ+ community. In the present study, the Traveller community was recorded as an ethnic minority due to the structural disadvantage and social stigma experienced by this group, whereby they are named as a protected group within Irish legislation (Haynes et al, 2021).Similarly, while social attitudes towards LGBTQ+ people have significantly improved in Ireland, such individuals continue to experience discrimination and social exclusion (Irish College of General Practitioners, 2020). Thus, for the present study LGBTQ+ individuals were included as a vulnerable group within the Irish population. These additional VGs were factored into the overall scoring of the policy, and the Irish national mental health policy was therefore scored on 14 VGs, rather than the original 12 VGs included in *EquiFrame*.

Summary Indices of EquiFrame

The four summary indices of *EquiFrame* are defined below (Mannan et al, 2011):
(1)**Core Concept Coverage:** The policy was inspected with respect to the quantity of Core Concepts mentioned out of the 21 Core Concepts identified. This ratio was then expressed as a rounded-up percentage.

(2) **Vulnerable Group Coverage:** The policy was examined with respect to the number of Vulnerable Groups mentioned of the 12 Vulnerable Groups identified. This ratio was then expressed as a rounded-up percentage.

(3) **Core Concept Quality:** The policy was examined with respect to the number of Core Concepts within it that were rated as 3 or 4 (as either stating a specific policy action to address a Concept or an intention to monitor a Concept) out of the 21 Core Concepts identified; and this ratio was expressed as a rounded-up percentage. When several references to a Core Concept were found to be present, the top-quality score received was recorded as the final quality scoring for the respective Concept.

(4) Each document was given an **Overall Summary Ranking** in terms of it being of High, Moderate or Low ranking according to the following criteria:

(i) High = if the policy achieved ≥50% on all of the three scores above.

(ii) Moderate = if the policy achieved ≥50% on two of the three scores above.

(iii) Low = if the policy achieved <50% on two or three of the indices above.

Scoring

Each Core Concept obtained a score on a scale from 1 to 4. This was a ranking of the quality of commitment to the Core Concept within the policy document:

1 = Concept only mentioned.

2 = Concept mentioned and explained.

3 = Specific policy actions identified to address the Concept.

4 = Intention to monitor Concept was expressed.

For each policy, the presence of Core Concepts was assessed for each Vulnerable Group that was identified in the policy. If no Vulnerable Group was mentioned but a Core Concept was addressed, the Core Concept was still recorded

As this study comprised a policy document content analysis, there were no direct ethical considerations.

RESULTS

Table 1 presents the results of the policy content analyses of the mental health policies using *EquiFrame's* summary indices. The Irish policy produced a **High** Overall Summary Ranking; while Liberia, Kenya, South Africa, and India each received a **Moderate** Overall Summary Ranking. Each of the policies exceeded *EquiFrame's* criterion of 50% for both Vulnerable Group Coverage and Core Concept Coverage.

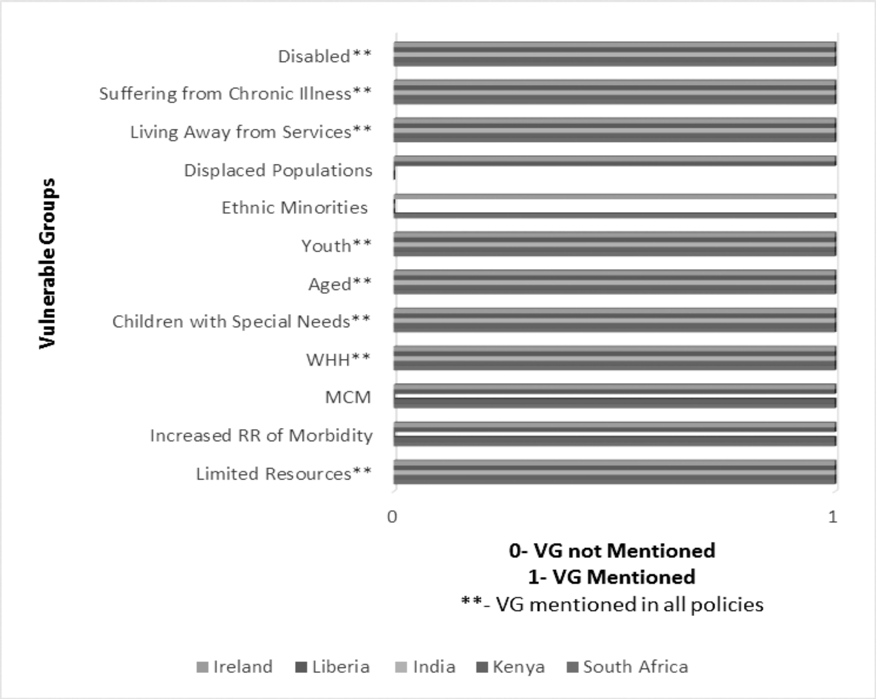
All Vulnerable Groups were mentioned at least once across all of the mental health policies. However, the Vulnerable Groups of *Ethnic Minorities* and *Displaced Populations* were only mentioned in two of the five policy documents (see Figure 1). This finding supports the construct validity of the categories used in *EquiFrame*, as they appear relevant within the policy domain, at least within the policies analysed. Notably, at least 8 out of 12 Vulnerable Groups were mentioned in each policy, i.e., *Limited Resources*, *Women- headed Household*, *Children with Special Needs*, *Aged*, *Youth*, *Living Away from Services*, *Suffering from Chronic Illness*, and *Disability*.

In total, 11 of the 21 Core Concepts were mentioned in all five policy documents (see Figure 2). The Core Concept of *Entitlement* was only mentioned in the Liberian Mental Health Policy. It was the only Core Concept not mentioned in the Irish policy. Particularly noteworthy was the Mental Health Policy of Ireland, which mentioned all Vulnerable Groups and only excluded 1 Core Concept. Having reflected on the more general findings from the application of the framework to each of the five policies, findings are presented below in more detail with respect to individual policy documents.

Table 1: ***EquiFrame*** **Summary Indices Scorings across Policies**

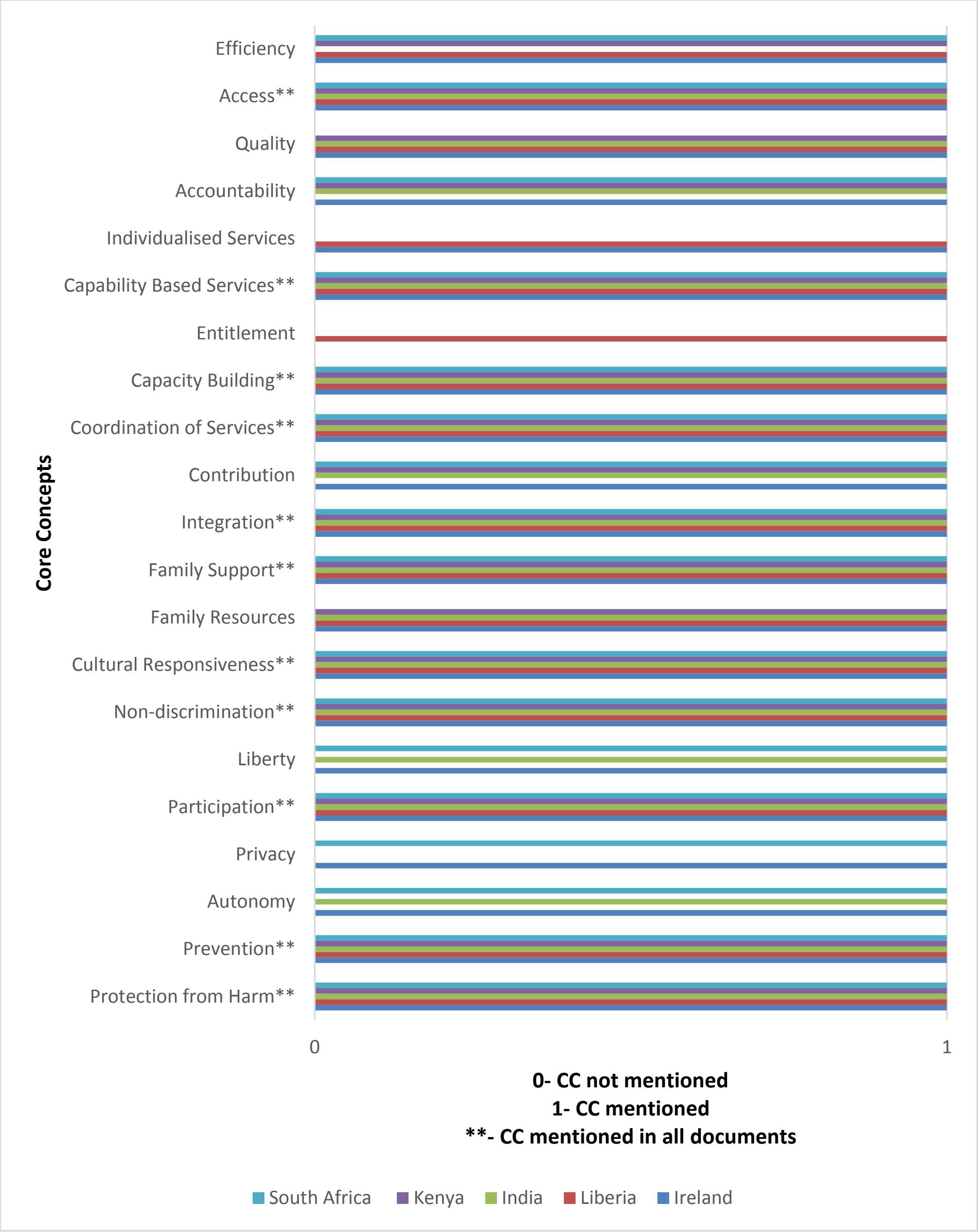
Mental Health Policy	Vulnerable Group Coverage	Core Concept Coverage	Core Concept Quality	Overall Summary Ranking
India	67%	81%	43%	Moderate
Ireland	100%	96%	53%	High
Kenya	84%	77%	48%	Moderate
Liberia	92%	77%	43%	Moderate
South Africa	92%	81%	38%	Moderate

Figure 1: Vulnerable Groups mentioned in each Policy



WHH = Women Headed Household; MCM = Mother Child Mortality; Increased RR of Morbidity = Increased Relative Risk of Morbidity

Figure 2: Core Concepts mentioned in each Policy



South Africa's Mental Health Policy

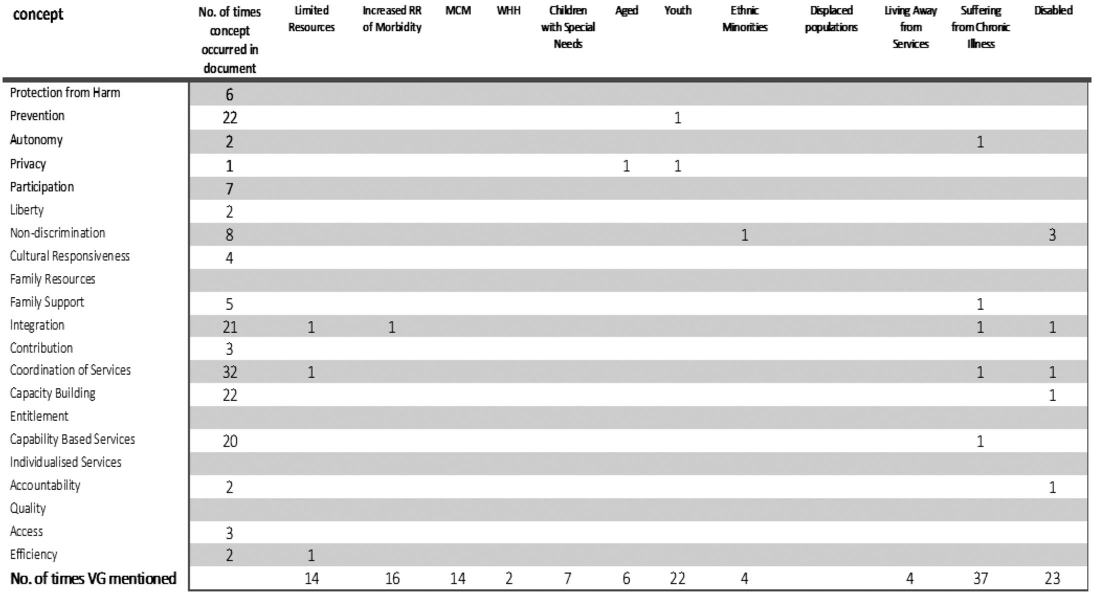
Vulnerable Group Coverage for this policy was 92%. The VG of *Suffering from Chronic Illness* was most frequently mentioned (37 times), followed by *Disabled* (23 times),*Youth* (22 times), *Increased Relative Risk for Morbidity* (16 times),and *Women-Headed Household* and *Limited Resources* (both mentioned 14 times). The remaining VGs were all mentioned under 10 times, while the VG of *Displaced Populations* was not mentioned in the policy (see Figure 3).

Core Concept Coverage for this policy was 81%. A total of four Core Concepts were not mentioned explicitly in the policy, namely *Family Resources*, *Entitlement*, *Individualised Services* and *Quality*. The most frequently mentioned Core Concept was *Co-ordination of Services* (32 times), followed by *Capacity Building* and *Prevention* (both mentioned 22 times), *Integration* (21 times), and *Capability Based Services* (20 times). The remaining Core Concepts were each mentioned less than 10 times.

With regard to Core Concept Quality, the document received a score of 38%. Eight of the Core Concepts mentioned were scored as '3' or '4', signifying that the policy either indicated actions to address the concept or expressed an intention to monitor the concept. The Core Concepts of *Integration*, *Capacity Building* and *Non-discrimination* were each mentioned with an expressed intention to monitor the Core Concept. The Core Concepts of *Cultural Responsiveness*, *Autonomy*, *Protection from Harm*, *Co-ordination of Services* and *Capability Based Services* were mentioned in relation to particular policy actions to address the Core Concept.

Accordingly, the South African National Mental Health Policy scored above 50% for Core Concept Coverage and Vulnerable Group Coverage, and below 50% for Core Concept Quality. The policy therefore scored above 50% on two of three of *EquiFrame's* summary indices and was given an Overall Summary Ranking of 'Moderate'.

Figure 3: Core Concepts and Vulnerable Groups identified in the South African Mental Health Policy



concept	No. of times concept occurred in document	Limited Resources	Increased RR of Morbidity	MCM	WHH	Children with Special Needs	Aged	Youth	Ethnic Minorities	Displaced populations	Living Away from Services	Suffering from Chronic Illness	Disabled
Protection from Harm	6												
Prevention	22							1					
Autonomy	2											1	
Privacy	1						1	1					
Participation	7												
Liberty	2												
Non-discrimination	8								1				3
Cultural Responsiveness	4												
Family Resources													
Family Support	5											1	
Integration	21	1	1									1	1
Contribution	3												
Coordination of Services	32	1										1	1
Capacity Building	22												1
Entitlement													
Capability Based Services	20											1	
Individualised Services													
Accountability	2												1
Quality													
Access	3												
Efficiency	2	1											
No. of times VG mentioned		14	16	14	2	7	6	22	4		4	37	23

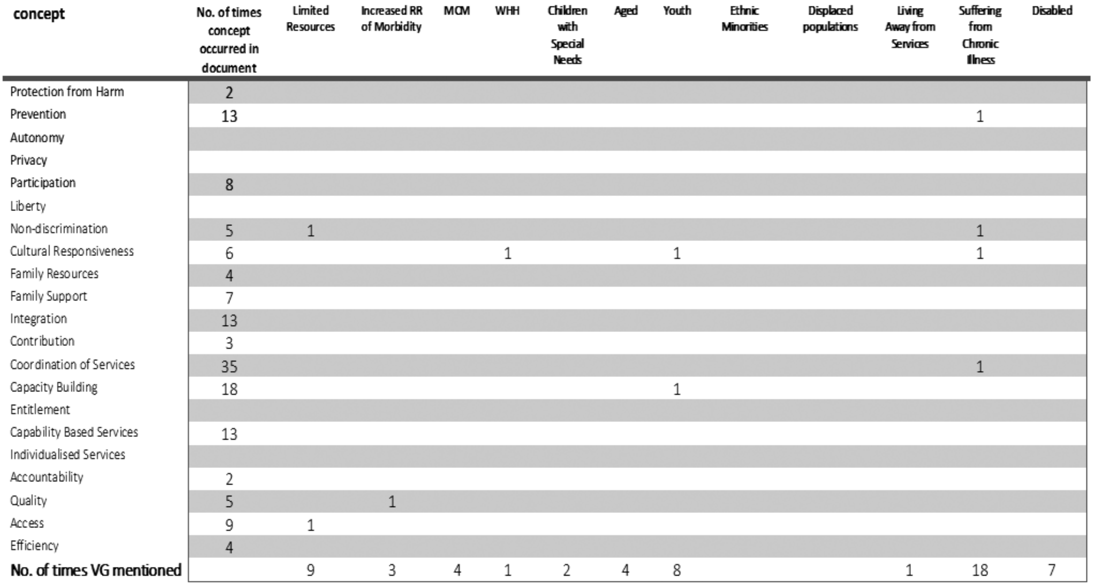
Kenyan Mental Health Policy

Vulnerable Group Coverage for this policy was 84%. The document failed to mention two VGs, namely *Displaced Populations* and *Ethnic Minorities*. While *Suffering from Chronic Illness* was the most frequently mentioned Vulnerable Group (18 times), all other Vulnerable Groups were mentioned less than 10 times throughout the document. The VGs of *Living Away from Services* and *Women-Headed Household* were only mentioned once in the policy (see Figure 4).

Core Concept Coverage for this policy was 77%. *Co-ordination of Services* was explicitly mentioned 35 times, followed by *Capacity Building* (18 times), *Integration*, *Prevention*, and *Capability-Based Services* (13 times each). All other Core Concepts were mentioned less than 10 times. The policy failed to mention five Core Concepts - *Autonomy*, *Privacy*, *Liberty*, *Entitlement*, and *Individualised Services.*

Ten of these Core Concepts were scored as '3' or '4', meaning that the policy either indicated actions to address the concept or expressed intention to monitor the concept. These Core Concepts were *Participation*, *Co-ordination of Services*, *Efficiency*, *Accountability*, *Capacity Building*, *Quality*, *Integration*, *Prevention*, *Family Support*, and *Contribution*. Due to the policy scoring above 50% for two of three of *EquiFrame's* summary indices, the policy received a 'Moderate' Overall Summary Ranking.

Figure 4: Core Concepts and Vulnerable Groups identified in the Kenyan National Mental Health Policy



concept	No. of times concept occurred in document	Limited Resources	Increased RR of Morbidity	MCM	WHH	Children with Special Needs	Aged	Youth	Ethnic Minorities	Displaced populations	Living Away from Services	Suffering from Chronic Illness	Disabled
Protection from Harm	2												
Prevention	13											1	
Autonomy													
Privacy													
Participation	8												
Liberty													
Non-discrimination	5	1										1	
Cultural Responsiveness	6				1			1				1	
Family Resources	4												
Family Support	7												
Integration	13												
Contribution	3												
Coordination of Services	35											1	
Capacity Building	18							1					
Entitlement													
Capability Based Services	13												
Individualised Services													
Accountability	2												
Quality	5		1										
Access	9	1											
Efficiency	4												
No. of times VG mentioned		9	3	4	1	2	4	8			1	18	7

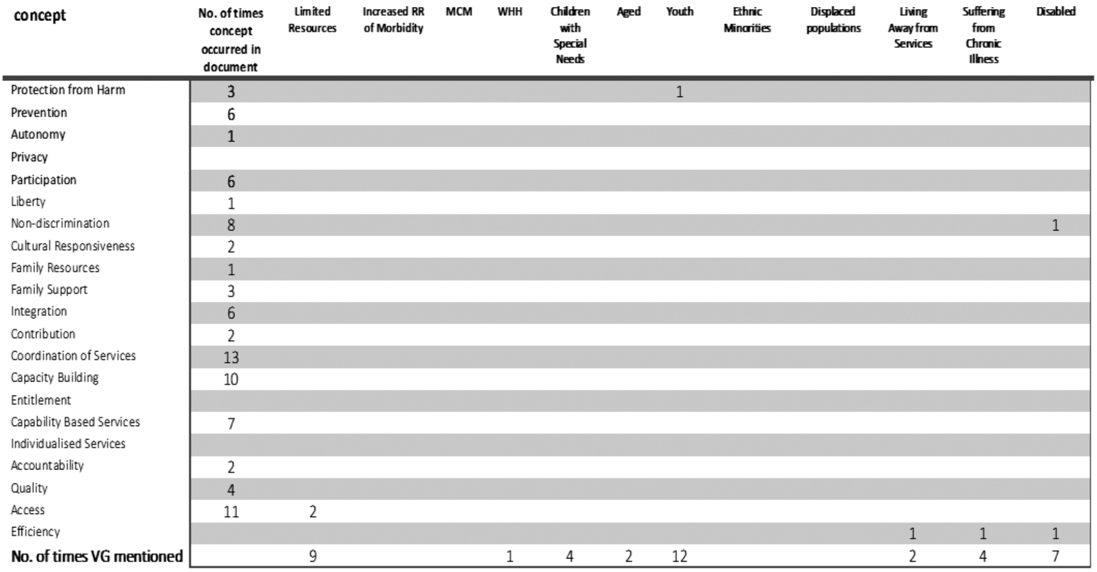
India's Mental Health Policy

Vulnerable Group Coverage for this policy was 67%. *Increased Relative Risk for Morbidity*, *Mother Child Mortality*, *Ethnic Minorities*, and *Displaced Populations* were not mentioned throughout the policy. *Youth* was the most frequently mentioned Vulnerable Group (12 times), while all other Vulnerable Groups mentioned were cited less than 10 times.

Core Concept Coverage was 81%.The Core Concepts of *Privacy*, *Entitlement*, and *Individualised Services* were not mentioned in the policy. *Co-ordination of Services* was the most commonly mentioned Core Concept (13 times), followed by *Access* (11 times), and *Capacity Building* (10 times). The remaining Core Concepts were mentioned less than 10 times throughout the document (see Figure 5).

Core Concept Quality was 43%, with eight Core Concepts being expressed with regard to specific policy actions to address the CC (no CCs were expressed with the intention to monitor). These CCs were *Participation*, *Co-ordination of Services*, *Family Resources*, *Access*, *Capability-Based Services*, *Capacity Building*, *Non-discrimination*, *Family Support*, and *Integration*. The policy scored above 50% for two of *EquiFrame's* summary indices and below 50% for Core Concept Quality. The document therefore received a 'Moderate' Overall Summary Ranking.

Figure 5: CCs and VGs identified in the Indian National Mental Health Policy



concept	No. of times concept occurred in document	Limited Resources	Increased RR of Morbidity	MCM	WHH	Children with Special Needs	Aged	Youth	Ethnic Minorities	Displaced populations	Living Away from Services	Suffering from Chronic Illness	Disabled
Protection from Harm	3							1					
Prevention	6												
Autonomy	1												
Privacy													
Participation	6												
Liberty	1												
Non-discrimination	8												1
Cultural Responsiveness	2												
Family Resources	1												
Family Support	3												
Integration	6												
Contribution	2												
Coordination of Services	13												
Capacity Building	10												
Entitlement													
Capability Based Services	7												
Individualised Services													
Accountability	2												
Quality	4												
Access	11	2											
Efficiency											1	1	1
No. of times VG mentioned		9			1	4	2	12			2	4	7

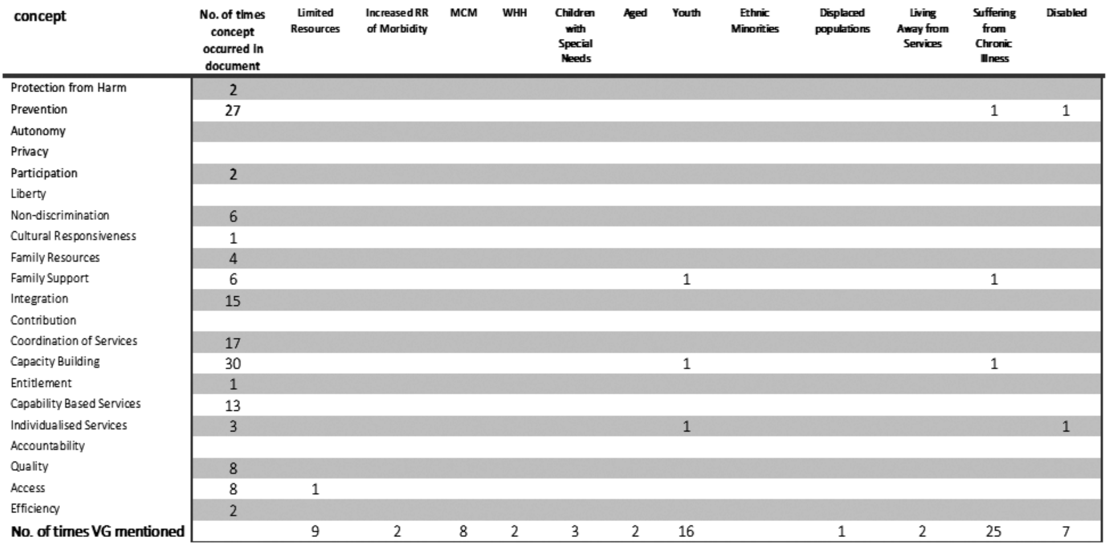
Liberian National Mental Health Policy and Strategic Plan

Vulnerable Group Coverage for the Liberian National Mental Health Policy and Strategic Plan was 92%.The policy mentioned all VGs, with the exception of *Ethnic Minorities*. The most commonly mentioned VG throughout the policy was *Suffering from Chronic Illness* (25 times), followed by *Youth* (16 times). All remaining VGs were cited less than 10 times in the document (see Figure 6).

The policy's Core Concept Coverage was 77%. The Core Concept of *Capacity Building* was referred to in the document most frequently (30 times), followed by *Prevention* (27 times), *Co-ordination of Services* (17 times), *Integration* (15 times) and *Capability-Based Services* (13 times). The remaining Core Concepts mentioned were cited less than 10 times. The document did not explicitly mention *Autonomy*, *Privacy*, *Liberty*, *Contribution*, or *Accountability*.

With regard to Core Concept Quality, the following Core Concepts received a score of '3': *Participation*, *Prevention*, *Capacity Building*, *Quality*, *Co-ordination of Services*, *Integration*, *Family Support*, *Individualised Services*, and *Capability- Based Services*. The document's overall Core Concept Quality was 43%. The Liberian National Mental Health Policy scored above 50% for two of *EquiFrame's* summary indices and below 50% for Core Concept Quality. The policy therefore received a 'Moderate' Overall Summary Ranking.

Figure 6: CCs and VGs identified in the Liberian National Mental Health Policy and Strategic Plan



concept	No. of times concept occurred In document	Limited Resources	Increased RR of Morbidity	MCM	WHH	Children with Special Needs	Aged	Youth	Ethnic Minorities	Displaced populations	Living Away from Services	Suffering from Chronic Illness	Disabled
Protection from Harm	2												
Prevention	27											1	1
Autonomy													
Privacy													
Participation	2												
Liberty													
Non-discrimination	6												
Cultural Responsiveness	1												
Family Resources	4												
Family Support	6							1				1	
Integration	15												
Contribution													
Coordination of Services	17												
Capacity Building	30							1				1	
Entitlement	1												
Capability Based Services	13												
Individualised Services	3							1					1
Accountability													
Quality	8												
Access	8	1											
Efficiency	2												
No. of times VG mentioned		9	2	8	2	3	2	16		1	2	25	7

Ireland's National Mental Health Policy

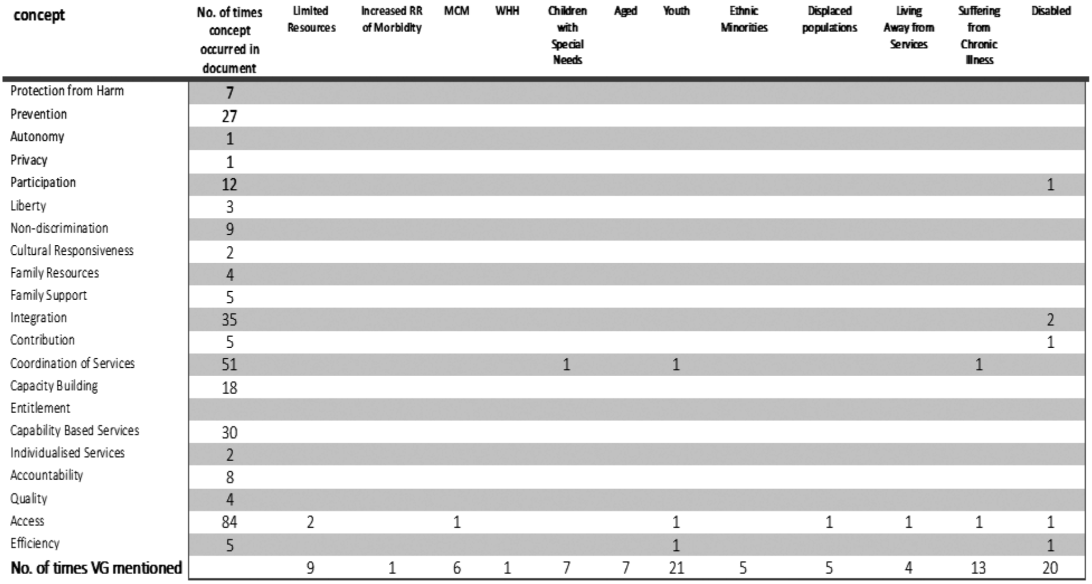
Vulnerable Group Coverage for the Irish National Mental Health Policy was 100%. The VGs of *Increased Relative Risk for Morbidity* and *Women-Headed Household* were only mentioned once in the document. *Youth* was the most frequently mentioned VG (21 times), followed by *Disability* (20 times), and *Suffering from Chronic Illness* (13 times). The remaining VGs were all cited 10 times or less throughout the policy (see Figure 7). Notably, the policy also included additional VGs in the Irish population, including LBGTQ+ people (4 times) and the Traveller Community (2 times). Thus, this policy mentioned 14 VGs in total.

Core Concept Coverage for this policy was 96%. The policy mentioned all Core Concepts, with the exception of *Entitlement*. The most commonly mentioned CC was *Access* (84 times), followed by *Co-ordination of Services* (51 times), *Integration* (35 times),*Capability-Based Services* (30 times), *Prevention* (27 times), *Capacity Building* (18 times), and *Participation* (12 times). The remaining Core Concepts were mentioned less than 10 times throughout the policy (see Figure 7). This policy produced the highest frequency counts for the number of times that a Core Concept was mentioned.

The policy's Core Concept Quality was 53%. The CCs of *Integration*, *Participation*, *Access*, and *Non-Discrimination* were all expressed with an intention to monitor;

while *Contribution*, *Capability-Based Services*, *Family Resources*, *Co-ordination of Services*, *Prevention*, *Capacity Building*, and *Family Support* were mentioned with specific policy actions to address the CC. The Irish National Mental Health policy scored above 50% on all three of *EquiFrame's* summary indices and was therefore given an Overall Summary Ranking of 'High'.

Figure 7: Core Concepts and Vulnerable Groups identified in the Irish National Mental Health Policy



concept	No. of times concept occurred in document	Limited Resources	Increased RR of Morbidity	MCM	WHH	Children with Special Needs	Aged	Youth	Ethnic Minorities	Displaced populations	Living Away from Services	Suffering from Chronic Illness	Disabled
Protection from Harm	7												
Prevention	27												
Autonomy	1												
Privacy	1												
Participation	12												1
Liberty	3												
Non-discrimination	9												
Cultural Responsiveness	2												
Family Resources	4												
Family Support	5												
Integration	35												2
Contribution	5												1
Coordination of Services	51					1		1				1	
Capacity Building	18												
Entitlement													
Capability Based Services	30												
Individualised Services	2												
Accountability	8												
Quality	4												
Access	84	2		1				1		1	1	1	1
Efficiency	5							1					1
No. of times VG mentioned		9	1	6	1	7	7	21	5	5	4	13	20

DISCUSSION

The aim of the present study was to assess the level of commitment to Core Concepts of human rights and the inclusion of Vulnerable Groups in the national mental health policies of Ireland, Kenya, South Africa, India, and Liberia. The overall goal of the study was to identify best-practice mental health policies that support the efforts of the SDGs in promoting right-based and equitable mental health policies and to identify policies that may require urgent revision.

Significant variability was found for *EquiFrame's* summary indices across the national mental health policies analysed. Particularly noteworthy was the Irish Mental Health policy as the only policy to receive a 'High' Overall Summary Ranking. This policy explicitly mentioned all Vulnerable Groups and mentioned 20 out of 21 Core Concepts. Although all other policies received a 'Moderate'

Overall Summary Ranking, significant differences were nonetheless found between policies regarding Vulnerable Group Coverage and Core Concept Coverage, as reflected in Table 1. All policies received their lowest scores for Core Concept Quality, signifying a need for policymakers to ensure specific policy actions and monitoring mechanisms to address human rights in mental health policies. This finding aligns with the 2020 Mental Health Atlas, which reported substantial gaps between the existence of policies, plans and laws, and their implementation and monitoring (WHO, 2021). Similarly, in a previous *EquiFrame* analysis of the mental health policies of Malawi, Namibia, and Sudan, Mannan et al (2013) reported that Core Concept Quality was below *EquiFrame's* criterion of 50% for the Sudanese and Malawian mental health policies.

Vulnerable Group Coverage

Each of the policy documents exceeded *EquiFrame's* criterion of 50% for Vulnerable Group Coverage. Despite all policies scoring above 50%, there was a stark contrast for Vulnerable Group Coverage across policies. For example, the Indian mental health policy scored the lowest for Vulnerable Group Coverage at 67%, and the Irish mental health policy scored the highest at 100%. The Indian, Kenyan, and Liberian mental health policies failed to explicitly mention the VG of *Ethnic Minorities*. Ethnic minorities are common across all countries and cultures, despite the variation of particular ethnic minorities within countries. The Irish mental health policy mentioned the Traveller community, which was recorded as an ethnic minority group in this study. Irish Travellers constitute an indigenous minority, with distinctive cultural values, history, language, traditions, and customs (https://itmtrav.ie/what-is-itm/irish-travellers/), of which nomadism is a key component (McElwee et al, 2003). Importantly, ethnic minorities are more vulnerable to mental health issues, discrimination, and greater disadvantage (Elliott & Masters, 2009).Ethnic minority groups, who may already face prejudice and discrimination with regard to their group affiliation, may confront double stigma when faced with mental health problems (Gary, 2005).

Notably, the Irish mental health policy also included other Vulnerable Groups, such as the LGBTQ+ community. Being a part of the LGBTQ+ community is correlated with an increased risk for mental health issues and stigma (Wishart et al, 2019) and the LGBTQ+ community is a group that should be acknowledged globally (Connell et al, 2017). Recognising particular mechanisms of exclusion and the detailed barriers and needs of specific Vulnerable Groups in policies is critical to ensuring equitable healthcare access.

Although all Vulnerable Groups were mentioned in at least one of the analysed policies, it is important to examine if all vulnerable groups are equally salient across different types of policies (MacLachlan et al, 2012). When analysing policies, certain assumptions may lead to conceptual foreclosure. For example, it may be argued that mental health policies already address the *Increased Relative Risk for Morbidity* group, therefore negating the need to evaluate the policy's inclusion of this group. However, the high comorbidity of mental health disorders (Roca et al, 2009) demonstrates the critical need to include this Vulnerable Group in mental health policies. It is important to be able to compare policies regarding the inclusion of vulnerable groups and to then study the contextual relevance of such groups (MacLachlan et al, 2012).

Core Concept Coverage and Core Concept Quality

While each of the policies exceeded *EquiFrame's* criterion of 50% on Core Concept Coverage, the Liberian, Indian and Kenyan mental health policies failed to include the Core Concept of *Privacy*; and the Liberian and Kenyan policies did not mention the Core Concepts of *Autonomy* and *Liberty*. Each of these Core Concepts plays a vital role in the protection of people with mental health problems. It is crucial that the right to privacy is protected for those with mental health concerns (United Nations, 2015). With regard to autonomy, informed consent is a key component in receiving appropriate care and treatment for mental health disorders (WHO, 2008). Correspondingly, the right to liberty ensures the protection of Vulnerable Groups from unwarranted confinement when in the custody of a mental health system or service provider (Mannan et al, 2011). The right to liberty is also crucial to ensuring that individuals have the right to make informed decisions regarding their personal mental health (Cairney, 2019).

The Irish, Indian and South African mental health policies failed to include the Core Concept of *Entitlement*, indicating the need for policies to demonstrate how Vulnerable Groups may qualify for specific benefits that are relevant to them. Individuals with mental health disorders are entitled to similar rates of disability benefits as those who suffer from a physical disability (WHO, 2008). Specifying entitlements and disseminating information on such entitlements amongst service-users can aid in treatment-seeking processes and alleviate financial concerns.

With regard to Core Concept Quality, with the exception of the Irish mental health policy, all policies scored below *EquiFrame's* criterion of 50%. Importantly, the Liberian and Indian policies failed to express any intention to monitor the implementation of Core Concepts that were mentioned. Although the Irish policy scored above *EquiFrame's* criterion of 50%, it only received a score of 53% for Core Concept Quality. This finding adds to and supports previous findings from the WHO, which highlighted a limited number of countries that have successfully developed monitoring mechanisms for mental health resources (WHO, 2021). The Core Concept Quality scores in this study illustrate the need for policymakers to more effectively ensure specific policy actions and monitoring mechanisms for Core Concepts of human rights in mental health policies.

Study Limitations

This study analysed the South African National Mental Health Policy which was in operation from 2013–2020 and is therefore effectively out of date. However, at the time of the study, a revised version of this policy had not yet been made available. This was also the case for the Liberian Mental Health policy, which was dated from 2016–2021. A revised version of this policy had not yet been published at the time that this study was conducted, so the analysis dealt with the most up-to-date version of the policy that was available in 2021. The Indian National Mental Health policy was developed in 2014 and did not have a fixed date of termination/revision. Importantly, as the development of the Indian and South African mental health policies precedes the adoption of the SDGs by UN Member States in 2015, these policies cannot fully support the SDGs. The lack of adherence to the SDGs in terms of social inclusion in these policies indicates an urgent need for policy revision.

During the development of *EquiFrame*, a number of stakeholders argued that policies often use the term "all" with regard to "all people" in order to be fully inclusive, negating the need to mention particular vulnerable groups (MacLachlan et al, 2012). Notably, all the analysed policies used broad terminology at times, such as "all people" or "all citizens". However, such policies still mentioned specific Vulnerable Groups while failing to mention others, which may exacerbate the social exclusion of these groups. For example, the Indian policy referred to persons with disabilities, but failed to consider ethnic minorities. The use of broad and all-encompassing terminology fails to address the needs, concerns, and barriers to accessing health services of particular vulnerable cohorts (Mannan et al, 2012). Thus, this study did not account for broad terminology such as "all" and "all people" in its analyses.

Although it was not feasible to analyse a broader range of policies in this study, future analysis of cognate policies – such as transportation, health, social protection, and education policies – may support co-ordination of services and integration of mental health across different sectors. If mental health is not prioritised across all sectors and national policies, it will not be possible to realise the interdependent goals set out in the SDGs (Smith, 2018).

While *EquiFrame* focuses on *policy content*, it is important to also examine *policy processes* in terms of social inclusion and adherence to human rights, such as policy development, implementation, monitoring and evaluation. For this purpose, *EquIPP* (Equity and Inclusion in Policy Processes) is a framework for the development of equitable and inclusive policy processes and is applicable across high-, middle-, and low-income countries (Huss & MacLachlan, 2016; MacLachlan et al, 2016; Ebuenyi et al, 2021). Participation in the development of policies ensures that the needs of Vulnerable Groups are represented and provides an opportunity for such groups to hold their government accountable (Jones, 2009).For example, Chinyama et al (2018) analysed the content of the Malawian HIV and AIDS Policy using *EquiFrame*, alongside the participation of Vulnerable Groups in policy processes using *EquiPP*. Using *EquiFrame* and *EquIPP* in future studies will enable an evaluation of the extent to which both mental health policy content and policy processes are rights-based, equitable, and socially inclusive. As proposed by MacLachlan et al (2019), "policy assessments, through the use of methodologies such as EquiFrame and EquIPP, can tell us much about the priority accorded to issues of inclusion of vulnerable groups and about prevailing negative attitudes and behaviours in society".

It is also noteworthy that while *EquiFrame* produces a list of Vulnerable Groups developed through extensive participatory consultations, it is not possible for the framework to list all existing vulnerable groups across all contexts. For example, many of the social groups recognised by the Global Fund (The Global Fund, 2020) as most at-risk are not accounted for by *EquiFrame*, including transgender individuals, drug users, sex workers and prisoners. This point emphasises the need for researchers to be aware of the flexibility of the *EquiFrame* framework in accordance with context and purpose. If policymakers and stakeholders are not aware of the specific Vulnerable Groups within their population, this will hinder the analysis of policy content. The objective of *EquiFrame* is to provide guidance for policy content analysis by providing various summary indices in accordance with the Core Concepts of human rights and equity. However, as all Core Concepts and Vulnerable Groups included in EquiFrame are supported by a substantial evidence base, it is advised that any modifications to the framework are well-rooted in human rights documents and literature relative to the particular context (MacLachlan et al, 2016).

CONCLUSION

Policymakers recognise the value of policy analysis, as it enables them to show a commitment to endorsing social inclusion and human rights in their policies (MacLachlan et al, 2016). While *EquiFrame* was developed for content analysis of policy documents, the framework may also be advantageous to other guidance and planning documents where human rights coverage and social inclusion are relevant. The use by researchers and policymakers of these freely accessible policy analysis tools, namely EquiFrame and EquIPP, can support social inclusion and human rights in mental health service provision. Greater understanding of the content of such documents can be gained by assessing the context in which the document was developed.

The critical need for mental health policy reform is extensively acknowledged by policymakers, mental health professionals and scholars (WHO, 2018). Policymakers have emphasised the need for a collaborative approach with regard to mental health policies that avails of knowledge from decision-makers, service-providers, and service-users (Mechanic et al, 2014). In order to achieve this collaborative approach, there must be active and meaningful participation of marginalised groups in the development of policies to support successful policy implementation (MacLachlan et al, 2014). Importantly, communicating policy analysis findings with communities and policy beneficiaries is also critical to attaining the desired outcomes of policies.

Inclusive and equitable public policies are a key component in attaining the SDGs. As proposed by Huss and MacLachlan (2017), “policies must confer entitlements, protect the human rights of vulnerable groups, whilst aligning actions and objectives with the global vision of sustainable development”. In comparison to 2014 and 2017 data, the WHO 2020 Mental Health Atlas indicated that a greater number of countries reported that their policies encouraged a shift towards respecting the human rights of individuals with a mental health condition and psychosocial disabilities, an increase in mental health resources within the community, and the promotion of independence and inclusion of these individuals (WHO, 2021). Despite this, the number of countries that reported adopting a recovery approach to mental healthcare and the inclusion of vulnerable groups in the decision-making processes of policies decreased slightly from 2017 (WHO, 2021).

Although each of the policies in this study demonstrated moderate to high levels of commitment to Core Concepts of human rights and inclusion of Vulnerable Groups, there is a need for revision of all policies to address the low scores received for Core Concept Quality. There is an urgent need for updated Indian and South African National Mental Health policies due to the date of their development. As these policies were created in 2014 and 2013, respectively, they cannot fully support the SDGs, which were adopted by India and South Africa in 2015. It is evident that each of the policies analysed in this study requires urgent revision with regard to the development of monitoring mechanisms and specific policy actions addressing Core Concepts of human rights. *EquiFrame* offers a valuable tool for evaluating Core Concepts of human rights and inclusion of Vulnerable Groups in national policies, which are considered key in successfully realising the SDGs.

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Appendix 1: Table of Core Concepts and Definitions

No	Core concept	Key question	Key language
1.	**Non-discrimination**	Does the policy support the rights of vulnerable groups with equal opportunity in receiving health care?	Vulnerable groups are not discriminated against on the basis of their distinguishing characteristics (i.e., Living away from services; Persons with disabilities; Ethnic minority or Aged).
2.	**Individualised Services**	Does the policy support the rights of vulnerable groups with individually tailored services to meet their needs and choices?	Vulnerable groups receive appropriate, effective, and understandable services.
3	**Entitlement**	Does the policy indicate how vulnerable groups may qualify for specific benefits relevant to them?	People with limited resources are entitled to some services free of charge or persons with disabilities may be entitled to respite grant.
4	**Capability- based Services**	Does the policy recognise the capabilities existing within vulnerable groups?	For instance, peer to peer support among women- headed households or shared cultural values among ethnic minorities.
5.	**Participation**	Does the policy support the right of vulnerable groups to participate in the decisions that affect their lives and enhance their empowerment?	Vulnerable groups can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation.
6.	**Coordination of Services**	Does the policy support assistance of vulnerable groups in accessing services from within a single provider system (inter-agency) or more than one provider system (intra-agency) or more than one sector (inter-sectoral)?	Vulnerable groups know how services should interact where inter-agency, intra-agency, and inter-sectoral collaboration is required.
7.	**Protection from Harm**	Are vulnerable groups protected from harm during their interaction with health and related systems?	Vulnerable groups are protected from harm during their interaction with health and related systems.
8	**Liberty**	Does the policy support the right of vulnerable groups to be free from unwarranted physical or other confinement?	Vulnerable groups are protected from unwarranted physical or other confinement while in the custody of the service system/provider.
9.	**Autonomy**	Does the policy support the right of vulnerable groups to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?	Vulnerable groups can express "independence" or "self-determination". For instance, a person with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice.
10.	**Privacy**	Does the policy address the need for information regarding vulnerable groups to be kept private and confidential?	Information regarding vulnerable groups need not be shared among others.

No	Core concept	Key question	Key language
11.	**Integration**	Does the policy promote the use of mainstream services by vulnerable groups?	Vulnerable groups are not barred from participation in services that are provided for general population.
12.	**Contribution**	Does the policy recognise that vulnerable groups can be productive contributors to society?	Vulnerable groups make a meaningful contribution to society.
13.	**Family Resource**	Does the policy recognise the value of the family members of vulnerable groups in addressing health needs?	The policy recognises the value of family members of vulnerable groups as a resource for addressing health needs.
14.	**Family Support**	Does the policy recognise individual members of vulnerable groups may have an impact on the family members requiring additional support from health services?	Persons with chronic illness may have mental health effects on other family members, such that these family members themselves require support.
15.	**Cultural Responsiveness**	Does the policy ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person?	i) Vulnerable groups are consulted on the acceptability of the service provided. ii) Health facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e., respectful of the culture of vulnerable groups.
16.	**Accountability**	Does the policy specify to whom, and for what, services providers are accountable?	Vulnerable groups have access to internal and independent professional evaluation or procedural safeguard.
17.	**Prevention**	Does the policy support vulnerable groups in seeking primary, secondary, and tertiary prevention of health conditions?	
18.	**Capacity Building**	Does the policy support the capacity building of health workers and of the system that they work in addressing health needs of vulnerable groups?	
19.	**Access**	Does the policy support vulnerable groups- physical, economic, and information access to health services?	Vulnerable groups have accessible health facilities (i.e., transportation; physical structure of the facilities; affordability and understandable information in appropriate format).
20.	**Quality**	Does the policy support quality services to vulnerable groups through highlighting the need for evidence-based and professionally skilled practice?	Vulnerable groups are assured of the quality of the clinically appropriate services.
21.	**Efficiency**	Does the policy support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of vulnerable groups?	

Appendix 2: Table of Vulnerable Groups and Definitions

No.	Vulnerable Group	Attributes or Definitions	Supporting Literature
1.	**Limited Resources**	Referring to poor people or people living in poverty	See Annex XXII
2.	**Increased Relative Risk For Morbidity**	Referring to people with one of the top 10 illnesses, identified by WHO, as occurring within the relevant country.	See Annex XXIII
3.	**Mother Child Mortality**	Referring to factors affecting maternal and child health (0-5 years).	See Annex XXIV
4.	**Women Headed Household**	Referring to households headed by a woman	See Annex XXV
5.	**Children (with special needs)**	Referring to children marginalized by special contexts, such as orphans or street children	See Annex XXVI
6.	**Aged**	Referring to older age	See Annex XXVII
7.	**Youth**	Referring to, younger age without identifying gender	See Annex XXVIII
8.	**Ethnic Minorities**	Referring to non-majority groups in terms of culture, race or ethnic identity	See Annex XXIX
9.	**Displaced Populations**	Referring to people who, because of civil unrest or unsustainable livelihoods, have been displaced from their previous residence	See Annex XXX
10.	**Living Away from Services**	Referring to people living far from health services, either in time or distance	See Annex XXXI
11.	**Suffering from Chronic Illness**	Referring to people who have an illness which requires continuing need for care	See Annex XXXII
12.	**Disabled**	Referring to people with disabilities, including physical, sensory, intellectual or mental health conditions, and including synonyms of disability	See Annex XXXIII

Predictors of Quality of Life of Persons with Physical Disabilities in Indonesia

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ABSTRACT

Purpose: *Indonesia lacks policies and programmes that would reduce barriers towards improving the Quality of Life (QOL) of persons with disabilities. This cross-sectional study assessed the QOL of persons with physical disabilities in Indonesia and identified its predictors.*

Method: *A total of 202 participants with physical disabilities completed the attitude subscale of Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF), the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0), and the World Health Organisation Quality of Life (WHOQOL-BREF) scale. The Rasch model converted the ordinal data to the interval logits scale. Multiple linear regression was used to analyse the QOL predictors.*

Results: *Participants reported a mean WHOQOL-BREF score of 0.12±0.98 (or poor QOL). The participants perceived people's attitudes as impactful barriers (-1.68 ± 1.44). There was a significant difference in participants' mean WHODAS 2.0 scores with poor (-0.38 ± 1.06) and good QOL (-1.79 ± 0.77). The regression revealed the following significant QOL predictors: severe disability (B = −1.089), moderate disability (B= −0.697), employment (B = 0.544), attitude barrier (B = −0.096), and age (B = −0.015).*

Conclusion: *Factors such as unemployment, perceptions of impactful attitudinal barriers, and ageing are associated with the poor QOL reported by persons with moderate to severe physical disabilities. It is necessary to ensure equal employment opportunities and remove stigma in society to promote QOL improvement for them.*

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Key words: *physical impairment, disability, environmental factors, quality of life*

INTRODUCTION

Impairment is a problem in body function and structure, such as a significant deviation or loss (World Health Organisation, 2013). A disability results from the interaction between a person's health condition (such as having impairment because of stroke or multiple sclerosis) and environmental factors that hinder the person's full activities and participation on an equal basis with others. Persons with disabilities experience more barriers, such as negative attitudes, discrimination, inaccessible healthcare services or assistive devices, and social participation barriers in their daily lives, than those without disabilities (Visagie et al, 2017); these may lower their well-being or quality of life (QOL) (Bakula et al, 2011; Rajati et al, 2018).

Quality of Life refers to a person's self-perception regarding his/her position within the cultural context and personal goals, expectations, standards, and concerns (The WHOQOL Group, 1995). Typically, a good QOL implies experiencing good health, subjective well-being, and life satisfaction (Goode, 1994). There is extensive evidence indicating poor QOL among persons with disabilities (Dijkers, 1997; Albrecht & Devlieger, 1999; Livneh et al, 2004; Lucas, 2007; Strine et al, 2008; Bredemeier et al, 2014). However, according to some studies the factors influencing QOL, as reported in existing literature, are varied and contradictory, contributing to discrepancies in the QOL of persons with disabilities. Some persons with moderate or severe disabilities frequently reported good or even excellent QOL, while others reported poor QOL. This is related to their ability to adapt effectively to difficulties (Albrecht & Devlieger, 1999). Other studies investigated the QOL predictors to explore the possible cause of discrepancies. Some studies have demonstrated that age, gender (Stucki, 2005), education, marital status, employment status (Amato et al, 2001) and duration of disability (Stucki, 2005) could not predict QOL. In contrast, other studies indicated that QOL is predicted by age, gender, physical disability level, and physical activity (Kosma et al, 2009). However, the impact on the level of QOL differs with age, income, and cultural context (Grabowska et al, 2022).

These QOL discrepancies emphasise the need for identifying subgroups of persons with disabilities who may be at particular risk of experiencing poor QOL and suggest that poor QOL was affected by factors other than the presence of impairment *per se* (Emerson et al, 2020). For example, the relatively poor QOL of adolescents and youth with disabilities reflects the difficulty in accessing essential material resources (e.g., a weatherproof coat) and social activities (e.g., a memorable event celebration or birthday party) (Savage et al, 2014; Shahtahmasebi et al, 2011). Poor QOL emerged as a more significant risk factor among persons with physical disabilities who encountered difficulties in accessing financial support and benefiting from social protection (Ashok et al, 2015).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) declared the importance of ensuring improved QOL among persons with disabilities globally, by improving their access to social protection without discrimination (Lombardi et al, 2019; United Nations, 2014). In Indonesia, the government partially covers the needs of persons with disabilities through various health and insurance schemes (Kemenkumham, 2016). However, the prevalence of disabilities due to chronic health conditions, higher medical costs, negative attitudes towards persons with disabilities (Adioetomo et al, 2014) and lack of assistive device coverage for persons with disabilities through the insurance scheme might inhibit them from taking advantage of Indonesia's health and social insurance system (Larasati et al, 2017).

Developing an intervention programme for improving QOL is essential to reduce medical costs (Eriksson et al, 2010; Wu et al, 2015; Haraldstad et al, 2019) and prevent worsening conditions (Robinson et al, 2017; Haraldstad et al, 2019; Phyo et al, 2020). According to previous studies, poor QOL could increase the desire to hasten death through depression and low self-worth among persons receiving palliative care (Robinson et al, 2017). Lower QOL is also associated with higher mortality risk among participants over 18 years of age (Phyo et al, 2020). Thus, it is crucial to identify the predictors of QOL among persons with disabilities in order to develop effective intervention programmes to enhance their QOL (World Health Organisation, 2015).

Existing Indonesian studies have inadequately investigated QOL and its predictors in persons with disabilities, including those with physical disabilities. A study in Indonesia by Rachmat et al (2019) reported that personal factors such as optimism, religiosity, and self-efficacy could predict the QOL of persons with disabilities, without investigating their socio-demographic status that represents environmental and personal factors. Thus, according to the study, the association of QOL with socio-demographic characteristics in Indonesian persons with disabilities remains unclear. Moreover, the study provided no information on health insurance status, assistive device usage, and attitudinal barriers (e.g., stigma or discrimination) towards persons with physical disabilities. Therefore, it is crucial to improve the understanding of QOL and disability-related factors in Indonesia.

Given these situations, the current study investigated attitudinal barriers, levels of disability, and QOL and its predictors among persons with physical disabilities in Indonesia. It was hypothesised that the QOL of persons with physical disabilities would vary and be predicted by socio-demographic factors (e.g., age, gender, marital status, education status, employment status, and personal income), policy-modifiable factors (e.g., health insurance status, assistive device usage status, and attitudinal barriers), and disability-related factors (e.g., types of physical impairment and disability levels).

Objective

This study was conducted to highlight QOL discrepancies and identify its predictors in persons with physical disabilities. The findings are expected to raise public awareness and obtain support for changes in disability-related issues, as well as enable policymakers to recognise the urgency in addressing the problem through informed decision-making and policy reform. Furthermore, policymakers may be encouraged to prioritise effective strategies for enhancing QOL among persons with physical disabilities.

METHOD

Study Setting

This quantitative cross-sectional study was performed in Bandung, Indonesia, from April to May 2019. Bandung was specifically chosen because it has an excellent registration system for persons with impairments and a well-implemented community-based rehabilitation (CBR) programme (Ferial, 2016). Before conducting the field survey, health cadres (community volunteers promoting health in their local communities) and research assistants from the social office were trained by the authors.

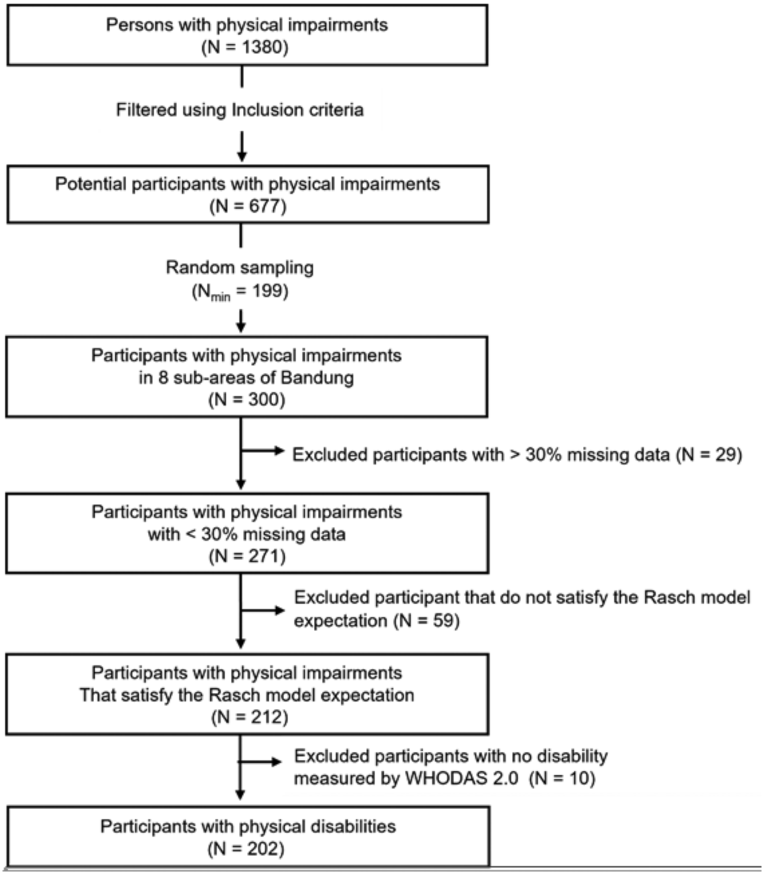
Study Participants

Health cadres, community volunteers whom healthcare professionals have trained to support health promotion programmes (Friska et al, 2022), guided the research assistants to reach the potential participants. The research assistants explained the study's objective to the potential participants and obtained their written informed consent. Participants completed the questionnaire independently. They were allowed to ask the surveyor if they did not understand questions and were free to withdraw from participation at any stage of the study.

The flowchart below (see Figure 1) shows the sample selection process. A list of 1380 registered persons with physical impairments was obtained from the Social Office of Bandung. A new list was created based on the inclusion criteria, and the sample was randomly selected.

The inclusion criteria were persons from 18 to 60 years of age, residing in Bandung and living with only physical impairment (no other impairments of vision, hearing, and cognition).

Figure 1: Diagram of the Sample Selection Process



A minimum sample size of 199 persons with physical disabilities was calculated using the G*Power version 3.1.9.6(Faul et al, 2007; Erdfelder et al, 2009) (F test, Linear multiple regression: fixed model, R^2 deviation from zero, 15 predictors). Questionnaires were distributed to 303 potential participants at their homes, and 300 (99%) completed questionnaires were returned. The researchers excluded 88 (29.3%) participants for ≥ 30% missing data or failing to satisfy the Rasch model's expectations (person outfit and infit mean square (MnSq) > 1.5 logit) (Boone et al, 2014), to prevent data bias; thus, a total of 212 participants were retained. Of these, 10 participants (4.7%) indicated not having a disability and 202 (95.3%) stated having a disability in accordance with the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0). As per the study's inclusion criteria, the 10 participants without disabilities were excluded. The responses from the 202 persons with physical disabilities (those with physical impairment and experiencing disability) were analysed.

Data Collection

Data was collected on three factors:

1) Socio-demographic factors, including age, sex (male, female), marital status (single, married), education status (uneducated, elementary school, high school or higher), and employment status (unemployed, employed);

2) Policy-modifiable factors, including health insurance status (uninsured, government-subsidised, contributory payment), assistive device usage status (non-user, user), and attitudes barrier;

3) Disability-related factors, including the type of physical impairment (hemi-, para- or tetraparesis or paralysis, other), and disability levels (mild, moderate, severe, and extreme).

Instruments

The study employed three self-administered and validated instruments:

- The Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF) attitude barrier subscale (Whiteneck et al, 2004),
- The WHODAS 2.0 (Hilfi et al, 2021; Yuliana et al, 2021), and
- An abridged version of the World Health Organisation Quality of Life assessment (WHOQOL-BREF) questionnaire (Purba et al, 2018).

The researchers translated the CHIEF-SF into Bahasa Indonesia. No back translation took place. The WHODAS 2.0 and WHOQOL-BREF Indonesian versions were obtained from the WHODAS and WHOQOL groups.

According to the Rasch model analysis described in Supplementary Table 1, all instruments used in this study are valid and reliable.

The attitude barrier subscale of CHIEF-SF (consisting of two items each on other people's attitudes at home and discrimination in society) was used to determine whether the attitudinal barrier has been an impactful barrier for participants in the last 12 months. Each item was rated for frequency of occurrence on a 5-point scale (0 = never, 1= less than monthly, 2 = monthly, 3 = weekly, 4 = daily) and for magnitude (1 = a little problem; 2 = a big problem) (Whiteneck et al, 2004).

The 32-item WHODAS 2.0 was used to measure health and disability at the population level based on the International Classification of Functioning, Disability and Health (ICF)(World Health Organisation, 2010). This questionnaire assesses functioning in the last 30 days in six domains of life: cognitive (domain 1), getting around (domain 2), self-care (domain 3), getting along with people (domain 4), household activities (domain 5), and social participation (domain 6). Responses were rated on a 5-point Likert scale (0 = no difficulty, 1 = mild difficulty, 2 = moderate difficulty, 3 = severe difficulty, and 4 = extreme difficulty).

The WHOQOL-BREF is a 26-item self-reported questionnaire measuring QOL. Each item of the WHOQOL-BREF is scored on a 5-point Likert scale (1 = very low, 5 = very high) asking "how much," "how satisfied," or "how completely" the respondent feels concerning the domains listed. In this study, the overall QOL was measured by calculating the average of the four domain scores, with higher scores indicating higher QOL levels (Mesafint et al, 2020).

Data Analysis

Since the Likert rating responses did not meet the assumption of normal data distribution (Kuzon et al, 1996; Jamieson, 2005), the Rasch model analysis using WINSTEPS 3.75 (Winsteps®, Beaverton, Oregon)(Linacre, 2012) was utilised to convert the ordinal data into equal-interval scale. This made it possible to obtain each participant's Log Odds Unit (logit) score once the construct validity of the instruments had been confirmed (Boone et al, 2014). All the translated instruments used in this study were evaluated and found valid and reliable.

The range of logit scores on the CHIEF-SF attitude barrier subscale spans from -3.58 to 2.24. The higher scores indicate greater perceived attitude barriers. A mean score of logit ≥ -1.94 represents an impactful attitude barrier (Research Department, 2001). The logit scores of the WHODAS 2.0 range from -6.82 to 6.36, with the following categories (World Health Organisation, 2010) :1) no disability or full functioning (-6.82 to -3.62 logit), 2) mild disability (-3.61 to -1.41 logit), 3) moderate disability (-1.40 to 0.05 logit), 4) severe disability (0.06 to 3.65 logit), and 5) extreme disability (3.66 to 6.36 logit). However the logit scores of WHOQOL-BREF range from -7.32 to 7.89 logit and use a cut-off score of 0.69 logit to classify participants as having "poor" (versus "good") QOL (Silva et al, 2014; Bani-issa et al, 2018).

SPSS Statistics 27 (IBM Corp., Armonk, New York) was then used to perform statistical analyses. The means, standard deviations, frequencies, and percentages were calculated for computing the descriptive statistics. The chi-squared test was used to compare the categorical variables. The independent samples t-test and Kruskal-Wallis H test were used to compare two and more than two groups of continuous variables among participants, respectively.

Pearson's correlation was used to evaluate the relationship between WHODAS 2.0 and WHOQOL-BREF scores with criteria as moderate (0.50–0.69), high (0.70–0.89), or very high (0.90–1) (Hinkle DE et al, 2003). The regression was used to identify the predictors of QOL (dependent variable). Multicollinearity was evaluated using tolerance of collinearity statistics and variance inflation factor (VIF) at less than 0.10 and more than 10, respectively. If multicollinearity was detected among variables, they were removed from the regression analysis. Adjusted R square (adjusted R^2), unstandardised coefficient (B), and 95% confidence interval (CI) were determined for all variables. Statistical significance was set at $P < 0.05$.

Ethics Approval

The Research Ethical Committee of Universitas Padjadjaran (No. 140/UN6.KEP/EC/2019) and Gunma University (No. HS2019-318) approved the study's ethics. The corresponding Social Office of Bandung approved the survey permit (No. 460/1966-Dinsosnangkis).

RESULTS

Socio-demographic Factors

Table 1 presents the participants' socio-demographic characteristics (n = 202). The age average of the participants was 41.4 ± 12.5 years. Among them, 56.9% were males. More than half (53.0%) of the participants were single. It was found that 13.9% of participants had no formal education, and around 70% were unemployed and had no income.

Policy-modifiable Factors

As seen in Table 2, 70.8% of the participants reported that they had government-subsidised-type health insurance, 52.8% had assistive devices supporting their daily activities, and 37.6% perceived that attitudinal barriers (e.g., people's negative attitudes or discrimination) affected them.

Disability-related Factors

Table 2 also shows the results of disability-related factors. While half of the participants had hemiparesis/plegia, the rest of the participants had paraparesis/plegia (18.8%), tetraparesis/plegia (5%), and other impairments (26.2%) such as limb amputations and malformation. As for the disability level, 32.2% and 67.8% of participants experienced mild and moderate to severe disabilities, respectively.

Quality of Life

The WHOQOL-BREF mean score was 0.12 ± 0.98, and 71.8% of the participants reported poor QOL. The WHOQOL-BREF mean scores differed significantly according to age, employment status, and personal income. The details are shown in Table 1.

Table 1: Quality of Life (QOL) of Participants by Socio-demographic Factors

Variables	**n**	**%**	**QOL**			***P***	**Poor QOL (M < 0.69)**		**Good QOL (M ≥0.69)**		***P***
			M	SD	Int		n	%	n	%	
All participants	202	100	0.12	0.98	Poor		145	71.8	57	28.2	
Socio-demographic factors											
Age; mean= 41.36±12.53											
Age group (years)											
18–30	45	22.3	0.36	0.81	Poor	**0.003**[a]	30	66.7	15	33.3	**0.017**[c]
31–40	46	22.8	0.19	1.22	Poor		31	67.4	15	32.6	
41–50	50	24.7	0.27	0.93	Poor		31	62.0	19	38.0	
51–60	61	30.2	-0.23	0.98	Poor		53	86.9	8	13.1	
Sex											
Male	115	56.9	0.15	1.00	Poor	0.689[b]	81	70.4	34	29.6	0.625[c]
Female	87	43.1	0.09	0.95	Poor		64	73.6	23	26.4	
Marital Status											
Single (widow/er)	107	53.0	0.20	1.00	Poor	0.217[b]	74	69.2	33	30.8	0.379[c]
Married	95	47.0	0.03	0.95	Poor		71	74.7	24	25.3	
Education Status											
Uneducated	28	13.9	-0.19	0.74	Poor	0.096[a]	24	85.7	4	14.3	**0.031**[c]
Graduated from elementary school	78	38.6	0.05	0.97	Poor		60	76.9	18	23.1	
Graduated from high school or above	96	47.5	0.27	1.03	Poor		61	63.5	35	36.5	
Employment Status											
Unemployed	143	70.8	-0.13	0.89	Poor	**< 0.001**[b]	118	82.5	25	17.5	**< 0.001**[c]
Employed	59	29.2	0.73	0.92	Good		27	45.8	32	54.2	
Personal monthly income (in 10000 IDR); mean=53.40±100.22											
No income	143	71.5	-0.13	0.89	Poor	**< 0.001**[a]	118	82.5	25	17.5	**< 0.001**[c]
IDR 1 – 150 (USD 105.90)	32	16.0	0.68	1.09	Poor		13	40.6	19	59.4	
IDR 150 – 300 (USD 211.79)	22	11.0	0.73	0.57	Good		12	54.5	10	45.5	
≥ IDR 300	3	1.5	0.91	0.88	Good		1	33.3	2	66.7	

[a] Based on the Kruskal-Wallis H test;

[b] Based on the results of independent sample t-test;

[c] Based on the results of chi-squared test; QOL, quality of life; N, the total number of participants; %, percentage; M, mean; SD, standard deviation; Int, interpretation of QOL Level; P, p–value; IDR, the Indonesian Rupiah; USD, the United States Dollar.

Supplementary Table 1. Instrument's reliability and validity

	Instruments								
		WHODAS 2.0							
Psychometric Attribute	**Attitude/ support barrier (CHIEF–SF)**	**Overall**	**Cognitive (domain 1)**	**Getting around (domain 2)**	**Self-care (domain 3)**	**Getting along with people (domain 4)**	**Household activities (domain 5)**	**Participation in society (domain 6)**	**WHOQOL–BREF**
Number of items	4	32	6	5	4	5	4	8	26
Outfit Mean Square									
Mean	0.91	0.99	0.97	0.94	0.96	1.07	0.95	0.98	1.01
Standard Error Measurement (SEM)	0.16	0.10	0.15	0.14	0.16	0.17	0.16	0.10	0.10
Item separation	2.97	7.06	4.92	9.04	5.40	2.37	7.87	3.92	6.88
Item reliability	0.90	0.98	0.96	0.99	0.97	0.85	0.98	0.94	0.98
Test reliability (alpha)	0.69	0.97	0.94	0.95	0.93	0.85	0.94	0.86	0.92
Unidimensionality									
Raw variance	31.50%	56.30%	69.00%	79.10%	75.30%	60.90%	79.10%	49.70%	43.30%
Unexplained variance in 1st contrast	3	4.7	1.7	1.7	1.9	1.9	1.9	2.4	2.4

Acceptable raw variance > 20%; acceptable unexplained variance in 1st contrast < 5; acceptable reliability > 0.60; acceptable separation >2; acceptable mean -1.5-1.5; CHIEF–SF, the Craig Hospital Inventory Environmental Factor–Short Form; WHODAS 2.0, the World Health Organization Disability Assessment Schedule 2.0; WHOQOL–BREF, the abridged version of World Health Organization Quality of Life instrument.

Among the age groups, those between 51–60 years reported the lowest mean QOL score (-0.23 ± 0.98). The unemployed participants (or those with no income) and participants with personal income < IDR 1,500,000 had mean QOL scores ranging between -0.13 ± 0.89 and 0.68 ± 1.09, respectively, while employed participants with personal income > IDR 1,500,000 (USD 105.90) reported good QOL. For most socio-demographic variables, the proportion of participants with poor QOL was generally higher than those with good QOL, except for those who were employed (54.2%) and those with personal income IDR 1 – 1,500,000 (59.4%) and ≥ IDR 3,000,000 (66.7%) groups.

Table 2: Participants' Quality of Life (QOL) by Policy-intervention Modifiable Factors and Disability-related Factors

Variables	n	%	QOL			P	Poor QOL (M < 0.69)		Good QOL (M ≥0.69)		P
			M	SD	Int		n	%	n	%	
Policy-modifiable factors											
Health Insurance											
No insurance	34	16.8	0.12	1.06	Poor	0.702[a]	23	67.6	11	32.4	0.839[c]
Government subsidised	143	70.8	0.09	0.96	Poor		104	72.7	39	27.3	
Contributory payment	25	12.4	0.27	0.93	Poor		18	72.0	7	28.0	
Assistive device usage status											
None	94	47.2	0.28	1.03	Poor	**0.026**[b]	57	60.6	37	39.4	**< 0.001**[c]
User	105	52.8	-0.03	0.89	Poor		86	81.9	19	18.1	
Attitude barrier											
Not impactful barrier	126	62.4	0.26	0.91	Poor	**0.009**[b]	85	67.5	41	32.5	0.079[c]
Impactful barrier	76	37.6	-0.12	1.03	Poor		60	78.9	16	21.1	
Disability-related factors											
Physical Impairment Type											
Hemiparesis/plegia	101	50.0	0.14	0.89	Poor	**0.005**[a]	71	70.3	30	29.7	0.071[c]
Paraparesis/plegia	38	18.8	-0.11	1.05	Poor		32	84.2	6	15.8	
Tetraparesis/plegia	10	5.0	-0.65	1.15	Poor		9	90.0	1	10.0	
Other	53	26.2	0.12	0.97	Poor		33	62.3	20	37.7	
Level of Disability (WHODAS 2.0):											
Mild disability	65	32.2	0.82	0.94	Good	**<0.001**[a]	26	40.0	39	60.0	**< 0.001**[c]
Moderate disability	89	44.0	-0.01	0.80	Poor		71	79.8	18	20.2	
Severe disability	48	23.8	-0.58	0.66	Poor		48	100.0	0	0.00	
Extreme disability	0	0.00	NA	NA	NA		NA	NA	NA	NA	

[a]Based on the Kruskal-Wallis H test; [b]Based on the results of independent sample t-test; [c]Based on the results of chi-squared test; QOL, quality of life; N, the total number of participants; %, percentage; M, mean; SD, standard deviation; Int, interpretation; P, p–value; CHIEF–SF, the Craig Hospital Inventory Environmental Factor–Short Form; WHODAS 2.0, the World Health Organisation Disability Assessment Schedule 2.0; NA, not available.

The WHOQOL-BREF mean scores also differed significantly according to assistive device usage status, attitude barriers, physical impairment type, and disability level. Even though both non-users and users of assistive devices, on average, revealed poor QOL, non-users demonstrated a higher mean QOL score (0.28 ± 1.03) than the users (-0.03 ± 0.89). Participants who perceived attitudinal barriers as impactful showed significantly lower mean QOL scores (-0.12 ± 1.03) than those who did not perceive them as impactful. Participants with hemiparesis/plegia had a higher mean QOL score (0.14 ± 0.89) than those with paraparesis/

plegia, tetraparesis/plegia, or other impairments (e.g., limb amputation or malformation). Participants with mild levels of disability indicated good QOL scores. The proportion of participants with good QOL was higher in the group with mild levels of disability. Table 2 provides further information about The WHOQOL-BREF mean scores according to assistive device usage status, attitude barriers, physical impairment type, and disability level.

Results presented in Table 3 show the profile of all participants, and of those participants with poor QOL and good QOL, in terms of (i) perception of attitudinal barriers and (ii) overall disability level (32-item version of WHODAS 2.0) and within each WHODAS 2.0 domain.

Table 3: Means of Attitude/Support Barrier subscale (CHIEF-SF) and WHODAS 2.0 scores of all Participants and among Participants with poor and good Quality of Life (QOL)

Variables	All participants			Quality of Life (QOL)					
				Poor (M < 0.69)			Good (M ≥0.69)		
	M	SD	Int	M	SD	Int	M	SD	Int
Attitude barrier subscale (CHIEF-SF)	-1.79	1.44	Impactful barrier	-1.68	1.42	Impactful barrier	-2.03	1.47	Not impactful barrier
Disability domain (WHODAS 2.0):									
Overall disability*	-0.79	1.17	Moderate	-0.38	1.06	Moderate	-1.79	0.77	Mild
Cognitive (domain 1)*	-3.02	3.37	Mild	-2.45	3.32	Mild	-4.44	3.06	No
Getting around (domain 2)*	0.36	3.99	Severe	0.98	3.73	Severe	-1.19	4.20	Mild
Self-care (domain 3)*	-2.61	3.96	Mild	-2.07	3.90	Mild	-3.96	3.82	No
Getting along with people (domain 4)*	-2.70	2.73	Mild	-2.20	2.74	Mild	-3.92	2.31	No
Household activities (domain 5)*	-0.39	4.79	Moderate	0.34	4.54	Severe	-2.19	4.97	No
Social participation (domain 6)*	-0.99	1.28	Moderate	-0.74	1.19	Moderate	-1.59	1.31	Mild

CHIEF-SF' mean score of ≥ -1.94 logit represents the perceived impactful barrier; WHODAS 2.0 level: 1) no disability (-6.82 to -3.62 logits); 2) mild disability (-3.61 to -1.41 logits); 3) moderate disability (-1.40 to 0.05 logits); 4) severe disability (0.06 to 3.65 logits); 5) extreme disability (3.66 to 6.36 logits); QOL, quality of life; M, mean; SD, standard deviation; Int, interpretation; *, significant with $p < 0.001$.

It was observed that the mean score for the attitude barrier was -1.79 ± 1.44. The mean score for the overall disability level (32-item of WHODAS 2.0) and the domains ranged from -0.99 ± 1.28 to 0.36 ± 3.99. The overall disability level of the participants with poor and good QOL was generally moderate (mean = −0.38 ± 1.06) and mild (mean = −1.79 ± 0.77), respectively. The means of the overall

WHODAS 2.0 and its domains in participants with poor and good QOL were significantly different ($p < 0.001$).

Predictors of Quality of Life

The WHODAS 2.0 logit scores had a moderate negative correlation with WHOQOL-BREF logit scores ($r = -0.585$, $p < 0.001$). This correlation suggests that the higher the level of disability, the lower the QOL, and vice versa. Figure 2 shows all participants' scatter patterns of bivariate correlations between the WHODAS 2.0 and WHOQOL-BREF logit scores.

Figure 2: Correlation between WHODAS 2.0 and WHOQOL-BREF Scores

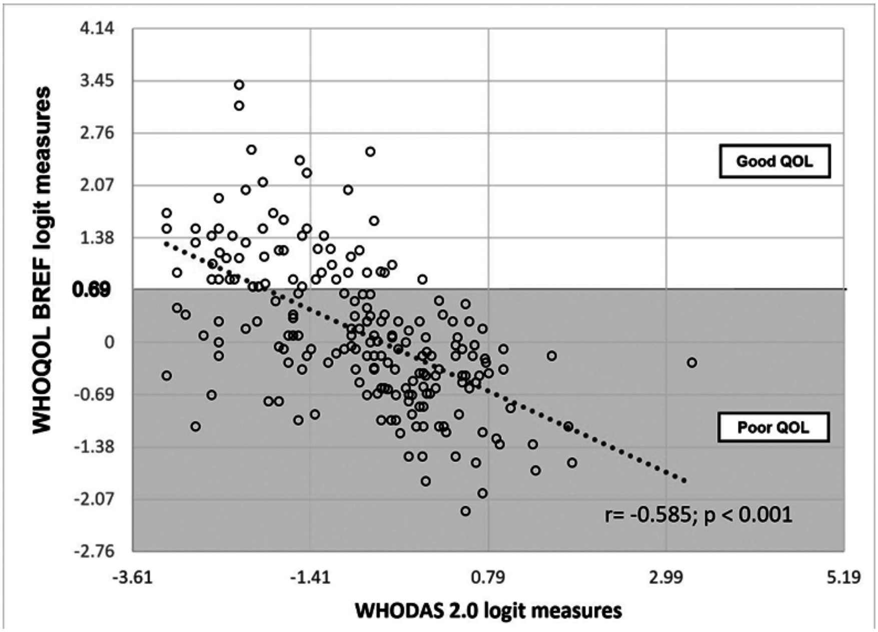


Table 4 presents the results of multiple linear regression analyses for the QOL predictors. Prior to performing multiple linear regression, the personal income variable was excluded in the regression analysis because of multicollinearity.

Table 4: Multiple Linear Regression Analysis of Quality of Life (QOL) of Participants with Physical Disabilities

Variables	**QOL**			
	B	95% CI		p
		Lower	Upper	
Socio-demographic characteristics				
Age	**-0.015**	-0.026	-0.005	**0.004**
Sex (reference, male)				
Female	0.070	-0.167	0.306	0.562
Marital status (reference, single)				
Married	-0.051	-0.308	0.206	0.695
Education status (reference, uneducated)				
Graduated from elementary school	0.072	-0.284	0.427	0.691
Graduated from high school or above	-0.054	-0.417	0.309	0.770
Employment status (reference, unemployed)				
Employed	**0.544**	0.264	0.824	**<0.001**
Policy-modifiable factors				
Health insurance status (reference, no insurance)				
Government subsided	0.064	-0.244	0.372	0.682
Contributory payment	0.344	-0.082	0.769	0.112
Assistive device usage status (reference, not user)				
User	-0.146	-0.369	0.078	0.200
Attitude/support barrier	**-0.096**	-0.176	-0.016	**0.019**
Disability-related factors				
Physical impairment types (reference, Other)				
Hemiparesis/plegia	-0.190	-0.461	0.082	0.170
Paraparesis/plegia	-0.054	-0.409	0.301	0.764
Tetraparesis/plegia	-0.418	-0.982	0.146	0.146
Disability level (reference, mild disability)*				
Moderate	**-0.697**	-0.955	-0.439	**<0.001**
Severe	**-1.089**	-1.431	-0.748	**<0.001**
Regression model statistics				
N	202			
Adjusted R^2	**0.377**			
P-value	**<0.001**			

It was found that severe disability (B= −1.089), moderate disability (B= −0.697), employment (B = 0.544), attitude barrier (B = −0.096), and age (B = −0.015) were the significant predictors of QOL with 37.7% of the variance in their QOL being explained by the predictors (adjusted $R^2 = 0.377$, $p < 0.001$).

DISCUSSION

The study aimed to contribute evidence-based data to design effective strategies for persons with physical disabilities and enhance people's understanding of disability-related conditions in Indonesia.

Although the results indicate that, on average, participants with mild and moderate or severe disability typically reported good and poor QOL scores, respectively, the chi-squared test showed that 40% of participants with mild disability reported poor QOL and 20.2% of participants with moderate disability reported good QOL. This study's results are similar to results in other studies, suggesting that persons with the same impairment experienced different levels of disability and QOL, depending on their contextual factors, i.e., personal and environmental factors (Fellinghauer et al, 2012).

The regression results implied that disability levels, employment, people's negative attitudes towards persons with disabilities, and age were significant predictors of participants' QOL. A study by Muslimah et al (2019) demonstrated that older age, lower education levels, unemployment, comorbidity, and moderate disability were significantly associated with poor QOL in rehabilitated post-ischemic stroke clients over 18 years old in Yogyakarta, Indonesia. In Chicago, a study by Albrecht and Devlieger (1999) inferred that health conditions, limited resources, lack of knowledge, and environmental barriers increase the risk of poor perceived QOL among persons with moderate or severe disabilities.

Participants' QOL was significantly correlated with their employment status. About 70% of the participants had no job or income, and 81.38% of participants with poor QOL were unemployed. In England, physical impairments *per se*, difficulty with transportation, lack of incentives, and difficulty in finding a job can be the reasons for unemployment among people with disabilities(Donnell, 1998). However, the reason for the low employment rate in Indonesia is debatable. In 2014, the Indonesian Ministry of Health (Indonesian Ministry of Health, 2014) reported that 60.3% of persons with a disability could not receive education or graduate even from elementary school, contributing to low employment access.

Persons with physical disabilities might be limited in social interaction, activities, and participation, increasing the risk of poor QOL (United Nations, 2006; World Health Organisation, 2013). This study indicated that disability level and other people's negative attitudes significantly predicted participants' QOL. Importantly, the findings imply that higher disability levels, mainly in household activities and social participation domains, correlate considerably with poor QOL. This finding reflects that support from family and community to reduce the difficulty of performing household activities and social participation are crucial to improving their QOL. These results are consistent with studies in India (Datta & Datta, 2014) and Canada (Mayo et al, 2002) reporting that persons with lower daily living activities showed significant correlations with lower QOL.

However, a Dutch study found a different result, implying that the QOL of the Dutch population with physical disabilities was not significantly correlated with social participation (Van Campen & Iedema, 2007). People's characteristics, personal goals for participation, and people's perceptions of social participation may contribute to these results. In Indonesia, the societal member interaction is intimate, intense, and valuable. Therefore, Indonesians' emphasis on social participation may impact their QOL. These differences between the characteristics of the Dutch and Indonesian populations may explain the varied findings.

A study in Guangzhou showed that other people's negative attitudes towards persons with disabilities influenced their poor QOL (Zheng et al, 2014). Consistently, around 10% of persons with disabilities in Indonesia face difficulties in their family and community life (Adioetomo et al, 2014). Family members' treatment of persons with disabilities at home significantly impacts their QOL. In Indonesia, a person with a moderate or severe disability imposes greater demands on families' financial resources for expenses such as personal assistance, medical care, and prosthetic aids, which can affect the family's dynamics and engender negative attitudes towards persons with disability (Cameron & Contreraz Suarez, 2017).

In this study, age was negatively associated with QOL. On average, participants' QOL was poor among the age subgroups, but the lowest QOL was observed in participants aged 51–60 years. Issues particular to this age group may contribute to lower QOL, such as living with no income or job, experiencing moderate or severe disability levels, and being single. In Purworejo, Indonesia, being female, single, or having low education and socio-economic status were significant predictors of poor QOL among older people (Ng et al, 2010).

The findings reported in this study raise some concerns regarding QOL in persons with physical disabilities in Indonesia. Regardless of their impairments, it is crucial to recognise other contextual factors (World Health Organisation, 2013), such as older age, unemployment, and attitude barriers, that can worsen the QOL of persons with a physical disability.

Improving the QOL of persons with physical disabilities is essential. The current study implied that the government agencies, social cadres, disability organisations, and CBR should collaborate to facilitate inclusiveness for persons with physical disabilities by: 1) ensuring equal employment opportunities and optimising vocational rehabilitation (e.g., self-esteem and marketing skills) to enhance their economic independence through sustainable self-employment; 2) removing attitude barriers to accessing essential public services, such as healthcare services; and, 3) increasing health and social protection coverage and properties, including health insurance and assistive device accessibility. In addition, immediate policy and programmatic action are crucial to improving the QOL by enhancing work abilities and support systems to remove barriers for persons with physical disabilities (Ferdiana et al, 2021).

Although this study's results did not show a significant association between the participants' QOL and the health insurance type, the study provided novel findings regarding this association in Indonesia. About 72% of the participants with poor QOL had government-subsidised-type or contributory payment-type health insurance. It is assumed that some participants did not utilise their health insurance benefits, such as healthcare services. This conclusion is consistent with the finding of the Centre for Health Financing of the Indonesian Ministry of Health, indicating the lack of utilisation of healthcare benefits among 20%–50% of insured people (Agustina et al, 2019). However, further investigation is needed into the health insurance-related factors among Indonesian persons with physical disabilities.

Since disability is a human condition, it can affect all individuals regardless of their impairment and health status. Thus, future research that performs a comparative QOL analysis of persons with and without disabilities is essential. This comparison will strongly encourage Indonesian policymakers to support disability-related policies.

Study Limitations

This study has certain limitations. First, self-administered questionnaires are inherently subject to response biases due to differences in participants' understanding of the questions. Second, participants were recruited only from one Indonesian region (Bandung). This parameter limits the generalisability of findings to other Indonesian areas. Third, QOL predictors were not analysed specifically for participants with each level of disability (mild, moderate, severe, or extreme) because of the limited sample size. Fourth, this study lacked clear criteria for categorising mild, moderate, and extreme disability levels.This led to two concerns: 1) the inability to precisely compare and analyse participants' QOL based on their levels of disability, and, 2) the reduced generalisability of the results to a broader group of persons with disabilities. Future studies can overcome these limitations to have a better understanding of disability levels and the QOL relationship.

CONCLUSION

Persons with moderate to severe physical disabilities in Bandung, Indonesia, reported poor QOL. In addition, factors such as unemployment, perceptions of impactful attitudinal barriers, and ageing are associated with poor QOL in persons with moderate to severe physical disabilities. It is critical to ensure equal employment opportunities and remove stigma in society to promote QOL improvement for persons with moderate to severe physical disabilities.

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Have Thailand's Personal Assistance Services for Persons with Disabilities Evolved?

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ABSTRACT

Purpose: *The study aimed to analyse power relationships among stakeholders in the Thai Personal Assistance service system, using the Critical Disability Theory and Independent Living (IL) philosophy.*

Method: *A qualitative research methodology was applied to three groups: Personal Assistants (PAs), persons with disabilities working with PAs, and administrators of PA service delivery agencies in four provinces of Thailand. Fifty-eight respondents participated in in-depth interviews and three focus-group discussions. Interpretative Phenomenological Analysis (IPA) was used to analyse the data.*

Results: *Personal Assistant services introduced by the Thai Independent Living movement were incorporated into the law, but implementation was largely managed and delivered by government offices responsible for charitable modes of care, with an emphasis on volunteering. Personal Assistants were perceived as caregivers of older adults. During the COVID-19 pandemic, PA services provided support to persons with disabilities and filled gaps in family care. However, people with disabilities who use their services are often under the control of PAs and are unable to achieve self-determination and full social participation.*

Conclusion and Implications: *Among persons with disabilities, group leaders are active agents who strive for more participation at all levels in the PA system structure. It is important to train PA service users and organisations to manage and monitor PA services for persons with disabilities. Hence, developing a PA career path with appropriate working benefits is necessary for creating sustainable PA services.*

Key words: *persons with disabilities, Critical Disability Theory, personal assistant, Thailand*

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INTRODUCTION

The Independent Living (IL) movement began in the United States in the 1970s and spread internationally to Britain (Barnes et al, 1999), northern European countries and Asia from the 1980s onward (Nakanishi, 2000). In 2007, Japanese IL leaders with disabilities, a group focusing on persons with extensive disabilities, established the Asia-Pacific Network for Independent Living Centres with members from Korea, Taiwan, Mongolia, Thailand, Cambodia, Vietnam, Myanmar, the Philippines, Malaysia, Pakistan, and Nepal (Disabled Peoples' International Asia-Pacific Region, 2012). In Thailand, the concept of Independent Living was understood as *"people with disabilities support their friends with disabilities … to be self-reliant as much as possible through thinking about solutions of problems from the perspective of individual persons to social systems or structures …"* (Punpuing, 2008). The idea of the social model of disability, which views disability as a socially created problem and not an attribute of an individual (World Health Organisation, 2002), became known among people with disabilities through the Independent Living movement in Thailand. Although the IL movement in Thailand empowers persons with disabilities through IL as its core principle, it still targets social awareness and accommodation to achieve the rights of persons with disabilities and their full participation in society (Churut, 2023), which can be regarded as a practice of the social model of disability. According to the IL philosophy, Personal Assistants (PAs) provide a user-led model of support in which persons with disabilities have choices and control in managing their support (Sukonthavit, 2023). This differs from other forms of care-related work, such as caregivers or village health volunteers, as the correlation between persons with disabilities and PAs resembles an employer–employee relationship, which includes the expectation of minimising the negative thoughts surrounding feelings of indebtedness or dependency common in supportive relationships (Porter et al, 2022) and empowering persons with disabilities through the achievement of Independent Living (Sukonthavit, 2023). In the United States and European countries, PAs are the key to empowering people with significant impairments who previously depended on residential care to remain in community settings. In Europe, in particular, people with disabilities can receive payments through arrangements such as Independent Living funds to directly manage their own staff (Morris, 1993; BBC, 2015).

Development of Thai Personal Assistance Services

Prior to Thailand's ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2008, Thai leaders within the IL movement advocated and incorporated the nation's PA services into the Quality-of-Life Promotion and Development of Persons with Disabilities Act (Persons with Disabilities Empowerment Act) of 2007 (Yokoyama, 2021; Punpuing and Churat, 2022). The Act defines the terms "personal assistant" and "caregiver" to differentiate their varying roles and duties (Ministry of Social Development and Human Security – MSDHS, 2007). Thus, "assistant" indicates someone who provides personal assistance to persons with disabilities to enable them to perform essential daily activities, while a "caregiver" is a parent, child, spouse, relative, sibling, or any other person who cares for a person with disability. The MSDHS is responsible for managing PA services, which are funded by the Persons with Disabilities Empowerment Act.

Residential care is uncommon for persons with extensive disabilities, as the Thai government has limited the expansion of governmental residential care institutions. Regardless of whether persons with disabilities remain at home with their family or choose to live alone, they may not fully participate in society. The IL movement envisioned PA services as alternatives to previous charitable or medical models of disability. This model involved enhancing the choices and control of persons with extensive disabilities in their lives, providing more opportunities for self-help skill training, and further integrating them into society.

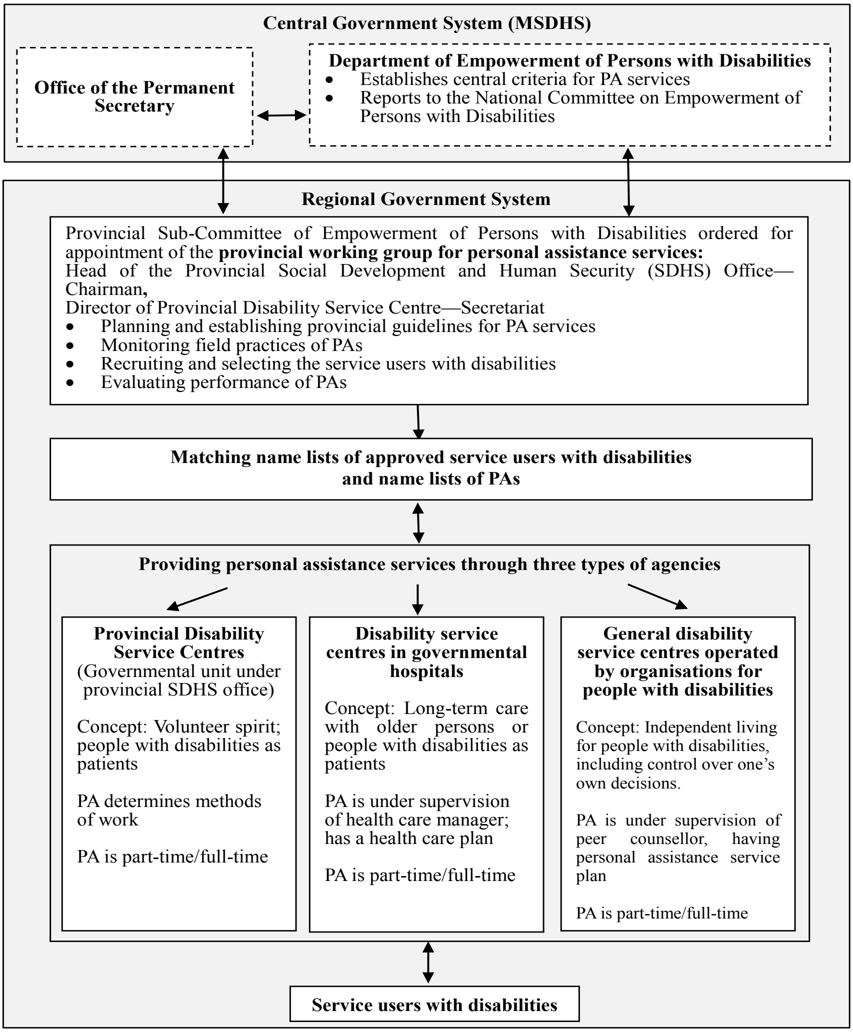
Implementation Structure of Personal Assistance Service Delivery

According to the Thailand National Statistical Office (2017), the estimated target group of PA services includes those with disabilities aged 5 years and older, who have experienced difficulties in self-care, or a number of around 716,263 people. In this group, 9.1% had no caregivers, 85.0% had household members as family caregivers, and 5.8% had non-household caregivers. PA services under the MSDHS began in 2012, and by 2022 there were 1,261 PAs (the number of PAs was obtained from MSDHS through e-mail on January 26, 2022). A PA works with between one to nine persons with disabilities and, on average, five persons (Rodthong, 2020). Within 10 years, the number of PAs in each provincial office of the MSDHS increased from 5 people (Kachondham, 2016) to 14 on average (Rodthong, 2020).

Figure 1 illustrates the structure and service-management configuration of the PA system. The Department of Empowerment of Persons with Disabilities (DEP) under the MSDHS plays a major role in the central government system as it establishes a taskforce on PA systems. This taskforce is composed of representatives from organisations of persons with disabilities and government officers under the DEP;

its duties include establishing a service model, training curricula, evaluations, and service standards for provincial-level implementation. The Provincial Office of MSDHS governs the operations of PA service management. The nation delivers PA services to its users through three types of agencies: MSDHS provincial disability service centres, disability service centres in government hospitals, and general disability service centres staffed by organisations of persons with disabilities. The management structure indicates that provincial-level authorities and service delivery units have the most powerful impact on service quality.

Figure 1: Thailand's PA Service System under the Ministry of Social Development and Human Security



Central Government System (MSDHS)

Office of the Permanent Secretary

Department of Empowerment of Persons with Disabilities
- Establishes central criteria for PA services
- Reports to the National Committee on Empowerment of Persons with Disabilities

Regional Government System

Provincial Sub-Committee of Empowerment of Persons with Disabilities ordered for appointment of the **provincial working group for personal assistance services:**
Head of the Provincial Social Development and Human Security (SDHS) Office—Chairman,
Director of Provincial Disability Service Centre—Secretariat
- Planning and establishing provincial guidelines for PA services
- Monitoring field practices of PAs
- Recruiting and selecting the service users with disabilities
- Evaluating performance of PAs

Matching name lists of approved service users with disabilities and name lists of PAs

Providing personal assistance services through three types of agencies

Provincial Disability Service Centres
(Governmental unit under provincial SDHS office)

Concept: Volunteer spirit; people with disabilities as patients

PA determines methods of work

PA is part-time/full-time

Disability service centres in governmental hospitals

Concept: Long-term care with older persons or people with disabilities as patients

PA is under supervision of health care manager; has a health care plan

PA is part-time/full-time

General disability service centres operated by organisations for people with disabilities

Concept: Independent living for people with disabilities, including control over one's own decisions.

PA is under supervision of peer counsellor, having personal assistance service plan

PA is part-time/full-time

Service users with disabilities

Source: Interview with Thai Persons with Disabilities Network for Independent Living, November 2022

Literature from 2016 to 2020 provides a retrospective illustration of the opinions and situations of PAs in Thailand, with a noteworthy lack of definition for the term "Independent Living" or a discussion as to whether it would fit Thai culture. Some researchers have suggested that PA services should be provided by people or volunteers in the community, especially for those who live alone or have no family caregivers (Yutthaophat and Boonyarattanasoontorn, 2018). Successful PA-related case studies have examined IL centres that follow the IL philosophy of facilitating the integration of persons with extensive disabilities into community life. PA services delegated under MSDHS provincial disability service centres have incorporated a charity-based model of care (Table 1; Kachondham, 2016). Critical Disability studies view disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, as well as a social and political definition based on societal power relations (Reaume, 2014). In this regard, Kachondham (2016) notes two important issues: 1) charity-based care does not reflect the needs of persons with disabilities, and 2) the government does not allocate enough budget and human resources to operate PA services for both IL centres and the MSDHS. Given this, the literature has also recommended that PA working conditions be improved and that the local government should participate in PA service arrangements (Rodthong, 2020).

Table 1: Comparison between PAs from the IL Centre and MSDHS

	Philosophy	**Objectives**	**Suitable Role and Responsibilities**	**Training Organisations**	**Problems**
PA from IL Centres	- Social model of disability - People with disabilities should be able to make decisions for service	Independent Living	Support people with disabilities in the working age	Disabled People's Organisation	Limited budget for managing PAs
PA from MSDHS	- Sense of charity - Mutual support, which is like a relationship between parents and children or among siblings	Care	Support older adults with disabilities	Government Organisations	- Limited number of trained PAs - Government training does not reflect the needs of people with disabilities

Source: Edited by the author, based on information from Kachondham, 2016

Objective

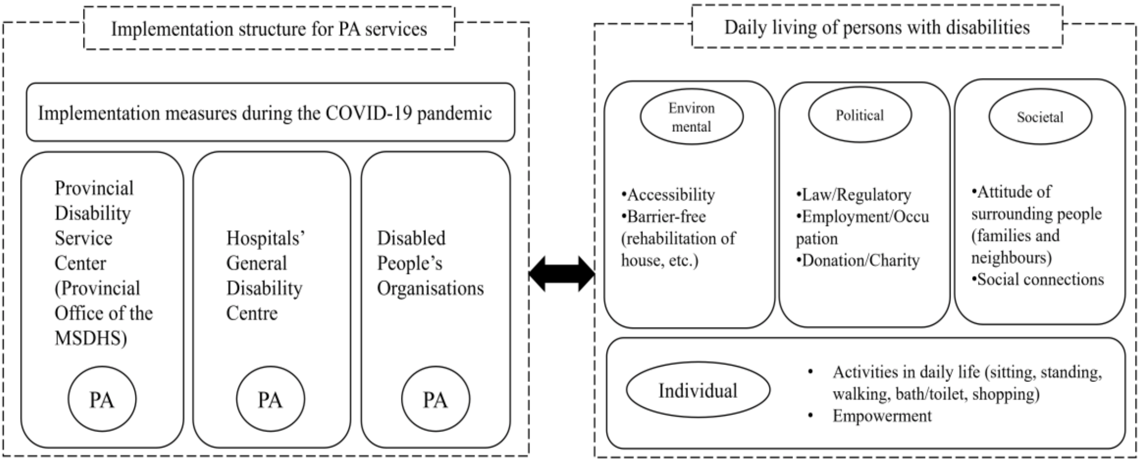
This research analyses the power relationships among stakeholders in the Thai Personal Assistance service system using a Critical Disability Theory perspective and the Independent Living philosophy.

METHOD

Study Design

A qualitative design was used. Critical Disability Theory recommends analysis of disability as a cultural, historical, relative, social, and political phenomenon (Stanford Encyclopedia of Philosophy, 2019). The current study carefully explores the experiences of persons with disabilities, including oppression or discrimination in PA services, through qualitative research or, specifically, dialogues with persons with disabilities through semi-structured interviews. Figure 2 illustrates the conceptual framework of the analysis.

Figure 2: Conceptual Analysis Framework for the Research



Source: Author's own

Study Population

The target groups of this research were: 1) Personal Assistants, 2) persons with disabilities working with PAs, and 3) administrators and/or staff in PA service delivery units, MSDHS provincial disability service centres, hospital disability service centres, and IL centres. Four provinces were selected - Pathum Thani, Nonthaburi, Nakhon Pathom, and Chonburi - as these have an IL centre providing provincial-level PA services and it is possible to compare two different types of PA services delivered in the same province. The plan was to interview four PAs and four PA users in each category. Eventually, 0–5 PA informants were recruited through MSDHS provincial offices and IL centres respectively, based on their availability and accessibility to online meeting applications or devices. In principle, the provincial offices of the MSDHS and IL centres selected one client receiving services from an interviewed PA to represent PA service users, as this would clearly delineate the relationships and interactions between PAs and their clients. However, the number of PA users was less than that of PA informants in the case of MSDHS, as many of their PA users were old, sick and in bed; therefore, MSDHS offices could not find PA users who could attend the online interview. Table 2 presents the number of samples in each category and the identification numbers.

Table 2: Number of PA Services Research Participants from the IL Centre and MSDHS

Province	MSDHS			IL Centre			Total
	PA	**User**	**Staff**	**PA**	**User**	**Staff**	
ID number	MS-PA-01-16	MS-user-01-10	MS-staff-01-05	IL-PA-01-09	IL-user-01-09	IL-staff-01-07	
Pathum Thani	4	3	2	1	1	1	12
Nonthaburi	5	3	1	4	4	2	19
Nakhon Pathom	3	2	1	0	0	2	8
Chonburi	4	2	1	4	4	2	17
Total	16	10	5	9	9	7	56

Source: Author's own

Data Collection

Three focus group discussions and several in-depth interviews were conducted from April 21, 2022, to January 9, 2023. Of the interviews, 15 were conducted face-to-face (at PA clients' homes, the MSDHS provincial office, IL centres, and a meeting venue), while 44 were conducted online (through online meeting applications downloaded to informants' smartphones or personal computers). As the four provinces lack a hospital disability service centre, two administrators from a network of hospital disability service centres were interviewed as key informants, and a literature review was conducted. Consent was obtained from all 58 interviewees, either on paper or audio recorded.

Data Analysis

Interpretative Phenomenological Analysis (IPA) was used to analyse the data of the in-depth interviews and focus group discussions, in order to explore in detail how participants made sense of their personal and social worlds (Smith and Osborn, 2003). The qualitative data included the nature of the work done by PAs during COVID-19. Their experiences with socially constructed disabilities were analysed using the conceptual framework derived from the Critical Disability Theory.

Ethics Approval

This study was approved by the Graduate School of Human Sciences, Osaka University, on March 3, 2022.

RESULTS

Power Relationships among Stakeholders in the Thai Personal Assistance Service System

As shown in Figure 1, the organisations of persons with disabilities can be considered a minority voice within this system. The interviews in this study revealed that these organisations have hardly made substantial impacts on the system at either the central policy level or at the level of service delivery units. With their complex policy processes, representatives from IL centres sometimes fail to participate in the final resolutions. At the service delivery level, these organisations are rarely encouraged to expand or recognised as best practices. Currently, three IL centres provide PAs under government systems. One IL leader discussed interactions with the government.

> *"The government officers in charge were open to listen to our suggestions. However, there seems to be nothing changed in the past five years. A university researcher was assigned to analyse a model of PA service and training curricula, but without proper consultation from the IL centres. They expressed the feeling that the recommendation for future PA service (*proposed by the Independent Living of Persons with Disabilities Foundation) *which we handed in at the 10-year PA seminar* (in May 2022), *were too strong and gave pressure to the government office*" (IL- staff- 04).

The social movement of people with disabilities in Thailand can be regarded as an emancipatory approach which means working from within existing systems and trying to change them (Pojmann, 2005). It aims to realise the equal distribution of resources, as well as the affirmation of people with disabilities' rights and identity as a minority group in society (Fraser, 1997). However, both intentions are far from being achieved in the current PA service situation.

The Dominant Provider-led, Charity-based Service Model

The PA service process demonstrates that most PA services occur without client involvement. The Personal Assistant and predefined list of PA tasks were appointed by experts in the provincial-level PA service working group. This study discovered that many PA users misunderstood that PAs worked as volunteers, not as paid workers receiving an allowance from the MSDHS. These users did not realise the choices and controls inherent to their roles.

Familiarity with the charity model of care, the training background for caregivers, and the volunteer spirit of PAs from the MSDHS provincial disability service centres have led to the recruitment of older persons with disabilities as the primary group of PA service users. For example, MS-PA-15 explained that she held three positions at the same time: civil defence volunteer, caregiver for four persons (since 2013), and PA for three persons (since 2018). She selected her PA service users — a 67-year-old woman, a 77-year-old man, and an 80-year-old woman — and proposed their names to the MSDHS.

MS-PA-01 was a 63-year-old woman who graduated from an advanced course aimed at providing care to older adults. She worked with five people with disabilities. In a day, she worked with two people for three hours with each person. She said that she did not take leave and could work for 30 days in a month. Her main work involved preparing breakfast, providing bedding and bathing assistance, and delivering medicines to people with disabilities who had no support from their families. She withdrew funds from these clients to buy necessities. She also worked for the family members of her service users, as village health volunteers do normally.

> *"Recently, I had a new case. I personally purchased a SIM card to give to a young man. His mother had physical leg impairment. His father has no eyesight. The client's brother also had a psychiatric disorder. I take care of only two people in the official record, but in fact, I take care of four people, including a person without disability. I felt pity ('Na Songsan' in Thai), as the young man must bear increasing burdens" (MS-PA-01).*

Sometimes, when the PAs have more experience and knowledge of medical care or rehabilitation, the nature of their work more closely approximates that of a village health volunteer. For example, MS-User-05 is a 22-year-old man who uses a wheelchair after a traffic accident and works with MS-PA-14, a 52-year-old woman, who has experience as a village health volunteer and an MSDHS volunteer. His PA was his mother's friend, who came to see him on Saturdays and Sundays to bring medical consumables to treat the wound. She sometimes provided rehabilitation to allow him to walk. He recognised his PA as a village health volunteer. He did not know she was his Personal Assistant until his mother explained this to him. This case clearly demonstrates that the PA's current work was implemented under two concepts: a charitable model of support and a medical model of disability.

In addition to PA services, persons with disabilities in the community can access informal support from neighbours or community leaders. People in a community try to support persons with disabilities by paying for electricity, water, and the Internet, and sometimes offering low-cost or free housing rentals. (The MSDHS offers home renovation services for persons with disabilities, but a rented house cannot be renovated by a lessee.) It was even noted at the interviews that some PAs have become involved with local politicians because they can distribute charity donations to persons with disabilities as part of political campaigns.

> *"I took a person with disabilities to village leaders asking for 5,000THB donations to repair his motorised three-wheeler"* (MS-PA-13).

Persons with disabilities had received cash donations from village leaders.

The PA has a significant influence on clients' decision-making and self-determination.

MS-PA-13 had told MS-User-09, *"You should not go to Independent Living activities as you would not get anything,"* and the latter followed the PA's instructions. He did not have the opportunity to understand the rights of persons with disabilities. It is difficult for people with disabilities to control their PAs without knowing about their rights. In some cases, PAs ask their users to sign on work records without actually performing their job duties. MS-User-01 and her younger sister claimed that the earlier PA of MS-User-01, who was an ex-village leader, did not work but asked MS-User-01 to put her thumbprint on a working report.

MS-User-01 added that she gives her pocket money to her current PA, *"I give my money to my friend* (MS-PA-01)."

Even though the PAs were different people, it was observed that the superiority–inferiority dynamic in the PA–User relationship remained the same.

"I do not have a wheelchair as I cannot sit in a wheelchair", reported MS-User-01. The real reason was not that the user could not sit in the wheelchair; it was because the PA had claimed inability to lift the user as it caused the PA body pain.

In another case, MS-User-02 said that he needed a helper who could carry heavy tools for him to do his own business and earn a living. He found it difficult to start his new business as his MS-PA-03 worked for only 1–2 hours a day with him.

MS-User-10, who lived with her granddaughter, said that she wanted to participate in vocational training to support her family, but her MS-PA-15 immediately said, *"You cannot do that as you don't have strength in your hands."*

Verbally or non-verbally, people with disabilities are politically, economically, and socially exploited in their relationships with their PAs.

PAs can fulfil the Family Support Role in an Emergency

When their PAs could not come to work during the day, some service-users became self-isolated in their homes because their family members went out to work or to school.

MS-User-06, who had physical and visual disabilities, chose to take a herbal supplement to sleep in the daytime because there was no one to take care of him. Some of the service users were left without clean clothes or had soiled diapers because their family members did not bathe them, as reported by IL- User-06, IL- PA-06, and MS-PA-16.

For instance, IL-User-06 was a 31-year-old man with a tracheotomy and physical impairment that had occurred when he was 19. He had been using the help of a PA from the age of 20. While he lives with relatives, no one is at home with him during the day. Currently, two PAs are despatched from the IL Centre to take care of him from 9am to 1pm, Monday to Friday. The current contract does not allow him to use a PA on weekends. Consequently, the relatives do not change his diaper for the entire weekend. The PA had to self-quarantine owing to COVID-19, but the IL Centre sent him a substitute as his personal situation was known. The client was concerned that it would become increasingly difficult to be given a substitute as the number of PAs reduced.

> *"Many PAs are old, and it is hard to have young PAs. This may be due to the low allowance for PA work. However, I still need to use a PA because I need support*

> *for the toilet. My relatives do not provide physical care even on weekends. I need to wait until the PA comes (on Mondays)" (IL-User-06).*

DISCUSSION

Distortion of IL Philosophy in General PA Service

Ever since the early development of PA services, the concept of Independent Living has been continuously distorted. Some groups of social work professionals from the MSDHS and healthcare professionals in hospital disability service centres have suggested that organisations of persons with disabilities have insufficient resources to deliver PA services. They asserted that PA services operate better in government units. While most of these professionals agree with the IL philosophy, the implementation of PA services manifests as a charity-based model focusing on long-term care for older adults. They believed that the PAs and caregivers of older persons were the same or interchangeable. Amidst the criticisms and dissatisfaction with PA services from organisations of persons with disabilities, the process is ongoing to adopt a new policy to allow caregivers of older persons to work as PAs. In Thailand, the Ministry of Public Health (MOPH) manages two major positions for public health at the community level: village health volunteers and caregivers trained under the MOPH. Village health volunteers are selected from over ten households, pass the training curriculum determined by the MOPH, and voluntarily conduct activities including health promotion, prevention of diseases, support for primary medical care, referral of clients, rehabilitation, and control of consumption for health (Department of Health Service Support- DHSS, 2011). Caregivers also receive MOPH training. One trained caregiver is expected to work with 5–10 bedridden older adults. They provide services for supporting daily activities such as eating, bathing, and toileting (National Health Security Office -NHSO, 2016). Thus, caregivers act as assistants to their family or *Phu Chuai Phu Dulae*. They work voluntarily and receive a small allowance (Health Research and Development Office -HRDO, 2021). The work of village health volunteers and trained caregivers is based on a charitable model of care and a medical model of disability. The former model sees disability as a personal tragedy with people with disabilities being objects of pity; it portrays people with disabilities as those who need "help," "care," and "protection" from people without disability (Edmonds, 2005). The medical model views disability as a feature of a person directly caused by disease, trauma, or other health conditions that require medical care provided in the form of individual treatment (WHO, 2002). The charity model of care reproduces internalised oppression of people with disabilities. Their feelings of inferiority are unconsciously conveyed through their attitudes. Furthermore, some of the people with disabilities act or exaggerate their difficulties in moving or having to remain in bed for long hours, so as to be qualified as a PA user on the MSDHS.

The misunderstanding and misinterpretation of the IL philosophy among policymakers and stakeholders, and decreased participation from organisations of persons with disabilities in significant decision-making processes, have become barriers to the expected outcomes of PA services according to the IL philosophy. These barriers also appear in some European countries, where such terms as "independent living" and "personal assistance" have often been exploited and misused by organisations that are not operated or controlled by persons with disabilities (Jolly, 2009).

PA under IL Philosophy working with Persons with Severe Disabilities in Thailand

More PA service users from IL centres were in the working-age group and had higher education than PA users from provincial offices of MSDHS. They attended training in IL and received peer support from groups of people with disabilities. They also remained with their families and had family caregivers. As it relates to the IL philosophy, a client's relationship with the PA often involves self-confidence and social participation. Furthermore, the leaders of the IL movement have made efforts to spread IL philosophy as co-organisers or lecturers in MSDHS training for PAs.

In another example, IL-User-04 is a 66-year-old woman with cerebral palsy who worked at home during the spread of COVID-19. She received 24-hour support from her PA for daily living, including taking bath, changing clothes, eating, toilet functions (specifically, changing a urine bag), cleaning, washing, hospital transportation, and preparing for work. Her PA spoke compassionately about her.

> *"People with disabilities are the same as people in general. They can spend their life the same as other people do — eating, going outside, and driving a car. I have friends with disabilities, so disability is normal* (*"Ruang Pokati"* in Thai) *for me"* (IL- PA-03).

The PA conveyed respect for the user as an employer, and the user, rather than the PA, performed decision-making functions. Even though the situation allows IL-User-04 to have a PA for 24 hours, she claimed that she was burdened (“*phara*” in Thai) and felt oppressed (“*kod-dan*” in Thai), as the current government system covers a daily allowance of only 8 hours for a PA and she has to pay for the remaining 16 hours in the day from her pocket money. The burden and oppression that she mentioned were not about her impairment but about her experience of discrimination constructed socially and politically.

The Invisibility of PAs

PAs worked during the COVID-19 pandemic because of their meagre allowance, which is typically 50 THB per hour, with an additional 100 THB per day for transportation expenses, paid according to the number of days worked in a month. This allowance can range from 3,000-9,000 THB per month depending on the number of hours worked. There is no compensation if the PA takes leave of absence because of COVID-19. Many participants in the current study mentioned the lack of working benefits and the necessity of higher wages for PAs.

Village health volunteers gained attention and respect during the COVID-19 pandemic. Perhaps this came from both the wide medicalisation in society (Zola, 1978) and Buddhist thoughts encouraging social assistance for people in need in Thai society (Matsusono [ed.], 2019). The work of PAs should be clearly differentiated from medical care or charitable work. PA services should be recognised as essential professional work, as it realises the rights of persons with disabilities. Thai journalists with physical impairments have reported in an interview (in January 2023) that the current social system in Thailand treats persons with disabilities as inferior citizens. The allocation of a smaller budget to work with persons with disabilities can be recognised as social oppression and discrimination from the perspective of the Critical Disability Theory.

Limitations

Although the methodology of this study was comprehensive, it has some limitations. In particular, this study did not analyse PAs according to the client’s type of disability. This is noteworthy because PAs can also work for people who have disabilities other than physical ones.

CONCLUSION

The Independent Living movement wishes to challenge the way of caring in PA work or, specifically, the interaction of superiority and inferiority in the PA–User relationship and the perception of persons with disabilities as a whole. Ratzka (2017) states that the overarching aim of personal assistance is to enable individuals to live as much as possible in the way they would live without their disability, according to their respective individual and unique personal resources, backgrounds, interests, and preferences.

In Thailand, PAs currently assist with daily living activities and do not work towards client self-determination or social participation. The nature of PA work is still a charity-based model of care, rather than a social model of disability or an empowerment approach. Eventually, funding for PA services is used to provide services based on a charitable or medical model of disability, which differs from the initial purpose determined by the law. Although PAs have supported people with disabilities and responded to family needs during the COVID-19 pandemic, they are not recognised as professionals or career-focused, but rather as volunteers.

Implications

Article 19 (b) of the UN Convention on the Rights of Persons with Disabilities determines that persons with disabilities have access to the personal assistance necessary to support their living and inclusion in the community. The MSDHS training of PAs should be separate from that of caregivers for older persons, as they have different work ethics, roles, and responsibilities. Implementation of PA services by disability service centres at hospitals that are currently controlled by medical professionals, such as care managers and caregivers, can be transformed into user-oriented services. Hospitals providing PA services can work closely with local Disabled People's Organisations to ensure the quality of service and the rights of people with disabilities. IL centres should expand their capacities and networks to provide PA services under the IL philosophy and social model of disability, and to realise the rights of persons with disabilities nationwide.

It is also important to train PA service users to encourage self-determination before working with them. Hoshika (2007) suggested that people with disabilities must experience two steps before engaging PA services: 1) the development of self-confidence, and 2) understanding how they can make requests of PAs while maintaining good relationships with them. The second point is clearly difficult to achieve without the first (Hoshika, 2007). The development of Thailand's direct payment system from persons with disabilities to PAs could be considered as an alternative to empowering the former in self-determination.

Developing a PA profession with a fair salary and working conditions as well as securing proper funding for PAs are other important aspects for sustainable PA services.

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Perceived Family and Organisational Support among People with Dwarfism in Tamil Nadu, India: A Qualitative Inquiry

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ABSTRACT

Purpose: *Despite the fact that society has slowly become more inclusive of those who are viewed as different, people with dwarfism still experience discrimination in every aspect of life. This study aims to understand their perceptions about family and organisational support in combatting the day-to-day challenges they encounter.*

Method: *Face-to-face in-depth interviews using a semi-structured interview guide were conducted with twelve adults with dwarfism. The selected participants were those currently living with their families and with membership in the Tamil Nadu Dwarfism Welfare Association, an NGO, for at least two years. The gathered data was analysed manually using the thematic analysis technique.*

Results: *The major themes that evolved were infrastructural modification, emotional support, access to education, career guidance and partner selection. Each theme had sub-themes which were examined through the lens of both family and organisational support.*

Conclusion: *Support from family can be constructive as well as destructive, often on the basis of the socio-economic status of the immediate family members. On the other hand, support from welfare organisations for the empowerment of people with dwarfism is in general positive. However, the findings from this study cannot be generalised to all people with dwarfism as the study focused solely on the perspectives of members of an organisation, and there were many people who were reluctant to participate in the in-depth interviews.*

Key words: *people with dwarfism, people of short stature, family support, organisational support*

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INTRODUCTION

Dwarfism is a medical condition, with a characteristic of unusually short height of about 147 centimetres or less, caused by changes in bone and cartilage growth (Little People of America, 2020). In India, the Rights of Persons with Disabilities Act was amended in 2016, raising the number of disabilities from 7 to 21, that included dwarfism as one form of physical disability. In spite of this amendment, dwarfism is recognised as just a physical difference in body size rather than a disability, and the accompanying medical conditions are not always apparent (Thompson et al, 2008). Experts in the field of disability studies argue that no other collective identity with respect to impairment has been shaped predominantly by cultural representation (Pritchard & Kruse, 2020). The roots of this misrepresentation can be traced back to the stereotypical portrayal of people with dwarfism in popular culture, especially in art, literature and media (Barnes, 1991; Pritchard & Kruse, 2020). For years they have been considered to be less human and less worthy of respect (Garland & Thompson, 2009) as they are often associated with entertainment. In circuses they are encouraged to perform the role of clowns, and when it comes to modern cinema, they are hired to act as comedians. These representations have shaped, and continue to shape, the perceptions of society by laying emphasis on their appearance rather than talent. Such prejudices have created conceptual tension and forced people with dwarfism to remain among the vulnerable groups, struggling to make ends meet.

Day-to-day Challenges

The social complexities of dwarfism are perceived differently from other forms of physical disability (Ablon, 1990) as they do not possess any cultural markers of disablement to indicate functional limitations, like a wheelchair or any additional forms of assistive devices (Pritchard, 2014). However, in reality, it is observed that the differences in their body structure, including shorter limbs, shorter fingers and bowed legs, have resulted in infrastructural barriers to accessing public spaces and amenities. Since the built environment is constructed for an average-sized person, the mismatch in their height has an impact on how they interact with the social space (Pritchard, 2020). Their accessibility issues begin at home, where many aspects of a standard house, such as shelves, switchboards, countertops, doorknobs, etc., are designed for an individual of average height (Baidi et al, 2018). In the case of public places, accessing public amenities like restrooms, ATMs, shopping complexes, and restaurants become tedious. The absence of appropriate seating arrangements in the employment, educational and healthcare sectors is one of their major concerns. Above all, transportation is a persistent obstacle, making daily commutes challenging. To resolve such infrastructural barriers, it is significant to recognise people with disabilities, not as a homogeneous group but as a group made up of various impairments with diversity (Shakespeare, 2006). This perspective will certainly aid in considering the needs of people with dwarfism before implementing suitable infrastructural facilities for the physically challenged in public spaces (Pritchard, 2016). Furthermore, they experience psycho-social challenges on a daily basis, that consequently lower their mental well-being (Kathryn & Alan, 2020). They are categorised as physically unfit to perform certain roles and are labelled as people with a difference. Humiliating names, unsolicited comments and derogatory phrases are used on them, owing to the difference in their bodily features. People with dwarfism are stared at in public and are often subjected to unauthorised picture-taking (Ellis, 2018). As a result of all this, fear of being negatively judged is implanted in their minds and restricts their engagement in social situations. In order to combat the aforementioned challenges and become resilient, support from the family and the organisation becomes vital.

Operationalisation

Family support is conceived as an informal means of assistance provided to people with dwarfism by their immediate family, including parents, siblings, spouse and children.

Organisational support refers to formal support received by people with dwarfism from the welfare association functioning exclusively for people with dwarfism.

Need for Family and Organisational Support

For people with dwarfism, one of the available resources to promote adaptation is the support received from both the informal and formal institutions, namely the family and the organisation.

Family is the intrinsic social institution which is pertinent to fulfil the needs of people with dwarfism by providing a wide range of assistance to them (Grossman et al, 2016). Family support begins with acceptance, the most influential element in providing support to combat their environmental challenges (Lara et al, 2017). The emotional support obtained from family helps to reduce their psychological distress (Benka, 2012) and promotes a sense of belongingness. People with dwarfism possess innate potential necessary to successfully navigate life (Onalu & Nwafor, 2021) and the family strengthens this by inculcating a set of life and social skills to enhance their social competence.

In addition, people with dwarfism experience problems with their self-esteem and body image that arise due to stigmatisation and social expectations (Silva et al, 2017). In this regard support from organisations functioning exclusively for people with dwarfism promotes a certain philosophy on how to live with the existing conditions (Pritchard, 2021). It also aids them in voicing their own opinions, determining their needs, expressing views and standpoints on priorities, assessing services, advocating change and public awareness. It encourages them to form secondary social relationships and enlarge their support networks, especially with those who share similar experiences.

Therefore, for a person with dwarfism to successfully navigate the existing social system, support from the family and organisations is indispensable.

Objective

The existing literature on people with dwarfism focussed only on the issues of stereotyping, cultural depiction and media portrayal. The denial of not belonging to the category of traditional handicaps (Thompson et al, 2008) failed to lay emphasis on the support mechanisms necessary to combat their challenges. Hence, this study is framed to understand the perceptions of people with dwarfism regarding the support received from family and organisations.

METHOD

Study Setting

Tamil Nadu is a South Indian state, with Chennai as its capital city. The Tamil Nadu Dwarfism Welfare Association, located in Chennai, is the only non-governmental organisation functioning exclusively for the empowerment and welfare of people with dwarfism in the state. This organisation has around 60 individuals with dwarfism as its members, from both rural and urban backgrounds, representing different parts of the state. They work closely with the government agencies to promote their accessibility, especially in the educational, employment and healthcare sectors.

Study Participants

Purposive sampling technique was used to select 12 participants, in the age group of 20-40 years, from the aforementioned non-governmental organisation, emphasising equal representation of men and women. This technique has the flexibility of targeting the participants who are expected to provide rich and in-depth information related to the research questions.

Inclusion criteria of the study:

Participants who were those currently living with their family (to elicit their perceptions about family support), with at least two years of membership experience with the non-governmental organisation (to understand their perceptions on organisational support). In order to represent the study participants, the researcher has used the terms 'people with dwarfism' and 'people of short stature' alternately.

Data Collection

Constructivist approach takes an epistemological stand, in which knowledge is regarded to be constructed (Gerstenmaier & Mandl, 2001). This approach views reality from the perspective of the study participants. Individual face-to-face in-depth interviews were carried out by the first author for about 45-60 minutes to gather information on the research objectives. The researcher introduced herself and her affiliation with the university and assured participants that the study was only for the purpose of enriching scientific evidence through academic writing. Participants were made aware of the aims and method of the study and were offered the freedom to leave the study at any time. Permission to record the interview and written informed consent forms were obtained from all the participants and their data confidentiality was guaranteed. Interviews were initiated with the set of open-ended questions, followed by probing questions on the basis of their response. A few of the sample open-ended questions as indicated in the guide are given below:

- Can you tell us about your family and in what ways they were supportive?
- How does your family help you to cope in times of distress?
- What kind of informational support do you receive from the organisation?
- What role does the organisation play in empowering your personal life?

Data Analysis

Data analysis was done manually by the researchers. The audio recordings were transcribed verbatim and translated to get a deeper understanding. Thematic analysis (Braun & Clarke, 2006) was carried out, wherein the researchers read the transcripts multiple times for familiarize with the available data and then started to generate initial codes manually. After the completion of initial coding, an overarching category was derived by clubbing similar meaningful codes. The codebook had labels or tags assigned to the segments of data that captured meaningful concepts or ideas. The summarised data was aggregated for interpretation and systematically grouped in categories to form themes. The researchers discussed and further revised the themes during subsequent meetings until the final themes were established.

Ethical Considerations

Permission to conduct the study was received from the research supervisor and the lead researcher's doctoral committee members had a thorough scrutiny of the study design, semi-structured interview guide and study procedures.

RESULTS

Socio-demographic Profile

The socio-demographic profile of the respondents is summarised in Table 1. Equal representation was given to both male and female participants, with a majority (67%) belonging to the age group of 30-40 years. Half of the respondents (50%) had education below secondary school level; the study found evidence of dropout rates. Despite all the participants being in the working-age category, only 7 of them were employed. This is due to the misconception that people with dwarfism are incapable of completing a task and lack productivity. Half of the respondents were married; one respondent had a spouse with dwarfism while the remaining five were married to persons with other forms of physical disability. This proves that the average height person is generally not interested in marrying a person with dwarfism. The widow who participated in the study had lost her husband due to HIV. Four participants had one child each; among them, two of the children were born with dwarfism.

Table 1: Socio-demographic Profile of the Respondents

Characteristics	Category	No. of Respondents	Percentage
Age (years)	20-30	4	33
	30-40	8	67
Education	Below Secondary	6	50
	Up to Higher Secondary	2	17
	Under graduation	4	33
Employment Status	Unemployed	5	42
	Employed	7	58
Marital Status	Married	6	50
	Unmarried	5	42
	Widow	1	08
No. of Children	Nil	8	67
	One	4	33

Perceived Family and Organisational Support

In-depth interviews with the participants revealed common themes, and each theme is examined through the lens of both informal and formal institutional support. The results revealed their perceptions and standpoints in having a supportive family and a supportive organisation (see Table 2).

Table 2: Perceived Family and Organisational Support

Themes	Sub-themes
Infrastructural Modification	• Infrastructural adjustments at home • Infrastructural changes at public places • Access to transport
Emotional Support	• Care and compassion • Coping strategies
Support to Access Education	• Impart art, skill and scientific education • Information on education • Advocate on educational policies/inclusion
Career Guidance	• Assist to start business • Assist to get loans • Information on job opportunities
Partner Selection	• Aid to build heterosexual relationships • Convention for mate selection

Infrastructural Modifications

Family members play an integral part in making infrastructural modifications, especially at home, and ensure that the living environment is accessible and comfortable. Family makes the effort to customise infrastructure in the kitchen, bedrooms and bathrooms, by lowering the switchboards, door handles, countertops, cots and clotheslines. However, the study results revealed that family support towards making infrastructural changes at home depends on two major factors. A considerably wealthy family can afford to modify the home on par with the height of the person with dwarfism. Also, a family composed of more than two individuals with dwarfism is more likely to make infrastructural changes.

> *"…My wife loves to cook and since she spends most of her time in the kitchen, for her convenience, I have lowered the tabletop and dishwashing sinks. We share similar life experiences as persons with dwarfism, and so it's easy for me to understand her needs and modifying the kitchen was the initial step taken. We intend to renovate the entire house to our height very soon…"* (P6: Employed male).

However, families that cannot afford to make modifications extend their support by placing step stools and sticks to get onto or to reach something placed at a height. In public places, the family members assist the individuals with dwarfism to make use of available amenities. Transportation assistance from family members seems to be invaluable, such as accompanying them during travel, driving them to their destinations, and making travel arrangements. Extensive support is provided within the home and outside, by helping them complete their household chores and even accompanying them to accomplish their outside tasks.

> *"… I work for a private company, and I commute to the office by local train regularly. I will have to wait for hours to get onto a less crowded compartment as I face difficulty in breathing when jammed in crowd. Knowing this, my brother volunteered to drop me to office in spite of his busy schedules. I feel really blessed to have an understanding brother like him…"* (P2: Unmarried male).

The organisation working exclusively for people with dwarfism is focussed on building an inclusive society that accommodates people of different shapes and sizes. Respondents stated that the personal experiences in relation to the barriers in accessing public amenities, are conveyed among the members of the organisation.

The shared thoughts are then discussed in the forum to contemplate potential adjustments. Such efforts from the organisation have begun to bring about infrastructural changes in the employment sector, in educational institutions, restaurants and places of entertainment, specifically, had initiated modification in the seating arrangements. Locating the infrastructural difficulties encountered in public places, the organisation advocates it to the existing governmental bodies and expects constructive modifications.

> *"… I avoid visiting a restaurant mainly because the seating arrangements and hand washing cabinets are placed at a height unreachable to me. I shared this with one of my member friends of the organisation, during a casual conversation. This incident initiated them to visit that particular restaurant and advocated them to modify the amenities there. Now, people like me can visit and enjoy food there peacefully as the infrastructure in that restaurant has become disability friendly…"* (P10: Unmarried woman).

Emotional Support

For a person with dwarfism, family must handle the caregiving role with caution. Apart from giving practical help to alleviate their daily lives, it is equally important to address their emotional needs. Respondents emphasised that living with the condition of dwarfism itself is stressful, and they often go through the problem of low self-esteem. These depressive spells are managed through the efforts of family members by fostering open communication, spending quality time, acknowledging their ideas and empathising with them.

> *"… I lost my husband due to HIV and that was the most difficult phase of my life. This incident put me under depression, had nightmares of my future, had sleepless nights, and was uncertain of my future. Later, my mother started to sleep with me and whenever I woke in the middle of night, she used to sit along with me and listen to my grief. She helped me to accept the reality and motivated me constantly. Thanks to her* (she teared up) *…"* (P8: Widow).

At the same time a few respondents stated that their emotional needs are not taken care of by family members. During periods of hopelessness, the family members had failed to address their need and provide emotional back up. They perceived that their family members bully them sometimes, by using derogatory phrases and passing unsolicited negative comments. This gave rise to frustration, which gradually lead to isolation from the entire family unit.

> *"…I am the eldest son of my family, and I was so desperate of being not able to find a partner of my own preference. My family never empathised with my situation; rather they used statements like 'nobody will volunteer to marry a guy like you'. Whenever I hear such sentences, I regret for being born like this…"* (P3: Unmarried man).

Since the members of the Dwarfism Welfare Association undergo similar life experiences, they get a significant degree of emotional support from one another. Respondents claimed that they frequently encounter stigmatisation, body shaming, and stares from the public, all of which have a negative impact on their emotional stability. By affiliating themselves with the organisation, the essential strategies to overcome such negative experiences are brought to light. That, in turn, has certainly brought a positive change to their lives, such that the fear of uncertainty has been completely struck down. They are reassured that in time of hardships they can rely on the members of the organisation for emotional assistance.

> *"…I was an introvert and the fear of being negatively judged led me to stay indoors. Due to the compulsion of my neighbour (visually challenged), I joined as a member in Tamil Nadu Dwarfism Welfare Association. There I made a great friend who stands by me during the toughest times. Whenever I get stressed, she is my go-to person, she knew to bring me back to track and help me gain positivity…"* (P12: Unemployed woman).

Support to Access Education

Respondents stated that their families never compromised on educating them and ensured that their disability status should never be a barrier in receiving education. The assistance from family seems to be crucial especially during the transition period, such as moving from one grade to the other or moving from one institute to another. Family makes an effort to gather information regarding the availability of different disciplines of study, collaborates with teachers, and assists in the decision-making process.

> *"... In addition to dwarfism, I also have an issue with my spine and that is why I can't walk. I very well remember my dad carrying me on his shoulders daily to my school. Because I was a female with disability, people around advised my dad to discontinue my education. Yet, he was very particular that my disability should never stop me from attaining quality education. I am a B.Ed graduate*

> *and the only reason for my success is my dad …"* (P10: An undergraduate female).

Apart from providing formal education, the family also focusses on imparting life skills and social skills necessary for day-to-day life. Emphasis on participation in extracurricular activities that align with their personal interests, like sports, singing, joining the scouts, etc. are taken care. Families strongly believe that people with dwarfism are completely capable of contributing to the community through acquisition of knowledge.

> *"…I was subjected to constant criticism for my height and my elder brother supported me so much that he made me learn a traditional dance form named 'Marakkalaattam' – which is performed by standing on a wooden stilt that projects me as a tall woman…"* (P7: 27-year-old female).

However, the ignorance of parents in comprehending the importance of education has led to a large number of dropouts at secondary school level. The educational qualifications and exposure of the parents, to an extent, influence the educational attainment of people with dwarfism. Financial status of the family also remains as an unavoidable element in determining the quality of education provided.

> *"… My classmates often bullied me for my height, and I gradually started to lose interest in going to classes. My parents never knew the importance of education and they never forced me to continue my education. Back then I didn't think of the disadvantages of discontinuing my studies, but now I deeply regret..."* (P5: Male participant).

People with dwarfism did not have the privilege of being accommodated in courses like catering, medicine, architecture, physical education and, in particular, those streams where laboratory work is involved. They are unable to opt the courses they desire, by virtue of their disability status. In this regard the welfare organisation plays a significant role in advocating inclusive education policies, promoting equal opportunities and striving to remove the environmental barriers that hinder access to education. Through counselling and mentoring, the organisation provides individualised support to overcome the challenges in attaining education. Furthermore, it concentrates on providing guidance and information from educated professionals to choose the appropriate discipline, while also providing financial assistance to those from low-income families.

> *"… After the completion of my undergraduate course, I was directionless, as I was the first graduate in my family. When I approached the organisation*

> *for help, they linked me to an IT professional and he instructed me to purse a diploma course related to software. That piece of guidance has brought me this far and now I work for a start-up in my hometown…"* (P4: Unmarried male).

Career Guidance

Career guidance is a lifelong process that aids in the financial independence of people with dwarfism. Right from childhood the family encourages them to engage in activities that help to discover their talents, interests and passion. Additionally, it assists them to embrace their uniqueness, rather than focussing on limitations, and celebrates their achievements and milestones. Family equips them with appropriate skills to enhance social competence and supports them to become financially self-reliant. People with dwarfism and their families constantly get updated on the employment opportunities by associating with professionals in their field of interest. Nonetheless, a considerably wealthy family would support them financially to start a business in line with their interest and capability.

> *"... My brother is an electrician and he used to take me to his workplace every day and taught me from scratch on how the system works. I studied only till 8th grade and through his support I have now become an electrician, and under me 8 average- heighted people work…"* (P1: Employed male).

There was evidence of ineffective families that failed to assist their family member with dwarfism in establishing a career. Lack of family support in career guidance resulted from factors such as unawareness of available opportunities, being overprotective, having difficulty in making informed decisions regarding jobs, and misconceptions about the potential of people with dwarfism.

> *"…Though I completed my under-graduation programme, people are reluctant to provide me a job. My younger brother is a HR Manager in a multinational company, yet he refuses to refer me to his clients. When my own family members abandon me, I feel so depressed..."* (P3: Unemployed male).

Over the years people with dwarfism are affixed with the role of entertainers, especially in the circus and movies. The welfare organisation works extensively to bring about changes in the stereotypical jobs made available to them. To empower them, the organisation assists in finding suitable job opportunities by establishing connections with those companies committed to diversity and inclusion. With the support of governmental bodies, the organisation avail loans to them to start their own businesses and encourages members to start small-scale businesses among themselves. Support and resources for business planning and management are offered by the organisation. Most significantly, the ambiguity around employment for a person with dwarfism is resolved by approaching the organisation.

> *"... I worked in a private supermarket as cashier and the organisation forwarded me an employment poster of a leading Multinational Company inviting physically challenged people to take part in the recruitment process and I'm currently working for the same as data entry operator..."* (P11: 35-year-old female).

Partner Selection

Respondents stated that like other people, they too desire to marry and start families of their own. Yet, the societal norm is that, in order to marry, the criteria of desirability should be met. Considering them as undesirable and unfit, society is not keen to engage in marital relationships with them. Families strive to find partners for individuals with dwarfism with the aid of arbitrators and matrimonial sites.

> *"… Since I was firstborn, my parents started to look for a groom immediately after my schooling. My father's friend came with the proposal of a guy who has hearing impairment. We met each other and when he gave his consent of marrying me, even I was okay with it…"* (P11: Employed married woman).

However, when it comes to romantic relationships, there are families that impose their personal preferences rather than respecting the decisions of people with dwarfism. Respondents feel that their families must create a non-judgemental space whereby their wishes are discussed and respected.

> *"… My family members, with the help of an arbitrator tried looking for a partner for me. When it didn't work, they chose a girl who is my relative. The problem is I'm not okay with her and neither is she okay with me. Yet both our families are compelling us to marry each other. I really don't know where this is heading…"* (P4: Unmarried male).

From its end, the organisation organises a convention by inviting the eligible bachelors to meet suitable partners for heterosexual relationships and has thus simplified the process of partner selection. The consent of both the individual and the family is taken into consideration in the matter.

> *"...... I met my husband in the matrimonial convention; we liked each other and with the support of our family members we got married and have a non-dwarf girl child"* (P9: Married female).

DISCUSSION

The qualitative nature of this study provided an opportunity to analyse the common patterns of family and organisational support among people with dwarfism, as perceived by them. Family is an integral social institution with the capacity to influence the behaviour of a person with dwarfism in a positive way and provide support to enhance their quality of life (Pfeiffer & Albon, 2022). The process of family support begins by accepting them despite their disability status, which in turn builds a sense of belongingness (King et al, 2006). The study themes indicated the significance of support extended by family members, in the aspects of infrastructural, emotional, educational, career and partner selection processes, in order to foster their resilience. Delving deeper into family support, parents play a significant role in strengthening their social competencies through inculcating appropriate skills. Interrelated with this, across their life span, is support from siblings who assume greater family caregiving roles when ageing parents are no longer able to provide support (Arnold et al, 2012). Thereupon, intimate partner relationships allow them to expose their thoughts freely and support is manifested through mutual trust and emotional bonding (Abed et al, 2015). In all this, the economic and social statuses of the family remain as major determinants in influencing the support mechanism. Counterproductive family support is displayed among low-income families, and they exhibit dominance and neglect towards people with dwarfism (Shah, 2010).

Similarly, the support from the organisation for people with dwarfism plays an indispensable role in multiplying their social relationships and networks. Interactions with people of similar experiences elicit better advice and strategies that, when implemented successfully, help them to enhance their self-efficacy. From this study, it is evident that people with dwarfism associate themselves with 'Tamil Nadu Dwarfism Welfare Association' for various reasons: to build social connections, for partner selection and to alleviate their social issues. ' The Little People of America' (LPI) and 'Dwarf Athletic Association of America' (DAAA), are a few examples of welfare associations that are functioning exclusively for people with dwarfism, to enhance their daily living and to promote athletic competition respectively. In spite of the advantages of being part of the organisation, large number of people with dwarfism are yet to associate themselves with it. They are reluctant because of the constant fear of being negatively judged and the deep-rooted internalised stigma that has been experienced. Also, it appears that a lot of them are unaware of this organisation, its functioning and significance. It is high time to sensitise these people about the importance and benefits of associating themselves with the welfare organisation. In a nutshell, both family and organisational support are regarded as essential sources of support to enhance their quality of life.

Limitations of the Study

- Measuring support was challenging for the authors as it encompasses a range of different types of support like emotional, financial, instrumental, etc., and the participants perceive and value support differently.
- Since the authors focused on understanding the perspectives of members of the organisation, it is difficult to generalise the findings to non-members of the organisation.
- The authors faced quite a few rejections from people with dwarfism as they were anxious and apprehensive about taking part in the in-depth interview.

CONCLUSION

The study focussed on the perceived family and organisational support extended to people with dwarfism. This support is considered as a major resource in helping to combat their day-to-day challenges. Support from family is evidently both constructive and destructive and is shaped on the basis of the socio-economic status of the entire family. In contrast, the support from the welfare organisation is perceived to provide positive assistance for their empowerment. Therefore, associating themselves with the organisation for dwarfism will certainly be productive in many aspects.

Implications of the Study

- Findings from the research on perceived family and organisational support of people with dwarfism will aid future researchers to extend the scope in understanding their livelihood challenges from the context of an unsupportive environment.

- Counselling and support on the needs and challenges should be given to primary caregivers to better understand the experiences of people with dwarfism.
- The organisations working with people with dwarfism can advocate to policy makers on the development and enforcement of accessible standards in public spaces, public buildings and transportation; also to promote inclusive educational and employment policies.

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School-aged Children with Down Syndrome in Galle, Sri Lanka: Relationship between Level of Disability, Resource Use and Caregiver Burden

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ABSTRACT

Purpose: *The study assessed the relationship between the level of disability amongst school-aged children with Down Syndrome and overall caregiver burden, and the potential moderating effects of social support and external service access on the caregiver/child relationship in Sri Lanka.*

Method: *Caregivers were recruited to complete the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) assessment, the Caregiver Difficulties Scale (CDS), and to answer questions regarding resource use. A subset of 15 surveyed caregivers were also invited to participate in semi-structured interviews. Regression analyses were used to investigate the impact of resource usage on the association between level of disability and caregiver burden.*

Results: *Lower perceived levels of child disability were related to less caregiver burden. Thirty-seven percent of caregivers reported receiving assistance from external sources. The relationship between the child's level of disability and caregiver burden was attenuated by family support for caregiving and by school attendance in a general class in a mainstream public primary school.*

Conclusion: *External sources of support reduce caregiver burden but may not be available to many caregivers.*

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Key words: *resource needs, resource availability, Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD), Caregiver Difficulties Scale (CDS), childhood disability, Sri Lanka.*

INTRODUCTION

Down Syndrome (DS) is caused by the presence of an extra chromosome (known as trisomy 21) and affects approximately 1 in 1,000 to 1 in 1,100 new-borns (World Health Organisation, n.d.). Individuals with DS have a characteristic set of physical features including hypotonia, small mouth and ears, and a flat nasal bridge, which are often compounded with gastrointestinal tract anomalies and obstructive sleep apnea (Korenberg et al, 1994; Pediatrics, 2001). Children with DS are often prone to physical conditions including ligamentous laxity, decreased strength, and shortened arms and legs, that can inhibit the rate of gross motor development (Fish, 2010). As children with DS reach school-age, verbal, functional, and attention deficits become more pronounced (Grieco et al, 2015).

Caring for Children with Down Syndrome

Caregivers and families of children with DS are disproportionately burdened when compared to caregivers of children and youth with other special health care needs (Phelps et al, 2012).Parents of children with DS are significantly more likely to cut back their working hours or stop working due to their child's health (Phelps et al, 2012). Children with Down Syndrome have more pronounced unmet needs and, consequently, parents of these children feel more stress, which is attributed to caregiving (Hauser-Cram & Shonkoff, n.d.; McGrath et al, 2011; Skotko et al, 2011). Parents and caregivers of children with DS have also cited important personal lessons such as developing increased patience, acceptance, and flexibility (Skotko et al, 2011).

Children with DS stand to benefit from involvement in peer support groups to overcome limitations in creating and maintaining peer social networks during key developmental periods (Fish, 2010). Children with DS have generally been found to have lower physical activity levels when compared with their peers (Wentz et al, 2021). Subsequently, physical therapy has also often been recommended to minimise abnormal compensatory movement patterns (Fish, 2010). Globally, paediatric physical therapists have recommended more physical activity in children with DS, beginning in infancy through to adolescence (Wentz et al, 2021).

Support for Caregivers

Given the difference in stress between varying neurodevelopmental disorders, interventions that promote support to children and their families should be syndrome-specific (Ashworth et al, 2019). Presently, many low- and middle-income countries lack institutionalised support systems for children with neurodevelopmental disabilities. This places an added burden on caregivers (Al-Kandari & Al-Qashan, 2010). Subsequently, many parents turn to the community and/or family resources for support, but many others lack the knowledge of which support systems exist and/or feel uncomfortable soliciting such support (Al-Kandari & Al-Qashan, 2010).

Generally, parents of children with DS have recommended seeking out resources and support groups such as early intervention programmes, seminars or workshops to others in similar circumstances (Skotko et al, 2011). Other recommendations to caregivers of children with DS have included finding a good physician and learning how to advocate on behalf of their child's needs (Skotko et al, 2011). Some low- and middle-income countries, such as Zambia, have introduced new programmes to train caregivers to be interventionists, using empirically supported and parent-mediated interventions for developmental differences such as DS (Pierucci et al, 2023). These interventions aim to target improvements in children's language skills and their ability to play (Pierucci et al, 2023).

Support for Children with Disabilities and their Caregivers in Sri Lanka

Within Sri Lanka, DS is the most commonly identified aneuploidy or abnormality in the number of chromosomes in children, with a prevalence of 76.3% amongst clients with chromosomal anomalies (Thillainathan et al, 2015). While some demographic studies on the prevalence of generalised chromosomal anomalies have taken place in Sri Lanka, little research has been conducted regarding the availability, utilisation and effectiveness of support systems and resources specifically for children with DS and their caregivers.

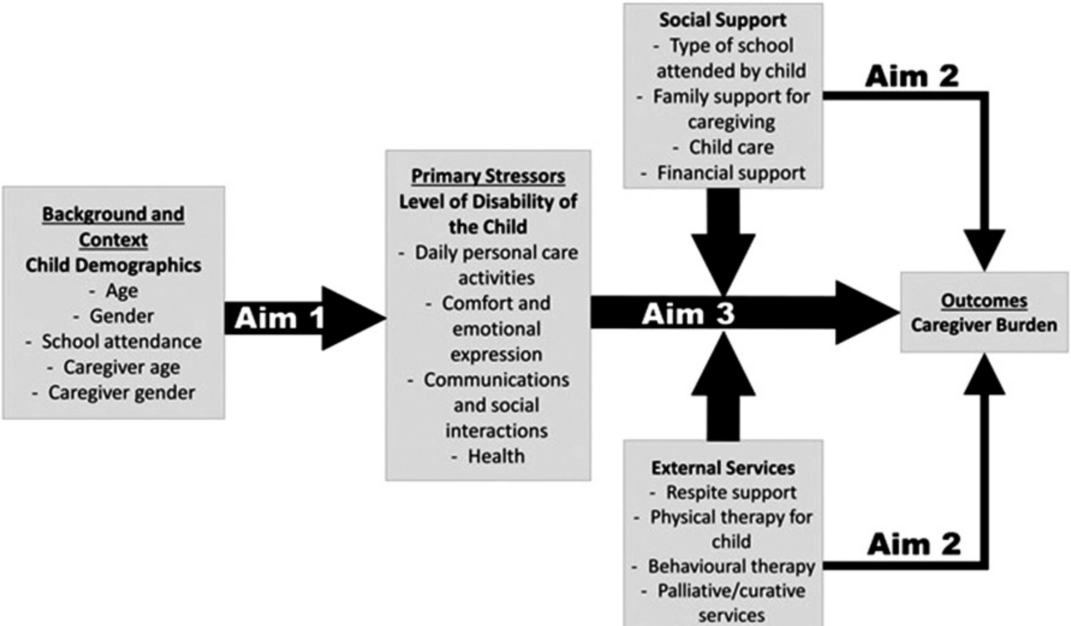
Children with disabilities in Sri Lanka, like children elsewhere, have been found to benefit from inclusive education models (Furuta, 2006). Examples of such models include special programmes in formal education settings, special schools within resource centres, and/or non-formal educational activities that could function as alternative educational opportunities (Furuta, 2006). Moreover, family, community, spiritual, cultural, and rehabilitative outcomes have been found to positively influence mothers' perceptions of their child's disability in Sri Lanka (Landry et al, 2015). Access to medical, social, rehabilitative, and/or public health infrastructure have also been suggested to be critical in alleviating the burden that caregivers face (Landry et al, 2015).

Objective

This study had three aims focused on understanding the experiences of children with Down Syndrome, aged 5-12 years, and their caregivers in Galle, Sri Lanka (see Figure 1):

1. To describe the general level of disability amongst school-aged children with DS and examine possible socioeconomic predictors of the level of disability;
2. To assess the need for and use of DS-related external services and social support; and,
3. To analyse whether primary stressors, social support and external services moderate the relationship between level of child disability and overall caregiver burden.

Figure 1: Description of the Study Aims



METHOD

Study Setting

This study took place in the Galle District on Sri Lanka's south-western coast. The study consisted of interviews and surveys with caregivers of children with Down Syndrome, and was conducted through the Faculty of Medicine at the University of Ruhuna.

Study Participants

Caregivers of children with DS between the ages of 5 and 12 years were selected through direct contact at standard schools with standard classes, standard schools with special needs classes, and schools designed specifically for children with varying disabilities. Through word-of-mouth, attending special needs drop-in centres, and connecting with local social services, researchers also approached caregivers of children who did not attend school.

Inclusion criteria for caregivers:

- They should have lived within the Galle District for at least six months;
- Be able to speak, read, and understand Sinhala or English; and
- Be a primary caregiver for a child with DS (Wijesinghe et al, 2015).

Verbal and written consent was obtained from all the participants.

Data Collection

This study was based upon an explanatory mixed-methods design comprised of a two-phased qualitative and quantitative approach consisting of a 75-question survey and a 10-question semi-structured interview with a smaller subset of the sample. The survey consisted of questions from two pre-existing scales: the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) and the Caregiver Difficulties Scale (CDS). Additional questions about demographics and the availability of medical-, rehabilitative-, respite-, counselling- and other services were also included. Participants were asked to elaborate on key points of interest from the survey. Both the survey and interview questions were written in English and translated into Sinhala. A researcher conducted both the surveys and interviews in Sinhala.

Participants were compensated with 700 Sri Lankan rupees (LKR) for filling out the survey and another 700 LKR for participating in the qualitative interview.

Measures

CPCHILD Assessment

The CPCHILD questionnaire was developed by healthcare professionals from the Hospital for Sick Kids and the Bloorview Research Institute in Toronto (Narayanan et al, 2006). The measure assesses children's levels of disability from the perspective of their caregiver. Caregivers are asked to rank their child's abilities, emotions and health across four domains: Personal Care/Activities of Daily Living; Comfort and Emotions; Communication and Social Interaction; and Health (Narayanan et al, 2006, 2007). Generally, caregivers were asked to assess the level of difficulty or discomfort in the child when trying to perform certain functions of daily living, such as eating, bathing, getting in and out of vehicles, and communicating with different groups of people over the prior two weeks. Measures of level of difficulty varied and were based on the set of questions. Some questions use a 3-point Likert scale ranging from "substantial" difficulty to "none", while others use a 7-point Likert scale ranging from "not possible" to "no problem." For each question, raw scores were later converted into a scale ranging from '0' (worst outcome) to '100' (best outcome) (Narayanan et al, 2007). CPCHILD provides a summary of five continuous variables: one overall mean score and four subscale mean scores ranging from '0' to '100', with higher values associated with lower levels of childhood disability.

CPCHILD has been confirmed to have sufficient reliability and validity as a measure in multiple studies for applications with cerebral palsy (Narayanan et al, 2006; Zalmstra et al, 2015). The section on mobility was removed in this study since it was less applicable to children with DS, and this was accounted for when tabulating overall scores.

CDS Assessment

The Caregiver Difficulties Scale (CDS) was created by researchers at the University of Ruhuna, Galle (Wijesinghe et al, 2015). This assessment measures caregiver burden by asking 25 questions associated with "concern for the child", "impact on self", "support for caregiving", and "social and economic strain" using a 5-point Likert scale (Wijesinghe et al, 2015). The survey consisted of a series of caregiving-related questions including asking whether caregivers feared for their child’s present or future state of being; whether caregivers felt their personal health was affected by their child’s condition; and whether specific people (e.g., spouse, neighbours, other family members) help caregivers with their physical and emotional caregiving responsibilities. Caregivers’ responses to each question were assessed on a 6-point scale ranging from “always” to “not applicable.” A final aggregate score was calculated for overall caregiver burden in the sample by calculating the mean of all CDS scores ranging from ‘0’ to ‘100’. The face-, construct-, content-, and consensual validity of the CDS have been established through item generation in previous studies (Wijesinghe et al, 2013). Previous tests have also established satisfactory internal consistency and reliability (Wijesinghe et al, 2013).

Data Analysis

STATA version SE/15 (StataCorp., 2017) was used to analyse the data and generate descriptive statistics. For categorical variables, raw data frequencies and percentages were tabulated. CPCHILD and CDS scores were calculated for each participant and aggregated to estimate subsection and overall means and standard deviations. Child and caregiver demographic information were then related to CPCHILD and CDS scores. Relationship and demographic indicators of level of child disability and caregiver burden were estimated through simple linear regression analysis. Significant variables were entered into multivariable regression models to assess the effect on CPCHILD and CDS scores. The associations between CPCHILD and CDS scores were also assessed, using a significance level of 0.05. Variables that yielded significant associations were included in further multivariable regression models to estimate possible moderator effects of specific social supports and external services on the relationship between level of disability of the child and caregiver burden.

Qualitative data was analysed separately. A thematic analysis was conducted using NVIVO to identify common phrases, trends, and themes. Per-question summaries were drafted and revisited to determine commonly recurring cross-sectional themes across questions.

Ethics Approval

This study was approved by the Institutional Reviews Board at the University of Ruhuna, Sri Lanka, and Duke University, USA.

RESULTS

Participant Characteristics

One hundred and twenty-five caregivers of children with Down Syndrome participated in the study. The mean age of the children was 8.4 ± 2.2 years with a range from 5 to 12 years (see Table 1), and 50.4% of children were male. Among them, 18.4% had never attended school, 5.6% were currently not attending school and 76% were currently attending school. The majority (88%) did not follow the regular curriculum, and most of them attended either a special class in a mainstream public school (38.5%) or a special school (32.8%) for children with disabilities.

Table 1: Child Characteristics

Variable	Frequency	%	Mean (SD)	(Min, Max)
Child Sex (n=125)				
Male	63	50.40		
Female	62	49.60		
Child Age (n=125)			8.4 (2.2)	(5, 12)
Child Educational Status (n=125)				
Never schooled	23	18.40		
Currently non-schooling	7	5.60		
Attending preschool	5	4.00		
Attending school	90	72.00		
Child Grade (n=125)				
1st grade	8	6.40		
2nd grade	3	2.40		
3rd grade	2	1.60		
4th grade	1	0.80		
5th grade	1	0.80		
Not applicable	110	88.00		
School Type (n=122)				
Not applicable	29	23.77		
Mainstream school – general class	6	4.92		
Mainstream school – special class	47	38.52		
Special school	40	32.79		
Number of Years of Schooling (n=122)			2.0 (1.8)	(0, 8)
Cardiac Comorbidities (n=125)	36	28.80		
Respiratory Comorbidities (n=125)	7	5.60		
Gastrointestinal Comorbidities (n=125)	32	25.60		
Other Comorbidities (n=125)	62	49.60		

Caregiver characteristics are presented in Table 2. Most of the caregivers (83.2%) were female and were on average 46.7 ± 8.8 years old at the time of the survey. Most of them (90.4%) were married and almost all (96%) were the biological parent of the child with DS. Approximately one-third (27.2%) worked in either full-or part-time jobs, with another third (32%) reporting that they were unemployed.

Table 2: Caregiver Characteristics

Variable	Frequency	%	Mean (SD)	(Min, Max)
Caregiver Sex (n=125)				
Male	21	16.80		
Female	104	83.20		
Age at Birth of Child (n=125)			37.9 (8.9)	(9.0, 64.4)
<30 years	29	23.20		
31-40 years	53	42.40		
>40 years	43	34.40		
Caregiver Work Status (n=125)				
Unemployed (due to child's health)	40	32.00		
Unemployed (for other reasons)	0	0.00		
Searching for a job	0	0.00		
Working full- or part-time (outside the house)	26	20.80		
Working full- or part-time (at a home-based business)	9	7.20		
Homemaker	50	40.00		
Caregiver Marital Status (n=125)				
Single	2	1.60		
Married	113	90.40		
Widowed	5	4.00		
Divorced/Separated	5	4.00		
Caregiver Education Level (n=125)				
No school	2	1.60		
Below grade 5	7	5.60		
Fifth to tenth grade	21	16.80		
Up to ordinal level	51	40.80		
Post-high school diploma or up to advanced level	37	29.60		
Degree or diploma	7	5.60		
Monthly Income (in LKR) (n=125)				
Less than 5,000	17	13.60		
5,001 - 20,000	63	50.40		
20,001 - 35,000	24	19.20		
35,001 - 50,000	19	15.20		
Over 50,000	2	1.60		

Aim 1: Child and Caregiver Demographics and Level of Disability (CPCHILD)

The overall mean level of child disability was 64.8, with sub-scores of 59.6 for personal care and activities of daily living; 68.4 for comfort and emotions; 68.4 for communication and social interaction; and 47.8 for health.

All demographic variables were regressed against CPCHILD in simple models to assess for significant associations. Significant associations are listed in Table 3 and were later included in the multivariable model. The type of school that children attended was significantly associated with overall CPCHILD scores. Caregivers who had children attending general classes in mainstream schools reported lower levels of disability in their children ($\beta=17.7$, $p<0.05$), as did those whose children attended special classes in mainstream schools ($\beta=13.4$, $p<0.05$) and in special schools ($\beta=12.8$, $p<0.05$), in comparison to children who were not attending school. Female caregivers reported lower levels of disability in their children ($\beta=7.5$, $p<0.05$) as compared to their male counterparts, as did caregivers who worked full- or part-time at home-based businesses ($\beta=10.3$, $p<0.05$) and those who self-identified as homemakers ($\beta=5.6$, $p<0.05$). Caregivers' education level was also significantly associated with CPCHILD scores. Caregivers who completed secondary school reported their children had lower levels of disability ($\beta=12.9$, $p<0.05$), as did those who had a degree or diploma ($\beta=21.5$, $p<0.05$), in comparison to those with less than a 10th-grade education.

Variables which had significant associations with the CPCHILD assessment were included in linear multivariable regression models (Table 3). In the multivariable model, female caregivers had a significant association with reporting lower levels of child disability ($\beta=9.3$; $p<0.05$). Moreover, caregivers of children who attended general classes in mainstream schools ($\beta=18.1$, $p<0.05$), special classes in mainstream schools ($\beta=11.6$, $p<0.05$) and special schools ($\beta=12.0$, $p<0.05$) were also associated with lower levels of child disability.

Table 3: Child and Caregiver Demographics with Level of Disability of Child (CPCHILD scores): Simple and Multivariable Linear Regression

	CPCHILD Simple Regression	**CPCHILD Multivariable Regression**
	Coefficient (95% CI)	**Coefficient (95% CI)**
Model Intercept		**29.1 (14.3, 43.9)**
Educational Status		
Never schooled (REF)	53.2 (48.2, 58.2)	
Currently non-schooling AND/OR Attending preschool	6.1 (-2.5, 14.6)	5.6 (-5.2, 16.4)
Attending school	15.3 (9.7, 20.9)**	-13.7 (-28.0, 0.6)
School Type		
Not applicable (REF)	54.7 (50.1, 59.2)	
Mainstream school - general class	17.7 (6.6, 28.7)**	18.1 (6.3, 29.9)**
Mainstream school - special class	13.4 (7.6, 19.2)**	11.6 (5.1, 18.2)**
Special school	12.8 (6.8, 18.8)**	12.0 (5.4, 18.6)**
Caregiver Gender		
Male (REF)	58.6 (52.8, 64.3)	
Female	7.5 (1.3, 13.8)**	9.3 (2.6, 16.1)**
Caregiver Work Status		
Unemployed (due to child's health) (REF)	60.6 (56.4, 64.8)	
Working full- or part-time (outside the house)	6.1 (-0.6, 12.7)	5.2 (-2.3, 12.7)
Working full- or part-time (at a home-based business)	10.3 (0.6, 20.0)**	9.1 (-0.7, 18.9)
Homemaker	5.6 (0.0, 11.2)**	1.3 (-4.3, 6.9)
Caregiver Education Level		
Less than grade 5 (REF)	54.5 (45.9, 63.1)	
Fifth to tenth grade	6.1 (-3.h1, 17.3)	-0.3 (-10.7, 10.1)
Up to ordinal level	12.9 (3.6, 22.1)**	8.0 (-1.5, 17.5)
Post-high school diploma or up to advanced level	9.2 (-0.4, 18.7)	5.5 (-4.2, 15.1)
Degree or diploma	21.5 (8.6, 34.5)**	11.7 (-2.5, 25.8)
Caregiver Income Level* **		
Less than 5,000 (REF)	58.0 (51.7, 64.4)	
5,001 - 20,000	5.9 (-1.2, 13.1)	2.3 (-4.8, 9.3)
20,001 - 35,000	11.4 (3.1, 19.7)**	2.8 (-5.7, 11.2)
35,001 and above	9.8 (1.3, 18.3)**	-0.8 (-10.6, 9.0)

Note: CI, confidence interval
**P<0.05
***1 USD = 160 LKR at the time of the survey"

Aim 2: Use of Social Support Systems and External Services

Table 4 outlines the frequencies in responses for social supports used by children with DS and their caregivers. The majority (56%) of caregivers stated that they had more than one co-caregiver, with most naming their spouse as the main co-caregiver (31.2%). Almost all (92.8%) caregivers reported receiving caregiving assistance from family and friends.

Table 4: Social Supports for Children with Down Syndrome and their Caregivers

Variable	Frequency	%
Main Co-Caregiver (n=125)		
Spouse	39	31.20
Grandparent caregivers	1	0.80
Siblings of the child	9	7.20
Other relatives	4	3.20
Neighbours	1	0.80
None	1	0.80
Other – More than one co-caregiver	70	56.00
Receive Government Assistance (n=125)		
Yes	25	20.00
Receive Social Services (n=125)		
Yes	25	20.00
Receive NGO Assistance (n=125)		
Yes	0	0.00
Religious Observances (n=125)		
Yes	97	77.60
Type of Religious Observance (n=36)		
Buddhist rituals	34	94.44
Islamic rituals	1	2.78
Going to temple (unspecified religion)	1	2.78
Participate in Recreational Activities (n=125)		
Yes	4	3.20
Family and Friends Support (n=125)		
Yes	116	92.80
Provider of Support (n=28)		
Spouse	3	10.71
Other family member	25	89.29
Support Level Provided by Family/Friends (n=116)		
Full	37	31.90
Almost full	49	42.24
Partial	25	21.55
Minimal	5	4.31

Table 5 describes the use of external services by caregivers for themselves and their child. Of those surveyed, 7.2% said they had special facilities in their home to support their child. Approximately one-third (36.8%) utilised external support for caregiving. Very few reported using behavioural therapy (16.8%) for their children.

Table 5: External Service Use for Children with Down Syndrome and their Caregivers

Variable	Frequency	%
Special Facilities at Home (n=125)	9	7.20
External Support (n=125)	46	36.80
Behaviour Therapy (n=125)	21	16.80
Physical Therapy (n=125)	15	12.00
Palliative Therapy (n=125)	8	6.40
Preventive Therapy (n=125)	15	12.00

Most interviewed caregivers had minimal knowledge of Down Syndrome prior to being tasked with caregiving responsibilities. They reported that they obtained information about DS from medical professionals following the delivery of their child. Many learned about DS from attending clinics conducted by the hospital, reading existing literature, and conducting internet searches. Caregivers used a variety of strategies including speaking to doctors and other parents, and engaging with television, newspaper, and internet sources to fill gaps in their understanding.

There were broad variations in the caregivers' experiences of finding external resources such as physical, behavioural, and speech-language therapies for their child. Approximately half (46.7%) of those interviewed reported having no trouble finding therapies for their child or not requiring any therapy for their child. Almost half (42.8%) of the participants had trouble accessing resources such as physiotherapy and speech-language therapy because of transportation or timing issues, such as not being able to receive sufficient time off work.

When speaking of challenges, the most prominent difficulties reported were related to family finances, managing the child's comorbidities, and finding adequate schooling. Many caregivers stated that their income was not satisfactory to meet expenses and that they did not have sufficient time to take on additional economic opportunities.

Moreover, caregivers struggled to find ways to cope with their child's comorbidities, such as learning how to interact with their child given the speech impediments, or navigating medical problems and challenges. When facing both financial issues and difficulty in supporting their child's comorbidities, one caregiver reported using the internet to find materials to conduct speech therapy to assist her son by herself.

Caregivers also reported difficulties in finding teachers and classrooms that could support their child's development, with most reporting that they sent their children to special schools or special units in mainstream schools. Factors that influenced these decisions included proximity to the school, rejection of the child by teaching staff in mainstream schools, referrals from other parents, and the opportunity for increased individual attention. One caregiver stated that her child had studied in a mainstream school up until the fifth grade but began struggling to keep up with the class as the curriculum progressed, prompting them to transition the child into a special education unit. Some caregivers reported taking part in advocacy and awareness initiatives by supporting other children with DS in their spare time, and advocating to local government authorities to develop improved facilities that would be more accessible to children with DS. For instance, one caregiver, who also worked as a teacher, said that she tries to encourage parents of children with DS to enrol their children in school.

Aim 3: Relationship of Child's Level of Disability on Overall Caregiver Burden (CDS score)

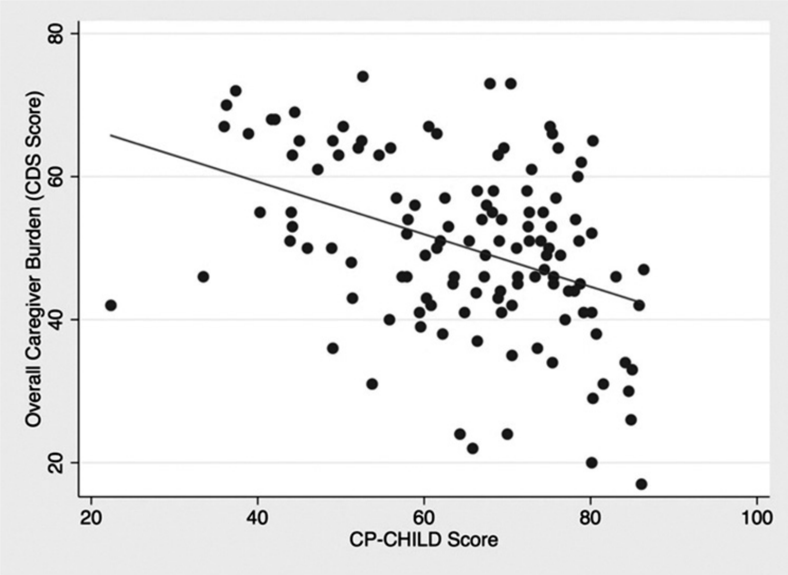
Overall, the mean CDS score for caregiver burden was 50.2. A simple linear regression model for mean CDS score and the level of disability (CPCHILD) was estimated (see Table 6). Lower caregiver burden scores were associated with lower levels of child disability for personal care and activities of daily living ($\beta=-0.2$, $p<0.05$), comfort and emotions ($\beta=-0.3$, $p<0.05$), communication and social interaction ($\beta=-0.2$, $p<0.05$), and health ($\beta=-0.5$, $p<0.05$), but the association for overall child disability scores ($\beta=-0.4$) was not statistically significant (see Figure 2).

Table 6: Relationship between Level of Disability of Child (CPCHILD score) and Overall Caregiver burden (CDS score): Simple Linear Regression

	CDS Mean
	Coefficient (95% CI)
CPCHILD Personal Care/Activities of Daily Living	
Model intercept	59.7 (54.8, 64.6)
Coefficient	-0.2 (-0.2, -0.1)**
CPCHILD Comfort and Emotions	
Model intercept	71.5 (58.1, 84.9)
Coefficient	-0.3 (-0.4, -0.1)**
CPCHILD Communication and Social Interaction	
Model intercept	67.1 (53.7, 80.5)
Coefficient	-0.2 (-0.4, -0.1)**
CPCHILD Health	
Model intercept	71.9 (60.8, 82.9)
Coefficient	-0.5 (-0.7, -0.2)**
CPCHILD Overall	
Model intercept	74.0 (64.1, 83.7)
Coefficient	-0.4 (-0.5, -0.2)

Note: CI, confidence interval
**P<0.05

Figure 2: Relationship between Child Disability (higher CPCHILD score indicates lower level of disability) and overall Caregiver Burden (CDS score)



Aim 3: Relationship of Child's Level of Disability, Social Support Use and External Service Use on Overall Caregiver Burden (CDS score)

Table 7 outlines simple linear regressions of external service use and social support use against the child's level of disability (CPCHILD score) and overall caregiver burden (CDS score). Family support for caregiving (β=-14.2, $p<0.05$) and school attendance in a general class in a standard school (β=-15.1, $p<0.05$) yielded significant negative associations.

Multivariable regressions were developed based on significant associations from the simple linear regressions for social supports and external services with overall caregiver burden. The multivariable models regressed the CPCHILD score, child's school type, family support for caregiving, use of government assistance, and assistance from external sources against caregiver burden scores. Since none of the external service variables were found to be significant in the simple regression models, only the assistance from external sources variable was further analysed. The child's level of disability (β=-0.4, $p<0.05$) became significantly associated with caregiver burden when controlling for the effects of other variables. Family support for caregiving (β=-10.1, $p<0.05$) was significantly associated with lower caregiver burden.

Table 7: Relationships between Child's Level of Disability, Social Support, and External Service Use with Caregiver Burden (CDS score): Simple Regression and Multivariable Regression with and without interaction terms

	CDS Simple Regression	**CDS Multivariable Regression**	**CDS Multivariable Regression (incl. Social Support as moderator)**	**CDS Multivariable Regression (incl. External Services as moderator)**
	Coefficient (95% CI)	**Coefficient (95% CI)**	**Coefficient (95% CI)**	**Coefficient (95% CI)**
Model Intercept	**-**	**80.4 (69.6, 91.2)**	**81.1 (41.2, 121.0)**	**67.4 (51.8, 83.0)**
CPCHILD Score	74.0 (64.1, 83.7)	-0.4 (-0.6, -0.3)**	-0.3 (-1.0, 0.3)	-0.3 (-0.5, -0.0)**
Coefficient	-0.4 (-0.5, -0.2)			
School Type (n=122)				
No school (REF)	50.4 (46.0, 54.8)	REF	REF	
Mainstream school – general class	-15.1 (-25.8,-4.5)**	-4.7 (-14.4, 4.9)	-1.0 (-79.4, 77.5)	
Mainstream school – special class	1.4 (-4.2, 7.0)	8.9 (3.5, 14.3)**	10.6 (-13.0, 34.2)	
Special school	0.1 (-5.7, 5.9)	6.0 (0.5, 11.5)**	10.6 (-13.0, 38.9)	
Family Support for Caregiving	63.3 (55.6, 71.1)	-10.1 (-17.3,-2.9)**	-10.3 (-47.5, 26.9)	
Coefficient	-14.2 (-22.2, -6.1)**			

	CDS Simple Regression	CDS Multivariable Regression	CDS Multivariable Regression (incl. Social Support as moderator)	CDS Multivariable Regression (incl. External Services as moderator)
	Coefficient (95% CI)	**Coefficient (95% CI)**	**Coefficient (95% CI)**	**Coefficient (95% CI)**
Model Intercept	**-**	**80.4 (69.6, 91.2)**	**81.1 (41.2, 121.0)**	**67.4 (51.8, 83.0)**
Government Assistance	49.0 (46.6, 51.4)	5.0 (0.2, 9.8)**	-17.6 (-44.8, 9.7)	
Coefficient	5.7 (0.4, 11.1)			
At-Home Special Families	49.9 (47.7, 52.2)			
Coefficient	3.2 (-5.2, 11.6)			16.9 (-14.0, 47.8)
Assistance from External Sources	51.6 (48.9, 54.3)	-2.4 (-6.3, 1.6)		
Coefficient	-3.8 (-8.3, 0.7)			21.6 (-0.9, 44.0)
Behaviour Therapy	50.1 (47.7, 52.5)			
Coefficient	0.4 (-5.4, 6.3)			38.4 (8.9, 67.8)**
Physical Therapy	50.6 (48.3, 52.9)			
Coefficient	-3.8 (-10.5, 2.8)			-11.5 (-40.9, 17.9)
Palliative/Curative Therapy	49.9 (47.7, 52.2)			
Coefficient	3.4 (-5.5, 12.3)			-27.3 (-70.6, 16.1)
Preventive Care Services	50.1 (47.8, 52.4)			
Coefficient	0.6 (-6.1, 7.3)			-34.6 (-61.3, -7.9)
Interaction Terms				
CPCHILD Score*No school			REF	
CPCHILD Score*Mainstream school – general class			-0.1 (-1.2, 1.0)	
CPCHILD Score*Mainstream school – special class			-0.1 (-0.4, 0.3)	
CPCHILD Score*Special school			-0.1 (0.6, 0.3)	
CPCHILD Score*Family Support for Caregiving			-0.0 (-0.6, 0.6)	
CPCHILD Score*Government Assistance			0.4 (-0.1, 0.8)	
CPCHILD Score*At-Home Special Facilities				-0.3 (-0.8, 0.2)
CPCHILD Score*Assistance from External Sources				-0.3 (-0.7, 0.0)**
CPCHILD Score*Behaviour Therapy				-0.7 (-1.2, -0.2)**
CPCHILD Score*Physical Therapy				0.2 (-0.3, 0.6)
CPCHILD Score*Palliative/ Curative Therapy				-0.5 (-0.2, 1.3)
CPCHILD Score*Preventive Care Services				0.6 (0.1, 1.1)**

Note: CI, confidence interval
**P<0.05

Aim 3: Social Supports as a Moderator of Level of Child's Disability (CPCHILD score) on Overall Caregiver Burden (CDS score)

The moderator effects of specific social supports on the relationship between the child's level of disability and caregiver burden were analysed using multivariable regressions. For these models, three variables with significant associations in the simple models were selected: school type, family support for caregiving, and government assistance (see Table 7). No significant associations were observed for any of the tested variables within this multivariable model.

Aim 3: External Services as a Moderator of Level of Child's Disability (CPCHILD score) on Overall Caregiver Burden (CDS score)

The moderator effects of external services on the relationship between the child's level of disability and caregiver burden were assessed, using all external service variables (see Table 7). In simple regressions, the overall CPCHILD score (β=-0.3; $p<0.05$) and receiving behavioural therapy (β=38.4, $p<0.05$) were significantly associated with caregiver burden. When included as interaction terms in a multivariable model, three of the variables: assistance from external sources (β=-0.3, $p<0.05$), behavioural therapy (β=-0.7, $p<0.05$), and preventive care (β=0.6, $p<0.05$) displayed significant associations.

DISCUSSION

Socioeconomic Predictors of the Level of Disability

CPCHILD has not been previously used to measure disability levels for DS, making it difficult to draw comparisons with populations elsewhere. In earlier CPCHILD studies of children with cerebral palsy, severity scores were reported to range between 52.0 and 56.2. This study's adjusted score of 64.8 demonstrates lower levels of disability than studies for children with cerebral palsy (Narayanan et al, 2006; Zalmstra et al, 2015).

Significant predictors of the caregivers' perception of their child's level of disability included school type, caregiver sex, caregiver work status, caregiver education level and family income level. Significant relationships were found between enrolments in general classes and lower caregiver burden scores. Levels of perceived disability were lower amongst children who attended general classes in mainstream schools than among children who attended special classes or special schools. The decision of which school type to enrol children in is ultimately at the discretion of the caregiver in Sri Lanka (Padmani, 2003), with previous studies indicating that the mental age scores of children with DS are strongly related to the type of school attended (Sloper et al, 1990). It is likely that children attending general classes can do so because they have lower levels of disability.

Consistent with existing literature, most caregivers were female – possibly due to historical and cultural traditions that place more caregiving responsibilities on women (Barros et al, 2017). Lower levels of caregiver burden were associated with older children, suggesting that there may be an association between perceived decreases in the level of the child's disability by caregivers as children age. This could possibly stem from caregivers having a better understanding of how to manage their child's disability and learning styles (Fish, 2010).

External Services and Social Support for Children and Caregivers

Despite low uptake of services, caregivers identified needs for external services. For example, caregivers reported a need for speech-language therapy. As children age, disability related to language, particularly the use of expressive language, declines (Chapman, 1997; Grieco et al, 2015). Barriers to accessing speech-language therapy included a lack of knowledge on locating services, access barriers (either through transportation or lack of time), and/or an inability to afford services.

It is of particular significance to note that this study did not specify what participants thought external services were and so it is unclear what services participants were thinking about as they answered questions related to external services. Such issues could be mitigated in future studies by conducting cognitive interviews of survey questions prior to widely conducting the survey with participants, and/or amending questions to call out specific types of external services of interest.

Relationship of External Services, Social Supports, and Primary Stressors with overall Caregiver Burden

Lower levels of disability amongst children with DS were related to lower overall levels of caregiver burden. This is consistent with previous studies where CDS measured caregiver burden for children with cerebral palsy in Sri Lanka and found that a child's functional deficits contributed to caregiver burden (Wijesinghe et al, 2015). It could also be postulated that when there is a higher level of disability in the child, caregiver burden will subsequently be higher as well. This is particularly showcased within the context of how it was found that caregiver burden was reported be higher among caregivers of children attending special schools or special classes in mainstream schools. The causal direction of this relationship warrants further study.

Similar to the previous discussion of the term 'external services', future studies should take care to either more specifically define what is encompassed within government services or conduct cognitive testing of survey items prior to widespread use to ensure participants' understanding of the questions are in line with researcher intents of such probes.

Moderator Effects of Social Supports and External Services on Level of Disability and Caregiver Burden

Mean CDS scores were regressed against mean CPCHILD scores, demographic, and resource access information. No support services were found to have a significant moderating role on the relationship between the level of disability and caregiver burden. This information conflicts with previous studies that have shown social supports to be a moderator of caregiver well-being (Demirtepe-Saygılı & Bozo, 2011). It is possible that the interpretation of social supports within this study was misunderstood by caregivers because it was presented generally, without providing examples within the survey, leaving it open to broad interpretation. This issue could be overcome in future studies by conducting cognitive interviews to test participant interpretations of such questions prior to deployment.

In contrast, certain external services were shown to have significant associations with caregiver burden, and acted as moderators of the relationship between disability level and caregiver burden in this study. Receiving assistance from external sources and attending behavioural therapy were found to be associated with lower levels of caregiver burden. Since these sources are designed to help mitigate the child's level of disability and improve coping mechanisms (for the child and/or caregiver), this association is consistent with prior assumptions.

Study Strengths and Limitations

Previous studies in Sri Lanka have used similar measures to assess other developmental disabilities within the country but this was the first study to apply this measure to better understand DS. A strength of this study was its diverse participant pool in terms of sociodemographic backgrounds and access to disability services. As to limitations, both CPCHILD and CDS were originally designed for children with CP. Moreover, there were limited descriptions of resource availability, external services, and social supports. Given that the section on mobility was removed from the CPCHILD tool that was used in this study, the reliability or validity of the overall tool may have been somewhat affected. While measures were taken to remove that portion from any calculations that were done to account for this loss, future studies would benefit from assessing the reliability and validity of the modified tool. Furthermore, both sets of quantitative and qualitative tools used general language that may have left room for differing interpretations. Future studies could also include objective clinical assessments of children to measure level of disability more and compare those results against caregiver perceptions of their child's level of disability.

As this was a cross-sectional study, care should be taken in drawing causal inferences about the observed associations. Longitudinal studies would better assess the effects of access and availability on the child's level of disability or caregiver burden for DS in Sri Lanka over time. Future research is also necessary for further examination of resource availability and usage for children with DS and their caregivers in the region. Studies should further investigate the barriers preventing resource accessibility for caregivers and their children with DS and better understand the impact of comorbidities for children with DS in Sri Lanka.

CONCLUSION

Overall, higher levels of child disability were associated with higher levels of caregiver burden. Despite moderate levels of child disability, approximately one-third of caregivers reported receiving assistance from external supports, with most caregivers relying on assistance from friends and family.

Future research is warranted to further examine resource availability and usage for children with DS and their caregivers within the region. Larger samples and expansion to other regions within Sri Lanka could further improve understanding of the challenges faced by caregivers and their children with DS, especially given the recent economic challenges that Sri Lanka is facing. Future studies should also seek to understand how terms such as external services, government services, and social supports are interpreted by local populations prior to widespread deployment, through cognitive testing of survey questions in the context of caregiving for children with Down Syndrome in Sri Lanka and/or south Asia.

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The first author can be contacted regarding further analyses of the study data.

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Factors influencing Nutritional Needs of Children with Disabilities in United Arab Emirates: Special Education Teachers vs Parents

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ABSTRACT

Purpose: *The United Nations, in its Sustainable Development Goals, has strongly encouraged countries to promote good eating habits among children. However, children with disabilities are likely to have poor eating habits, resulting in their being underweight or overweight. Using a health literacy model by Nutbeam as a framework, this study has attempted to gain insights into the factors which may impact the understanding and practice of stakeholders regarding nutritional needs of children with disabilities in the United Arab Emirates (UAE).*

Method: *The revised Food and Nutritional Literacy Scale was used to collect data from 149 parents and special education teachers. The collected survey data was analysed by computing the mean and subjecting it to t-test and one- and two-way Analysis of Variances.*

Results: *The results showed that parents and teachers were ambivalent about knowledge and practical skills to promote good eating habits among children with disabilities. Also, variables such as age, participant type, nationality, gender, and awareness of nutritional policy were found to influence awareness about nutritional needs of children with disabilities.*

Conclusion: *It is recommended that policymakers in the UAE expedite public education and professional development by key stakeholders in the area of safe and good nutrition for children with disabilities.*

Key words: *nutrition, parents, special education teachers, policy, United Arab Emirates*

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INTRODUCTION

In 2017, the United Arab Emirates (UAE) government formulated the National Action Plan on Nutrition which aimed to improve the nutritional needs of all persons living in the country (United Arab Emirates Government, 2017, 2021). The policy reiterates the commitment of the government to provide strategic direction for building a healthy society. The effort of the government is in conformity with Goal 2 of the United Nations Sustainable Development Goals, which encourages countries to promote healthy living and develop systems that enhance healthy eating among all children (United Nations, 2015). While this policy is laudable, there are limited discussions on inclusion and steps to promote the nutritional needs of children with disabilities. These children are vulnerable and at risk of malnutrition in many societies including the UAE. Globally, a number of studies have reported that children with disabilities are at risk of being malnourished, overweight, or underweight (Groce et al, 2014; de Vinck-Baroody et al, 2015; Hill et al, 2015; Sedgewick et al, 2020). However, empirical research concerning the level of awareness of nutritional needs of children with disabilities (Groce et al, 2014) among stakeholders is lacking.

According to the World Health Organisation (WHO, 2011), the term “disability” refers to cognitive, physical, and sensory impairments which affect the day-to-day living experience of individuals. It is estimated that 15% of the global population is living with a form of disability (WHO, 2011), whereas in the UAE, disability affects approximately 8% to 10% of the population (Sheik, 2018). However, in all spheres of human development, these individuals are at risk of exclusion and discrimination (Heward, 2017; Opoku et al, 2020; Morgan, 2021). Although laws and policies have been enacted to improve the lives of persons with disabilities, there are lapses in service provision (Gaad, 2011, 2015, 2019). For example, children with disabilities are believed to be receiving inadequate teaching services in classrooms (Gaad, 2011; Sheik, 2018). Additionally, parents encounter challenges (related to accessing appropriate rehabilitation services, stress and limited access to work) in raising children with disabilities (Sheik, 2018; Opoku et al, 2021). While these trends have culminated in government efforts to enhance services, little to no attention has been paid to the nutritional needs of children with disabilities in countries such as the UAE.

Good eating habits are fundamental to the development of children (UNICEF, 2019, 2020). Healthy eating habits can promote growth and immunity to diseases (Ptomey & Wittenbrook, 2015; Food and Agriculture Organisation - FAO, 2018, 2022; UNICEF, 2019). Because of this, international bodies such as the FAO (2022) have begun developing nutritional guidelines which could be adopted to promote good eating habits among children. However, the growing body of literature has reported an intricate relationship between children with disabilities and poor nutrition (de Vinck-Baroody et al, 2015; Hill et al, 2015; Karpur et al 2018; Kamal Nor et al, 2019; Sedgewick et al, 2020; Narzisi et al, 2021). Specifically, children with disabilities are more likely to be overweight or underweight. This could be attributed to poor eating habits, irregular eating patterns, lack of physical activity, inadequate sleep, or genetic disorders (Hill et al, 2015). The consequences of poor eating habits can continue throughout the life of an individual (Sedgewick et al, 2019). It is therefore necessary to address poor eating habits to ensure the optimal development of individuals with disabilities.

Parents and special education teachers (a term used interchangeably as teachers in this study) spend more time with children with disabilities than any other professional or stakeholder involved in their development. While parents are the primary carers for their children with disabilities, they may lack the requisite skills to promote the development of their children (Staples & Diliberto, 2010; Opoku et al, 2021). Moreover, only a few teachers, especially special education teachers, are trained to support the education of children with disabilities (Gaad, 2011; Sheik, 2018). Given the important role of teachers and parents (Staples & Diliberto, 2010), access to nutritional services for children with disabilities is imperative to maintain their health.

Objective

This study aimed to develop insights into the factors which may impact the understanding of stakeholders, especially teachers and special education teachers, about nutritional needs of children with disabilities. Since parents and teachers are important adults in the lives of children with disabilities, it is useful to compare the awareness of teachers on the one hand and parents on the other. The current study was guided by Nutbeam's health literacy model (1998 , 2000) which explains the health information required by individuals in order to maintain healthy lifestyles in society. According to Nutbeam (2008), health literacy is a product of knowledge and practical skills. While knowledge refers to one's cognition and understanding of nutritional needs, practical skills refers to one's ability to apply the acquired knowledge (Nutbeam & Lloyed, 2021).

The study was guided by the following research questions:

1. What is the association between demographic variables (such as gender, age, nationality and participant type) and understanding of the nutritional needs of children with disabilities in the UAE?
2. Will participant type (parents and teachers) moderate the relationship between other background variables and understanding of nutritional needs of children with disabilities in the UAE?

METHOD

Study Setting

Located in West Asia, the UAE comprises a federation of seven Sheikdoms: Abu Dhabi, Ajman, Dubai, Fujairah, Ras Al Khaimah, Sharjah, and Umm Al-Quwain (Gallagher, 2019). The study participants were drawn from Abu Dhabi and Dubai which are the two Emirates with the largest number of persons with disabilities, schools, and rehabilitation centres.

Study Participants

The study participants were parents and special education teachers who were recruited from two of the seven Emirates in the UAE.

The recruitment of participants was guided by the following criteria:

a) Either the parent or special education teacher of one or more children with disabilities,

b) A caregiver actively involved in the development of children with disabilities, or

c) Parent or teacher above the age of 18 years who has the capacity to give consent for participation in the study.

After obtaining ethical approval, rehabilitation centres and special and inclusive schools were contacted for recruitment. The virtual link to the survey was shared with the institutions which agreed to participate in this study. The institutions shared the link with the prospective participants.

Study Tool

The revised Food and Nutritional Literacy Scale (FNLIT) was used for data collection (Doustmohammadian et al, 2017). The tool was chosen because it was developed based on Nutbeam's theory of health literacy (Nutbeam, 1998, 2000) to measure awareness of nutritional needs among children. The instrument has two domains that align with Nutbeam's theory: cognition (understanding) and practical skills (functional, interactive and food choice). The cognition domain measures participants' knowledge of nutrition while the practical skills domain assesses preparedness to promote better eating habits among children with disabilities. While functional skills refers to the implementation of best nutritional practices, interactive skills refers to the ability of participants to educate children with disabilities about healthy foods. Food choice as skill refers to the ability of participants to make healthy food decisions for children with disabilities.

The revised scale consists of 32 items with four sub-scales: understanding (n=9), functional (n-10), interactive (n=6), and food choice (n=7). The items were scored using a five-point Likert scale ranging from '1' (strongly disagree) to '5' (strongly agree). A mean score of '4' was interpreted as more favourable on the sub-scales. The FNLIT yielded the following reliability scores: understanding = 0.88; functional = 0.89; interactive = 0.85; food choice = 0.83.

Data Collection and Analysis

The data was collected between November 2021 and March 2022. Data was then cleaned and transferred to SPSS version 28 for analysis. Data was normally distributed before being used to answer the research questions. To answer research question 1, t-tests and Analysis of Variance (ANOVA) (Pallant, 2020) were computed to understand the association between background variables, knowledge, and practical skills. To answer research question 2, two-way factorial ANOVA (Pallant, 2020) was computed to understand the moderation effect of participant type on knowledge and skills.

Ethics Approval

The study protocols were approved by the United Arab Emirates University (ERS 2021 8430).

RESULTS

A total of 149 participants took part in this study (see Table 1 for demographic composition of study participants). The mean scores showing participants' level of awareness of nutritional needs of children with disabilities were as follows:

understanding, M = 3.89; SD = 0.66; functional skills, M = 4.25; SD = 0.50; interactive skills, M = 3.53; SD = 0.68; and food choice, M = 3.87; SD = 0.57.

Influence of Demographic Variables

T-tests and ANOVAs were computed to understand the impact of demographic variables on the reported measures (see Table 1). T-tests were calculated to assess the difference between two-level demographics and measures. First, the differences between participant type and the three measures were obtained: understanding (t(147) = -4.65, p = 0.001, partial eta squared = 0.78), functional skills (t(147) = -2.40, p = 0.01, partial eta squared = 0.39), and interactive skills (t(147) = -3.23, p = 0.001, partial eta squared = 0.53). In particular, special education teachers were found to be more knowledgeable about their functional skills and more likely to interact with other stakeholders regarding nutritional needs than parents of children with disabilities.

In relation to nationality, differences were found between participants on understanding (t (144) = -1.92, p = 0.05, partial eta squared = 0.33) and interactive (t (144) = -1.96, p = 0.03, partial eta squared = 0.33). The results showed that being UAE citizens could influence teachers' and parents' understanding and interactions regarding food and nutrition of children with disabilities.

On gender, the difference was found only between participants on interactive skills (t (147) = 2.10, p = 0.02, partial eta squared = 0.36). Males who took part in this study were more likely than females to discuss nutritional needs of children with disabilities with others.

Table 1: Influence of Demographic Variables

N = 149	Sample	Understanding	Functional	Interactive	Food Choice
Participant type					
Parent	71 (48%)	3.64 (0.74)	4.14 (0.50)	3.35 (0.77)	3.92 (0.58)
Special education teacher	78 (52%)	4.11 (0.48)	4.34 (0.48)	3.70 (0.53)	3.81 (0.56)
t		-4.65#**	-2.40**	-3.18#**	1.20
Cohen's d		0.78	0.39	0.53	0.20

Nationality					
Emirati	91 (61%)	3.80 (0.69)	4.21 (0.48)	3.44 (0.70)	3.88 (0.60)
Expat	55 (39%)	4.01 (0.59)	4.28 (0.52)	3.66 (0.62)	3.84 (0.54)
t		-1.92*	-0.74	-1.96*	0.40
Cohen's d		0.33	0.13	0.33	0.07
Gender					
Male	26 (17%)	3.92 (0.42)	4.24 (0.50)	3.73 (0.48)	3.78 (0.44)
Female	123 (83%)	3.88 (0.70)	4.25 (0.50)	3.49 (0.70)	3.88 (0.60)
t		0.31	-0.06	2.10#*	-0.86
Cohen's d		0.07	0.01	0.36	0.19
Age					
21-30 years	38 (26%)	3.96 (0.64)	4.21 (0.60)	3.44 (0.65)	3.70 (0.63)
31-40 years	59 (41%)	3.81 (0.68)	4.26 (0.45)	3.54 (0.73)	3.94 (0.55)
41 years and above	49 (33%)	3.90 (0.65)	4.25 (0.47)	3.56 (0.64)	3.90 (0.55)
F		0.64	0.14	0.40	2.28
Partial eta squared		0.009	0.002	0.006	0.03
Nutritional Policy					
Familiar	99 (66%)	3.95 (0.60)	4.28 (0.49)	3.58 (0.61)	3.89 (0.57)
Never heard	45 (34%)	3.80 (0.74)	4.20 (0.51)	3.48 (0.75)	3.84 (0.60)
t		1.26	0.86	0.82	0.53
Cohen's d		0.23	0.16	0.15	0.10
Training in nutrition					
Taken PD	106 (71%)	3.86 (0.67)	4.23 (0.49)	3.48 (0.64)	3.85 (0.57)
No training	37 (29%)	3.99 (0.60)	4.30 (0.53)	3.66 (0.70)	3.89 (0.63)
t		-1.03	-0.73	-1.45	-0.35
Cohen's d		0.20	0.14	0.28	0.07

Moderation Analysis

Two-way factorial ANOVAs were computed to understand whether participant type would moderate the relationship of other demographic variables and measures (see Table 2). The results showed that participant type moderated the relationship between age and functional skills (F (2,146) = 2.92, p = 0.05) and were of moderate effect size. However, a post-hoc comparison using the Tukey HSD test showed a difference between the participants. To elaborate, in the parent group, participants between the age of 31-40 years, and at least 41 years old, better understood their functional role than those who were between the ages of 21-30 years. Similarly, teachers who were between 31-40 years of age, and at least 41 years old, had a better understanding of their functional role than those who were aged between 21-30 years.

Table 2: Effect of Participant Type and other Demographics on Measures

Source	df	MS	F	P	□2
Nationality					
Understanding	1	0.04	0.001	0.97	0.001
Functional	1	4.31	0.18	0.67	0.001
Interactive	1	11.98	0.77	0.38	0.005
Food choice	1	10.79	0.66	0.42	0.005
Gender					
Understanding	1	38.23	1.24	0.27	0.008
Functional	1	0.001	0.001	0.10	0.001
Interactive	1	42.02	2.77	0.10	0.02
Food choice	1	2.72	0.17	0.68	0.001
Age					
Understanding	2	19.34	0.63	0.53	0.009
Functional	2	68.03	2.92	0.05*	0.04
Interactive	2	15.50	1.01	0.37	0.01
Food choice	2	16.87	1.05	0.35	0.02
Nutritional Policy					
Understanding	1	5.99	0.20	0.66	0.001
Functional	1	1.30	0.05	0.82	0.001
Interactive	1	1.56	2.11	0.02*	0.001
Food choice	1	4.50	0.28	0.60	0.002
Training in Nutrition					
Understanding	1	10.37	0.34	0.56	0.002
Functional	1	17.32	0.70	0.41	0.005
Interactive	1	3.23	0.22	0.64	0.002
Food choice	1	13.14	0.80	0.37	0.006

In addition, participant type moderated the relationship between awareness of nutritional policy and interactive skills (1, 145) = 2.11, p = 0.02, small effect size, partial eta squared = 0.001.

DISCUSSION and CONCLUSION

This study was conducted using the health literacy model proposed by Nutbeam (1998, 2000) to develop insights into the nutritional needs of children with disabilities in the UAE. The study found ambivalence of participants regarding their knowledge and practical skills related to understanding the importance of nutritional needs of children with disabilities. Although participants appeared to have high levels of functional skills, they lacked the requisite skills to engage with children with disabilities about best eating practices and selecting or choosing appropriate food for them. Consequently, the participants appeared unsure about knowledge pertaining to the nutritional needs of children with disabilities. This implies that children with disabilities in the UAE may not be receiving proper nutrition. The stakeholders who spend more time with children with disabilities do not have the necessary knowledge and practical skills to promote healthy eating habits among children, affirming previous research findings that show that children with disabilities are susceptible to poor nutrition (Groce et al, 2013, 2014; Sedgewick et al, 2020).

Another trend identified in this study was the moderation of participant type on age and functional skills. In particular, older teachers and parents are more likely to know their role better in promoting the nutritional needs of children with disabilities than younger teachers or parents. This trend could be attributed to the years of experience of parents and teachers who took part in the study. In previous disability education research, it has been reported that the greater the age of teachers or parents, the more they develop requisite skills to support the development of children with disabilities (Teixeira et al, 2018; Yan & Deng, 2019; Opoku et al, 2021, 2022). Having spent more time with children with disabilities, they develop a better understanding about the pivotal role they have to play in promoting the children's nutritional needs. Conversely, younger teachers and parents have limited experience, and therefore may have limited awareness of their role in nutritional education. This finding underscores the need for health policymakers in the UAE to tailor training programmes for parents and teachers concerning their role in nutritional education and the nutritional requirements of children with disabilities.

The findings showed differences between teachers and parents who took part in this study. Teachers appeared to demonstrate more knowledge (understanding) and have better practical skills (functional and interactive ones) concerning the nutritional needs of children with disabilities than parents. This finding suggests that teachers who participated in this study better understand the nutritional needs of children with disabilities, have better insight into their role, and are more likely to interact with others about nutrition than parents. This understanding and insight is probably supported by the training received and the educational attainment of teachers. Indeed, Nutbeam (2008) has emphasised the importance of education in developing cognition and practical skills towards promoting healthy living. It is possible that teachers have either received some formal education or taken time to train themselves about nutrition and disability. Consequently, there is a need for policymakers to expedite public education about nutrition, especially among parents who are raising children with disabilities in the UAE.

There were also differences between participants based on nationality and gender on two sub-scales: interactive and understanding of nutritional needs of children with disabilities. For instance, participants who indicated that they were expats had higher scores on understanding and interactive skills than locals. Moreover, males had higher scores on interactive skills than females. This finding could be attributed to the culture and norms in the UAE. It is undeniable that UAE has a culture (Kargwell, 2012) where people show respect and maintain relationships with both intermediate and nuclear family members (Anadol & Bhery, 2020). There is a strong family bond between people (Anadol & Bhery, 2020), so they are unlikely to engage in discourse on personal issues with those who are not part of the family. This could explain the difference between locals and expats who may have a different cultural orientation. In the same way, in UAE culture females are more reserved and tend to limit their interactions to those in their inner or social circle. Therefore, it is not surprising that males who took part in this study were more likely to be interactive than females. These findings should encourage policymakers to be mindful of cultural practices and differences among people living in the UAE.

The study findings showed the moderation effect of participant type on knowledge of policy and interaction about nutritional needs of children with disabilities. Specifically, the findings revealed that parents or teachers who are exposed to the nutritional policy of UAE are more likely to interact with others about eating habits of children with disabilities. This finding is consistent with other studies which have found a similar effect of knowledge of policy on practices (Forlin et al, 2014; Chao et al, 2016; Ekins et al, 2016; Monteiro et al, 2019). The finding also supports Nutbeam's (1998) hypothesis that health literacy is a product of knowledge and skills. It is useful to postulate that as individuals acquire more knowledge, the greater the likelihood that they would be able to apply the acquired knowledge. In this study, it is apparent that acquisition of knowledge may help teachers and parents to better interact with others about food and nutritional needs of children with disabilities in UAE. Thus, policymakers in the UAE must engage with stakeholders such as teachers and parents about the nutritional policy and the latter's role in the promotion of good eating habits among children with disabilities.

Limitations of the Study

First, the data was collected virtually through schools and rehabilitation centres. As such, study bias must be considered since the data was collected through institutions that may have recruited parents or teachers. Second, the study was conducted in two out of the seven Emirates in the UAE, which limits the generalisability of the findings. Third, like all quantitative studies, there was no opportunity to delve deeper into the experiences of the participants with follow-up interviews. It is recommended that future qualitative studies explore the experiences of parents and teachers towards promoting eating habits among children in the UAE or in other similar contexts.

Strength of the Study

The strength of the study is that this is the first of its kind in the UAE which has attempted to use the health literacy lens (Nutbeam, 1998, 2000) to understand the factors which might influence the nutritional needs of children with disabilities. The findings showed that factors such as age, nationality, gender, and awareness of nutritional policy could influence knowledge and skills of teachers and parents towards promoting healthy eating habits among children with disabilities in the UAE. However, knowledge and skills remain low among the participants; this calls for deliberate efforts by policymakers to create awareness about the nutritional needs of children with disabilities (Groce et al, 2014; Hill et al, 2015; Sedgewick et al, 2020). This could be conducted through various social media platforms and television programmes targeting stakeholders such as parents and teachers who are involved in the development of children with disabilities. In addition, professional development programmes could be organised for parents and teachers to raise awareness about the policies, nutritional needs, and ways to promote healthy eating habits among children with disabilities in the UAE.

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REVIEWS

DISABILITY INCLUSIVE EDUCATION IN BANGLADESH

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ABSTRACT

This paper is aimed at starting a debate on disability and the inclusion of children with disabilities in the public school system under the Primary Education Development Programme 4 in Bangladesh. The analysis is based on a strategic Design Note developed by USAID, with the author as consultant, and is guided by the rights perspective of the Convention on the Rights of Persons with Disabilities (CRPD, 2006), notably Article 24 on inclusive education, and the Sustainable Development Goals (SDG4) (UN, 2015).

Extensive consultations were carried out in the course of developing the Design Note. Discussions and workshops were conducted with government agencies and stakeholders, notably civil society, organisations of persons with disabilities, the donor community and human rights organisations.

Mainstreaming disability into public schooling requires a reform in the primary education system. It is necessary in order to identify, enrol, maintain and retain learners with disabilities throughout the primary cycle.

Key actions entail creating an enabling environment and focusing on overcoming attitudinal barriers in the local community and school authority; improving school infrastructure; strengthening inclusion practises, notably with adapted pedagogy, as well as consolidating policy framework, coordination and governance, in addition to empowering users. These steps will enhance targeting and screening of a wide range of children with disabilities in school as well as out of school. By contributing to improved learning outcomes, fulfilling the right to education (Article 24 of CRPD) and achieving Sustainable Development Goals (SDG4), this could be a model of good practice for other countries in the region.

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Key words: Bangladesh; Disability; Inclusive Education; Convention on the Rights of Persons with Disabilities (CRPD); Sustainable Development Goals (SDGs)

INTRODUCTION

According to the Constitution of Bangladesh (Article 17, a, b, c) the right to education is guaranteed by the State and measures are taken to protect human rights on the grounds of disability (Constitute Project, 2017). The Ministry of Primary and Mass Education is mandated to provide primary educational services to all children, while secondary education is provided by the Ministry of Education. There are different forms of mainstream schooling for learners with disabilities who have mild educational needs. For learners with severe impairments, the Ministry of Social Welfare provides educational and rehabilitation services through its varied special education institutions - special schools and vocational training centres that serve over 21,000 learners with disabilities, including 1500 students with developmental disabilities - along with attempts to mainstream education within the public schooling system.

Primary education and vocational training for 1,200 children is provided in 12 special schools - of which 5 are for children with visual impairments, 5 for children who are deaf, and there are 2 centres for children with physical disabilities that provide vocational training. Residential schooling is available in the main cities for under a third of these children. Jatiyo Protibondhi Unnayan Foundation, a semi-governmental organisation established by the Society Act, provides special schooling for 18,000 children with disabilities (of various types) in 62 schools, as well as for 1500 students with neuro-developmental disabilities, namely autism, in 11 schools. The Autism and Neurodevelopmental Disabilities community is active and provides schooling to a considerable number of students with developmental disabilities, along with a growing mainstreamed education service.

Despite Bangladesh's achievements in the education sector, with the Net Enrolment Rate (NER) reaching 97.9% for primary education in 2015 and gender parity attained (Annual Sector Performance Report- ASPR, 2016), many challenges remain for achieving inclusive and equitable quality education and lifelong learning opportunities for all, as set out in the Sustainable Development Goals (SDGs), notably SDG4 (UN, 2015). The number of out-of-school children in the 6-10 year age group remains high, at around 17% with a repetition rate of

6% (ASPR, 2016) and cycle dropped-out rate of around 17.5% (BBS/SID, 2015). This group of out- of-school children and drop-outs or class-repeaters includes a variety of vulnerable children, particularly those with disabilities. Among them are a number of Rohingya children with disabilities who have taken refuge in Bangladesh from violence across the border in Myanmar. Currently, most learners with disabilities who are enrolled in primary schools are those with mild disabilities and are significantly at lower rates of national and international estimates. According to the Annual Sector Performance Report (2016), the total number of students with disabilities enrolled in primary education in mainstream schools is reportedly 67,793, but there is little known about their academic profile, performance, or the overall conditions of the school. That said, upon discussion with stakeholders and based on the analysis of the situation by the Campaign for Popular Education (CAMPE, 2011, 2015, 2016), it is clear that attitudes towards children with disabilities are changing from charity to societal responsibility, and there is recognition of the need to move away from teacher-centred instruction to learner-centred pedagogy for all children. Equal rights of children with disabilities to education, however, can be further enhanced. Three areas of action can be looked at in this regard: awareness-raising campaigns, namely concerning attitudes (CSID/Disability KaR, 2005; Das, 2011, World Bank, 2013; EU/Leonard Cheshire Disability, 2014), advocacy for the identification and removal of barriers, and legal reforms.

It should be pointed out that data on disability in Bangladesh is limited and there are different estimates of numbers of persons with disabilities, constituting 0.9% - 1.4% (BBS, 2015), but all are far below internationally agreed rates. A survey conducted by the Ministry of Social Welfare in 2013 put the number of persons with disabilities in Bangladesh at 1,526013, with nearly a quarter of a million persons having developmental disabilities. The disability prevalence among children in Bangladesh is estimated to be between 1.4 and 17.5%. This means that there are 805,000 - 10 million children with disabilities in the country (ASPR, 2017). The low disability figures in Bangladesh may be due to different methods of data collection and different definitions of what constitutes a disability. In fact, the Household Income and Expenditure Survey (HIES) 2010 included an innovative self-identifying module on disability that was based on the Washington Group Child Functioning module. However, discussions with stakeholders revealed that limited training provided to data collectors may be responsible for the low reported number of persons with disabilities. Data collectors were better able to report moderate or severe disabilities. There was also a tendency for parents to not report certain disabilities (i.e., intellectual) due to the family's standing in the community.

The policy framework regulating this sector in Bangladesh is quite extensive and, to a large extent, in line with international standards, namely the Convention on the Rights of the Child (CRC, 1989) and Convention on the Rights of Persons with Disabilities (CRPD, 2006). As such, there are a number of comprehensive legal provisions enacted, such as the Disability Act (Disabled Person's Rights and Protection Act, 2013) as well as the innovative Neurodevelopmental Disabled Persons' Protection and Trust Act (2013) (ICI/Shuchona, 2016). In terms of education, the document of reference is the National Education Policy (NEP, 2010) which makes mention of learners with disabilities with emphasis on special education, but further regulations/orders are needed for supporting learners with disabilities.

Despite such a comprehensive legal framework, there are notable challenges in the implementation of the Disability Inclusive Education policy and practices in the areas of specialised pedagogy including curriculum (textbooks/teaching and learning materials, exams) as well as teacher education and training and infrastructure (EU/Leonard Cheshire Disability, 2014). There are also foundational challenges in targeting, screening and reaching out to children with disabilities. The latter is pertinent to policy, programme and strategy respectively.

Currently, the primary education curriculum is hardly adapted (UNESCO, 2004; Das, 2011; JICA, 2013; EU/Leonard Cheshire Disability, 2014; IBE-UNESCO, 2016) and serves mainly learners without disabilities or those with mild disabilities. Yet, there exist organised structures designated to develop a curriculum and oversee their quality and standards, such as the National Academy for Primary Education and the National Curriculum and Textbook Board. Progress continues to be made in teachers' skills development, with a number of teacher education programmes being conducted by the special education department at the Institute of Education and Research of Dhaka University and Proyash Institute of Special Education and Research under Bangladesh University of Professionals. These institutes offer different degrees and diplomas in special education. There are other training structures such as the Upazila Resource Centre at the Upazila level, as well as civil society teacher education skills development providers such as the Centre for Disability in Development, Bangladesh Rural Advancement

Committee, and others. It is important that skilled graduates from such institutions be given priority in recruitment and, for the time being, be placed in schools where children with disabilities are enrolled.

Currently, there are more children with disabilities enrolled in mainstream education than in special education settings. It can be argued that the needs of teacher education for skills development are dependent on the needs of learners with disabilities. There are 3 broad categories of needs which include:

- Learners with mild disabilities who can benefit from mainstream schooling with very little accommodation, such as the provision of simple devices (i.e., glasses, magnifier, larger print and hearing aids for students with poor vision and hearing difficulties) or by making school facilities more accessible. Currently, learners with mild disabilities can be found in mainstream schools and there is evidence of successful inclusion (ASPR, 2017). That said, this analysis aims at increasing their number significantly by providing accurate data on those who are in schools, as well as reaching out to learners with mild disabilities among out-of-school children;
- Learners with moderate disabilities who can benefit from mainstream schooling but require significant rehabilitation and accessibility standards including removal of barriers. This may include those who use a wheelchair or those requiring adaptation in the classroom as well as accessible toilets. It also includes those requiring physiotherapy and/or speech therapy, such as children with cerebral palsy; however teaching staff require sound knowledge to work with these children;
- Learners with severe disabilities who can benefit from mainstream schooling but require major changes in pedagogy. This primarily includes three categories of learners with disabilities: learners who are blind, learners who are deaf and learners with developmental disabilities (the latter may also include those with learning or intellectual disabilities or with autism).

At present this latter category of children with disabilities is being taught in special schools/institutions. Under different stages of the Primary Education Development Programme (PEDP) 1- 4, UNICEF and UNESCO with support from a number of donor partners, notably USAID, have been actively involved in improving the quality and learning outcomes, the decentralisation and the reduction of disparities in the education sector (PEDP3, 2015). As such, the

Programme addressed barriers to inclusion and focused on making schools more disability-friendly while trying to reduce gender discrimination. This emphasis on equity and quality of learning outcomes and their mutual role in achieving Sustainable Development Goals (SDG4) is demonstrated in how disability inclusive education mutually contributes to achieving targets under Primary Education Development Programme 4 and subsequently the Sustainable Development Goals (SDG4).

Given the heightened level of debate and the political will in Bangladesh to advance the cause of children with disabilities, it is time to adhere to a rights perspective to children's education based on the social model of disability (Barnes and Sheldon, 2010; WHO, 2011).Within such a philosophy, all children of primary school age are included in mainstream schooling and provided with the support they need for quality education outcomes (Ainscow et al, 2011; Barton, 2013). This is in line with Article 24 of the CRPD which requires duty bearers to ensure that children with disabilities are not excluded from free and compulsory inclusive primary education and are provided with accommodation and effective individualised support that maximises academic and social development, consistent with the goal of full inclusion. It also requires qualified and trained teachers, a specialised pedagogy and modified school infrastructure (CRPD, 2006).

The Reality of Inclusion into Mainstream Primary Education: Some Prerequisites for Learners with Disabilities

Despite noticeable progress in primary education outcomes in Bangladesh, universal access is still hampered by out-of-school children and drop-outs, both of which include a large number of children with disabilities (Mizunoya et al, 2016). Given the hard living conditions for many of them and the limited facilities and infrastructure at schools, as well as the limited number of trained teachers, the prospect for effective inclusion can be challenging. Yet, there are continued efforts to make inclusion a reality and some prerequisites towards that end are as follows:

Identification, Screening and Classification of Disabilities

To determine if there is a disability, the person needs to be screened, identified, and classified. This could be a complex process when tools and trained personnel are limited and specialised facilities are required which are currently provided at the district level by a Chief Medical Officer. The medical report issued by the Upazila Health Complex or Government Hospital is necessary for a variety of purposes, such as for acquiring an identity card or stipend for children with disabilities (according to Law 39/2013). The official 'diagnosis' of disability qualifies persons with disabilities to receive services such as education and hence to be registered in the system.

The scope of coverage, extent and quality of existing classification services are unclear, but the Ministry of Health and Family Welfare has started a pilot training project for health personnel (mainly doctors and health workers) in 7 selected divisional Upazilas, for screening and early detection of autism and neurodevelopmental disabilities. Currently, a One-Stop-Service Centre is being pioneered with the support of the World Bank and this would resolve many challenges facing persons with disabilities in terms of information, referral and access to services needed for their rehabilitation, development and education. These 103 district level centres provide comprehensive lifecycle services including assessment and therapy (i.e., physiotherapy, speech, occupational therapy and counselling) and referrals, all of which are disseminated by the media.

While classification does not necessarily help the child to be and feel included and supported, many children need rehabilitation services and assistive devices; however their inclusion in school should not be conditional on this.

Rehabilitation Needs of Learners with Disabilities

To make effective use of education, many learners with disabilities would require to be rehabilitated in the first place. This may include the use of assistive devices such as glasses, hearing aids or crutches, therapy or treatment. Many learners with disabilities can follow mainstream schooling with little adaptation of pedagogy or school infrastructure. Equally, other learners with moderate disabilities could follow mainstream pedagogy, but require major rehabilitation support services including, for instance, artificial limbs, wheelchairs, physiotherapy or speech therapy. Such essential services can contribute to making education more effective and could lead to quality learning outcomes for learners with disabilities and contribute to achieving universal access to education. For learners with severe disabilities, a reform in pedagogy together with a shift in mindset is needed, to make it more specialised to their educational needs.

Currently, rehabilitation services are provided by the Ministry of Social Welfare and the Ministry of Health and Family Welfare, as well as by NGOs such as the Bangladesh Rural Advancement Committee's Limb and Brace Fitting Centre, Centre for the Rehabilitation of the Paralysed and Centre for Disability in Development. Other rehabilitation services are provided by Jatiyo Protibondhi Unnayan Foundation/Ministry of Social Welfare and 103 One-Stop-Service Centres at district level throughout the country.

For children with disabilities in school to qualify for orthopaedic services, they need to apply directly through the School Management Committee. There is a specific budget allocated for that purpose (50,000TK per Upazila – equivalent to US$ 600). This small amount covers a limited number of children who need secondary assistive devices. Among challenges to rural users are maintaining devices, repair issues and the need for regular replacement due to children growing rapidly. Such challenges may be overcome by local solutions such as Appropriate Paper Technology which is a cost-effective local-based technology that provides supplementary solutions for various rehabilitation needs of children with disabilities, mainly concerning creative alternatives to design, maintenance and spare parts (Hinchcliffe, 2007; Westmacott, 2015). Although Appropriate Paper Technology has been introduced in Bangladesh, its application remains on a limited scale.

Given the rural context of many local communities in Bangladesh, Community Based Rehabilitation may provide an innovative solution for reaching children with disabilities in remote settings and providing them with quality support services related to inclusive education. This structure has the potential of providing complementary inclusive education services such as home schooling. Community Based Rehabilitation is a strategy for community development focusing on rehabilitation, equal opportunities and inclusion of persons with disabilities. It can be considered as a comprehensive approach in supporting the inclusion of learners with disabilities in schools. Within Community Based Rehabilitation, both the community and individuals are considered as equal partners in the rehabilitation process. The needs, priorities and resources of the local community and that of persons with disabilities are defined locally. The key words in Community Based Rehabilitation are: awareness-raising to overcome attitudinal barriers; capacity building of the local community as well as participation and referral services (Turmusani et al, 2002; Hartley, 2006; WHO, 2010; Turmusani, 2017).

According to the Community Based Rehabilitation Matrix, there are five components that work together under this strategy. These are: inclusive education, livelihood, health, social and empowerment. Examples of interplay between components include: how health component (i.e., assistive devices) contributes to the rehabilitation and preparedness of children with disability to receive effective education or how empowerment component helps in raising awareness and advocacy on rights of children with disabilities to inclusive education.

The Community Based Rehabilitation approach is more in line with actual inclusion and it works because Community Based Rehabilitation works with the community as a whole as well as the individual child. That tends to include collaboration with local schools.

The Community Based Rehabilitation approach is already in operation on a smaller scale in rural Bangladesh. For example, under the Disabled Rehabilitation and Research Association's health and inclusive education programmes, 200 Community Based Rehabilitation workers in 30 districts are trained to ensure quality services (DRRA, 2017).

Research Agenda, Disability Data and Evidence-Based Knowledge

Despite a growing capability in education sector data management in Bangladesh, evidence-based knowledge on the situation of learners with disabilities is still limited regarding the size of this population as well as the reality of their school inclusion, learning outcomes and community life. Data on disability in general is not accurate and there are different estimates of persons with disabilities, but all are far below international rates constituting 0.9% - 1.4% (BBS/SID, 2015; BBS, 2016). The low figures for prevalence of disability in Bangladesh may be due to using different methods of data collection and different definitions of what constitutes a disability.

Pertinent to this discussion is the importance of strengthening comparable data at all levels (mezzo, micro and macro). The Washington Group on Disability Statistics has the potential to provide such comparable data and can be linked to a thematic survey and national census accordingly (Altman, 2016). Although known for its simple application and accuracy, the Washington Group requires that considerable training be provided to data collectors on disability definitions and identification of invisible disabilities. The short set of questions of Washington Group may be appropriate for census data. These questions concern difficulties the person experiences in doing certain activities including: difficulties in seeing even if wearing glasses; difficulties in hearing even if wearing hearing aid; difficulties in walking or climbing steps; difficulties in remembering or concentrating; difficulties with self-care; difficulties in communication (understanding or being understood). These are measured on a scale of effort ranging from ‘ability to perform the task’ to ‘complete difficulty’.

An example of a well-running database can be seen in the Education Management Information System – which is a form of administrative data collection used to monitor students and schools. For effective management, a national database can be created on diverse children and their wide range of educational needs from line ministries. Data on disability can be established concerning the rehabilitation needs of children with disabilities, accessibility standards in schools, public services and roads, accessible transport, accessible Information and Communication Technology, etc. It is important that all databases be linked to a central system as well as to the Bangladesh Bureau of Statistics and Ministry of Planning.

Upazila Resource Centre

With one of the largest primary education systems in the world, a certain level of centralisation is necessary to ensure standards, competence and accountability. Yet, the learning process takes place at the schools’ level in small local communities. To bridge the gap between different layers of authorities from Directorate of Primary Education at the central level to School Management Committee at the school level, a linking chain has to be found where information and competence flow smoothly from one structure to another. This role is assumed by the Upazila Resource Centre, a structure at sub-district level representing the nearest education authority to schools.

In addition to its supervisory role, the Upazila Resource Centre plays a vital role in transferring knowledge and skills to schools. As such, its role in building competence in disability inclusive education is crucial. Its officers can be trained on thematic disability inclusive education and may serve as specialists in the subject area when necessary. They can provide training including sub-cluster training to mainstream teachers/principals, monitor their performance and report information to the Directorate of Primary Education through the Education Management Information System.

An area for supporting teachers who have learners with disabilities in their classroom is the management of an Individual Education Plan, including its development and implementation. An Individual Education Plan is based on specialised teaching and is linked to adapted pedagogy which includes the curriculum and teaching and learning materials. It measures the capacity and potential of learners with disabilities for achieving education goals set out in the curriculum in a way comparable to their peers, by using adapted methods of learning.

Typically, the Individual Education Plan assesses the level of existing competence for learning the new competence, identifies available and required resources (i.e., adapted teaching and learning materials) to help learners acquire the new skill and determines an appropriate method of skill acquisition and a timeframe to make this happen. Yet, when it comes to learners with disabilities, tasks such as 'listening' have a prerequisite of being able to hear in the first place. For those who are hard of hearing or deaf this means using Bangladeshi sign language in order to develop this competence. Methods of skill acquisition may include dividing the competence into components or smaller steps to facilitate its acquisition, extra time for repetition or using specific teaching and learning materials such as geospatial forms.

This is not an impairment focused approach, but rather a recognition that in inclusive education the school system and curriculum are redesigned based on the needs of ALL learners, with and without special needs (Hehir et al, 2016). In order to accommodate all learners with disabilities, a reform in the system is needed and that requires specialised pedagogy for learners with more substantial educational needs, such as those with severe disabilities. This is not a medical categorisation of impairment, but rather a pragmatic understanding of the pedagogical needs of this group that would otherwise be forgotten if not made explicit. It may be especially true for a group of children with more complex neurodevelopment disabilities which require specific attention and a clear diagnosis made by a multidisciplinary team, and not only by a medical doctor. Therefore, while all types and degrees of disabilities are targeted in this Design Note, those with significant educational support are singled out due to their need for a specialised and adapted pedagogy.

Design Note’s Objectives and Description of Activities

Given the progressive nature of disability inclusive education, the Design Note’s objectives are numerous but they focus on improved quality of learning outcomes and consequently on social participation and inclusion (Turmusani and Fougeyrollas, 2018).This is to recognise that the child has the right to be included FIRST. Social participation is a prerequisite for learning effectively and reaching learning outcomes.

The first objective of the Design Note concerns significantly increasing the number of children with disabilities who are receiving primary education in Bangladesh, with a target of 60% (equal to 600,000 out of an estimated 1 million school age children) achieved by the end of the Primary Education Development Programme 4.This means increasing the number of learners with disabilities by adding 2 students per school annually. This attainable target aims at increasing access of children with disabilities by adding fewer than 10 children per school over a period of 5 years (lifecycle of the project). The ultimate goal is to achieve 100% coverage rate by enrolling all estimated 1 million children with disabilities by 2030 in line with SDGs agenda.

Other objectives include: incorporating appropriate disability inclusive education modules into teacher education programmes for teachers of mainstream schools; adapting primary education curriculum in all subject areas including Bangla and Math; and making text books and teaching and learning materials available in Braille, sign language and simplified texts for learning difficulties, as well as adapting assessments and exams, and making the school environment disability-friendly. Specifically, this includes accessible premises such as the entrance, playground and interior design of classrooms, as well as accessible water, sanitation and hygiene facilities, including gender-segregated toilets and drinking water.

There are a wide range of activities which could be proposed to meet the above objectives. However, the success of proposed action is largely determined by the environment within which it operates. An *enabling environment* for education along with favourable conditions is likely to help in the implementation of activities. This includes, for example, the government’s commitment and political will, the firm engagement of development partners in supporting the sector, and the active involvement of the local community, notably organisations of persons with disabilities. A good strategy towards that end is one that focuses on *identification* *and removal of barriers* (i.e., obstacles related to accessibility, attitudinal barriers or discriminatory policy and practices…), provides individualised educational support to learners and one that aims at empowering users to fulfil their rights.

Target Groups

Given the vastness of Bangladesh's education system, target groups can include a wide range of constituents, but their two main categories include:

Rights holders - These are the primary constituents of rights and they have entitlements by the power of the law. They include:

- Primary beneficiaries - learners across the disability spectrum.
- Secondary beneficiaries – peers, teachers, parents, organisations of persons with disabilities, local communities,

Duty bearers - They are typically state agencies that provide services mandated by laws, but this may also include non-state service providers. They include:

- Line ministries - primarily Ministry of Primary and Mass Education / Directorate of Primary Education, Ministry of Education, Ministry of Social Welfare, Ministry of Health and Family Welfare, Ministry of Women and Children Affairs, Ministry of Labour.
- Other service providers - such as Bangladesh Rural Advancement Committee, Campaign for Popular Education and other NGOs

Components of Disability Inclusive Primary Education

Based on international standards, namely CRPD, the following are suggested components for Disability Inclusive Education in Bangladesh under PEDP4. For the sustainability of action, it is important that these are implemented under a sector-wide approach with the Government of Bangladesh taking the leading role and organisations of persons with disabilities actively involved as partners and advisors.

a) Increasing access of children with disabilities to mainstream public education through improving their reception at schools. This includes, for example, simplification of procedures of registration and exemption of fees.

b) Elimination of barriers linked to access to education such as child labour (MLE, 2010, 2013) and early marriage of girls (UNICEF, 2015).

c) Reinforcing the capacity of the Cell on Inclusive Education, operating under the Directorate of Primary Education at the Ministry of Primary and Mass Education. As a policy planning unit, the role of the Cell on Inclusive Education can be strengthened in overseeing regulations, coordination and monitoring, as well as in providing technical support for disability inclusion to different divisions of the Directorate of Primary Education.

d) Skills development of teachers.

e) Adapted curriculum, textbooks, teaching and learning materials and exams.

f) Strengthening the existing policy framework including monitoring the implementation of article 24 of CRPD.

g) Reaching out to children with disabilities who are out of the school system through Community Based Rehabilitation. A conducive approach for reaching the out-of-school children may be characterised by following strategic focus: being preventive in nature; proactive in focus: referral based and rights proclaimed.

In Practical Terms

To conclude, pending the full implementation of the disability-inclusive education Design Note into the Directorate of Primary Education under Primary Education Development Programme 4, it is important to continue serving the existing population of learners with disabilities who are found in schools. It is equally important to widen opportunities for increasing universal access (Sustainable Development Goals - SDG4) to other children with less educational needs (mild/moderate disabilities) to enter and/or re-enter schools, given that their accommodation in school is often cost-free. For this to happen, changes may be necessary at different levels:

- At policy level - until relevant policy on ‘targeting’ is elaborated or updated, regulations (i.e., circulars, orders, etc.) issued by the Ministry of Primary and Mass Education/Directorate of Primary Education concerning the right to inclusive education of all children, including those with disabilities, can be effective and may open up opportunities for the inclusion of this marginalised group.
- Attitudes of teachers and the Head teacher - a positive attitude on the part of teachers and Head teachers towards disability and disablement can greatly

ease the learning process of children with disabilities and help in their inclusion. An introductory teacher education guide on how to identify and include learners with disabilities into mainstream classrooms can be useful as it would provide needed guidance on the issue until the curriculum/ textbooks/teaching and learning materials /exams are adequately revised and/or developed.

- School infrastructure - although water, sanitation and hygiene are being made accessible under the Primary Education Development Programme 4, it is important to ensure that accessibility standards are being respected in the design and execution of work according to the National Building Code (NBC, 2008). That said, learners with disabilities require more than accessible water, sanitation and hygiene facilities. Schools with disability-friendly infrastructure also include: accessible buildings (i.e., secured ramps to the entrance of school and classroom/facilities); interior design of classrooms and safe playgrounds. Much of the above alterations can be limited and may cost very little, especially if included in the universal design (CHRC, 2007) of new facilities. For example, a library on the second floor requiring a lift or a ramp can be moved down to the first floor, and this would enable learners with mobility challenges to access facilities more easily.
- The family and local community - bringing about social change regarding disability and children with disabilities requires collective effort by everyone, including the individual, family and local community. As a main stakeholder, family collaboration in the learning process cannot be overemphasised and so too is the collaboration of the local community where schooling and learning process takes place. It is important that attitude change happens at grass-roots level and within the community so that action is sustainable.
- Strengthening linkages with line ministries and other stakeholders and setting up coordination and collaboration mechanisms to carry out certain activities proposed in the Design Note, including that of identification, assessment, rehabilitation and education of children with disabilities. For example, collaboration between stakeholders for the provision of complementary rehabilitation services such as assistive devices.
- Enhancing the capacity of the Cell on Inclusive Education at the Directorate of Primary Education - despite a competent workforce, currently there are no staff members appointed as technical reference on disability issues. This may

hinder the ability of this unit to mainstream disability into its own inclusive education programme as well as to different divisions of the Directorate of Primary Education, not least concerning its role as policy planner, monitor or provider of technical support to decentralised structures in districts or at the Upazila level. Training and skills development on disability inclusive education and oversight issues is therefore necessary and can best be embedded in larger inclusive education training programmes.

- Improving evidence and knowledge base - creating a unified national database (which includes thematic issues such as disability and rehabilitation) within the Education Management Information System and making effective use of Information and Communication Technology in education for enhanced pedagogy as well as for data management, monitoring and reporting. It is important to link the identification of children with disabilities to the monitoring system and as such collect disaggregated data on children with disabilities and key indicators of their school inclusion. The Washington Group on Disability Statistics has the potential to provide such comparable data and can be used among good research practices.

The continued leadership of USAID (USAID, 2017) in promoting the rights of learners with disabilities for quality and equitable education is highly commendable but remains limited. A sector-wide approach with Government of Bangladesh taking the leading role and organisations of persons with disabilities actively involved as partners and advisors may lead to fruitful results. Given the context, it is recommended that the community of donors (i.e., development partners) continue promoting the inclusion of learners with disabilities in primary education in Bangladesh under their respective sponsored/supported components of Primary Education Development Programme 4, following a twin-track approach to include mainstreamed interventions across Primary Education Development Programme 4 as well as targeted projects. A focus on empowering organisations of persons with disabilities and enhancing their role in bringing about social change and reaching out-of-school children is an area that could be explored further.

To raise awareness on the issue, create energy and maintain momentum, it is important to increase the visibility of persons with disabilities who are recruited in the primary education system at all levels, from schools up to key positions at the Ministry of Primary and Mass Education and Directorate of Primary Education.

The continued dialogue between development partners, government and stakeholders through disparity working groups, debates and sharing successful models of good practices, give an opportunity to influence policy and practices. For effective dialogue, users' voice (learners with disabilities) can add richness and insights to the conversation and enhance its quality of inclusiveness.

CONCLUSION

While there are different levels of school integration, it is important to note that schools for ALL help greatly in overcoming the exclusion of marginalised groups, but they do not necessarily guarantee the inclusion of learners with disabilities. Disability inclusion requires a reform in the school system to make it geared towards the specific needs of learners with disabilities (improved capacity to identify, enrol, maintain and retain learners with disabilities throughout the primary cycle).

It is important to recognise that the provision of quality education for learners with disabilities requires the recognition of disability as a cross-cutting issue throughout the Primary Education Development Programme 4 components and sub-components including areas such as gender, language, education in emergency, water, sanitation and hygiene, school infrastructure, teacher education, curriculum development and decentralised practices. It has much to do with the quality and efficiency of educational services as well as governance and management structure of the primary education system. Unlike other marginalised groups (i.e., children living in poverty or in areas hard to reach) whose inclusion into the education system requires minimum changes, learners with disabilities would require a reform in the system to become more accommodating to their educational needs. A shift in perspectives is therefore needed towards learner-centred pedagogy and this involves investment in infrastructure, skills and knowledge and inclusion practices. In fact, inclusive pedagogy can be beneficial to everyone in the classroom and not only to learners with disabilities. For example, working in small groups is likely to increase the participation and involvement of all students in various classroom activities. Equally, sign language can be acquired by all learners and can be used effectively as a communication tool. All this ought to take place under a human rights framework, being guided by the Convention on the Rights of Persons with Disabilities (CRPD) and other international treaties in which Bangladesh has ratified and harmonised its national laws accordingly. CRPD (Article 24) is therefore the point of reference against which to measure progress targeting inclusive education for learners with disabilities.

In line with an inclusive approach to primary education, all types and degrees of disabilities are included in this Design Note. The focus is placed on changes that need to happen in the education system that will help improve education outcomes for the full range of children with disabilities. For example, ensuring education spaces adhere to building accessibility standards (for any and all children with disabilities ranging from mild to severe); facilitating the learning and use of Bangladeshi Sign Language (so that hearing and all children within the range of mild to severe hearing disabilities can benefit); integrating 'differentiated learning' into core teacher training programmes so that children with and without learning disabilities can benefit.

To include some or all of the above groups into mainstream classroom education, a reform in the primary education system is needed, starting by creating an enabling environment and focusing on overcoming attitudinal barriers in the local community and school authority, improving school infrastructure and enhancing inclusion practices including pedagogy, policy, governance, and by changing attitudes. Together this may help improve learning outcomes, fulfil the right to education and achieve Sustainable Development Goals (SDG4).

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BRIEF REPORTS

Technology-Assisted Early Disability Identification and Monitoring in Children: A Model for Middle- and Low-Income Countries

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ABSTRACT

The initial 1000 days after birth is the period of major brain development. It is found that children with various neurological, musculoskeletal and developmental disorders and those "at high risk of disability" show early identifiable signs and symptoms. If an appropriate level of intervention is initiated at an early age, when neuroplasticity is at the maximum, positive changes could be made to a great extent in their overall development. Recent advances in the technology could be used for early screening and monitoring of children. In this brief report the authors discuss a technology-assisted early disability identification and monitoring system which is ideal for middle- and low-income countries.

Key words: *disability, early identification, early intervention, assistive technology, children*

INTRODUCTION

Early identification of children with disabilities and "at high risk of disability" is of great significance during gestation and in the first 3 years after they are born. Neuroplasticity of the brain is higher during the initial 1000 days after birth, hence starting early intervention strategies during this critical period in children with developmental problems has shown better clinical outcomes.

Developmental delay is a delay in achieving age-appropriate development compared with typically developing children in cognitive, motor, speech,

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language, and social domains (Abo El Elella et al, 2017). In India, around 10% of children experience developmental delays with a risk of disability (Shekhawat et al, 2022). It is reported that only around 50% of developmental problems among children are detected before the age of 5 years (Singh et al, 2017). Developmental disorders such as Autism Spectrum Disorders, hearing impairment, visual impairment, motor impairment, intellectual impairment, and behavioural conditions can be detected in the initial years of a child (Lipkin et al, 2020). Evidence from observational studies shows that preterm delivery is one of the leading causes of various neurodevelopmental disabilities in children. Visual, hearing, cognitive, and motor disabilities are frequently seen in preterm babies. Hence, close monitoring of these children for developmental milestone achievement delays and behavioural changes in their initial years of childhood is recommended(Scharf et al, 2016). Experts recommend screening of children aged 18 to 24 months for early identification and management of Autism Spectrum Disorder (ASD) (Sanchack & Thomas, 2016). Cerebral Palsy (CP) is one of the most common physical disabilities among children and is usually diagnosed after 2 years of age. The delay in diagnosis has negative consequences in the development of these children (Byrne et al, 2017). A follow-up programme conducted in the United States of America among babies admitted in neonatal intensive care units showed that early identification and intervention in cerebral palsy is feasible(Byrne et al, 2017). Spinal Muscular Atrophy (SMA) is the most common neurodegenerative disease in childhood, and early identification and intervention during infancy show substantial improvement in neurodevelopmental outcomes (Vill et al, 2021).

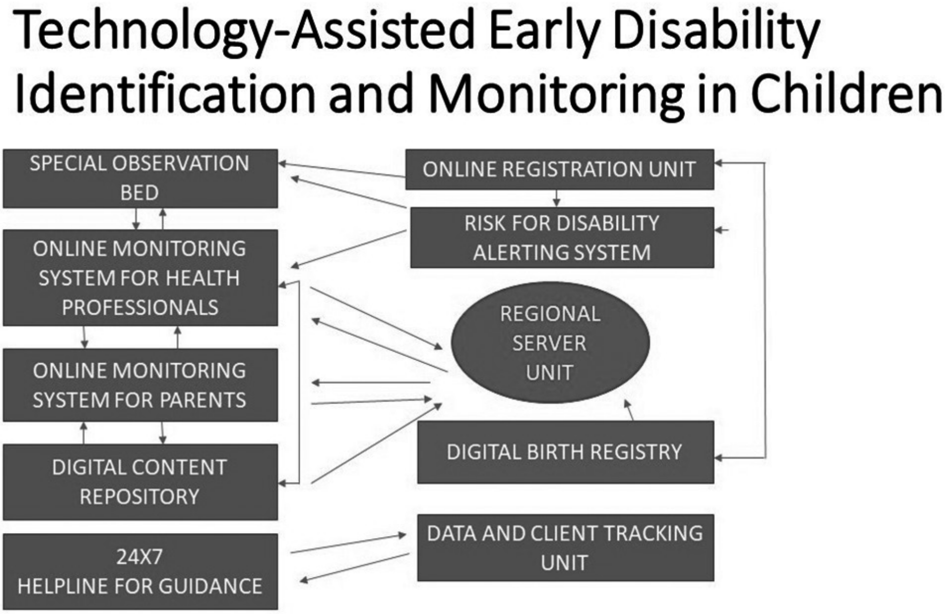
Developmental Monitoring (DM) is a dynamic and ongoing process of gathering information regarding the developments of children by health professionals and making clinical judgments based on it and on personal experience. Developmental Screening (DS) is a more formal and structured evaluation using validated developmental screening tools. Growing evidence recommends using both DM and DS in tandem for better clinical outcomes (Barger et al, 2018; Barger et al, 2022). However, such a DM- and DS-system is currently not integrated into primary healthcare in low- and middle-income countries. Thus, keen observation and monitoring of children for any developmental problems by parents, caregivers, and health professionals are of great relevance. Using a parent-completed screening questionnaire has been found to be relatively accurate, economical, and time saving (Singh et al, 2017). However, such text-based screening tools are considered to be passive. Telephone-based developmental screening for developmental problem detection seems promising (Nelson et al, 2019), although an e-screening tool for developmental delay with rich multimedia content was found to be more engaging and easily comprehensible compared with routine text-based screening tools (Cheng et al, 2017). It has been reported that by restricting screening to disabilities that can be diagnosed at pre-school age, a large segment of children who are at risk for developing disabilities is being missed (Masefield et al, 2021). Even in countries like the United States of America, where well-established early identification and screening is available and 85% of development monitoring agencies are involved in developmental screening for ASD, only 39% are conducting diagnostic assessment before the age of 3 years (Williams et al, 2021). Another major reported concern is poor follow-up adherence for early intervention in spite of positive referrals from developmental screening centres (Schoeman et al, 2017). The South Carolina Early Intervention Programme, which was a 2–tier screening programme, led to a five-fold increase in referrals for early intervention services for children "at risk for ASD". Only 2.5% of those identified children were found negative for ASD (Rotholz et al, 2017).

Considering all these aspects, it was felt that effective use of technology would enhance the sensitivity of at-risk children with disabilities and disability identification systems. The authors propose an active disability surveillance system model using technology.

Technology-Assisted Early Disability Identification and Monitoring in Children

Components of the system are as depicted in Figure 1.

Fig 1: Components of Technology-Assisted Early Disability Identification in Children



1) **Online Registration Unit**: Here, mandatory online registration of all new-born children into the screening and monitoring system will be done along with birth registration. The unit will activate the "Risk for Disability Alerting System" if there are identified risk factors for disability in collected data, such as history of a differently-abled child in the family, a mother more than 35 years of age during gestation, a preterm baby, low birth weight, neonatal respiratory distress, and neonatal seizures.

2) **Special Observation Bed**: The special observation bed will be of adequate size to accommodate children up to 2 years of age and will have safety features like padded edges, padded railings, accessible doors and a safety net above. The bed will be equipped with a face analysis system, speakers in multiple locations, a series of colour lights, a mobile visual display unit, a high-resolution camera with video recording, and image capture capabilities. The facial analysis system compares the facial image of the child and detects facial dysmorphism and facial abnormalities. The sound speakers in multiple locations randomly emit sounds of various frequencies and help in monitoring the response of the child. A series of coloured lights

that emit light randomly will help in detecting the visual responses of the child. A mobile visual display unit, showing audio-visual content moving overhead across the bed, will help to detect the audio-visual tracking ability of the child. The high-resolution camera will help capture images and videos of good clarity, which will be compiled in a digital content repository. With the aid of artificial intelligence, analysis of audio-video content can help detect abnormalities among infants, such as weakness, paralysis or reduced activity of limbs, reduced eye contact, absence of visual tracking of objects, and non-responsiveness to sound.

3) **Online Monitoring System for Health Professionals**: The system has dynamic developmental screening and monitoring tools to aid in the surveillance of children with disabilities and at risk for disabilities. Age-specific developmental milestone-based modules will be created and integrated into the system. This helps in tracking the age-specific motor, social, and language milestone levels of each child. Putting the age of the child in the artificial intelligence-integrated developmental screening and monitoring system will help in checking the extent of age-appropriate achievement in motor, social, and communication domains of developmental milestones. Online registration data, initial screening data, and periodic follow-up data will be integrated to reduce duplication of entries and promote ease of access for all related health professionals. Additionally, the system will allow data to be shared after masking sensitive personal information for policymaking and research purposes. To further enhance the surveillance, data of gestational mothers who are at high risk for delivering a differently-abled child can be added to the system for close monitoring of such children after birth.

4) **Online Monitoring System for Parents**: This component of the system facilitates more parental participation and information sharing about certain disabilities like ASD, communication disorders, and muscular dystrophies where the child will develop symptoms a few months after birth. Here, each parent will have access to the data and related documents of their child. Parents can upload images and videos of their child, related to developmental monitoring, for health professional feedback. Specific guidelines will be prepared regarding the distance, light, sound, angle, orientation, file size, length, and resolution of uploading images and videos. Parents can download selected data files for further medical consultation, rehabilitation, and social security measures. They can register for online consultation with

health professionals for expert guidance in developmental monitoring and interventions.

5) **Digital Content Repository**: All digitally entered data will be securely stored in this repository with easy retrieval capabilities. The repository will be connected to all other components of the system.

6) **Risk for Disability Monitoring System:** This is the most important segment of the proposed model. This highly sensitive system will track if any risk for disability is detected by other components of the system such as the online registration unit, special observation bed, online monitoring system for health professionals and online monitoring system for parents, digital content repository or data and client tracking system.

7) **Data and Client Tracking Unit:** The unit ensures that all health professionals provide periodic developmental monitoring by online/offline consultations, and enter data related to such visits. Reminder email/messages will be sent to the parents regarding the date and time of consultations. If a developmental monitoring follow-up visit is missed, the client will be tracked, and a new follow-up visit date will be arranged with the help of the 24x7 Helpline Unit. Parents will also be reminded to upload images and videos of their child at pre-specified periods for developmental monitoring purposes.

8) **24x7 Helpline for Guidance:** The helpline assists in the smooth functioning of the system by providing multilingual audio, video and email-based communication. Web robots will be enabled in the related website for customer assistance. The unit works in coordination with the data and client tracking unit for better efficiency of the services through the proposed model. Parents and other stakeholders can reach the helpline for support and guidance in using the system. Multilingual and disability-friendly interfaces provide smooth and hassle-free communication.

9) **Regional Server Unit:** For providing better data safety, privacy, and security, a regional server unit will be maintained. The regional server can be at the sub-district level, district level, or state level based on the population density and data volume. The server unit will help identify regions of high disability risk and effective policy- making and utilisation of resources.

Integration of Proposed Model with Digital Birth Registry

The integration of the proposed model with the Digital Birth Registry at hospitals or at the regional level is advised for better coverage of disability risk screening. This will help to closely monitor children born with a risk for disability, including those with low birth weight, those that are born preterm, and those with neonatal seizures.

Mandatory screening of all new-borns in a specially designed observation bed in Neonatal Units prior to their discharge is recommended. This robotic-controlled unit records and analyses the information received using big data analysis. The proposed system will self-disinfect after each session. Big data analysis and machine learning integration in the database will help to identify children with risk factors through data mining and analysis of images and videos uploaded into the system. The proposed model can also be used for monitoring the efficacy of interventions through periodic recording of images, audio and video of beneficiaries and their analysis. Incidence, morbidity, and mortality-related data of various disabilities among children can also be generated from this system. Apart from the online consultation, referral to healthcare institutions, early intervention and rehabilitation units can be done through this platform.

For the successful functioning of the proposed model, effective collaboration of technical experts, healthcare professionals, allied healthcare professionals, rehabilitation professionals, social workers, and policymakers is essential. Accessibility can be enhanced with the integration of desktop and android versions of the proposed model. The level of investment in early childhood development will determine the quality of productive human resources and the progress of the nation. Although the initial investment for implementation will be higher, the system will be cost-effective on a long-term basis. Resource mobilisation can be done through pooling of Corporate Social Responsibility funds of companies, crowdfunding, and providing tax incentives for donations to the project. Cross-subsidisation can be considered by collecting service charges from the affluent segment of the population and providing free services for people from poor financial backgrounds.

Use of voluntary services of retired healthcare professionals and an educated segment of the population for digital verification of documents, related entries, regional-level deciphering, and translation of contents into English for pan-country access can be sought. Such a double review process will reduce the error rates in the system and mitigate problems that may arise due to the use of regional languages in documents. Training for related staff can be done through direct instruction, online instruction, or hybrid instruction. Online guidance and a 24-hour helpline will be helpful. The proposed model can later be modified and upgraded into a holistic repository of medical, rehabilitation and social security data of the beneficiary, with varying levels of accessibility for all concerned stakeholders.

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