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Contents

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Editorial

Original Research Articles

Reviews

Editorial

Editorial Message

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Dear Readers,

With deep appreciation and a growing sense of responsibility, we present to you Volume 35, Issue 2 of the Disability CBR and Inclusive Development Journal. This edition is a tapestry of voices, experiences, and critical reflections from Brazil, Ethiopia, India, Bangladesh, and Indonesia. Together, these eight articles take us into homes, communities, clinics, schools, marketplaces, and policy corridors each story revealing the complex and often invisible realities faced by persons with disabilities and their families.

What binds these contributions together is a simple but profound truth: disability is not located within a person's body or mind, but in the way our societies are structured. The challenges people face are not because of their impairments, but because of environments, attitudes, systems, and services that exclude, ignore, or patronize them. The authors in this volume remind us that inclusion is not a checklist it is a mindset, a movement, and above all, a moral commitment to human dignity.

We begin our journey in Brazil, where an integrative review on the social determinants of health among people with disabilities brings sharp attention to structural inequities. The article unpacks how access to employment, adequate housing, transportation, and opportunities for participation are critical health determinants often outweighing the impact of medical interventions. This piece lays the groundwork for understanding disability as deeply interconnected with poverty, policy, and social justice.

From India, we hear multiple voices each highlighting a different dimension of exclusion and resilience. A study from rural Tamil Nadu looks at the quality of life among individuals with locomotor disabilities, revealing how economic insecurity, limited education, and social stigma create daily barriers. And yet, amidst these challenges, people find ways to survive and hope. The study also reminds us that rehabilitation must go beyond physical function to address emotional and social well-being.

In another Indian article, the focus shifts to children with cerebral palsy, and the gap between existing rehabilitation practices and a child's right to dignity, education, and play. Drawing on both policy frameworks like Samagra Shiksha Abhiyan and the realities of families, the authors argue for school-linked, child-centered, and rights-based models of care. Therapy, they suggest, should not be something that pulls a child out of their social world—but something that enables them to thrive within it.

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This call for a more human approach is echoed in a heartfelt letter from Zelalem Dessalegn Demeke in Ethiopia, who writes about children with cerebral palsy not as clinical cases but as children first. He introduces the "F-words" of childhood—Function, Family, Fitness, Fun, Friends, and Future—as a framework for rethinking rehabilitation. His words call us to stop medicalizing childhood, and to create spaces where every child can laugh, play, learn, and be loved.

In Bangladesh, we turn to the vital but often overlooked role of Community Health Workers. These frontline workers who often serve remote and underserved communities have the potential to bridge the vast rehabilitation gap. While the article finds encouraging attitudes toward disability among these workers, it also identifies a lack of training, resources, and systemic support. The message is clear: we cannot expect inclusion at the grassroots without investing in those who work there.

Building on this theme of capacity building, another study from India evaluates a competency-based CBID training program. Using the Success Case Method, the research shows that well-designed training rooted in real-world practice and reinforced with mentoring can dramatically improve the confidence, skills, and effectiveness of grassroots workers. The study is not just a report it's a roadmap for how we can build inclusive systems from the ground up.

Accessibility, too, is examined through a critical audit of urban shopping malls in Mysore, India. While these malls may appear modern and polished, the absence of Braille signage, auditory guidance, accessible toilets, and trained staff makes them subtly but powerfully exclusionary. The article challenges the idea that physical infrastructure alone guarantees access; it is design, empathy, and intentionality that make public spaces truly inclusive.

Finally, in a touching qualitative study from Indonesia, we hear the voices of parents navigating inclusive education. Their stories are filled with emotion: pride in their children's achievements, fear of discrimination, and an unyielding commitment to inclusion. The study reveals that inclusion is not just about getting children into classrooms it's about how schools listen to families, respect children's needs, and co-create a sense of belonging. It reminds us that when we include families, not just students, we build stronger and more compassionate systems.

What emerges across these diverse contributions is a call to action:

See differently. Disability is not an individual's problem—it is a societal issue. We must confront the attitudinal, architectural, and institutional barriers that prevent people from fully participating in society.

Listen deeply. The lived experiences of persons with disabilities, caregivers, and community workers are not anecdotal—they are data, expertise, and evidence that must shape policy, practice, and research.

Act collectively. Inclusion is not the responsibility of one ministry or sector. It requires a coordinated, community-led, rights-based approach that is grounded in equity and powered by empathy.

To all the authors, research participants, caregivers, children, and community members who made this issue possible we thank you. Your courage, insight, and determination bring this journal to life. You challenge us to move beyond good intentions, to reimagine systems, and to co-create a world where everyone regardless of ability can lead a meaningful, joyful life.

The Editorial Team

Disability CBR and Inclusive Development Journal

Editorial

Letter to the Editor

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Dear Editor,

I extend my appreciation to Francis and Nongpoh (2025) for their insightful discussion on cerebral palsy (CP) rehabilitation in India, which raises critical ethical and practical concerns about the pervasive impairment-focused rehabilitation model. Their call for a shift from impairment-focused therapy to a strength and activity/participation-based rehabilitation approach aligns with contemporary evidence (Novak et al., 2020) and the principles of child rights and dignity as outlined in the United Nations Convention on the Rights of the Child(United Nations, 1989).

The authors’ concern about prolonged therapy hours raises significant ethical and developmental issues. While intensive interventions targeting activity and participation can improve functional outcomes (Novak et al., 2020), therapists should ensure that the intensity and duration of interventions don't impinge on children's opportunities to play, socialize, and engage in self-directed activities—crucial aspects of childhood necessary for holistic development and overall quality of life (Rosenbaum & Gorter, 2012) In addition, prolonged, impairment-focused interventions—frequently intensive and discomforting—may yield adverse outcomes rather than benefits, with evidence indicating associations with pain (Houx et al., 2021; McKearnan et al., 2004) and limited impact in functioning (Jackman et al., 2022).

A separate issue is the unfair blame parents face when outcomes like walking or reduced contractures in CP cases are not achieved, something I’ve noticed in clinical settings. Studies show that children at Gross Motor Function Classification System (GMFCS) levels IV–V are unlikely to achieve independent walking regardless of intensity of therapy (Palisano et al., 1997) and not all impairments can be “fixed” (Rosenbaum & Gorter, 2012) Yet, therapists often question parents’ commitment to intensive schedules—such as multiple weekly clinic visits and hours of daily exercises—without recognizing the burden on family well-being, child comfort, and its impact on the children’s ability to engage in other experiences(Demeke et al., 2023; King & Chiarello, 2014). This unwarranted criticism adds pressure to caregivers already stretched by therapy demands, sustains a misplaced focus on "normalcy" like typical gait or posture, and increases emotional strain while raising unrealistic hopes. (Rosenbaum & Gorter, 2012) “F-words” framework—Function, Family, Fitness, Fun, Friends, and Future—proposes a practical shift, prioritizing participation and practical abilities over unattainable impairment-focused goals.

The authors also highlight another significant issue: parents’ or therapists’ reluctance to adopt or prescribe assistive technologies, such as mobility aids and seating devices, due to misconceptions that children will eventually walk or sit “normally” or it will hinder the children’s ability to achieve walking . This refusal, rooted in a belief that such devices are a last resort, leads to diminished childhood experiences due to lack of mobility, inappropriate postures, and secondary complications like chronic pain and deformities(Sabet et al., 2022). (Moll & Cott, 2013) discuss this paradox, noting that an overemphasis on physical impairment correction through rehabilitation can marginalize children, overshadow their social psychological development, and potentially reinforce parental resistance to tools that deviate from walking as the ultimate goal. However, current evidence supports the view that access to mobility aids is not a fallback option but a fundamental right—allowing children to explore, develop, build relationships, and actively shape their own lives (Sabet et al., 2022).

To achieve this balance, several key strategies should be considered. First, rehabilitation programs should adopt a family-centered approach, ensuring that therapy goals align with the child's interests and daily routines rather than imposing rigid therapy schedules and programs(Rosenbaum & Gorter, 2012) Second, integrating therapy into play-based and school activities can make interventions more engaging and less burdensome while improving motivation and outcomes. Third, hybrid therapy models that combine professional sessions with structured home-based exercises can provide flexibility while maintaining therapeutic intensity. Finally, periodic reassessment of therapy intensity should be conducted to adjust treatment plans according to the child's progress, personal goals, and overall well-being (Jackman et al., 2022)

While the shift toward participation-based rehabilitation is well-supported, it is important to acknowledge the nuances and challenges associated with its implementation. In many low- and middle-income countries (LMICs), access to advanced rehabilitation services and assistive technology remains limited(Ibarra-Rodríguez, 2025). This necessitates policy reforms and equitable resource allocation. Without addressing these systemic barriers, the benefits of participation-focused rehabilitation may remain out of reach for many children with cerebral palsy.

Clinicians, researchers, and policymakers must work collaboratively to develop strategies that integrate therapeutic goals with broader developmental needs. Rehabilitation should not be about relentless correction or fixing of impairments but about enabling children to explore their potential in ways that are meaningful to them. I once again commend the authors for initiating this important dialogue. It is through such critical discussions that we can collectively advance best practices in cerebral palsy rehabilitation and ensure that children receive care that upholds both scientific integrity and human dignity.

Sincerely,
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Editorial

Response to a Letter to the Editor

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Dear Zelalem,

Thank you sincerely for your profoundly thoughtful and well-articulated letter in response to the recent article by Francis and Nongpoh. It was a privilege for our editorial team to read your reflections, and I want to personally express our appreciation for the depth, compassion, and clarity with which you raised such critical issues in the field of cerebral palsy rehabilitation.

What immediately stood out to us in your letter was your ability to bridge rigorous evidence with the lived realities of children, families, and professionals—especially in contexts where resources are limited and the pressure to “correct” or “normalize” disability is high. Your points around the ethical implications of prolonged, impairment-focused therapy were especially moving. Too often, these approaches are assumed to be beneficial without considering their emotional, physical, and developmental costs. Your reminder that children have a right to joy, spontaneity, and play—not just progress measured in clinic terms—was both powerful and necessary.

We were also deeply touched by your discussion of the often invisible burden placed on caregivers. You voiced what many parents may feel but are rarely given the space to express: the fatigue, guilt, and emotional strain that can come from being caught in a cycle of never-ending therapy goals, sometimes at the expense of the child’s broader well-being. You brought attention to this dynamic with empathy and honesty, and we believe it’s a conversation that needs to be heard far more widely in the rehabilitation community.

Your advocacy for a shift toward participation-based, family-centered rehabilitation grounded in the "F-words" framework (Function, Family, Fitness, Fun, Friends, and Future) aligns closely with the values we seek to promote through this journal. Your call for us to see assistive technologies not as a “last resort” but as tools for liberation and access also reflects an urgently needed reframing in clinical mindsets—especially in places where stigma and misconceptions persist.

We were especially grateful that you rooted your arguments in both global research and the local context of Ethiopia, drawing from your own clinical and academic work. It adds depth and relevance that is so often missing in top-down policy conversations. Your insights remind us that we must not only rethink the what and how of therapy—but also the why. And that “why” must be centered on the child’s lived experience, autonomy, and right to thrive—not just survive.

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At Disability, CBR and Inclusive Development Journal, we strive to be a platform where these kinds of human-centered, equity-driven discussions can flourish. Your contribution exemplifies this spirit and adds immense value to the ongoing global dialogue around disability, rehabilitation, and inclusive practice.

Thank you once again for your contribution, for your courage in naming uncomfortable truths, and for your commitment to dignity-based care. We look forward to continuing this important conversation with you and others who share your vision of rehabilitation as a tool for empowerment and inclusion.

With deep appreciation and warm regards,
Solomon Mekonnen
Editor, Disability, CBR and Inclusive Development Journal
On behalf of the Editorial Team

Original Research Article

An Assessment of Community Health Workers' Knowledge, Attitude and Practice of Rehabilitation Services in a Dhaka District Sub-Unit

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ABSTRACT

Purpose: In the world of today around 2.4 billion people need various degrees of rehabilitation. Community health workers are a means of delivering rehabilitative services to these individuals at the level of primary health care. This study aimed to determine the knowledge, attitude, and practice of rehabilitation services by community health workers in a selected sub-unit of Dhaka district in Bangladesh.

Method: Simple random sampling technique was used to select 107 community health workers from the Savar region. A cross-sectional design was employed, using a self-administered questionnaire. Bloom's cut-off ≥80%, ≥90%, ≥75% was used to determine adequate knowledge, a positive attitude, and good practice, respectively. The data was analysed using SPSS version 25.0.

Result: The results showed that a significant proportion of community health workers, specifically 105 (98.1%) and 89 (83.2%), exhibited inadequate knowledge and poor practice. However, it is noteworthy that 87 (81.3%) of them had a positive attitude towards rehabilitation services. A significant statistical association was observed between socio-demographic factors such as age, education, designation, and experience, and the levels of knowledge, attitude, and practice.

Conclusion: Overall, although delivery of these services was poor, community health workers had a positive attitude towards rehabilitative services. They need to broaden their knowledge and practice to provide effective rehabilitation services. The current study was constrained by the lack of a standardised questionnaire to assess community health workers' knowledge, attitude, and practice. The findings cannot be generalised as the study was conducted in only one 'upazila' and the situation in other 'upazilas' could differ. Also, discussion from a national perspective was not possible due to dearth of research and literature on the subject in Bangladesh.

Keywords: rehabilitation service, community health worker, knowledge, attitude, practice

INTRODUCTION

The World Health Organisation and World Bank (2011) estimate that 15% of the world's population is impaired. Based on the World Health Survey and Global Burden of Disease estimates, 1 billion people worldwide have severe disabilities (Kostanjsek et al, 2013). In 2021, 2.4 billion people worldwide will need rehabilitation services. "Rehabilitation is a combination of therapies designed to improve functioning and decrease disability in people with chronic health problems who interact with their environment" (World Health Organisation, 2021).

Rehabilitation's purpose is to maximise function and minimise disability (Bickenbach et al, 2021). Bangladesh, a nation with low and middle income, has a 2.8% disability prevalence rate, with a greater proportion in rural than in urban areas (Islam et al, 2016). While the rehabilitation services are usually available in urban areas, the large population of 76.7% in rural areas have very limited information and access to rehabilitation services (Al Imam et al, 2022). The inadequacy in 4 domains: information, communication, infrastructure and capacity development, affects disability-friendly health services in Bangladesh. Services changes in those domains could be possible if proper measurement is taken from the community level (Torsha et al, 2022). A primary factor contributing to this situation is the acute lack of workers with rehabilitation experience and knowledge.

This might be enhanced by providing affordable, short-term training to mid-level therapists/ workers (Stanmore & Waterman, 2007). Bangladesh has developed many community-based health workers in recent years in purpose of basic health-care services (Mubin et al, 2021). CHCPs, HAs, and MHVs are responsible for promoting, preventing, and providing services such as limited clinical services, rehabilitation, palliative care, and referral to their community in the fields of maternity, newborn, paediatric, and adolescence care, contraception, nutritional, and infectious and non-infectious disease prevention and treatment. CHCPs and MHVs help HAs, accountable for the day-to-day operations of CCs and delivering necessary medical care. Along with their duties at the CCs, CHCPs, HAs, and MHVs are mandated to organise home visits, maintain registries of clients and pregnant women, and deliver vaccines at home.

As a result, they have a greater chance of identifying rural residents who may have disability and need rehabilitation services (Directorate General of Health Services - DGHS, 2019). It has been suggested that community-based service delivery approaches be used to address the rehabilitation workforce shortage (World Health Organisation, 2010). So, it could be a game changing factor if this work force is utilised properly to facilitate persons with disability with rehabilitative services in their community.

Community health workers are the first to visit clients and can greatly improve rural rehabilitation programmes. A rehabilitation service approach is needed for rural-urban healthcare referrals (Nesbit & Clark, 2019a). Insufficient information can affect CHCP, HA, and MHV rehabilitation service practices and attitudes. There is currently a shortage of data on the knowledge, attitude and practice (KAP) levels of community health workers, which is critical for developing a systematic rehabilitation service strategy in community settings (Islam et al, 2015).

OBJECTIVE

This research aimed to examine rehabilitation KAP among community health workers that are related to delivery of services, in order to identify gaps and make relevant policy recommendations.

METHOD

Study Design and Site

The study design employed was a cross-sectional survey conducted in Savar*Upazila*. The *Upazila* is approximately 24 kilometres (15 miles) northwest of Dhaka and is home to about 1,387,426 people.

Participants

The study sample consisted of 107 community health workers. As per the report provided by Md. KhalekHossain, an office assistant at the Upazila Health Complex in Savar, there are around 230 operational community health workers in the region.

Sampling

Simple random sampling technique was used to select participants who met all the inclusion criteria. The study included:

- Community healthcare providers, health assistants, and multipurpose health volunteers who were practising in community clinics located in Savar.
- Participants were between 18 and 65 years of age.
- Those who were expressed their willingness to participate and provided informed consent.

Data Collection

Face-to-face interviews were conducted with the 107 participants. The survey instrument from another study on community health workers – 'Knowledge, Attitude, and Practise about malaria prevention' (Habimana et al, 2016) - was adapted and modified to fit the context. It comprised 11 items on knowledge, 4 items on attitude, and 9 items on practise regarding rehabilitation services. In the context of knowledge-related inquiries, a correct response was assigned a score of '1', while an incorrect response was assigned a score of '0'. The anticipated upper limit of the knowledge score was 33. An elevated score indicated a satisfactory level of comprehension regarding rehabilitation services. The authors modified Likert-item questions appropriately to assess attitudes in the context of rehabilitation services. The participants' responses were measured on a Likert scale consisting of 5 points: 'strongly agree', 'agree', 'neutral', 'disagree', and 'strongly disagree'. Each point on the scale was assigned a score of '1' for each positive statement. A question was reversed to reduce biases. Questions related to practise were assigned a score of '1' for a correct response and '0' for an incorrect response. The KAP levels of community health workers were measured on Bloom's cutoff point accordingly: ≥ 80% (≥ 26 points out of 33), ≥ 90% (≥ 3 points out of 4), and ≥ 75% (≥ 6 points out of 9) were used to determine adequate knowledge, positive attitude, and good practise, respectively (Ashebir et al, 2022).

Data Analysis

A pretest of the questionnaire was conducted on a representative subset of 10% of the sample, and any necessary adjustments were subsequently implemented. The statistical analysis was conducted using SPSS version 25.0. The socio-demographic data and knowledge, attitudes, and practises of the study population were analysed using descriptive statistics, including measures such as frequency and proportion. The study conducted a chi-square test of independence to investigate the potential association between the socio-demographic characteristics of participants and their knowledge–attitude–practice levels. The analysis used a significance level of 5%, indicating that any p value <0.05 was considered significant at a confidence interval of 95%.

Ethical Considerations

The "Bangladesh Health Professions Institute" Research Ethics Committee granted clearance (memo no. CRP/BHPI/IRB/09/2021/492) for the survey. The research was carried out in accordance with the principles outlined in the Declaration of Helsinki. The survey was structured to ensure anonymity, confidentiality of the data was maintained, and the outcomes did not reveal the identities of the participants.

RESULTS

Socio-Demographic Characteristics of Respondents

The study achieved a response rate of 100% (n=107), with 65 (60.7%) of the respondents identifying as female and 42 (39.3%) identifying as male. Most of the participants, comprising 86 individuals (80.4%), were within the age range of 21 - 40 years. As per the data, 19 individuals (17.8% of the sample) were below the age of 20. Only 2 participants (1.9% of the sample) fell within the age range of 41- 60 years. The level of education of the participants was categorised as follows: SSC (n=20, 18.7%), HSC (n=58, 54.2%), Bachelor's degree (n= 16, 15.0%), Master's degree (n=11, 10.3%), and other qualifications (n=2, 1.9%). The allocation of individuals was computed for CHCP (n=15, 14.0%), MHV (n=82, 76.6%), and HA (n=10, 9.3%). The study revealed that the majority of participants, comprising 76.6% (n=82), had work experience ranging from 1 to 5 years. A smaller proportion of participants, comprising 17.8% (n=19), had work experience ranging from 6 to 10 years, while only 5.6% (n=6) had work experience exceeding 10 years. (see table 1)

Table 1: Socio-Demographic Characteristics of the Study Participants (N=107)

Variables	Number (n = 107)	Percentage (%)
Gender		
Male	42	39.3
Female	65	60.7
Age		
Less than 20 years	19	17.8
21-40 years	86	80.4
41-60 years	2	1.9
Educational Level		
SSC	20	18.7
HSC	58	54.2
Bachelor's Degree	16	15.0
Master's Degree	11	10.3
Others	2	1.9
Designation		
CHCP	15	14.0
MHV	82	76.6
HA	10	9.3
Work Experience		
1-5 years	82	76.6
6-10 years	19	17.8
More than 10 years	6	5.6

Assessment of Community Health Workers' Knowledge about Rehabilitation Services

It was found that only 2 participants (1.86% of the sample) possessed knowledge that could be considered adequate (≥ 80%). In contrast, the remaining 105 participants (98.1% of the sample) demonstrated knowledge that fell below the adequate level (<80%). Table 1 reveals that a notable proportion of participants, specifically 87 (81.3%) and 76 (71%) respectively, identified physical disability and speech disability as distinct categories of disability. Moreover, the participants identified mental illness as a type of disability in approximately 69 (64.5%) of the cases. The incidence rate of disability for cerebral palsy and Down syndrome were found to be 8 (7.5%) and 6 (5.6%) respectively. The significance of identifying disability types was assessed, and the findings indicate that 87 participants

(81.3%) recognised the importance of early intervention, while 79 (73.8%) acknowledged the role of creating awareness. It was observed that referral was performed by the minimum number of 38 individuals (35.5% of the sample). In relation to rehabilitation service providers, 80 (74.8%) of the respondents identified as physiotherapists, followed by nutritionists who were 45 (42.1%) in number, and speech and language therapists numbering 42 (39.3%). Occupational therapists, prosthetics and orthotics professionals, and other professionals constituted 29.9% (32), 10.3% (11), and 1.9% (2) of the sample, respectively. The findings of the study indicate that a proportion of the participants, specifically 19.6% (21) and 10.3% (11), exhibited positive responses towards laws that concern the protection and welfare of people with disabilities. (see table 2)

Table 2: Knowledge about Rehabilitation among Community Health Workers

Statement		Correct		Incorrect	
	N	n	%	n	%
K1. What type of disability do you use to identify?					
Autism of autism spectrum disorders (ASD)	107	24	22.4	83	77.6
Physical disability	107	87	81.3	20	18.7
Mental illness leading to disability	107	69	64.5	38	35.5
Visual disability	107	67	62.6	40	37.4
Speech disability	107	76	71	31	29
Intellectual disability	107	61	57	46	43
Hearing disability	107	52	48.6	55	51.4
Deaf blindness	107	22	20.6	85	79.4
Cerebral palsy	107	8	7.5	99	92.5
Down syndrome	107	6	5.6	101	94.4
Multiple disability	107	10	9.3	97	90.7
Other disability	107	15	14	92	86
K2. Why it is important to identify the types of disability?					
To provide early intervention	107	87	81.3	20	18.7
To do appropriate referral	107	38	35.5	69	64.5
To supports their rights	107	39	36.4	68	63.6
To create awareness	107	79	73.8	28	26.2
Others	107	21	19.6	86	80.4
K3. Who provides rehabilitation services?					
Physiotherapist	107	80	74.8	27	25.2
Occupational Therapist	107	32	29.9	75	70.1
Speech & Language Therapist	107	42	39.3	65	60.7
Prosthetics & Orthotics	107	11	10.3	96	89.7
Psychologist	107	34	31.8	73	68.2
Nutritionist	107	45	42.1	62	57.9
Doctor/ General Physician	107	36	33.6	71	66.4
Others	107	2	1.9	105	98.1
K4. Are you able to identify the type of disability?	107	107	100	0	0
K5. Is it important to identify the types of disability?	107	107	100	0	0
K6. Have you ever received any formal training on disability?	107	28	26.2	79	73.8
K7. Do you know about Persons with Disabilities' Rights and the Protection Act 2013?	107	21	19.6	86	80.4

K8. Do you know about Protection of Persons with Neuro-developmental Disability Trust Act, 2013?	107	11	10.3	96	89.7
K9. Do you know about Bangladesh Rehabilitation Council Act, 2018?	107	4	3.7	103	96.3
K10. According to Bangladesh Rehabilitation Council Act, 2018, do you know what the minimum educational qualification of a Rehabilitation Practitioner is?	107	0	100	107	100
K11. Which ministry manages rehabilitation services?	107	32	29.9	75	70.1

Assessment of Community Health Workers' Attitudes towards Rehabilitation Services

Among the 107 participants, a majority of 87 individuals (81.3%) exhibited a positive attitude, which was defined as a score of 90% or higher. The minority, specifically 20 individuals (18.7%), exhibited a negative attitude. A significant proportion of the community health workers, specifically 105 (98.1%), were of the positive view that the community level is an ideal platform for the promotion of rehabilitation services. A substantial majority of community health workers, specifically 96 individuals (89.7%), exhibited a positive attitude towards the theory that people with disabilities require rehabilitation services to enhance their overall quality of life. The majority of community health workers, i.e., 85 individuals (79.4%) agreed that referrals are important for ensuring appropriate treatment. Conversely, a minority cohort of 46 community health workers exhibited a positive attitude, comprising 43.0% of the total sample. (see table 3)

Table 3: Attitude towards Rehabilitation among Community Health Workers

Statement		Correct		Incorrect	
	N	n	%	n	%
A1. To improve quality of life, person with disability needs rehabilitation service	107	96	89.7	11	10.3
A2. One of the means of expanding rehabilitation services is to promote at the community level	107	105	98.1	2	1.9
A3. Practice of referrals is crucial for appropriate treatment of clients	107	85	79.4	22	20.6
A4. The provision of rehabilitation services does not necessitate the involvement of rehabilitation service providers at the outset	107	46	43.0	61	57

Assessment of Community Health Workers' Practise of Rehabilitation Services

All participants (n=107) reported serving a maximum of 10 persons with disabilities per week, indicating a positive practise. Approximately 55.1% of the participants, specifically 59 individuals, opted to refer them to an alternate organisation. Surprisingly, none of the individuals surveyed (0%) possessed any documentation pertaining to disability and rehabilitation legislation. Only a small proportion of the sample, specifically 6 individuals (5.6%), adhered to the guidelines outlined in the Persons with Disabilities Rights and the Protection Act of 2013, which require the identification of various types of disabilities. (see table 4)

Table 4: Practice of Rehabilitation among Community Health Workers

Statement		Correct		Incorrect	
	N	n	%	n	%
P1. Do you have copies of all the laws related to disability and rehabilitation?	107	0	0	107	100
P2. Have you read the laws in the last six months?	107	14	13.1	93	86.9
P3. Do you know all the current news or information about disability and rehabilitation?	107	33	30.8	74	69.2
P4. Do you screen disability?	107	41	38.3	66	61.7
P5. Do you provide any type of emergency treatment for people with disabilities?	107	43	40.2	64	59.8
P6. Do you separate disabilities according to Persons with Disabilities' Rights and the Protection Act, 2013?	107	6	5.6	101	94.4
P7. Do you serve any (number) persons with disability in a week?	107	107	100	0	0
P8. Do you refer a person with disabilities to graduate practitioner for his/ her appropriate treatment?	107	25	23.4	82	76.6
P9. Do you refer a person with disabilities to any organisation?	107	59	55.1	48	44.9

Association between Socio-demographic Variables and KAP

The findings indicate a significant statistical association between the educational level, job designation, work experience, and KAP levels of the participants. A significant association was observed between educational level and knowledge level ((4, *N*=107) = 11.5, *p* = 0.021). The large (or "strong") association between the two variables is indicated by Cramer's V of 0.329 and degrees of freedom = 4. The statistical analysis revealed a significant association between designation and knowledge level ((2, *N*=107) = 7.04, *p* = 0.029). The effect size, as measured by Cramer's V of 0.257 and degrees of freedom = 2, indicates a medium (or "moderate") association between the two variables. A significant association was observed between experience and knowledge level ((2, *N*=107) = 9.91, *p* = 0.007). The large (or "strong") association between experience and knowledge level was indicated by Cramer's V of 0.304 and degrees of freedom =2. A significant association was observed between educational level and attitude level ((4, *N*=107) = 9.70, *p* = 0.046). The calculated Cramer's V of 0.301 and degrees of freedom = 4 suggest a large (or "strong") association between the two variables. The statistical analysis revealed a significant association between designation and attitude level ((2, *N*=107) = 7.49, *p* = 0.024). The effect size, as measured by Cramer's V of 0.265 and degrees of freedom = 2, indicates a medium (or "moderate") association between the two variables. A significant association was observed between experience and attitude level ((2, *N*=107) = 7.49, *p* = 0.024). The analysis revealed a medium (or "moderate") association between the two variables, as indicated by Cramer's V of 0.265 and degrees of freedom = 2. A statistically significant association was observed between age and practise level ((2, *N*=107) = 5.94, *p* = 0.051). The strength of the association was "moderate", as indicated by Cramer's V of 0.236 and degrees of freedom = 2. A significant association was observed between educational level and practise level, with a chi-square value of (4, *N*=107) = 15.43 and a p-value of 0.004. The calculated Cramer's V of 0.380 and degrees of freedom = 4 indicate a "strong" association between the two variables. The statistical analysis revealed a significant association between designation and practise level ((2, *N*=107) = 46.05, *p* = 0.000). The calculated Cramer's V value of 0.656 and degrees of freedom = 2 indicate a "strong" association between the two variables. The statistical analysis revealed a significant association between experience and practise level, with a chi-square value of 30.06 and degrees of freedom equal to 2, based on a sample size of 107 participants ((2, *N*=107) = 30.06, *p* = 0.000). The strength of the association was considered large or "strong", as indicated by Cramer's V value of 0.530. (see table 5)

Table 5: Association between Socio-Demographic Variables and KAP

Variable	Adequate knowledge Freq (%)	p value	df	Positive attitude Freq (%)	p value	df	Good practice Freq (%)	p value	df
Overall	2.00 (1.86)			87.0 (81.3)			18.0 (16.8)		
Gender									
Male	1.00 (2.38)	0.753	1	32.0 (76.2)	0.275	1	9.00 (21.4)	0.306	1
Female	1.00 (1.53)			55.0 (84.6)			9.00 (13.8)		
Age									
Less than 20 years	0 (0)	0.780	2	17.0 (89.5)	0.455	2	0 (0)	0.051	2
21-40 years	2.00 (2.32)			68.0 (79.1)			17.0 (19.8)		
41-60 years	0 (0)			2.00 (100.0)			1.00 (50.0)		
Education									
SSC	0 (0)	0.021	4	14.0 (70.0)	0.046	4	1.00 (5.00)	0.004	4
HSC	0 (0)			45.0 (77.6)			6.00 (10.3)		
Bachelor's Degree	2.00 (12.5)			16.0 (100)			7.00 (43.8)		
Master's Degree	0 (0)			11.0 (100.0)			4.00 (36.4)		
Others	0 (0)			1.00 (50.0)			0 (0)		
Designation									
CHCP	1.00 (6.66)	0.029	2	15.0 (100)	0.024	2	4.00 (26.7)	0.000	2
MHV	0 (0)			62.0 (75.6)			5.0 (6.09)		
HA	1.00 (10.0)			10.0 (100)			9.00 (90.0)		
Experience									
1-5 years	0 (0)	0.007	2	62.0 (75.6)	0.024	2	5.00 (6.09)	0.000	2
6-10 years	1.00 (5.26)			19.0 (100)			9.00 (47.4)		
More than 10 years	1.00 (16.7)			6.00 (100)			4.00 (66.7)		

DISCUSSION

Socio-Demographic Characteristics

The study found that most community health workers (80.4%) were between 21 and 40 years of age, while the least number (1.9%) were between 41 and 60 years old. It indicates that most community health workers were in the early to middle-age group. According to a study conducted in Kenya, most community health workers were between the ages of 31 and 40 (59.3%), with only 4.2% over the age of 50 (Crispin et al, 2012).

According to a report, globally there are 70% of female community health workers in service, whereas there are only 12% of male community health workers. Similar findings are presented in this study. Females made up the majority of community health workers in the sample (60.75%). This demonstrates that women are prioritised as primary health care providers in impoverished countries such as Bangladesh (Lehmann & Sanders, 2007). According to a study conducted in South Asia by Roy (2020), the minimal educational requirement for community health workers is schooling for MHVs and the 12th grade for HAs and CHCPs. This study found that the majority of community health workers (54.2%) had completed the Higher Secondary Certificate or 12th grade, whereas only a handful (18.7%) had completed the Secondary School Certificate (Roy, 2020).

According to the study's findings, 79.9% of community health workers had worked for 3–5 years, 10.6% for 6–10 years, and 4.2% for more than 10 years as community health workers. Only 5.1% of respondents had less than 3 years of work experience. A similar result was identified in this study, where 76.6% of community health workers had worked for 1–5 years, 17.8% had worked for 6–10 years, and 5.6% had worked for more than 10 years (Crispin et al, 2012).

Level of Knowledge

The findings indicated that only 1.9% of the community health workers in this study possessed adequate knowledge about rehabilitation services, while 98.1% possessed inadequate knowledge. This demonstrates that most of the community health workers lacked a basic understanding or appropriate knowledge of rehabilitation services. In southeast Africa, it was revealed that community health workers lacked adequate knowledge regarding rehabilitation; however, most participants obtained adequate knowledge following a five-year rehabilitation training programme (Nesbit & Clark, 2019b). The current study examines a comparable scenario. There are several probable explanations for these respondents' inadequate total knowledge level.

It is considered that factors such as educational level, designation, and work experience may influence one's level of knowledge. The current investigation discovered a statistically significant association between knowledge and educational qualifications. More education was associated with improved knowledge across all metrics except client enablement. The findings of a study conducted in Nigeria seem similar to these findings, in that a literate community can improve their knowledge and provide better services (Ande et al, 2004).

Additionally, it is possible to hypothesize that an individual's designation and work experience is related to his/her knowledge. The HAs (10%) and CHCPs (6.7%) have adequate knowledge, while the MHVs (0%) demonstrate adequate knowledge. Regrettably, a large proportion of community health workers lacked adequate knowledge. Additionally, 16.7% of those with more than 10 years of job experience had adequate knowledge, while 5.3% with 6 to 10 years of work experience had adequate knowledge. Most of the participants with different educational backgrounds showed an inadequate level of knowledge. This research found a substantial association between knowledge, education, designation, and work experience. In another study, inadequate knowledge was identified as a barrier to community health workers offering high-quality services in the community (Kane et al, 2016). Because rehabilitation is a critical component of basic healthcare, community health workers are the primary conduits for providing healthcare to community members. Thus, this study's outcome reflects a lack of proper knowledge on the part of community health workers regarding rehabilitation services, which must be addressed immediately.

Level of Attitude

The findings showed that most community health workers held a positive attitude towards rehabilitation programmes. It was found that they are concerned about community rehabilitation needs but cannot address them due to a deficiency of knowledge and resources. Educational attainment is considered to be associated with attitude. Additional analysis confirmed this. There was a strong association between attitude and educational qualifications. Most community health workers (81.3%) with varying educational backgrounds demonstrated a positive attitude towards rehabilitation services. As a result, they recognised the critical nature of rehabilitation services. A study by Paterson et al (1999) examined the attitudes of South Indian community-based rehabilitation (CBR) professionals towards people with disabilities and found that 80.3% had completed their Higher School Certificate, 11% had earned a Bachelor's degree, and 6.5% had earned a Master's degree. Additionally, this study suggested that the educational quality of community health workers is a possible indicator of attitude (Paterson et al, 1999).

The current study showed an association between attitude level and the designation of the participants. A large number of participants designated as MHV (75.6%) showed a positive attitude. Besides, there is an association between the attitude level and the work experience of the participants. Many participants, specifically 75.6% who had experience ranging from 1 - 5 years, exhibited a positive attitude.

Level of Practise

There was an association between age, education levels, designation, and work experience. The findings of this survey indicated that a total of 16.8% of community health workers have good levels of practise; in contrast, 19.8% were between 21 and 40 years of age. As for education level, 43.8% had a Bachelor's degree, 36.4% had a Master's, 10.3% had a high school certificate, and 5% had passed the secondary school exam. Despite their varied educational backgrounds, most community health workers (83.2%) engaged in poor rehabilitative practises. According to a survey done in Kenya (Olive et al, 2018), 73.7% said that the knowledge gained improved their job performance; simultaneously, 77.0% believed their training was sufficient to fulfil their obligations as community health workers. These findings indicate the need for training to enhance community health workers’ practise of rehabilitation services.

According to respondent designation, 90% of HAs, 26.7% of CHCPs, and 6.09% of MHVs engaged in good practise. Additionally, 66.7% of respondents with more than 10 years of work experience followed good practise, 47.4% with 6-10 years experience and 6.09% with 1-5 years experience also did the same. It demonstrates an increasing association between the number of working years and the level of practise. There was a significant association between level of practise, age, education, designation, and job experience. Community health workers with HA and CHCP designations performed better than others. It appears therefore, that more work experience influences good practise by community health workers.

Limitations of the Study

One limitation was generalisability of the findings. This study was conducted in a particular ‘*Upazila*’ and the findings may not apply to all other ‘*Upazilas*’. Also, it was not possible to discuss the issue from a national perspective due to insufficient literature and dearth of research in this field in Bangladesh.

CONCLUSION

Overall, the community health workers in the study sample exhibited inadequate knowledge of rehabilitation services, had positive attitudes, and were poor when it came to practise. Thus, it is concluded that they lacked sufficient knowledge and that their practise of providing rehabilitation services was unsatisfactory. The study found a significant association between knowledge, attitude, practise (KAP) and socio-demographic data. Age, educational qualifications, designation, and work experience had a significant association with KAP.

These findings imply that knowledge, attitude, and practise are all interrelated. It is suggested that community health workers be brought up-to-date on knowledge, training, and information regarding rehabilitation services. To this end, the following recommendations are made:

1) Policymakers, stakeholders, the ministry, and the government should exercise greater caution and recognise the importance of rehabilitation services within primary health care.

2) Existing rehabilitation and disability laws should be implemented expeditiously.

3) Regular training, resources, and information should be arranged to enhance the community health workers' knowledge, attitude, and practise of rehabilitation services.

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Original Research Article

The impact of a competency-based community-based inclusive development (CBID) training program in India

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ABSTRACT

Aim: This study aims to evaluate the effectiveness of a pilot Community-Based Inclusive Development (CBID) competency-based certificate course in India. Launched in 2021, the course was designed to equip grassroots workers with the necessary skills to improve quality of life outcomes and promote the integration and inclusion of people with disabilities within their communities.

Method: A qualitative case study methodology, using Brinkerhoff's Success Case Method (SCM), was employed to assess the outcomes of the training program. The study identified both successful and less successful applications of the acquired competencies in real-world settings.

Results: The findings indicate significant improvements in workplace competencies among trained fieldworkers, resulting in positive impacts on the lives of individuals with disabilities and their families in their communities. Additionally, the study offers recommendations to adapt and improve the CBID training program.

Conclusion and Implications: The results underscore the importance of competency-based training for grassroots workers, emphasizing its potential to drive inclusive development and advocating for increased investment by policymakers and training providers.

Keywords: Competency-Based Training, Success Case Method, Disability Inclusion, Training Evaluation

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INTRODUCTION

Practical or competency-based training is considered best practice in workplace education (Wesselink et al. 2017). Likewise, competency-based training is required to train community-based inclusive development (CBID) workers to provide basic rehabilitation and inclusion for local people with disability. CBID (a development from community-based rehabilitation – CBR) is a strategy used by over 100 Low- and Middle-income countries (LMICs) to facilitate rural disability services. It trains local people to meet basic rehabilitation and inclusion needs and refer on appropriately those needing more specialised support. The expansion of CBR into inclusive community development necessitated proficiency in new competencies and required upgraded competency-based training (CBT) (Cornielje&Tsengu, 2016). The Rehabilitation Council of India (RCI) is committed to working with the University of Melbourne to help develop quality competency-based CBID training.

Competence is the ability to integrate a variety of skills and knowledge to solve real workplace problems to the standard required (Misko, 1999). Competency-based training focuses on what a person can do because of their training – the training or performance outcome, not on the training inputs or processes (Guthrie, 2009). Many high-income countries, like Australia, moved to a competency-based model of training for trades and industry in the 1980s. The purpose of this reform in Australia was to formalise and improve occupational training and make Australian workers competitive. This involved working with industries to define the standards of competency required in each workplace. Today, these standards are contained in a comprehensive set of training packages for all Australian industries (Australian Skills Quality Authority, 2024; training.gov.au). These are expressed as units of competency, which specify the standard of performance required in the workplace and how these are to be assessed.

In India, methods of traditional didactic teaching and manualized instruction are inadequate to equip workers for complex CBID delivery. Consequently, a partnership between the government of India, experts from six leading Non-Government Organisations (NGOs), CBID providers, and the University of Melbourne's (UoM) Nossal Institute for Global Health and Melbourne Graduate School of Education supported the development of new competency-based CBID training. This was conceptualized as a 3-phase project –

1. Designing and field-testing an underlying CBID acquisition of competency model,
2. Developing and piloting a competency-based curriculum and training course
3. Evaluating the effectiveness of the course to advance trainee competency.

In Phase One, 36 competencies were identified as underpinning quality CBID (Gale, Gillis and Grills, 2021). These were described at two to four levels of proficiency in an Observational Reporting Tool, enabling competency advances to be tracked through training and a set of overall training standards were developed. An example of a competency with its advancing performance descriptors is provided in Table 1 (the full assessment tool is tabled in Appendix A – CBID Acquisition of Competency Model and the training standards in Appendix B – CBID Competency Standards)

Table 1: Example competency and performance descriptors

Competency	Descriptors of advancing performance
Understands statutory provisions.	• Names the main disability-related statutory laws, provisions, and procedures and their connections. • Applies the correct statutory provision and procedure to the situation. • Justifies proposed adjustments/ changes to community infrastructure/ practice using the legislation.

In Phase Two, a 6-month competency-based training course was developed, with the assistance of the Rehabilitation Council of India (RCI) curriculum writing experts and the original subject-matter expert team. This addressed three main subject areas of:

1. Inclusive Community Development (ICD) (focus on the community),
2. Assessment and Intervention (A&I) (focus on the person), and
3. Professional Behaviour and Reflective Practice (PB&RP) (focus on the worker).

The learning requirements of the 36 competencies were analysed to achieve learning outcomes through teaching and learning activities appropriate to each stage. Learning outcomes describe what trainees will do, say, make, or write to facilitate or demonstrate their learning, while teaching sessions supply the necessary input and support to achieve those outcomes. An example of this development for Competency 4 cited above is provided in Table 2.

Table 2: Curriculum planning for Competency 4: Understands statutory provisions.

Competency:	Novice	Advanced Beginner	Competent
Understands statutory provisions	A. Names the main disability-related statutory laws, provisions, and procedures and their connections	B. Applies the correct statutory provision and procedure to the situation	C. Justifies proposed adjustments/ changes to community infrastructure/ practice using the legislation
Learning Outcome:	Builds a portfolio of relevant policies, acts, and schemes	Completes under supervision an application form for a disability-specific and general certificate for a person/ family	Conducts a gap analysis, prepares a presentation, approaches the appropriate office, and negotiates for change of infrastructure or practise to support a local person/ family
Teaching Input:	Week: 2 Time: 90mins Topic: Disability, Legislation, Acts, Policies	Week: 13 Time: 90 mins Topic: Sources for general and disability-specific certificates	Week: 8 Time: Full day Topic: Visit to District, Block, and Panchayat to collect information on Local Governance System and how public representatives are categorised.
	Week: 2 Time: Half-day Topic: Acts and Policies - tabling of details (portfolio)	Week: 14 Time: Half-day Topic: Presentation and practice on filling up a referral form and referral register	Week: 18 Time: Half-day Topic: Case study and analysis of formation of advocacy group, development of campaign, and advocacy skills demonstrated in achieving goals.

Accreditation by the RCI was completed in April 2021 and two pilot trainings were successfully run by 10 National Institutes and the six NGO research partners, including CBM India in Karnataka – the RCI registered training provider for that state. This paper documents a formal evaluation of the competency outcomes of the CBM India Trust training course. This evaluation research aims to better understand the relationship between the type of training and competency outcome and in doing so contribute to continuing course improvements. The following research questions were conceived:

1. To what extent did the training develop workplace competence?

2. What client outcomes were achieved by CBID trainee intervention?
3. How can the training be improved?

METHOD

CBM as the case study partner

CBM is a leading disability and development organisation in India working on programs, advocacy, capacity-building, and knowledge generation to improve the quality of life, inclusion, and empowerment of people with disabilities. With this expertise, CBM has been involved in the development of the competency-based CBID training from its inception as one of the six NGOs working with the RCI and UoM. Since the approval of the curriculum in early 2021, CBM India has successfully shepherded two cohorts of students from the state of Karnataka through the course, drawing on a range of subject-matter experts delivering course content and coordinating practice sites in and around Bangalore.

In 2023, an informal process of information-gathering about differences in CBID ways of working pre- and post-training was carried out and reported on (CBM India Trust, 2023). This indicated that post-training, CBID workers had a greater scope of community involvement, due to many new technical skills in areas such as participatory rural appraisal, disability screening, writing formal applications, and educating families. Consequently, they were able to support people with disabilities to be better served in their local communities and to access a full range of government schemes, resources, and services. Supervisors of graduates of the training also spoke of improvements in disability identification and the number of families who were able to be linked to social protection schemes, as well as better communication and report-writing and personal improvements in confidence, proactivity, responsibility, and patience.

Following these positive informal reports and interest to understand more specifically the impact of training on worker outcomes, CBM was chosen as the organisation for this Success Case Method study.

Success Case Method for Training Evaluation

Given the focus on understanding the impact of training on competency-growth, the Success Case Method (SCM) was selected to answer the research questions (Brinkerhoff, 2005).

The SCM is a case-study research method for evaluating training. It is suited to competency-based training evaluations as it evaluates actual performance against a model of competency, rather than relying on self-identified perceptions of the value of training alone. In this study we used the SCM to understand the impact of training on competence – what parts of the training worked, what parts didn't, what results the training achieved, and what should be done to get better results in the future. The study used purposive sampling to identify concrete evidence of training effect in verifiable incidents where learning was applied. Instances of non-success were also documented.

Only a small number of highest and lowest success cases are needed for an SCM study. This is because, firstly, it has been shown that a small number is adequate to inform about the effects of training, and secondly, analysing the broad middle tends to underrepresent the best effects of a program and overrepresent the worst, also known as the tyranny of the mean (Brinkerhoff, 2005).

There are two main steps to an SCM study - firstly, locating by survey the success and non-success cases and secondly, interviewing them to document and gather stories about the nature of success and corroborating evidence for their claims. To achieve these steps, the following preparatory tasks were first completed:

1. Developing an impact model or theory of the way training leads to desired field-based outcomes,

2. Preparing a survey questionnaire to enable identification of high- and low-success cases against the expectations of the impact model,
3. Preparing interview questions for high- and low-success cases,
4. Gaining ethics approval

Developing an impact model

An impact model is a description of a successful outcome of training. For the purposes of an SCM evaluation, what is needed is a table listing the competencies expected by the end of the training (Key Skills and Knowledge), what the trainee will do in the workplace with those competencies (Critical Applications), what the direct result will be in those being served (Key Results), and what will be the broader sector and societal impact of that behaviour continuing (Business Impact).

In the case of the CBID training, the 36 competencies within the six competency domains which are the focus of training constitute the Key Skills and Knowledge. Critical Applications are the performance of the competencies in the workplace, the outcomes of that competent performance are the Key Results, and the features of a community where those competencies are being exercised consistently is the Business Impact. Thus, the impact model specifies the actions and results for which the SCM searched, both in the survey and the interviews. Table 3 sets out a summary of these details, with Critical Applications (2) specifying the real-world provision and Key Results (3) the real-world outcome. (provided in full at Appendix C).

Table 3: Impact model defining successful application of training.

Critical application	Key results
Provision of a trustworthy knowledge source in disability, human rights, inclusive community development, and government legislation and provisions…	…achieves knowledgeable and competent individuals and communities in disability, inclusion, and achievement of rights and entitlements.
Provision of respectful, supportive and culturally sensitive communication and interactions…	…achieves positive, long-term relationships between CBID workers and recipients.
Provision of disability identification, planning, and service linking for all 21 disabilities of the RPD Act, 2016…	…achieves individualized service provision and appropriate, timely linkages and referrals.
Provision of basic rehabilitation for specific needs…	…achieves maximised function, capability, and independence.
Provision of competent inclusive development facilitation and community capacity-building…	…achieves inclusion through effective grassroots action.
Provision of professional, knowledgeable, and ethical CBID workers…	…achieves a widely respected CBID profession.

Preparing a survey questionnaire

The survey questionnaire was administered to all graduates to locate potential success and non-success cases. The questions were answered with a rating scale, enabling a quantitative estimate of results to be calculated – the proportion of trainees who report using, or not using, the training in the workplace, and the scope of success achieved (Brinkerhoff, 2005). In the case of the CBID training, the survey questionnaire was grouped into three sections:

1. Questions on the specific application of the six competency domains covered in the training, enabling the impact of the CBID training on trainee work performance and satisfaction to be understood against the stipulations of the impact model.

2. Questions of general interest about the trainee, their experience, goals for training, and views about training effectiveness,
3. Demographic questions.

In addition to the survey questionnaire results, summative results on the Observational Reporting Form were also used to identify the high- and low-success cases. The high-success respondents were asked the same questions, while analysis of the survey responses of the low-success respondents enabled tailoring of the questions around their specific insights. The competency domains were prepared for the respondents and the translator in the following format (in brackets the summary descriptor):

1. (Understanding) Understands people, culture, disability, government provisions, and community development.
2. (Relating) Builds and maintains working relationships.
3. (Screening, planning and referring) Screens for disability, supports planning and goal setting, refers, and writes reports.
4. (Providing rehabilitation and training others) Provides basic rehabilitation and trains others to support and meet specific rehabilitation needs.
5. (Fostering inclusive communities) Facilitates inclusive community development.
6. (Taking on the role) Conducts oneself responsibly in the CBID fieldworker role.

Interviews took place online via Zoom, with interviewer, transcriber, respondents, and translator all located separately.

Gaining ethics approval

Ethics approval to conduct this research was granted by the Ethical Committee of the Sigma Institutional Review Board. The study purpose and measures to safeguard privacy and confidentiality were explained in a plain language statement and written informed consent was obtained (see Appendix E).

Qualitative data analysis method

The method used to analyse the data was thematic analysis, which allows qualitative and quantitative to be analysed to identify patterns in responses (Braun & Clarke, 2006). Progressing through six steps, data is sequentially categorised into themes connecting to the research concern:

1. Data set is read.
2. Initial codes are generated.
3. Themes are identified.
4. Themes are reviewed.
5. Themes are named and defined.
6. A written argument is produced about the story revealed by the data (involves placing the codes within the finalised themes and adding extracts from the data typifying each theme).

Two researchers independently read and re-read the responses to the interview questions for domain (step 1) and agreed with the interview questions being used initially to code the data (step 2). Following this, the second researcher proposed and named a set of five broad themes encapsulating the coded data (step 3). The first researcher then re-read the data through the lens of this thematic proposal, removed duplicate ideas (step 4) and produced and defined a final set of three unique themes (step 5). An example of how a theme was generated following review is given in Table 5 and the full description in Appendix F.

Table 5: Example of data coding, review and thematic identification

Step 2: codes from interview questions	Step 3: Initial themes identified	Step 5: Final themes with definition	Example trainee comment
Good outcomes	Personal achievements post-training	Useful learning for real results: effective training involves workplace application with real-world outcomes for recipient and worker	"I have learnt how to conduct myself responsibly" (3) "I have made successful application for a child with disability to attend school" (1) My line manager says I have a better way of working with people and better representation in the community (5)

RESULTS AND DISCUSSION

Respondent demographics

Three high-success respondents and three low-success respondents were identified using the results of the summative assessment tool and the questionnaire responses. All six agreed to be interviewed. Demographics for respondents are provided in Table 6.

Table 6: Demographics of SCM study respondents.

#	Gender	Age	Education	Work Experience	Prior training	Other
1	F	55	10th	Special educator for last 19 years, and worked in CBR programme for 13 years	No	Person without disability
2	F	35	10th	Urban Rehabilitation Worker (URW) for a year. Was not working earlier.	No	Physical disability
3	M	39	10th	Working as URW for the last 2 years prior to that worked in a hotel and for daily wages.	No	Physical disability
4	M	45	10th	Basically, an agriculturist and has been working as Village Rehabilitation Worker (VRW) for 13 years.	No	Physical disability
5	F	48	10th	13 years as VRW, 4 years as teacher for children affected with leprosy and as a volunteer in HIV project for 4 years	No	Physical disability
6	F	20	12th	No work Experience	No	Hearing Impaired

Summary of responses

The responses to the interview questions demonstrated a strong connection between competency-based training and trainee competence, confidence, and improved client outcomes as evident in the following noted achievements from the course:

- Disability identification: The training facilitated accurate recognition of disabilities.
- Disability expertise: identifying and comprehending the needs of individuals with disabilities has become a specialised skill.
- Legal and disability awareness: Gained a broader understanding of disabilities and associated legal frameworks.
- Referral and support skills: The ability to refer individuals, aid in planning and goal setting and connect them with suitable services and program has been demonstrated.
- Technical skill support: Proficiency in report writing, and the application of tools like Participatory Rural Appraisal have been developed.
- Collaborative success: Developed the ability to work alongside community workers, to achieve superior outcomes.
- Engagement and relationship building: Participants have mastered the art of engaging with parents, nurturing relationships, and connecting with individuals with disabilities.
- Enhanced communication: Colleagues, superiors and the community have absorbed improvements in communication abilities.
- Overcoming hesitation: Addressed the reluctance of affluent families to disclose disabilities, using in-depth technique, technical knowledge to persuade them.
- Role clarity and connection: Enhanced understanding of professional roles, built stronger rapport, and effectively connected individuals to services.
- Workplace recognition: Notable improvements in reporting, work methodology, and community representation have led to acknowledgement from senior management.
- Role model recognition: Acknowledged as a role model by the line manager and program director leading to increased respect in the workplace.
- Professional development: Trainees have also cultivated personal attributes such as self-assurance, professionalism, and responsible attitude in their field worker roles.
- Commitment to ongoing education: A focus on continual education and staying abreast of recent trends and developments.
- Career Advancement: Viewed the training as a pathway to expand its opportunities within the disability services sector.

In addition, specific recommendations and suggestions were received for improving the training:

- Blended learning approach: Integrate practical sessions with theoretical instructions for a more hands-on learning experience.
- Technological and device education: Expand the curriculum to include comprehensive information on assistive devices and emerging technologies.
- Legal and policy framework: Provide detailed insights into relevant legislation, policies, and their practical implementation.
- Post- lecture resources: Ensure the availability of reference materials for trainees to consult following theoretical lectures.
- Professional conduct guidance: Offer ample information and resources to guide trainees on responsible conduct in their field worker roles.
- Fieldwork preparation: Create a booklet containing common field-related questions and answers to prepare trainees for real-world scenarios.
- Training duration extension: Prolong the training to one year to facilitate thorough understanding and alleviate time- related stress.

- Sign language proficiency: Place a greater emphasis on sign language interpretation skills within the training.

The following benefits summarise the results of the CBM training according to the study respondents:

1. Enhanced workforce competencies: Improvement in skills, performance metrics, and employee development.
2. Improved client outcomes: Higher quality service, positive client satisfaction.
3. Organisational impact: Enhanced competencies in trainees have led to more efficient work processes, aiding in better talent management.
4. Benchmarking standards: To standardise and optimize competency development across the workforce.

Coding data into themes and aligning with the literature

Three themes generated from the process of uncovering the story told by the data:

- *Useful learning for real results* – effective training involves workplace application with real-world outcomes for recipient and worker (the latter through increased knowhow and transformation into the role).
- *Training elements detracting from learning* – Course overload and inadequate practice support hampers learning.
- *Features of best-practice training* –theory and practice kept together, maximise usability of learning, provide responsive on-the-job support, and ensure ongoing learning.

Theme 1: Useful learning for real results

This theme outlines how learning inputs must extend beyond general knowledge to sufficiency to meet requirements of addressing real life situations. This is the hallmark of competency-based training – emphasizing what a person can do from their training rather than the training inputs (Guthrie, 2009).

All respondents commented about the real-world usefulness of their training, giving examples of improving the situations for their clients. They commented on usefulness of the acquired knowledge:

- Respondent 4: "There is a close relationship between poverty and disability. Many people with disability don't read and don't know about disability and small things like how to get a maintenance allowance, disability card, rehabilitation, and assistive devices. My role is to give information to those who have difficulty accessing this… People with disability are being marginalised and given wrong information about sports and recreational activities and I can now give the right information."
- Respondent 5: "My earlier knowledge was limited to helping people get the maintenance allowance and ID card. This program has helped me gain a lot of knowledge about different services and schemes and how to link people… also about types of disabilities."

A key learning valued by trainees was the capacity to screen for one of the 21 disabilities of the RPD Act 2016 and avail entitlements for those identified. Other respondents noted the importance of developing competency in communication:

- Respondent 1: "I learned communication skills that have made parent counselling easier and helped me build relationships and form community groups… People have given me feedback about my communication – colleagues, teachers and the community have told me that I have improved in communication skills immensely."
- Respondent 3: "The training has helped me build rapport with people with disability and their families… There is lots of hesitation to reveal disability in the family, especially in people from a rich background as they think they will be looked

> down upon by the society… From the training I can convince people to come forward to receive information to help them and mobilise parents of children with severe disability to bring their children into the community."

The comment from Respondent 3 above also highlights the importance of the combined competencies of understanding and relationship-building to bring about attitude change, and the importance of broader support and positive attitudes provided by family members, trainers, and other trainees with disability:

- Respondent 1: My fellow trainees motivated me as they had disabilities, and this motivated me to learn."
- Respondent 4: "My brother motivated me as I look up to him and he encouraged me to enter this work while others were taunting me and telling me I was misguided and wouldn't get anything out of it… People with disability are most marginalised."

At the same time, some respondents noted gaps in their knowledge in some settings:

- Respondent 2: "I am an Urban Rehabilitation Worker (URW) and my role is difficult to implement because I come from the municipality – people don't understand the purpose of my visit. We need a booklet with answers to difficult questions and situations."
- Respondent 3: "*The training should have more in-depth information, e.g., we were told that the RPD Act 2016 requires 4% employment reservation for people with disability, but how do we ensure this right, how do we lobby, how do we make it happen? We need more information on how to make employers comply with the Act – this is what must be included in the training. The course must extend the knowledge to make it useful... The duration of the course should be one year to cover everything in sufficient depth.*"

These comments highlight the complexities of the CBID role and the challenge of working towards competency as it involves dimensions beyond performance of individual tasks. These have been described as consisting of task management skills, contingency management skills, and job/role environment management skills (Gillis and Griffin, 2005). Trainee placements need to be structured to support trainees to progressively develop in these aspects as well. The complexity of workplace situations needs to be managed so that learning can be pitched at the "just-right" level of challenge to help competency to swiftly advance. Quigley et al (2020) suggests incorporating the following teaching strategies and practical supports to optimise workplace-based learning:

- Demonstrations – trainees first observing trainers or fieldwork supervisors complete the workplace task.
- Shadowing – trainees and trainers/ fieldwork supervisors both completing the task, such as a screening assessment and then comparing and discussing results.
- Case discussions – trainees and trainers/ fieldwork supervisors sitting and discussing a case in more detail once basic understanding has been reached.
- Simulations – trainees practicing difficult skills or situations on each other first, until comfortable.
- Question and answer sessions – trainees having opportunity to ask experts about the difficult placement situations encountered.
- Making resources and helpful reading available – giving trainees access to best-practice guidelines or videos.
- Gradual increase of responsibility and independence – structuring workplace tasks to increase challenge. This includes possibilities of changing the task and/ or context. Task simplification may involve, for example, screening just one disability or availing just one entitlement, while context simplification may involve screening

that begins with the client group most familiar to the trainee. From there, increasing complexity can be scaled as the trainee becomes more proficient. This requires fieldwork placements to be carefully supervised, particularly during Phase 2 of the course.

Theme 2: Training elements detracting from learning

As noted above, respondents commented on the impact of course overload and inadequate practice support on learning:

- Respondent 2: "I was asked several questions by parents, like my purpose of visit. We need help to answer these questions."
- Respondent 3: "The duration of the training should be one year as there is a lot to learn and so there was pressure. There needs to be in-depth information on certain topics like the Act, but more time to learn so there is not the pressure."

The experience of overload and pressure is a factor requiring consideration by the training provider. A question to ask is whether the curriculum includes excess "knowledge bulk" not fundamental to the grasp or competent delivery of CBID – what is known as the "stuffed" curriculum (Cousin, 2006). This can be difficult to determine, but one approach would be to remove the least mentioned/ least affirmed domains of competency. For this study, the fourth competency domain – Intervention and Training for Specific Needs, received comments for just one aspect: supporting use of basic assistive technology and devices. In the other areas of this domain – enhancing social, emotional, and cognitive development and early learning, enhancing personal independence, communicating using different communication methods, and providing basic rehabilitation training to others, no mention of application of training was made. These areas require significant competency and training opportunity and close working with allied health professionals, so it is possible that the content supplied was inadequate to enable workplace application. A response may be to move this part of the Certificate training to an elective or a different curriculum, such as a Diploma course that also develops rehabilitation, supervision, and project management capacities.

As Brinkerhoff (2005) has noted, achieving performance results from training is a whole organisation challenge that training cannot accomplish alone. Factors and actions that determine the success of training transfer must also be considered. In work areas that carry possibility of societal stigma, personal characteristics and work influences are also a consideration. Personal characteristics include motivations, aspirations, experiences and supports that are socially formed and negotiated within homes, communities, and places of work. Work influences are all aspects of the work ecosystem in which the trainee evolves (Avon, 2021).

The responses in this study highlight the value of the presence of trainees with disabilities on the course. Other factors affecting training transfer and maintenance of the gains of training over time include the variable levels of system support in their new workplaces that graduates might receive, the governance and policy environments they work in, the work they are asked to do, the support from co-workers they receive, and the extent to which recipients of their service value their contribution (Naicker et al. 2019). As this case-study involved a non-government training provider able to provide considerable support to trainees during their training and employ several graduates, consideration should be given to the minimum level of competency that will be required for successful employment under more challenging conditions.

Theme 3: Features of best-practice training

Many features of quality competency-based training were noted and have already been mentioned:

- work-relevant learning and opportunities for practice (screening for disability, understanding challenges people face, types of disability and their entitlements, how to avail entitlements, map community assets, write reports, engage, counsel parents, build rapport, and convince people and the wider community),
- personalised learning and support – "The coordinator gave time to time updates and helped me catch up on the sessions I had missed due to other health issues",
- keeping theory and practice together – ("Doing assignments and day to day tasks simultaneously meant I was able to apply the things I learned in the training on field"; "After a few sessions of theory we should have a few practicals rather than having all practical after all theory"),
- life-long learning ("We need to extend our knowledge about use of assistive devices and information about new technologies"; "We need more detailed information on how to access the Act to make sure people with disability are getting their entitlements"; "We need to be able to identify more disabilities and how to help them").

In relation to lifelong learning, the motivation of adults to learn is so they can improve their knowledge to improve their professional and private lives (Chappell et al. 2003). Because knowledge is changing rapidly, lifelong learning is essential for them to remain up to date (Solomon, 2007). Courses teaching adults need therefore to:

- be situated in the real world (Edwards et al. 2004)
- work in partnership with them to determine learning objectives and design instructional content,
- draw on and develop collaborative, communication, problem-solving and self-initiating skills,
- draw on their own experience to solve case-study scenarios,
- make them responsible for their learning.

LIMITATIONS

The study provided an in-depth analysis of CBID training within Karnataka and among the CBM India Trust trained individuals, offering valuable insights for this setting. At the same time, its nature as a case study involving one context means it is not possible to draw broad implications or generalise from this research – for that, a larger-scale comparative study is needed.

However, with a small sample size has come the possibility of a more detailed examination of experiences at either end of the success and satisfaction continuum. As a result of using the Success Case Methodology, the benefits and issues of the training program have been able to be more clearly seen, supporting both the recommendations for broader uptake of the course as well as suggestions for its ongoing improvement.

CONCLUSION

This impact study aimed to investigate the extent to which CBID training enhances workplace competencies (RQ1), determine the client outcome resulting from CBID training interventions (RQ2), and identify ways to improve the training (RQ3).

In response to the first two research questions, the course received strong endorsement from the respondents (RQ1), who were able to illustrate the benefits of their learning on recipients of their work and on themselves in terms of skills and confidence. Many positive reports from others about their development and transformation into the role were sources of pride and motivation (RQ2).

The following summarises some suggestions for further improving the course which are generated from the data and analysis of the competency-based training literature (RQ3):

- Incorporate suggestions of best-practice workplace-based training, including "just right" challenge.
- Stuffed curriculum – remove elements that cannot be taught to sufficient depth in the time to enable successful and safe application.
- Training transfer – train people to the level of competency required for challenging conditions.
- Lifelong learning – make trainees partners with prior knowledge to work on and responsible for their own learning.

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APPENDICES

Appendix A - CBID Acquisition of Competency Model.

Work aspect	Competency	Performance level
1. Frameworks of Understanding	1.1 Understands community development and CBID	Defines barriers to and principles of inclusion in the community
		Explains the impact of backgrounds on the experience of disability and disability inclusion
		Compares different community perspectives on disability and inclusion
		Develops arguments to counter negative community attitudes and outlook
	1.2 Understands disability conditions (definitions, causes)	Lists the main factors that do and don't cause disability (Fact vs superstition)
		Describes the 21 disabilities under the RPD Act, 2016
		Explains the causes of disability to counter incorrect or superstitious understandings
	1.3 Differentiates between disabilities	Differentiates between obvious disabilities (e.g., vision/ hearing / evident physical disability)
		Identifies developmental disabilities, other neurological diseases
		Differentiates psychosocial disabilities and mental illness
	1.4 Understands statutory provisions	Names the main disability-related statutory laws, provisions, and procedures and their connections
		Applies the correct statutory provision and procedure to the situation
		Justifies proposed adjustments/ changes to community infrastructure/ practice using the legislation
	1.5 Understands background differences and their impact	Explains factors that contribute to and hinder inclusion of persons with disabilities by communities
		Identifies the interplay of [socio-economic/ gender/ caste/ religious] factors impacting observed situations
		Negotiates for the benefit of all, utilizing unwritten ground rules of different groups
2. Relationship Building and Maintenance	2.1 Reads family/ relationship structures and dynamics	Follows expected societal norms when relating to people and families living with disabilities
		Demonstrates respectful and supportive behaviour to people and families living with disabilities
		Identifies salient/ critical issues and features in family/ relationship dynamics
	2.2 Provides social and emotional support	Informs individuals and families about various strategies to improve emotional wellbeing
		Applies an emotional support strategy in response to an obvious (i.e., stated) need
		Provides emotional support in response to a holistic appraisal of needs
	2.3 Demonstrates effective listening	Responds to questions with appropriate basic information and advice
		Uses learned listening strategies to support understanding of the situation and need
		Discerns unspoken concerns and responds appropriately
	2.4 Respects disability as a source of knowledge	Restates in one's own words the right of people with disability to be treated equally
		Makes space and elicits the contribution and insights of people with lived disability experience
		Motivates the community to relate to and engage with disability from a strengths-based perspective
3. Assessment, Referral and Report	3.1 Screens for disability	Completes basic checklist as instructed
		Selects and administers appropriate checklist
		Factors in all circumstances that might be impacting assessment accuracy

Writing, Goal-Setting and Planning	3.2 Communicates findings of screening test	Reports low-stakes information (positive/ neutral in impact) about the screen Refers questions beyond scope of practice to relevant professionals and follows up to ensure they have been understood Communicates more difficult-to-hear information in consideration of the received
	3.3. Links people to professional intervention/ services	Ensures Disability Certification/ UDD Identifies the correct referral pathways and refers appropriately Identifies and refers people at risk and hard to reach Facilitates camps and campaigns to bring professional services to village level
	3.4 Writes reports	Documents basic information using prescribed format Provides simple interpretation of data/ results in reports Creates simple reports
	3.5 Supports individuals and families to set goals and plan	Identifies appropriate functional goals for a range of basic conditions (ICF) Participates in collaborative discussions with the family/ relationship Completes a family planning and goal-setting meeting according to guidelines Facilitates collaborative planning discussions and decision-making in the family
	3.6 Assists individuals and families to identify assets and strengths	Describes the strength-based approach Includes questions about assets and strengths in the planning process Interprets and incorporates findings about individual/ family strengths into the plan
4. Intervention and Training for Specific Needs	4.1 Enhances movement and physical functioning	Describes best-practice methods for improving functioning for common motor conditions Follows through on prescribed activities/ exercises Informs about correct use of basic assistive devices Notes changes to physical functioning because of therapy programs
	4.2 Enhances social, emotional, and cognitive development and early learning	Encourages social participation by the family in the community Informs family about available early learning resources Facilitates family resourcefulness in using what is available to foster development and learning
	4.3 Supports the use of basic assistive technology and devices	Identifies appropriate assistive devices for different conditions Informs family members about simple assistive techniques (e.g., human guide) Reminds individuals and families about the correct use of therapist-prescribed assistive technology (e.g., mobility devices, communication devices) Reports areas of functioning where assistive technology might be useful
	4.4 Enhances personal independence	Assists in facilitating independence in activities of daily living Independently facilitates independence in activities of daily living Builds capacity in family members to facilitate greater personal independence Problem-solves to overcome individual/ family resistance to improving personal independence

	4.5 Communicates using different communication methods	Describes and gives examples of different forms of communication for different disabilities/ needs Communicates one-step information (e.g., single words, greetings) in other formats as required Problem-solves to improve communication for an individual (receptive and/or expressive)
	4.6 Sensitizes and encourages others for disability support	Informs families about ways to support their member with a disability Coaches close community members to better connect/ interact with people with a disability they know Advocates to village functionaries about general disability needs and their responsibilities
5. Community mapping, advocacy and education and inclusive community development	5.1 Establishes necessary community connections	Lists main stakeholders in the village Plans and maps strategically, considering purpose for mapping and less obvious stakeholders such as schools Communicates with stakeholders to make/ strengthen community connections Obtains necessary directives from authorities (e.g., the Taluk)
	5.2 Enables utilization of community resources	Encourages families to use their existing (own) resources Motivates the community to actively contribute from its own resources Facilitates government resources to be available to individuals and families Brings external resources into the village
	5.3 Shares relevant information and documents compliance	Explains relevant support provision schemes, programs, and documents Collects data on access to provisions by people with disabilities Reports on compliance at the village level
	5.4 Advocates for inclusion with community leaders	Observes persuasive interactions with leaders With support, makes a case for greater inclusion to local leaders Interacts on one's own to persuade Block level leaders to engage in inclusive development
	5.5 Motivates individuals and families to join community groups	Identifies the factors preventing individuals and families from joining community groups Develops arguments supporting greater community participation by individuals/ family members Persuades/ makes a case for a family/ individual to join in community life
	5.6 Identifies potential leaders	Lists the characteristics of good leadership in simulations Identifies leadership skills in action in the community/ CBID workplace Identifies obvious leaders (from among individuals with disabilities, family members, community) Encourages and informs potential leaders about developing their leadership capacity
	5.7 Supports formation of groups and DPOs	Describes observed group formation processes Assists in the running of support group/ OPD meetings Encourages individuals and families to meet to discuss and problem-solve
	5.8 Organises inclusive programs and special days	Assists OPDs/community to run inclusive programs and special days Observes and participates in the organization of inclusive programs and special days Supports the community / DPO to conduct inclusive programs and special days/ events

6. Responsible Conduct in the Role	6.1 Takes on the requirements of the role	Identifies challenges to the role in one's own background and formulates arguments against these Demonstrates reliable, responsible, impartial behaviour with people of different backgrounds Adapts approaches to the needs of individuals / families/ communities
	6.2 Contributes as an active team member	Recognizes the value of different skill sets in a team Fulfils responsibilities within CBID and multidisciplinary teams Facilitates and fosters positive team functioning
	6.3 Conducts oneself in a trustworthy manner	Completes assigned tasks as arranged Keeps confidential information entrusted Demonstrates impartiality when dealing with parties who have opposing points of view
	6.4 Operates within relevant legal and regulatory framework	Complies with relevant laws and code of conduct/ SOP Ensures one's own workplace behaviour and interactions respect cultural and contextual norms Incorporates new ideas/ practice/ frames of reference into existing SOPs
	6.5 Preserves personal social-emotional wellbeing	Lists ways to support personal social-emotional wellbeing Identifies when the role they play is having an emotional impact Monitors their own wellbeing and seeks support
	6.6 Plans ongoing learning to improve CBID performance	Identifies gap in knowledge and skills Takes advantage of organized learning opportunities
	6.7 Prepares work plans	Prepares work plans according to prescribed formats Adapts work plans for unexpected events/ situations Plans work, taking into consideration longer-term goals

Appendix B. CBID competency standards (in ascending order)

Level 4: Above Standard	Advocates for community-wide adoption of universal design access principles and practices. Interprets data and results in professional reports. Justifies proposed changes to community practices using relevant legislation. Interacts persuasively with community leaders and identifies and equips potential leaders. Advocates to others for personal responsibility for ethical occupational practice. Is committed to developing their capacity in the field through advanced training.
Level 3: Competent	Completes functional assessments independently and makes a holistic appraisal of needs. Facilitates collaborative planning in the family, considering unique dynamics and individual and family strengths. Provides emotional support. Undertakes cross-sectoral intervention and trains others in the community. Reports on compliance at the village level and educates village functionaries. Facilitates community change through application of relevant legislation and understanding of the various community perspectives. Guides the community through PRA and builds capacity to achieve self-determined goals through self- directed advocacy. Plans in consideration of longer- term goals and strives for high professional standards and safeguarding of vulnerable people. Undertakes ongoing learning in consideration of needs and requirements of the role. Actively supports others' wellbeing and effectively advocates for the goals and commitments of their team.
Level 2: Advanced Beginner	Identifies less obvious disabilities and communicates sensitive information considerately. Completes basic assessments that include family strengths, trains family members in simple rehabilitation and makes appropriate referrals. Communicates useful information in a timely way and supports collaborative planning and goal setting. Identifies factors causing community exclusion and applies the correct statutory provision to link people to appropriate government entitlements. Elicits the insights, leadership, and independent goal setting of people with disability. With support, works alongside OPDs to bring inclusive programs and professional services to village level. Manages workload in routine tasks and adapts work plansEngages constructively with other team members and demonstrates responsible behaviour, respecting confidentiality and cultural norms. Takes responsibility for own wellbeing and makes use of available supports.
Level 1: Novice	Differentiates between obvious disabilities and follows societal norms in relating. Describes a contemporary model of disability and explains disability law and policy. Observes assessments, documenting results using prescribed formats, and assists in basic rehabilitation. Practices training family members in simulated settings. Explores inclusive development practices and explains the impact of barriers on disability. Participates in group meetings and observes successful advocacy and inclusive community events. Explains PRA and community mapping and profiling procedures and engages in mapping village stakeholders. Engages in group work. Reflects on responses to disability, identifies potential emotional impacts and challenges arising from attitudes, values, and background. Attends to feedback about gaps in their skillset.

Appendix C. CBID Training Impact Model.

1 Key Skills & Knowledge	2 Critical Applications	3 Key Results	4 Business Impact
	1. Frameworks of Understanding		
Understand community development and CBID	Inform about disability, rights, and entitlements. Identify relevant statutory provisions. Adjust support and interaction to different backgrounds.	Entitlements are procured appropriately for all 21 disabilities of the RPWD Act. Community barriers, needs, and resources are identified and addressed. Services based on the CBID matrix are implemented.	Superstitious understanding of disability causation is eliminated. Disabling barriers in the community are eliminated.
Identify disability conditions			
Differentiate between disabilities			
Understand and apply statutory provisions			

Understand and work with background differences and their impact		Grievances are redressed with a process suited to context. People with disability are aware of their rights and entitlements.	Implementation of relevant acts, policies, and schemes achieves just and inclusive outcomes for individuals and families of all backgrounds.
2. Relationship Building and Maintenance			
Read family/ relationship structures and dynamics	Build and maintain good working relationships. Support mental health and emotional wellbeing. Attend and pay attention to insights derived from lived experience.	People with a disability feel heard and respected when they communicate their needs and insights. Positive, long-term relationships exist between CBID workers and recipients	CBID worker valued byfamilies and community for their relational and interaction capabilities. People with disability and their families are respected in their local community.
Provide social and emotional support			
Demonstrate effective listening			
Respect disability as a source of knowledge			
3. Assessment, Referral and Report Writing, Goal-Setting, and Planning			
Screen for disability	Conduct a disability screen for the local community. Communicate findings of the screening appropriately. Incorporate and draw on strengths and assets when setting goals and planning.	Timely community-based identification of persons with disability. Proper documentation, reporting and referralprocesses followed. People are linked to correct professional services in a timely way. Goals and plans are negotiated and achieved.	Persons with disability are correctly identified. Persons with disability are appropriately assessed and followed up. Persons with disability and families draw on their assets and strengths. Repository of service providers with contact details is established.
Communicate findings of screening test			
Link people to professional services			
Write reports			
Support people/families to set goals & plan			
Assist individuals and families to identify assets and strengths			
4. Intervention and Training for Specific Needs			
Enhance social, emotional, and cognitive development and early learning	Consistent with workplace level, provide basic intervention and capacity-buildingfor individuals and families.	Timely community-based intervention for a range of disability-conditions is supplied.	Capacity and wellbeing of individuals and families living with disability is maximised.
Support the use of basic assistive technology and devices			
Enhance personal independence			
Communicate using different communication methods			

Sensitize & instruct others to give support			
5. Community mapping, advocacy and education, and inclusive community development			
Establish necessary community connections	Initiate inclusive community development activities in the local community. Coordinate, foster, and empower local inclusive community development activities. Give rationale for involvement in community action for inclusion. Follow correct procedures for organising inclusive programs and special days.	Local community functioning is rights-based. Contacts with NGO's and Government organisations have been established. People and families with disability know of support and advocacy groups of relevance. People and families with disability are part of support and advocacy groups relevant to them. People/ families with disability are part of the leadership of local inclusion activities.	All community services are linked through networking. All local resources are being utilised effectively. Physical and social environments are compliant in accessibility. There is wide community commitment to and involvement in inclusive development. Inclusive community development is long-term because it is locally led.
Enable utilisation of community resources			
Share information & document compliance			
Advocate for inclusion with local leaders			
Motivate individuals and families to join community groups			
Organise inclusive programs & special days			
6. Responsible Conduct in the Role			
Take on the requirements of the role	Relate professionally and in a trustworthy manner. Remain within the limits of their role. Complete work requirements on time Manage their wellbeing, and ongoing learning needs.	Individuals, families, and communities receive a professional, timely and competent service.	CBID workers are trusted in the workplace and family homes and considered for leadership roles and responsibilities. Individuals and communities are strengthened through reliable and effective disability inclusion and inclusive development.
Contribute as an active team member			
Conduct oneself in a trustworthy manner			
Operate within relevant legal and regulatory framework			
Preserve personal wellbeing			
Plan ongoing learning to improve skills			
Prepare work plans			

Appendix D. Survey questionnaire and demographics.

Section 1: Applications of specific aspects of the training

1. I have used the training to understand people, culture, disability, government provisions, and community development.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

		expect any results			

2. I have used the training to build and maintain working relationships.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not expect any results	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

3. I have used the training to screen for disability, support planning and goal-setting, refer, petition and link, and write reports.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not expect any results	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

4. I have used the training to provide basic rehabilitation and train others to support and meet specific rehabilitation needs.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not expect any results	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

5. I have used the training to facilitate inclusive community development.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not expect any results	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

6. I have used the training to conduct myself responsibly in the CBID fieldworker role.

Tried this and had clear and positive results	Tried this but had no clear results yet	Tried this somewhat, but do not expect any results	Tried this and it did not work	Have not tried this at all	Tried this, but not because of the training

<u>Section 2: Questions of general interest</u>

1. Prior to this training, had you received any disability-related training? Y / N
   If Yes, number of years _________
2. Prior to this training, had you worked in a disability-related field? Y / N
   If Yes, number of years _________
3. Due to the training, do you experience greater fulfilment in the work that you do?
   Y / N / NA
4. What were your hopes/ goals for the training?

(a)	(b)	(c)	(d)

become a full-time community health or rehabilitation worker	use the training as part of my position where necessary	use the training to achieve a job promotion	not use it at all

5. Which statement best describes your experience since participating in the training?

(a)	(b)	(c)	(d)	(e)
I learned something new, I used it, and it has led to some very worthwhile results	I learned and tried some new things, but can't point to any worthwhile results	While I may have learned something new, I have not been able to use it yet	I already knew about, and was doing, the things this training taught	I don't think I can really use what I learned in the training

6. What is your overall impression of the training?

(a)	(b)	(c)	(d)
The training has definitely vastly improved my community health work	The training offered valuable insights into community health work	The training was not really a good health and rehabilitation course	The training was disappointing and not useful at all

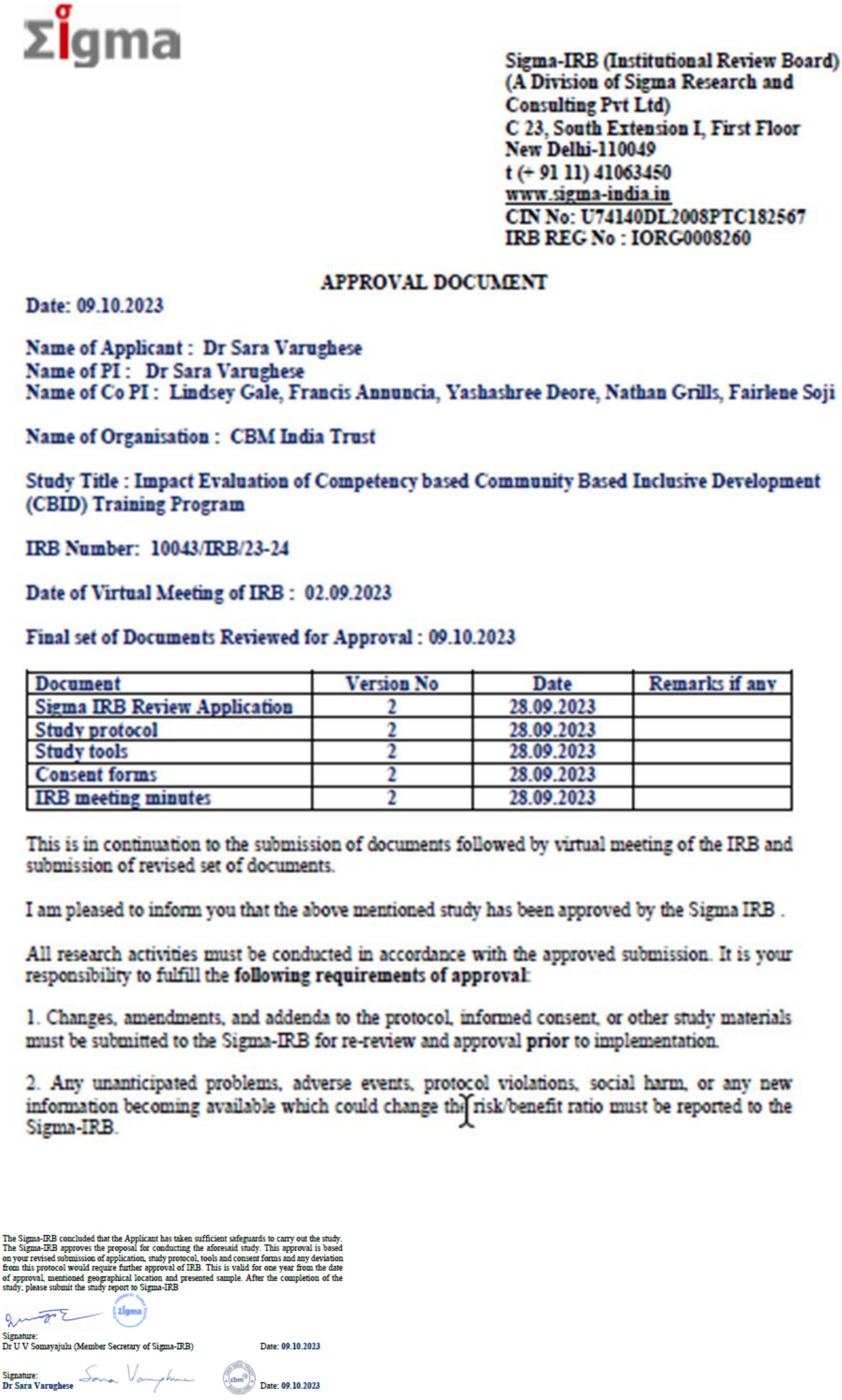
7. If you have not tried to apply the training at all, please provide reasons.

Section 3: Demographics

1. CBID Batch& Year:
2. Name:
3. Age with Date of Birth:
4. Gender:
5. Area of Domicile: Rural/Urban
6. Educational qualification:
7. If working, designation:

If you are person with disability, specify the type of disability.

Appendix E. Ethics approval



Sigma-IRB (Institutional Review Board)
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APPROVAL DOCUMENT

Date: 09.10.2023

Name of Applicant : Dr Sara Varughese
Name of PI : Dr Sara Varughese
Name of Co PI : Lindsey Gale, Francis Annuncia, Yashashree Deore, Nathan Grills, Fairlene Soji

Name of Organisation : CBM India Trust

Study Title : Impact Evaluation of Competency based Community Based Inclusive Development (CBID) Training Program

IRB Number: 10043/IRB/23-24

Date of Virtual Meeting of IRB : 02.09.2023

Final set of Documents Reviewed for Approval : 09.10.2023

Document	Version No	Date	Remarks if any
Sigma IRB Review Application	2	28.09.2023	
Study protocol	2	28.09.2023	
Study tools	2	28.09.2023	
Consent forms	2	28.09.2023	
IRB meeting minutes	2	28.09.2023	

This is in continuation to the submission of documents followed by virtual meeting of the IRB and submission of revised set of documents.

I am pleased to inform you that the above mentioned study has been approved by the Sigma IRB .

All research activities must be conducted in accordance with the approved submission. It is your responsibility to fulfill the **following requirements of approval**:

1. Changes, amendments, and addenda to the protocol, informed consent, or other study materials must be submitted to the Sigma-IRB for re-review and approval **prior** to implementation.

2. Any unanticipated problems, adverse events, protocol violations, social harm, or any new information becoming available which could change the risk/benefit ratio must be reported to the Sigma-IRB.

The Sigma-IRB concluded that the Applicant has taken sufficient safeguards to carry out the study. The Sigma-IRB approves the proposal for conducting the aforesaid study. This approval is based on your revised submission of application, study protocol, tools and consent forms and any deviation from this protocol would require further approval of IRB. This is valid for one year from the date of approval, mentioned geographical location and presented sample. After the completion of the study, please submit the study report to Sigma-IRB

Signature:
Dr U V Somayajulu (Member Secretary of Sigma-IRB) Date: 09.10.2023

Signature: Sara Varughese
Dr Sara Varughese Date: 09.10.2023

Appendix F.Data coding, review and thematic identification

Step 2: Initial codes	Step 3: Initial themes	Step 5: Final themes	Example comment
Training elements used	Application of training in the workplace	Useful learning for real results – Learning is useful when it can be applied in the workplace for real-world benefit that includes impact for the recipient and worker knowhow and transformation into the role	“I helped a person with physical disability who sat idle at home. Because of my intervention, he got a pair of crutches and has now started walking around. I also helped him get a small amount from the municipality and he now has a small shop and feels independent” (5) “I have learnt how to conduct myself responsibly” (3) “I have made successful application for a child with disability to attend school” (1) My line manager says I have a better way of working with people and better representation in the community” (5)
Application in workplace	Workplace application and results		
Good outcomes	Personal achievements post-training		
Trainee supports	Motivating factors for completing training	Training elements detracting from learning – learning is hampered by course overload and inadequate practice support.	“The learning and assignments were linked to the workplace and were very practical” (1) The assignments and day to day tasks were expected to be done simultaneously which was overburdening, but I was able to apply the things I learned in the training on field” (5) “When I do door-to-door screening, people don’t understand my role and it is very difficult to make people understand. I need to know how to tackle questions” (2)
Barriers to benefitting from training	–		
Suggestions to improve training	Suggestions to advance training	Features of training best-practice – best-practice CBID training keeps theory and practice together, maximises usability of learning, on-the-job support, and ongoing learning.	“After few sessions of theory we should have few practicals rather than having all practical after all theory” (1) “The training needs more in-depth information – it is not just knowing the 4% reservation but how to access and use the Act, how to lobby and make it happen, how to ensure this right. The course must be extended so the knowledge it provides is useful” (3) “We need to keep learning about use of assisted devices and info about new technologies regarding the assisted devices” (2)

Original Research Article

Indonesian Inclusive Schools: Unravelling Parents' Hopes and Concerns for the Future of Children with Disabilities

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ABSTRACT

Objective: Inclusive education is a miniature society that prepares children with disabilities to live in society after their education. This study aimed to explore parents' experiences of expectations and worries in schools, hopes and concerns for the future of children with disabilities attending inclusive/mainstream schools.

Methods: Ten parents, representing primary, middle, and secondary school education levels with varying disabilities, were interviewed face-to-face using a semi-structured interview guide. This study uses reflexive thematic analysis to examine the research results.

Results: Five primary themes were examined: parents' strategies for addressing their expectations and concerns regarding education, and their hopes and concerns regarding the future. Sub-themes presented some parents' perspectives on children's development, third-party support, and parents' resilience efforts to overcome worries and concerns, subsequently building expectations and hopes.

Conclusion: Inclusive education can show a positive relationship between children, parents, teachers, school authorities, and policymakers. Parents have complex struggles when they send their children to inclusive/mainstreaming schools. Long-term support gives parents optimism and the ability to seek other resources both when the child is undergoing education and for their future. Meanwhile, low support from mainstreaming schools and/or severe disability conditions creates more anxiety and frustration for parent about the development of their child’s education and future.

Limitations: Measuring parents' hopes, concerns, and strategies for sending their children to inclusive/mainstream schools with limited participants creates challenges for researchers. This research aims to describe social constructivism built from the experiences of parents who have children with disabilities, so it cannot be generalized. However, it would support transferability for further research that is more specific to the group of parents who had children with a common disability and or similar school level in another setting study.

Keywords: Inclusive education; parents’ hopes and concerns; parents of children with disabilities; parents’ strategies

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INTRODUCTION

Although the number of inclusive schools continues to grow alongside the development of new educational policies, children with disabilities still face significant barriers in accessing equitable education opportunities (UNICEF Indonesia, 2023). These barriers are often rooted in systemic factors such as the limited number of inclusive schools that are genuinely prepared to accommodate children with special needs, insufficiently trained educators, inadequate infrastructure, and low levels of awareness among parents and communities (Pratiwi, 2015). As access to special education institutions remains limited, inclusive schools are frequently positioned as the most viable alternative for children with disabilities. However, this perspective often reinforces the implicit notion that children with disabilities are better served in segregated settings rather than within mainstream education. Such assumptions risk undermining the very principles of inclusion (Natadireja et al., 2023; Tugiah & Trisoni, 2022). Furthermore, inconsistencies between national regulations such as the Ministry of Education Regulation No. 70/2009 on Inclusive Education and Law No. 8/2016 on the Rights of Persons with Disabilities reflect a lack of policy integration, which contributes to confusion and unequal implementation at the school level (Anggraini et al., 2022). The national initiative promoting child-friendly schools, intended as a benchmark for child-friendly cities, also poses practical challenges for educational institutions, particularly in creating learning environments that are genuinely inclusive and safe for all learners. A case study conducted in Malang highlights these challenges, revealing that both inclusive and mainstream schools struggle to provide appropriate support not only for teachers but also, and most critically, for children with disabilities and their families who seek equitable access to quality education.

The role of parents of children with disabilities in education

A growing body of research underscores the critical role of parental involvement in the educational development of children with disabilities. While educators and schools serve as the primary facilitators of learning, the consistent engagement of parents is widely recognized as a key determinant of academic and developmental success for these children (Elmira & Negmatzhan, 2022; Novitasari et al., 2023). Nevertheless, studies reveal that many parents remain unaware of the significance of their involvement or are uncertain about how to effectively support their children's learning processes (Pratiwi, 2015; Tugiah & Trisoni, 2022). These studies, however, often stop short of investigating the underlying causes of this lack of awareness. Parental participation is shaped by a complex interplay of factors, including economic constraints, prevailing parenting norms, and the severity of the child's disability (Logan et al., 2023). In contexts where systemic or institutional challenges arise, parents are expected to advocate for their children’s rights; however, many are reluctant to do so, particularly when such advocacy appears to contradict official policies or institutional authority (Mann et al., 2024). In Indonesia, cultural and religious traditions further complicate this dynamic. Deeply rooted Asian values and religious beliefs often position teachers as authoritative figures who should not be questioned, influencing parental behavior and engagement in school settings (Arifin, 2021; Yasin et al., 2023). For example, the Javanese philosophical concept of *‘nrima ing pandum’* which encourages individuals to accept one’s circumstances as part of divine will—can lead to passive acceptance rather than proactive advocacy (Mutia et al., 2023; Rakhmawati, 2022). Such cultural influences highlight the need for more context-sensitive approaches to fostering meaningful parental involvement in inclusive education.

The Impact of Inclusive Education on Parents' Psychological Condition

Inclusive education is widely perceived by parents as a promising avenue to fulfill the fundamental right to education for every child, including those with disabilities. It represents a hope that their children will have the opportunity to develop, learn, and grow alongside their typically developing peers (Jesslin & Kurniawati, 2020; Nur & Jafar, 2022). Meaningful collaboration and sustained support between schools and parents are critical in reinforcing these parental expectations both regarding the quality of education in inclusive settings and the long-term prospects of their children (Heryati et al., 2019; Logan et al., 2023; Mann et al., 2024; Novitasari et al., 2023; Novriani et al., 2023). Despite these positive aspirations, parents often encounter significant social and legal obstacles when navigating the realities of inclusive education systems (Logan et al., 2023; Mann et al., 2024). One of the most pressing concerns involves the vulnerability of children with disabilities in mainstream classrooms, particularly in relation to peer bullying and exclusion, which not only undermines their right to a safe learning environment but also heightens parental anxiety (Subasno et al., 2023). The interplay of hope and fear, shaped by both the potential and the risks of inclusive education, profoundly influences how parents conceptualize the educational journey of their children with disabilities. This emotional and cognitive tension forms the central focus of the present study.

OBJECTIVE

Inclusive education represents a critical dimension in the pursuit of equitable development and future opportunities for children with disabilities, affirming their right to be educated alongside their peers without disabilities. This study aims to investigate the lived experiences of parents whose children with disabilities are enrolled in inclusive or mainstream educational settings. Specifically, it explores how these parents perceive their children's developmental progress within such environments and the nature of the support provided by schools. The findings shed light on recurring themes related to parental expectations, anxieties, and the adaptive strategies they employ to navigate the complex interplay between hope and concern as their children engage with inclusive education systems.

METHOD

Study Setting

This study was conducted in the Greater Malang area, which comprises Malang City, Batu City, and Malang Regency, located in East Java Province, Indonesia. Among these regions, Malang City has positioned itself as a pioneer in inclusive education, having officially declared its commitment to this model ahead of the surrounding jurisdictions (Pemerintah Kota Malang, 2012). The local government has emphasized that no educational institution is permitted to reject students on the basis of disability. Within this context, two distinct types of schools can be identified: (1) inclusive schools, which provide special education teachers (also known as shadow teachers) with additional costs typically borne by parents, and (2) mainstream schools, which may accept children with disabilities but require families, particularly in cases of severe disability, to independently arrange for support personnel. Despite these policy declarations, reliable and comprehensive data remain limited. The Working Group of Special Assistance Teachers in Malang City has not yet compiled detailed statistics on the number of inclusive or mainstream schools, nor on the population of students with disabilities currently enrolled in those schools. Furthermore, data from the Central Statistics Agency (BPS) recorded 2,638 persons with disabilities in Malang City in 2021; however, this figure lacks disaggregation by age, gender, educational level, or other relevant demographic and educational variables (BPS Kota Malang, 2023). This data gap presents a challenge for the effective planning and evaluation of inclusive education initiatives in the region.

Study Participants

Participants in this study were selected using purposeful sampling techniques, as recommended for qualitative research aiming to gain in-depth insights from information-rich cases (Creswell, 2015; Galloway, 2005). The researchers identified potential participants through personal networks involving parents of children with special needs enrolled in inclusive or mainstream schools, as well as through referrals from the Special Assistance Teacher Working Group and the District Parent Support Group. Out of the 15 individuals contacted—either directly by the research team or via intermediaries such as teachers and parent group representatives—a total of 10 parents, each representing a different school in Malang City, consented to participate in the study.

This sample size is consistent with established qualitative research standards and was deemed sufficient to reach data saturation, a point at which no new themes or insights were emerging from additional interviews (Hennink & Kaiser, 2022). The diversity of school settings and family backgrounds among the participants further contributed to the richness and depth of the data collected.

Participant's inclusion criteria:

1. Participants were parents of children with disabilities attending inclusive/mainstream schools in the Greater Malang.
2. Many types of children's disabilities
3. Their children attended school from primary, middle, and secondary/vocational school.

Data Collection

This study adopted a social constructivist approach to guide the data collection process. Rooted in Vygotsky's theory, social constructivism emphasizes how individuals actively construct knowledge through interactions within their sociocultural environment (Davis et al., 2017). In this context, the lived experiences of parents whose children with disabilities attend inclusive or mainstream schools served as the central source of data. To capture these experiences, the researchers conducted in-depth, semi-structured interviews lasting approximately 30 to 60 minutes each. All interviews were conducted face-to-face to foster trust and allow for a more nuanced exploration of participants' narratives. Prior to each interview, the researcher introduced themselves, explained the purpose and scope of the research, and provided participants with a brief proposal summary outlining issues of confidentiality, anonymity, and participants' rights. Participants were given sufficient time to review this information and to ask questions before signing the informed consent form. The interviews were initiated using open-ended questions designed to elicit reflective and personal responses. The core guiding questions included:

1. Could you describe the forms of support and the challenges your child encounters in inclusive or mainstream schools, as well as your own experiences as a parent?
2. What are your expectations and concerns regarding your child's education in inclusive or mainstream settings?
3. What are your hopes and anxieties concerning your child's future?

These questions were designed to explore the dualities of hope and worry that characterize the parental experience in inclusive educational environments, aligning with the study's overarching aim to understand the emotional and practical dynamics that shape parental perspectives.

Data Analysis

This study employed a qualitative research design, utilizing reflexive thematic analysis (RTA) as the primary method for processing and interpreting the data (Braun & Clarke, 2006, 2012; Byrne, 2022). The RTA approach was selected for its alignment with the study's constructivist epistemology, which emphasizes the co-construction of meaning between researchers and participants. Following the data collection phase, the interviews were transcribed verbatim and carefully reviewed by the researcher. The analysis process began with initial coding, where segments of the data relevant to the research questions were identified and labeled. These codes emerged inductively, grounded in the participants' narratives, and were subsequently organized into overarching themes through a process of critical reflection. In accordance with the reflexive nature of the analysis, the researcher's subjectivity was acknowledged as an essential component of meaning-making. Rather than relying on a predefined codebook or seeking inter-rater consensus, the researcher engaged in an iterative and interpretive process that prioritized the depth and richness of participants' lived experiences. This approach allowed for flexible and evolving theme development, reflecting the diverse and nuanced perspectives of parents of children with disabilities in Malang City. The thematic findings are presented and discussed narratively, situated within the broader sociocultural context of inclusive education in Indonesia. The transparency of the analytical process enables critical engagement and opens the findings to further dialogue, ensuring both rigor and reflexivity in the interpretation of results.

Ethics Approval

This study received ethical clearance from the Research and Community Service Unit (UPPM) of STP-IPI Malang, in accordance with the institution's Research Implementation Guidelines and Standard Operating Procedures (SOP). Ethical standards were rigorously upheld throughout the research process to ensure the protection and dignity of all participants. First, informed consent was obtained from each participant prior to data collection. Participants were provided with clear and comprehensive information regarding the study's aims, methodology, potential benefits, and any foreseeable risks. They were given adequate time to consider their involvement before signing the informed consent form. Second, confidentiality and privacy were strictly maintained. All personal identifiers were anonymized in the transcripts and final report to ensure that individual participants could not be identified. Data was stored securely and used solely for academic purposes. Finally, participants were informed of their rights, including the right to decline participation or withdraw from the study at any stage without any form of penalty or adverse consequence. These measures reflect the researcher's commitment to upholding ethical research practices in line with national and institutional standards.

Table 1. Informants' Socio-demographic

Characteristic	Range Group	Total	Percentage
Sex	Female	9	90%
	Male	1	10%
Disability	physical disability	1	10%
	non-disability	9	90%
Age group	30-40 (years old)	3	30%
	41-50 (years old)	5	50%
	51-60 (years old)	2	20%
Ethnic	Javanese	10	100%
	Others	0	0
Religion	Islam	9	90%
	Catholic	1	10%
Education	Secondary	7	70%
	Undergraduate Degree	3	30%
Employment	Housewife	5	50%
	Home-based Businesses	3	30%
	Freelancer	1	10%
	Civil servant	1	10%
Children's Disability	Hereditary	1	10%
	Non-Hereditary	9	90%
Children's Education	State School	6	60%

	Private School	4	40%
Children's Grade Educational	Primary school (1 – 6 grade),	4	40%
	Middle school (7 – 9 grade),	3	30%
	Secondary school (10 – 12 grade)	2	20%
	Vocational school (10 – 12 grade)	1	10%
Number of Children	1	1	10%
	≥ 2	9	90%

Table 2. Parent's Information

Code	Sex	Role in School for Their Child	Child's Disability	School	Grade
P1	Female	Shadow teacher until 2nd grade	Asperger	Islamic inclusive school	3rd
P2	Female	Shadow teacher until now	Low Vision	Inclusive school	6th
P3	Female	Assisting if needed until 6th grade	Physical	Islamic mainstream school	8th
P4	Male	-	Learning	Mainstream school	9th
P5	Female	Assisting if needed until 6th grade	Physical	Mainstream school	11th
P6	Female	Assisting if needed until 6th grade	Learning	Inclusive vocational school	12th
P7	Female	-	Hearing, Slow-learner, and Epilepsy (3 years)	Islamic mainstream school	12th
P8	Female	-	Hearing	Islamic inclusive school	4th
P9	Female	-	Hearing	Mainstream school	4th
P10	Female	-	Autism	Mainstream school	8th

Table 3: The result of reflexive thematic analysis

Theme	Sub-theme
Parents' expectations of their child in education	• Social (religion) and academic development • Availability of a safe school environment • The child is socially acceptable • Independent
Parents' hopes for their child's future	• Getting a decent job • Achieving goals
Parents' worries for their child during education	• Social acceptance from peers (bullying, abuse) • Teachers' ability to handle children with disabilities • School support • Financial support • Accessibility
Parents' concerns in the future	• Unable to get a job • Living alone
Parents' strategies to deal with their worries and concerns	• Increase self-optimism, motivate and assist children • Increase children's independence • Seek the help of a third-party; teacher or parent support • Resignation to the God/pray and not having high expecta- • Deliver the expectations to siblings without disability

Parents' expectations during education

Parents whose children have disabilities, but not serious behavioural or cognitive problems are optimistic and supportive of their children's development. They even make sure that teachers at school respect their children.

“I saw, oh he has talent, right, he can sing, can perform. Then he was confident.” (P1)

“My child should get a better education.”(P4)

"I honestly informed the teachers that my son has a physical disability but otherwise performs well (good grades in academics)." (P5)

Parents always strive to ensure their children are in the right school environment. In schools labelled as inclusive, the expectations of support from the school and teachers are stronger than in mainstream schools that are willing to accept children with special needs. This also applies to regular schools with few students. Even if, parents should pay additional fees.

“For my son, the teacher focuses on (changes in) behaviour…. and later for the lessons, at home too. … the teacher also supports the lessons.” (P1)

“Fortunately, the teachers here know, if she's not in the mood, she can't be forced. I get permission to go home.” (P2)

Expert teacher who acts like a parent. The additional fees are reasonable for the student's needs, providing parents with peace of mind. I believe it is running well and remains monitored." (P6)

“(the teacher and his friends) are okay to accept my son.” (P7)

“Even though she is deaf, she must learn and pursue knowledge and religion.” (P8)

“I hope she can be more enthusiastic, better. Can take the lessons.” (P9)

Stories of acceptance of children with disabilities in previous classes or schools continue to lead parents to hope that their child's environment is discrimination-free. Parents' perspective is a good social environment also encourages their child's courage and independence.

“There is a change, he is more interacting with his friends. Perhaps it is because there is a role of the teacher who can bring students to mingle, and the students too (want to interact with my son).” (P3).

"His friends accepted him, even awarding his helper a prize. In high school, his friends (and teacher) continued to support him, guiding and helping him to various events. He has become independent, without parental assistance." (P5).

“I hope she doesn't feel inferior when he hangs out with her friends” (P8)

“(children with disabilities) are embraced... So, no special treatment, no specific treatment, but don't make the environment being uncomfortable. that's all.” (P10)

Parents' hopes for their child's future

Parents who have sent their children to junior high or high school or are critical of their children's development can more clearly describe their hopes and expectations for their children's future. They want their children to be independent, continue their higher education, get a decent job, or achieve whatever ideals their children hope for. Education is an important thing to change their future.

“I just think his future has to be bright someday. … So, maybe his college will be in the language department or something, later. It's a long way off, but it's starting to appear. So, maybehe'll take a course or tutoring, later.” (P1, housewife)

“I said, this child must be independent. Don't be demanded (her academic achievement)” (P2, housewife)

“He wants to be a preacher. Yes, Mom can only pray, I said, I hope what you want you to pursue, and I said may Allah answer.” (P3, home-based industry)

> "Can be independent... or self-employed. Can fulfil their own needs. So, that children do not depend on others. The only way is with this education. There's nothing else." (P4, home-based industry)
>
> "If he can prove that even though he's like this (has a disability), he can be (compared) to a normal child. He can go to college, and after college, he can work like a normal child." (P5, housewife)
>
> "So, for the time being, the hope is that there will be skills that can help her to be independent in the future." (P6, freelancer)
>
> "In terms of work, maybe he can open (and develop) his (our) own business ...; I am an online worker. I'm also disabled, so I can't work outside." (P7, female with a disability)
>
> "I hope she can work or can get a job or what is the term can face challenges in the future" (P8, civil servant)
>
> "I hope she can continue her (higher) education like ordinary children. Right now, there are a lot of successful children with disabilities, right?" (P9, housewife)
>
> "If it's academic, I won't pursue it. … he can work or make it happen, yes, what is it called, his dream is to work, have his own business." (P10, housewife)

Parents' worries about their children's education

In line with parents' main expectation in school of better social relationships for children with disabilities, ostracization, and bullying are major worries. Although parents ensure the social environment is safe for children with disabilities to get involved in school, previous classroom or school bullying to their children's experiences and news of peer bullying in some schools fuelled these traumas. 4 participants said that their children had been bullied. The potential for state schools to be unsafe for children with disabilities tends to be higher, 3 out of 4 students with disabilities who have experienced bullying in mainstream schools, attend state schools.

> "I'm afraid of adults too. I'm afraid there will be bullying (to my son). But so far nothing."(P1, her son in 3rd grade)
>
> "At home, if (at school) there are ignorant friends, when I ask my son, He doesn't want to answer. He sleeps all day. He doesn't want to communicate." (P3, her son in 8th grade, had been bullied in private primary school and had shadow teacher)
>
> "(Worried) because he doesn't know where the place is. Because he never goes out to interact. Once, he got his lunch (box) kicked (by his friends). Only one time.8th grade."(P4, his son in 9th grade, had been bullied in 8th grade state middle school)
>
> "(Primary School) His friends. Some were willing to accept him, some weren't. The problem is that nowadays there is a lot of bullying, how, well ... But my son, how, well… my son wants to be more advanced. you know." (P5, her son in 11th grade, had been bullied in state primary school and had shadow teacher)
>
> "I'm afraid of being bullied. My child won't be able to think and learn." (P6, her son in 12th grade)
>
> "Yes, I was worried about bullying at school, but I saw that since kindergarten (till now), all her friends were nice." (P9, her daughter in 4th grade, had been (feel) intimidated in 3rd grade when her friends (accidentally) knew she used hearing aid under a headscarf, state primary school, now the girl often do not attend class)
>
> "In 7th grade, there was no problem, he was comfortable. In 8th grade, … XY pulled his shirt. Then his friend told my son to date the girl. His friend said my son will be ganged up on" (P10, her son in 8th grade, had been bullied in 8th grade, state middle school).

Parents in inclusion schools are more likely to evaluate their child's development than parents in mainstream schools. Moreover, the presence of limited special teachers, the competency of class teachers to assist children with disabilities, and the capacity of parents as shadow teachers also cause long-term anxiety and fatigue in inclusive schools, especially for mainstreaming schools that don’t have proper support. This problem also affects parents with insufficient to pay for a shadow teacher while the children need special assistance at the state school.

> “Previously in 2nd grade, I was in the same class. But since the end, (I realize) why am I the one who goes to school?” (P1, private inclusive school)
>
> “I mean, the teachers are also not specifically assisting children with special needs. So, well, sometimes we are confused. My child has little concentration, well. If she doesn't want to learn, she can't be forced. So, yes sometimes (I) get tired too. I also can't force her; there are times when I am down, well.” (P2, state mainstreaming school)
>
> “Private (special schools near house) and the fees are expensive. … Entry in secondary school inclusion is different. The fees are different from the regular (students). But parents have a sense of calm; (the children) are supervised.” (P6)
>
> “Now, I'm also tired. Parenting, taking care of that child, that one. Not to mention the other one, the other one is disabled, the other one is small, home affairs, and then I'm tired so I'm not organised.” (P7, female with a disability)
>
> "I heard and felt it hurt, what it, the language (used by the class teacher) waswas more towards being impatient. ... I heard it outside the fence (quietly). Hey, why is it like this (accompanying a child with disabilities). (But) where can I confide in, because I have been placed in this (school). … If I want to move (to another school), I also have to provide special assistance teachers who... the price (must be paid) for one month is also quite expensive." (P10, mainstreaming school)

Parents who have children with little barriers caused by their disability also have anxiety while they are leaving their children in school. Parents worry that if something happens to their children under certain conditions, there are no friends or teachers to help or protect them, especially for (teenage) girls.

> “If you are worried, you are still worried. Children with physical limitations, afraid.Maybe falling afraid that no one will help.”(P3, female)
>
> "I expressed my concerns about the internship requirements to the teacher. I worried that the work environment wouldn't be fully inclusive and that the teacher wouldn't be able to monitor her closely during the internship. As my child is a girl, I fear potential negative experiences." (P6, female)

For parents who have children with physical disabilities, accessibility is an issue that needs to be considered when choosing and/or mobility at school.

> “My son uses a wheelchair there, so if his mobility is obstructed or it is difficult for him to mobile…” (P3)
>
> “I'm afraid my child will go to the bathroom. Then he wants to pray, he wants to do activities. … I'm looking for a school (for my son), not a multi-storey building.” (P5)

Parents' concerns in the future

Parents' anxiety about their children's future tends to increase when their children are about to end their school years. Parents who want their children to be independent in society also have high concerns. Especially when the types of disability require full assistance to carry out activities or they do not have siblings.

> “My husband said, our child is an only child. Poor, (alone) has no siblings.” (P1, female)
>
> “(If) I demand academics, but she doesn't have the independence. I'm afraid that later, where will she work? She can't take care of herself yet (starting to cry). I don't

> always accompany her to that point, well... I don't insist that her education must be this, this, no. Because I know what are my daughter's limits (crying).” (P2, female)
>
> “Many graduates of this vocational school who are inclusive students are also accepted in certain hotels, which accept children with disabilities. But, what kind of disability? Won't my child get in? That's still the case. Concern.”(P6, female; child with learning disability 12th grade, state vocational school)
>
> “I'm afraid, my son won't be able to work in the future. There will be no job opportunities. I'm afraid. The matter is, he can't work with a hard job. He also (started) having seizures (epilepsy) in 9th grade in middle school.” (P7, female with disability)
>
> “my daughter is, oh, she's so lazy. (can she want to continue education)” (P9)
>
> “(I afraid) I can't accompany him until he is an adult.” (P10)

Parents' strategies for dealing with worries and concerns

Parents often face more challenges in caring for children with disabilities. Some parents revealed that they had tried to think positively, motivate their children not to socially withdraw and dare to face situations in their environment, educate them to avoid bullying, assist their children in increasing their potential and monitor their social interactions. Some parents hold on to their optimism that their children's abilities will continue to develop during their education.

> “But I'm sure he has the potential that he will be able to develop in the future. …Maybe one day he can be a successful person. I'm sure. You can't think about the bad things. Because I'm afraid it will happen. So, I think good things, he can do it.” (P1, female)
>
> “We try to adjust to the child with a disability (to the lessons and school conditions because not every teacher understands about the child with a disability). Then I also train her to be independent (for daily activities).” (P2, female)
>
> “If someone is fighting, you avoid it. Tell the teacher. ...; I tell my son that he must know how to defend himself and carry himself. To that person not be ignorant and mean.” (P3, female)
>
> "I told my son that he needs to be self-reliant and not hold grudges against those who don't like him. He should always show good manners at school. As for future concerns, I see this as an ongoing educational process, and I hope my son will become more advanced through it." (P4, male)
>
> “Yeah whatever, we'll just follow you, we said that. The important thing is that we support everything he wants.” (P5, female)
>
> “My daughter, although she has a disability. Same as her older sister, who is normal. From their childhood, I taught her to always tell everything she did that day (in school).” (P6, female)

When parents encounter challenges in their children's education, their first point of contact is typically the teacher. Establishing good communication with teachers enables parents to make informed decisions regarding their child's education. Furthermore, teachers can offer support in addressing issues faced by students with disabilities, fostering their potential, and facilitating the development of positive social skills in each child.

> “I explained the situation … then they was prepared to handle such children at 'M' (inclusive) school. My son was the first child with special needs to enrol there. … If we told the teacher, well (the teacher) immediately responded (to handle the bullying experienced by my child).” (P4, male)
>
> “(When he was little, I asked my son’s therapist at “Q” special school), Sir, how much does it cost here? (He answered) It’s a bit expensive here. This child is fine. It’s just physical disability. Try a state primary school. He said that. I asked again, “Will he

> be accepted, Sir?” God willing, he will be accepted, Ma’am (he answered). If he’s not accepted, just come here.” (P5, female)
>
> “My daughter doesn't need a shadow teacher. So, I just need, what, well. Yes, I talked to her teacher to save my daughter from bullying (if any) from her friends.” (P6, female)
>
> “Starting from class, in the first grade, I asked how your friends, whether they were good or not.” (P9)

Parent support groups in each sub-district in Malang City are also one of the stakeholders who are a source for parents to overcome anxiety about their children's future. Information on skills training or business development obtained from the local/province Social Services, CSR, or other institutions for people with disabilities is provided through parent support groups. This can encourage parents' hopes to start integrating children with disabilities into productive communities after school.

> “So, my plan is, later when she graduates, InsyaAllah, through the parent support group, I want to include her in skill training so that (it can be) provision (for her future).” (P6, female)

Religious and/or cultural values are held firmly by parents as the foundation of their lives to continue to grow with their children. They express an attitude of resignation to the path of life that God has given to their family or children. By not having high expectations for children with disabilities, parents can reduce excessive worries about education and concerns future of children with disabilities.

> “I saw on social media, those studies (Tausyiah – forums for teachings of religion), that people with disabilities are special. They can help us in heaven and so on. So that's what makes me strong too.” (P1, Islamic primary inclusive school)
>
> “I can't ask for more. Because I also see the condition (his condition), right? …; In my (religion), I am taught, I pray, (I convey) to God, I entrust my child to my God.” (P3, Islamic middle mainstreaming school)
>
> “It's okay if we (get) God's temptation like this, its fine. Just be grateful. Children are just a gift from God. What else can I do? If it's about work, maybe I can open (and develop) his own business. But for the rest, I surrender. Just surrender. Surrender to God.” (P7, Islamic secondary mainstreaming school)
>
> “I think, I pray first. Let's us pray for it.” (P8, Islamic primary inclusive school)
>
> “… pray, ask for God's protection, I emphasize that. Because Mom can't protect you. Only God and angels can protect us.” (P10, state middle school)

The last resort of parents when the socialization ability or potential of the children with disabilities is still developing is family members. Some parents who have more than one child and are not disabled can place their expectations and hope for the protection and supervision of children with disabilities on their siblings. This is an anticipation when parents realize that one day, they will face death.

> "I have always made my older children aware of their younger sibling's physical limitations and urged them to care for him. I emphasise that when I'm no longer around, at least one of them should be there for their younger brother, including him in family activities to prevent feelings of isolation." (P3, she had 3 children)
>
> “In time, she will have to be on her own. Whereas, her (old) sister also (will) have her own life. So, even from the beginning, I tell her. Her (old) sister.When I'm not around (or die), she has to take care of his (younger) sister.” (P6, she had 2 children)
>
> “I said (to her old brother), your little sister has a disability. You must be a good example and be able to provide help or protect him when he needs it” (P8, she had 2 children)

> "I told (my children) that if father and mother were not there (passed away), you would live together (live in harmony). Therefore, if possible, those more prosperous help those less fortunate." (P10, she had 3 children)

DISCUSSION

The experiences of parents of children with disabilities present diverse social constructivism in inclusive education settings. The qualitative research design sought to explore the perspectives of those who have multiple roles in the family and at school. This study presents five major themes as findings [1] parents' expectations and [2] worries during their child's challenging education. This theme leads to [3] hopes and [4] concerns for the future of children with disabilities. The relationship between the first to fourth themes found [5] kinds of parents' strategies as resilience for facing worries and concerns towards their child's education and future.

Parents who seek help from third parties (teachers, therapists, neighbours, or members of their community) and receive (long-term) support tend to have high optimism (Slattery et al., 2017). They accept their children's conditions and continue to explore their children's potential with the help of third parties. Teachers who do not have an inclusive education background but are open can provide support for parents, as well as parents who are open to providing support for teachers. Parents are also more optimistic about their children's development and future. This also applies to cases of bullying experienced by children with disabilities in class or during elementary school.

Bullying of children with disabilities (because they appear different from students in general) in mainstream schools is still a concern for parents (Subasno et al., 2023). However, the development of socialization skills of children with special needs over time has made these concerns slowly fade. This is shown in children who have experienced bullying in elementary school and have experienced changes in self-confidence and social interaction skills in positive environments in inclusive/mainstream schools. When parents make further decisions, the involvement of children's roles is also important in their social development, which is considered to have increased significantly. In student activities outside of school, the acceptance and involvement of children with disabilities is more evident. This experience gives parents great hope that when their children complete their education, they will be better prepared to live in society like others (Juvonen et al., 2019; Khusheim, 2021).

Parents with dual roles and limited third-party support often feel confused and overwhelmed (Antwi, 2023). Frustration arises from expectations that their children will develop like their peers, compounded by the limited availability and competence of teachers for children with disabilities. Balancing the needs of their child requiring full assistance, caring for other siblings, and managing work and household responsibilities increases parental anxiety about their children's academic progress. However, previously frustrated parents felt more positive after opting for full educational support at school through special teacher assistance. This support, however, incurs additional costs, raising new concerns for parents with limited income.

Spiritual values from religion and culture help parents release anxiety when supporting children with disabilities (Gur& Reich, 2023; Kavaliotis, 2023). Parents of children nearing the end of school often surrender to God for guidance and strength. While they hope their children can secure a decent job, they lower expectations due to the disability. Parents of younger children with mild disabilities tend to remain optimistic. In some families, siblings protect their disabled siblings to ensure they live safely and decently when parents are no longer around.

Parents' experiences in inclusive education reveal that a child's disability severity significantly influences their attitudes, hopes, and concerns about education and the future

(Paseka& Schwab, 2020). Those with mild disabilities mainly worry about the social environment at school and the support from teachers and peers to enhance their child's confidence and academic success. In contrast, parents of children with more severe disabilities face dual concerns regarding academic and social skills. All parents require spiritual, financial, and social support, alongside a clear education system and relevant information, to uphold their children's educational rights and secure a prosperous future. Inclusive education should promote the active involvement of children, teachers, parents, schools, and the community to challenge stereotypes, foster self-confidence, and encourage collaboration (Anggraini&Subasno, 2022; Lopatynska et al., 2023). For parents, education is essential for securing their child's future, making it a non-negotiable priority.

This study shows that government and school strategies to ensure inclusive education policies and child protection have not been effectively felt by all children with disabilities. So, the government needs to review the substance and implementation of the policy in inclusive education and child-friendly schools starting from management to sources that can be utilized. The development of education is expected to truly provide support for the hopes of parents who want their children to obtain the fulfilment of educational rights and equal future opportunities.

LIMITATIONS STUDIES

Measuring parents' hopes, concerns, and strategies for sending their children to inclusive/mainstream schools with limited participants creates challenges for researchers. This research aims to describe social constructivism built from the experiences of parents who have children with disabilities, so it cannot be generalized. However, it would support transferability for further research that is more specific to the group of parents who had children with a common disability and or similar school level in other setting studies.

CONCLUSION

This research aims to convey the message that positive relationships between children, parents, teachers and policymakers can help parents find strategies to deal with concerns and encourage parents' expectations to be more realistic for a decent and quality future for children with disabilities. On the other hand, forms of support created in relationships with low frequency and communication can increase parents' anxiety about their child's future. These findings should be taken into consideration to open up better opportunities for inclusive education in the future.

RESEARCH IMPLICATIONS

- The research findings from the perspective of parents who have children with disabilities help researchers to develop future research.
- There is a need for guidance and counselling support for parents of children with disabilities even at the primary school level and parent support groups so that parents can increase their children's potential and be guided in making further educational choices.
- In general, the school needs to consider providing psychological consultation services for students and teachers at school. This is expected to support parents that their children are safe in the school environment without bullying and or abuse.
- The government needs to review the substance and implementation of the policy in inclusive education and child-friendly schools

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Original Research Article

Disability and Quality of Life of Persons with Locomotor Disability: Determining Factors

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ABSTRACT

Objective: People with locomotor disabilities face significant social and structural barriers, especially in emerging economies. Imbalances within social institutions contribute to their marginalisation and affect their participation in society. This study throws light on the issues that people with locomotive impairment confront, particularly in terms of their perceived quality of life.

Method: A descriptive research design was employed, using semi-structured interviews. Simple random sampling facilitated the selection of 98 persons with locomotor disability in Dharmapuri district of Tamil Nadu, India. Defined inclusion and exclusion criteria were adhered to.

Results: Findings indicated that persons with locomotor impairments were financially disadvantaged; mostly low-income (76.6%) and jobless (13.3%). Respondents who were married and had higher incomes or educational levels reported an improved quality of life, while those from rural areas, and low-income or illiterate backgrounds generally experienced a lower quality of life. Disability-related challenges varied on the basis of factors such as gender, age, marital status, family size, and social support. Furthermore, their health-related quality of life was affected across physical, mental, emotional and social well-being domains, impacting the ability to attain a good standard of living.

Conclusion: Individuals with disabilities are frequently judged solely on their flaws and are denied social participation. Construction barriers in a disadvantaged environment cause maximum inconvenience. Financial dependency on the pension scheme of the Government seems high in the study area. Persons with locomotor disabilities should be made aware of availability, accessibility and affordability of opportunities suited to their physical or mental abilities and independent living conditions.

Keywords: disability, locomotor impairment, social agency, social support, well-being, determining factors.

INTRODUCTION

Globally, one billion people are estimated to experience disability, which accounts for around 15% of the world's population (World Health Organisation, 2021). The vast majority of persons with disability live in emerging economies; the dilemma of measuring the challenges of disability in emerging economies is that mental health and physical

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ailments are the only issues that are taken into consideration (WHO, 2011; World Bank, 2020). In addition, the Asia Pacific Disability Fact sheet (2021) measured approximately 650 million people suffering from disabilities in the Asia Pacific region. Disability is defined as the result of the interplay between impairment and barriers. People with impairments have limited sense function such as mobility, cognition, or psychological difficulties, and the barriers can be attitudinal, such as discrimination, or environmental factors to the construction of disability (Asia Pacific Disability Fact sheet, 2021). The interaction of the aforementioned factors prevents people with disabilities from fully participating in society. The Persons with Disabilities Act of 2016 defines "locomotor disability" as "disability of the bones, joints, or muscles resulting in substantial restriction of limb movement or any form of cerebral palsy".

As follows, the context of locomotor disability varies in this study: Cerebral palsy, amputation, spinal cord injuries, and muscular dystrophies. Therefore, the repercussions of impairment are contingent upon the social settings that are associated with the various types of disabilities, such as those that manifest during infancy and throughout one's life also as a result of severity of their impairment. For example, persons with spinal cord injuries and amputations experience disability after a non-impaired existence, which has a negative impact on both their mental and financial well-being that necessitates significant adaptations in home and community spaces (Bulgarelli, 2020). However, this does not imply that people with disabilities from birth or early childhood are self-sufficient or do not need communal space; rather, they embrace their handicap and have a high reliance rate. According to surveys, the majority of people with locomotor impairments have difficulty in accessing the basic necessities and opportunities (Rehabilitation Council of India, 2000; Mamud et al, 2017). All individuals require a level of mobility in order to enter the labour force, become socially engaged, manage their financial situation, and increase their level of independence. In the overall picture, mobility is the mode to improve one's quality of life.

People with locomotor disabilities have impaired movement and face barriers that increase dependency and reduce the quality of life, compared to people with fewer physical barriers (Lee et al, 2022). Discrimination and socioeconomic hurdles are the basis of the issues that persons with disabilities face in their everyday social life (Janardhana et al, 2015). These variations are influenced by a variety of socioeconomic circumstances and different provisions for the well-being of different societies (Navarro-Carrillo et al, 2020). People with locomotor/physical disabilities may experience lower life satisfaction and quality of life as a result of low participation in society, stigma, and discrimination (Gnanaselvam, 2017). The purpose of this study is to evaluate the quality of life of people with locomotor disabilities.

BACKGROUND

According to the 2011 census, India's disability population equalled 26.8 million people, of which 22% were persons with locomotor disabilities. Locomotor disabilities have a negative influence on a person's quality of life due to mobilisation and dependency when compared to any other type of disability (Hamrin et al, 2012). The general perception is that people with disabilities can simply live as ordinary people in society and also live comfortably in a competitive society (Babik& Gardner, 2021).

The prominent sociologist Herbert Spencer (1898) has mentioned the similarity between society and the human body, arguing that just as the various organs of the body work together to keep the body functioning, so too do the various parts of society work together to keep societal functioning. Spencer referred to social institutions, patterns of beliefs and behaviors focused on meeting social needs through government, education, family, healthcare, religion, etc., (Ritzer, 1992), yet people with disability are unable to fully engage themselves in or intervene in social structures of the social system (Harris, 2019). As a result, both the individual and society will be unable to maintain stability and harmony in the society.

A segment of western sociologists concluded that, for the most part, the onus of handicap lay with society, which was accountable for their activities and placing constraints. However, unlike in the West, the subject of disability is largely absent in the social sciences discipline in India, creating a void in the understanding and putting the discipline at risk of practicing sympathy and charity rather than a sociological sensibility that sees disability as a human rights issue to be addressed through rehabilitation and social work (Vikash Kumar, 2017).

LITERATURE REVIEW

Locomotor impairment results in significant mobility restrictions, particularly in the legs or joints (Nakamura & Ogata, 2016; WHO, 2011). However, it is often seen as a condition affecting the bones, joints, and muscles. It makes it difficult for a person to move around (like walking, picking or holding things in hand, etc. (Wecapable, 2022). Disability is impacted by co-morbidity, which is linked to more serious barriers than single conditions. The existence of various health issues can make health care and rehabilitation management more difficult (WHO, 2011). Disability impacts many aspects of an individual's life through attitudinal barriers, physical barriers, communication barriers and financial barriers that significantly augment dependency their reliance on assistive technologies, mobility aids and accessible infrastructure. (Janardhana et al, 2015; Meena, 2015; WHO, 2011). The vast majority of the persons with disabilities reside in rural areas of emerging economies which can increase the rate of health-seeking behaviour and dependency that affect their quality of life (Jonckheere, 2020; United Nations, 2022). Moreover, different types of disability add up to a huge social well-being concern that has a significant social, financial, and mental impact (Adamson et al, 2003; Suganthi&Kandhaswamy, 2015; Nakamura & Ogata, 2018). Deterioration in walking, the onset of secondary impairments, persistent pain or weariness, a lack of physical fitness and an inactive lifestyle can all hinder adult emancipation. Due to the locomotor disability, functional movement, household management, and physical recreation are frequently restricted. Housing and intimate relationships are also restricted for these individuals as compared to able-bodied people.

In India, motor impairment accounts for the bulk of disabilities. The financial stress of losing daily wages, the need for frequent job changes, and the risk of losing a job lead to poor quality of life (Gupta et al, 2010; Gustafsson, 2012). Movement disorders cause functional limitations resulting in poverty and unemployment (Laskar et al, 2010; Hamrin et al, 2011; Padhyegurjar&Padhyegurjar, 2012). The persons with disabilities are still neglected and stigmatised in family and community activities (Rohwerder, 2018). As a result, society must assume the responsibility of caring for them by providing adequate social support and societal assistance (Wilson &Socior, 2015; Onalu&Nwafor, 2021). It is assumed that a person with disability can function as well as anybody else provided she/he is given appropriate training in alternative techniques and assistive devices (Meena, 2015; Borg &Ostergren, 2015). However, decreased social and economic role of persons with locomotor disability and deterioration in the quality of life increase dependency on health care and other basic services (Staples &Mehrotra, 2016; Maroof et al, 2017). People with disabilities and their families frequently pay significant costs to reach a living standard comparable to that of people without disability. Therefore, this study aims to assess the quality of life of persons with locomotor disability in terms of their socioeconomic conditions as well as their social wellbeing.

OBJECTIVE

The present study has the following objectives:

- To gauge the quality of life of people with locomotor disability and those with movement impairment
- To suggest suitable measures to improve the quality of life of persons with locomotor disability and people with movement impairment.

METHODS

Study Design

A descriptive research approach was used to assess the socio-demographic profile, disability profile, and quality of life of persons with locomotor disabilities in Dharmapuridistrict of Tamil Nadu, India.

Study Sample

The total population of persons with disabilities in the study area was enumerated to be 25,283 persons, among whom 7,381 were persons with locomotor disability (Population By type of Disability, Age and Sex, 2011 – TAMIL NADU | Open Government Data Portal Tamil Nadu, n.d.; Population of Differently Abled Persons – Enabled. In, n.d.).

The multistage random sampling method was utilised to obtain data from 98 persons with locomotor disabilities.

Inclusion criteria:

- Respondents who were 18 years of age and above, but below 60.
- Respondents from Dharmapuri district only.

Exclusion criteria:

- People living with disabilities other than locomotor disability.

Data Collection

A semi-structured interview schedule and validated measuring scales developed by the World Health Organization which have good internal consistency - Cronbach's alpha of 0.721(Grover et al, 2014) - were used. Those who were willing to provide information were interviewed in the regional language, with a schedule translated into Tamil.

Data Analysis

The data was coded in Excel and analysed in SPSS v26. Basic frequency distribution tables were obtained and to determine the level of significance between the independent and dependent variables, Chi-square tests have been used.

The findings of the analysis are listed below.

Ethical Considerations

Since the present study used an instrument developed by World Health Organization and the same was tested by Grover et al (2014) in the Indian context, there was no risk to the physical and mental well-being of the respondents. The purpose and outcome of the research were intimated to the respondents and informed consent was obtained from each individual before the interview.

RESULTS

Demographic Profile of Respondents

An almost equal number of respondents were between the ages of 18 and 58, with 71% being male and the rest female. In terms of marital status, about 60% of them were married. Three out of 10 respondents were found to be illiterate, with several records revealing that 19% were graduates and post-graduates. While a fair number of them were jobless, the others were found to be self-employed, either organised or unorganised. In addition, the Disability Welfare Office reported that nearly 40% of the respondents were receiving pensions under the Unemployed Assistance Scheme for persons with disability. The monthly income of the respondents ranged from Rs. 1000 - Rs. 20,000 and more, with nearly 60% earning between Rs1000 and Rs 5000 and 13% earning nothing. The families were discovered using statistics based on the nature and size of the respondents' families. The majority of the respondents lived in nuclear families, with 82 % of the families consisting of 3 to 5 members. Although a large percentage of persons with locomotors impairment (83.7%) accepted the concept of disability, roughly 16% of respondents were in denial about their disability (see Table 1).

Table 1: Demographic Profile of the Respondents (n=98)

SN	Variable	Category	Frequency	Percentage
1.1	Age (years)	18-27	25	25.5
		28-37	24	24.5
		38-47	26	26.5
		48-58	23	23.5
1.2	Gender	Male	70	71.4
		Female	28	28.6
1.3	Marital status	Unmarried	42	42.9
		Married	56	57.1
1.4	Educational qualification	Illiterate	35	35.7
		Primary school	14	14.3
		Secondary school	15	15.3
		High school	13	13.3
		Higher Secondary	2	02.0
		Higher Education	19	19.4
1.5	Occupation	Unemployed	15	15.3
		Unorganized	16	16.3
		Organized	09	09.2
		Self-employment	18	18.4
		Pension	40	40.8
1.6	Monthly income (INR.)	No income	13	13.3
		1000-5000	57	58.2
		5001-10,000	18	18.4
		10,001-15,000	0	0
		15,001-20,000	06	06.1
		20,001 and above	04	04.1

The data indicates a substantial linkage between respondents' married status and their quality of life [X2 (n=98), DF=1, p=0.004]. The married respondents were found to have a higher quality of life than single respondents. The results revealed a strong and significant relationship between the respondents’ monthly income and their quality of life [X2 (n=98), DF=3, p=0.000]. Respondents in the no-income and lower-income categories had a poor quality of life, while those in the above-average income group had a better quality of life. Similarly, variables like the place of residence and type of residence were found to have a substantial link and Association with quality of life. Respondents who lived in rural regions had a low quality of life, whereas those who lived in urban areas had a better quality of life. There appears to be a strong relationship between educational qualifications and quality of life [X2 (n=98), DF=5, p=0.016]. It was found that over 80% of respondents did not have a better overall quality of life. In terms of the general quality of life, about 69% of illiterate respondents had a poor standard of living. Furthermore, 85% of literate respondents who had completed graduation and post-graduation had a good quality of life (see Table 2).

Table 2: Significance of Quality of Life (n=98)

Variable	Category	Quality of Life		dx	X^2
		High	Low		
Age	18-27	15 (60%)	10 (40%)	3	0.669
	28-37	11 (45.8%)	13 (54.2%)		
	38-47	13 (50%)	13 (50%)		
	48-58	10 (42.5%)	13 (56.5%)		
Gender	Male	27 (38.6%)	43 (61.4%)	1	0.001
	Female	22 (78.6%)	6 (21.4%)		
Marital Status	Unmarried	28 (66.7%)	14 (33.3%)	1	0.004
	Married	21 (37.5%)	35 (62.5%)		
	Total	49 (50%)	49 (50%)		
Income	No income	10 (76.9%)	3 (23.1%)	3	0.001
	1000-5000	36 (63.2%)	21 (36.8%)		
	5001-10,000	1 (5.6%)	17 (94.4%)		
	10,001-15,000	0 (0.0%)	0 (0.0%)		
	15,001-20,000	1 (16.7%)	5 (83.3%)		
	20,001 and above	1 (25.0%)	3 (75.0%)		
	Total	49 (50%)	49 (50%)		
Settlement	Rural	48 (51.6%)	45 (48.4%)	1	0.168
	Urban	1 (20%)	4 (80%)		
	Total	49 (50%)	49 (50%)		
Type of Residency	Pucca	26 (54.2%)	22 (45.8%)	2	0.651
	Tiled	22 (46.8%)	25 (53.2%)		
	Hut	1 (33.3%)	2 (66.7%)		
	Total	49 (50.0%)	49 (50.0%)		
Literacy	Illiterate	24 (68.6%)	11 (31.4%)	5	0.016
	Primary Education	7 (50.0%)	7 (50.0%)		
	Secondary School	8 (53.3%)	7 (46.7%)		
	High school	6 (46.2%)	7 (53.8%)		
	Higher Secondary	1 (50.0%)	1 (50.0%)		
	Higher Education	3 (15.8%)	16 (84.2%)		

DISCUSSION

Disability significantly affects a person's social status, and the consequences vary based on his or her sex, age, marital status, family size, and social network. Persons with disability are frequently judged solely based on their flaws, and are denied basic human rights. According to the available data, men are more affected than women. Males accounted for 71% of the sample, while females accounted for 29%. Persons with disability do not have equal access to health care, work, education, or political involvement because of their condition, and are subjected to aggression, abuse, prejudice, and disdain. This study also revealed that males had a higher rate of locomotor impairment than females. Nearly half of the respondents were receiving pensions from the Unemployed Assistance Scheme for Disability from the Disability Welfare Office; the remainder were working in unorganised and self-employed jobs, and just a few of them remained unemployed. As a result, the study found that persons with locomotor impairments were financially disadvantaged. Only a small percentage of the study population had higher incomes, with more than three-fourths of them in the low-income and jobless category.

In terms of family structure, about 91% of respondents lived in nuclear families; this increases reliance on their family and makes them more likely to face challenges in meeting necessities. The rest lived in joint families. According to the study of disability acceptance, roughly 84% of persons with locomotor disabilities accepted the fact that they have impairment. The rest initially rejected the idea that they were impaired. In this regard, most of the respondents with good peer-group support and higher education believed that they were not persons with disability, while those who were illiterate or with lower literacy levels had internalised stigma due to their disability and were not able to perform normal functions. The majority of the respondents lived in rural regions, and many admitted they were alone or alienated from society as a result of the way people treat them. Most individuals are born with locomotor disabilities, or affected by polio and genetic disorders, and their perceptions of their impairment are some of the variables that affect their quality of life and social support.

Quality of Life

In the context of health and disability, quality of life is commonly referred to as Health Related Quality of Life (HRQOL) and includes domains that are related to physical, mental, emotional, and social functioning as well as the social context in which people live (Adamson et al, 2003; Suganthi&Kandhaswamy, 2015; Clarke et al, 2018). Overall, the results showed that the quality of life of people with locomotor disabilities was low among all the respondents because of their disabilities. Regarding the perception of quality of life and satisfaction with health by different age groups, an almost equal number of respondents, ranging in age from 18 to 58 years, perceived low levels of quality of life (Laskar et al, 2010; Hamlin et al, 2011). Male respondents rated their quality of life higher than female respondents (Lascar et al, 2010) found that financial stress in the form of lost daily pay, the need for frequent work changes, and the loss of a job is linked to a decline in a better quality of life (Gupta et al, 2010; Gustafsson, 2012).

An examination of the connections between domains of quality of life revealed that the domains of marital status, disability module, social interactions, and better environmental health have a direct effect on the quality of life. The quality of life is enhanced by marital status and social relationships, which improve environmental health and emotional support, resulting in a good quality of life. Overall, both male and female respondents had a similar quality of life in all dimensions of the general quality of life and disability module.

According to the results of this study, married respondents have a better chance of achieving a decent quality of life than unmarried respondents, since unmarried people have less social support. Deterioration in quality of life is exacerbated by a lack of social support. Maroof et al (2017) and Staples and Mehrotra (2016) studied the financial independence of people with locomotor disabilities. With a reduced social and economic role in society, as well as greater reliance on health care and other basic needs, there was deterioration in their quality of life. In a similar vein, the current study's findings demonstrate that the majority of people with higher and average incomes have the potential to enjoy a decent quality of life. Furthermore, the findings denote that a higher family income and economic status of an individual lead to good quality of life. Similarly, Hamrin et al (2011) found that because of poverty and unemployment the locomotor difficulties give rise to other problems like functional limitations than can be restrictive.

The analysis of the association between place of residence and quality of life showed that social relationships, social support and emotional support were low among people living in rural areas. The perception is that having a decent house and good shelter is a way to acquire good social support and a pleasant life. The study observed that the small proportion of respondents who were illiterate experienced a low quality of life and very few attained a high quality of life. People who lived in rural regions had poor social relationships, social support, and emotional support.

Study Limitations

The study had a few limitations. The respondents were unwilling or hesitant to answer questions about personal activities. Several of the interviews lasted longer than anticipated. Also, the researcher experienced transportation issues while collecting data in the field. Despite these barriers, primary respondent data was obtained and analysed effectively.

CONCLUSIONS

It was observed that persons affected by locomotor disability experienced multiple fears, and faced financial instability, socio-psychological dependency and poor standard of living. Persons with disabilities are subjected to insensitivity, brutality, and frequently pity, as a result of societal isolation and poor social welfare services. The disability limits their functional capability and the chance to fully engage in society. The difficulty of getting social support is greater for those with locomotor disability. Financial insecurity has an influence on family support and social participation, Dependency on the government's pension scheme seemed high among the study respondents; therefore an empowering strategy is required to improve their quality of life.

RECOMMENDATIONS

Based on the aforementioned findings, the following suggestions are made for the welfare of persons with disability, and particularly for people with locomotor disabilities.

Better quality of education and residence can improve the quality of life for people with locomotor disabilities. The study findings revealed that a disability-friendly environment was significantly lacking, particularly in rural areas. Programmes designed for people with locomotor disabilities could also focus on improving socioeconomic fulfilment to increase well-being. Although the majority of respondents stated that they have some financial security, they were unable to find work due to lack of education and the level of disability. The issues may be communicated to industrial sectors in order to encourage people with locomotor disabilities. Improved social support from neighbours, peers, and family members is also required for their emotional well-being. This should be made known to the general public.

Few studies on locomotor disability have been conducted in the last two decades. In future, studies that focus on the hurdles faced by persons with locomotor disabilities could improve knowledge and awareness.

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Original Research Article

Accessible Public Environment in Mysore: A Case Study of Malls

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ABSTRACT

Purpose: In India, the attitude towards people with disabilities is changing and they are increasingly participating in society. It is therefore essential to study the existing accessibility standards of buildings that are open to the public and find ways to improve access where necessary. The current study aimed to assess the accessibility standards of malls in the city of Mysore, India.

Method: Two malls were selected on the basis of convenience sampling. The on-site audit of the physical accessibility of the malls was based on the physical accessibility audit checklist prepared by the Accessible India Campaign (AIC).

Results: While both the audited malls had accessible parking, entrance, reception and lobby, and toilets, these areas could not be considered fully accessible. The needs of people with different disabilities had not been met.

Conclusion: The malls in Mysore are not well equipped to cater to the needs of persons with disabilities. To be truly accessible, the buildings should be able to accommodate the diverse needs of all groups of persons with disabilities.

Keywords: access audit, people with disability, malls, disability, barrier-free environment, built environment

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INTRODUCTION

According to the Persons with Disability Act of 1995, all individuals, regardless of their abilities or disabilities, are entitled to government benefits, equal opportunities, protection of rights, and full participation in society(Rashmi et al, 2018). An inclusive city and social inclusion are essential for this Act to become a reality. An inclusive society is defined as a society that enables individuals to live in an unrestrained manner with self-esteem and actively contribute to society(Lutfiyya & Bartlett, 2020).Access is an inalienable part of inclusivity (Layer, 2002).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006, to which India is a signatory, stipulates that state parties should enable persons with disabilities to live independently and participate fully in all aspects of life (Lombardi et al, 2019). Full participation includes private entities or organisations that offer facilities and services that are open or provided to the public, to consider all aspects of accessibility for persons with disabilities(Libertun De Duren, 2021).The Indian parliament passed the Rights of Persons with Disabilities Act in 2016 (RPWD Act, 2016) to fulfil the obligation to the UNCRPD, 2006, and mandated the standards of accessibility in the physical environment, different modes of transport, and public buildings (Balakrishnan et al, 2019). As part of the push for inclusive spaces, the Ministry of Urban Development, Government of India, published model building by-laws in 2016 (Jawaid et al, 2018).In reference to that, every building meant for the public should have a barrier-free environment. This includes provisions for differently-abled persons, the elderly, and children, including site development, access path/walkway, parking, building requirements, stairs, lifts, toilets, drinking water, and signage (Jawaid et al, 2018).

As per the most recent census in India, as many as 21.9 million persons, i.e., 2.1 % of the population, has some form of disability. Across all the states and Union Territories, on average, 2 % of the population is with disability. Karnataka, where 1.8 % of the population is with disability, is one of the States with a lower-than-national-average disability population (Saikia et al, 2017).

The State profile includes, for every 1000 population, eight people with visual impairments, two people with communication disabilities, one person with hearing impairment, five people with locomotor disabilities, and two with intellectual disabilities. Visual impairment is high in the Mysore division (a tier two city in the southern part of Karnataka state) compared with the other three divisions(Rashmi et al, 2018). Another vulnerable group that requires provisions for inclusion is the geriatric population, that is, those who are 60 years of age and above(Lakshmana & Maruthi, 2018).

According to reports on social media and in social science literature, the recent trend in people fulfilling their social needs has shifted to malls. The main reason behind this transfer of social life from traditional spaces to malls is the availability and ease of finding most requirements under a single roof, including shopping, food, cultural and social events(Hagberg & Styhre, 2013; Miller & Laketa, 2019; Verma & Misra, 2021).

Malls are usually part of large conglomerates that follow the same standards of construction in all cities. The Indian Government has mandated several provisions for social inclusion, including for persons with disabilities. Therefore, it is essential to understand whether the malls adhere to the government's recommended accessibility standards.

OBJECTIVE

The present study was undertaken to perform an accessibility audit of malls in Mysore city. The findings from this study will serve as a pointer to the accessibility of these public buildings which are emerging as important landmarks and public utilities in most cities across the country. To the best of the authors' knowledge, this is the first study all over India that addresses the accessibility aspects of public places such as malls.

METHOD

Study Design

A cross-sectional study was conducted in the selected malls of Mysore city, in the State of Karnataka, India.

Study Site

Mysore is a well-planned city with wide roads and flat terrain. It attracts many tourists and has a large population of retired people. For tourists as well as city residents, malls are popular destinations for shopping, food, social and cultural events, and entertainment.

Mysore has six malls, most of which are fairly recent constructions. The oldest mall opened in 2010.

Sample

A convenience sampling strategy was used. All six malls were approached and the audit procedure was explained. Only two mall authorities consented to participate in the study.

Mall A, one of the popular malls in Mysore, became operational after 2010. It has five floors with an area of approximately 262000 square feet.

Mall B, another popular and relatively newer mall, has five floors with approximately 585000 square feet of built-up area.

Data Collection

An on-site audit of the physical accessibility of malls was done, using the physical accessibility audit checklist prepared as part of the Accessible India Campaign (AIC) by the Department of Empowerment of Persons with Disabilities, Government of India.

The AIC checklist is a validated instrument within the framework of the International Classification of Functioning and Disability(Nischith et al, 2018; Garg et al, 2024).

The checklist has been developed with inputs from various stakeholders and is the tool recommended for auditing public buildings. The AIC checklist follows the Central Public Works Department (CPWD) guidelines for architecture and planning.

The checklist is divided into three sections:

The first section includes an audit checklist for the accessibility of information and communication relating to the service (website information).

The second section contains the evaluation of the service, addressing how services are provided in the building being audited.

The third section includes an audit checklist for the physical aspects of the building (external environment and internal environment).

The external environment includes parking, alighting and accessible routes.

The internal environment includes accessible entrance, reception, lobby, stairs and ramps, handrails, elevators, escalators, corridors, doors and doorways, toilets, cafeterias, drinking water facilities, and signage.

For this study a few components of the AIC checklist were selected, such as parking and exterior access, accessible entrance and internal environment, doors and doorways, and accessible toilets. A metallic Inch tape and a digital camera were used for the audit.

The audit was conducted by two physiotherapists who had over five years of experience in the area of community reintegration of persons with disability. The backgrounds of the malls were identified and the website details were taken before conducting the audit.

Data Analysis

A descriptive analysis of the collected data was done and the findings are represented in a Table (see Table 1).

RESULTS

Table 1: Key Findings of the Accessibility Audit of Malls

Audit Category	Sub-Category	Mall A	Mall B
Parking and Exterior Access	• Parking lot	Yes	Yes
	• Firm, levelled pathways between parking and building	Yes	Yes
	• Ramp	Yes	Yes
	• Accessible route connecting entrance, parking and alighting point, with adequate lighting	Yes	Yes
	• Tactile guiding path	No	No
Accessible entrance and internal environment	• Accessible entrance	Yes	Yes
	• Identification signage at the entrance	Yes	Yes

	• Satisfactory reception and lobby	Yes	Yes
	• Satisfactory corridor width	Yes	Yes
	• Auditory input regarding the direction	No	No
	• Tactile guiding path	No	No
	• Elevators	Yes	Yes
	• Ramp	No	No
	• Adequate space for wheelchair propulsion	Yes	Yes
	• Braille letters	No	No
Doors and doorways	• Door width 900 mm	Yes	Yes
	• Kick-plates on doors	No	No
Accessible toilet	• Outward-opening doors	No	Yes
	• A horizontal grab bar on the adjacent walls	No	Yes
	• A wash basin installed at a distance of at least 400mm from the side wall	Yes	No
	• Non-slip floor surface	Yes	Yes
	• Mirror at an accessible height	No	No
	• Toilet accessories at accessible heights	No	No

Parking and Exterior Access

Both the malls had parking areas of the required size, but there were no separate accessible parking bays reserved for persons with disabilities. According to CPWD guidelines, ideally in public places separate parking bays with a minimum size of 3600 x 6000mm should be provided for persons with disabilities.These accessible parking bays should be located within 500mm from the accessible entrance and should have signage and parking shelters. Since both malls did not have separate parking bays for persons with disabilities, the accessibility standards of existing parking areas (common parking areas) were assessed. The common parking areas of these malls had signage, shelter, and a firm, covered, levelled pathway of 1200mm width connecting the parking area with the building entrance. In addition, the malls had an accessible route connecting the entrance, parking and alighting points, with adequate lighting. However, both malls lacked tactile floor guidance in the parking area, for independent mobility for people with visual impairments.

Accessible Entrance and Internal Environment

The main entrance of mall A and mall B was accessible to all users including persons with visual impairments as there was a difference in floor finish that could be identified by the latter group. Though the entrance did not have an audio signal to assist the users, the main entrance was accessible for persons with disabilities to a larger extent because of the adherence to other accessibility standards.

Malls A and B had a reception counter identifiable from the entrance, with a clear clutter-free space in front. The counter-top was adequately illuminated and the counter surface was non-reflective; also, live assistance was available to guide persons to their destination. However, the staff members were not sufficiently trained to communicate in sign language. The lobby was at one level with adequate manoeuvring space for wheelchair users, but seating in the lobby was insufficient for waiting, especially when the malls were crowded.

The corridors of malls A and B were more than 1200mm wide, which falls within the CPWD guidelines, and were clutter-free without any protruding objects or other barriers.

The corridors were spacious enough to allow a wheelchair-user to turn around at some point. The floor finish was non-slip, non-reflective, and well-illuminated. Handrails were provided on both sides of the corridor but there was no colour contrast between the floor, walls, doors, and the ceiling.

Another accessibility standard that public buildings should maintain is the provision of ramps as an alternative to the stairs; these ramps should be not less than 1800mm in width. There should be landings provided at specified intervals and at the beginning and end of the ramp, and tactile warning blocks should be installed 300mm from the top, bottom, and landings of each ramp. Malls A and B did not have ramps as there were elevators everywhere.

Malls A and B had elevators that connected all the floors of the building, and these elevators had step-free access from the entrance. The elevator cabin was spacious and the elevator door width was 900mm, which falls within the recommended guidelines. However, visual and audio floor-announcement systems were absent in the lift, and the elevator call buttons and floor numbers outside the lift on each floor were not in Braille or raised lettering.

Doors and Doorways

Malls A and B had doors with a clear width of 900 mm and no thresholds on the floor. The doors had a lever-type handle, were double-hinged and swung both ways but had no kick- plates. In addition, automatic doors were provided at the entrance of both malls.

Accessible Toilets

Malls A and B had separate toilets but these were not fully accessible and did not follow accessibility guidelines. Mall B had toilets with doors opening outwards and a few toilets had sliding doors. However, mall A had toilets with doors opening inwards, which is not very disability-friendly. Mall B had a horizontal grab bar which was installed on the adjacent wall of the toilet, at a height of 200mm from the wheelchair seat. Mall A had a wash basin with automatic faucets installed at a distance of 400mm from the side wall.

Both malls A and B had non-slippery floor surfaces, but the mirror and toilet accessories were not at an accessible height for wheelchair users.

DISCUSSION

All citizens of India have the right to access the places and services which are meant for the public. The provision of an accessible environment is a fundamental human right. An accessible building facilitates the effective utilisation of resources and amenities within, while an inaccessible building hinders individuals, particularly those with disabilities, and results in distressing and debilitating experiences. An accessible environment is an indispensable feature of an inclusive society.

The repercussions of any inaccessible environment on persons with disabilities are:

- Social exclusion;
- Lack of self-esteem;
- The increased cost of living;
- Lack of opportunities including employment and education.

An inaccessible environment prevents persons with disabilities from going out and interacting with other people and being involved in cultural events, religious meetings, family functions, and leisure activities, all of which will lead to feelings of isolation and depression. In addition, an inaccessible environment makes them dependent on others for their needs which will lower their self-esteem. Moreover, dependence on others entails additional expenses as caregivers will have to be employed. When persons with disabilities have limited opportunities to explore employment, education, and career advancement, their quality of life will be impacted.

Malls are a relatively new concept in the country and the buildings are relatively disability-friendly. The audits of both malls revealed that they largely adhere to accessibility recommendations, indicating a shifting mindset towards inclusivity in India. Nevertheless, neither mall fully complies with the accessibility standards outlined by CPWD guidelines. While these buildings incorporate some general accessibility features, they were found wanting in accommodating the diverse needs of persons with disabilities. For instance, malls A and B in the study had spacious and wheelchair-friendly elevators. However, these elevators did not have Braille buttons or auditory assistance, which would have enabled persons with visual impairments to use the elevators independently. This is an important aspect to consider in making the malls truly accessible for all individuals. The absence of Braille letters and auditory guidance in the entire building hinders hassle-free access to these malls by persons with disabilities. Moreover, the mall staff are not adequately trained in sign language and such inadequate service results in unpleasant experiences for persons with disabilities. To make matters worse, malls are always crowded, especially during the weekend, so that it is almost impossible for persons with visual impairments to visit these places without the assistance of a caregiver or friend.

Another example is the toilets. Both malls had separate toilets which have been mentioned as accessible toilets. In actuality, these toilets do not meet all the criteria of accessible toilets. Ideally, accessible toilets should have doors that are outward-opening, double-hinged, or the sliding type. There should be a wheelchair installed in a corner, with the centre line of the wheelchair at a distance of 450mm to 500mm from the adjacent wall. The wheelchair should have a back rest and the seat height should be 450mm. A lever-type flush control should be installed at a height of 1100mm from the floor surface or on the transfer side of the wheelchair, and the force required to flush should be comfortable. A horizontal grab bar should be installed on the adjacent wall, at a height of 200mm from the wheelchair seat. A wash basin should be installed at a distance of at least 400mm from the side wall and there should be clear knee space of at least 750mm height x 750mm width x 200mm depth under the wash basin, with additional toe-space of 300mm height x 750mm width x 230mm depth. The toilet's floor surface should be non–slippery and there should be an alarm system within easy reach to alert persons outside, in case of an emergency. Visual alarms must be there to alert people with hearing disability in case of emergency, and although the door can be locked from inside there should be provision to release it from outside in case of emergency (Chapter 8 of CPWD Handbook). The malls that were audited for this study had few of these provisions. These cannot be called accessible toilets as they cannot be used by all groups of persons with disabilities.

In what ways can malls be made fully accessible for people, irrespective of the type of disability?

Some of the points to consider are:

- Employing adequately trained staff to accompany and assist persons with disability, especially in crowded and cluttered areas.
- Installing tactile pathways and Braille signage which will enable persons with visual impairments to explore the areas and resources of malls.
- Elevators must have Braille buttons so that persons with visual impairments can use them safely and effectively without any assistance.
- There should be an audio assistive system or audio guides that help persons with disabilities to find their way and navigate independently.
- The toilets and cafeterias should be completely accessible.

An inclusive design should embrace and accommodate the diversity of people and cater to the needs of all types of disability. Adherence to the country's law and taking necessary actions towards creating an inclusive city is a responsibility to be shared by everyone. The national accessibility standards must be followed in every State at a policy level. Accessible buildings and social inclusion will come to fruition only if there is greater awareness, accessibility-seeking behaviour, empowerment of persons with disability, and continued reinforcement by the law. Stakeholders must focus on measures like repeated access audits, and persons with disabilities and NGOs must be part of the decision-making, design, and implementation process. In addition, State parties should implement and ensure inclusive design in all infrastructure developments.

Implications

By reporting the accessibility standards provided by these malls, the findings from this study can guide persons with disabilities to utilise these facilities as best they can. Additionally, the recommendations from this audit will help the mall authorities and policymakers to improve the facilities to accommodate the accessibility needs of persons with disabilities.

Limitations

The major limitation of the study was that the AIC checklist was quite extensive, used unfamiliar terminologies and had some components which were not applicable in the Indian context. It would help if there were a more succinct checklist which factored in the cultural differences of different states, as well as the available resources and diversity of urban and rural populations. Further studies should explore the accessibility standards of malls in rural areas, urban areas, and suburban areas.

CONCLUSION

The current study, in a nutshell, discusses the extent to which malls in India are prepared to accommodate people with disability.

The study found that both the malls that were audited had accessible parking, entrance, reception and lobby, and toilets. However, these areas did not fully accommodate the needs of people with different disabilities. Greater accessibility of the built environment can be achieved by increasing awareness, empowerment, and accessibility-seeking behaviour among persons with disabilities and by the reinforcement of the law.

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DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Reviews

Child Rights and Cerebral Palsy Rehabilitation in India

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INTRODUCTION

The prevalence of Cerebral palsy (CP) is increasing worldwide and is currently estimated at 1 - 4 per 1000 live births(Gulati& Sondhi, 2018; Paul et al, 2022; Saranti et al, 2024). Though there is a dearth of high-quality studies from India, the observed prevalence of Cerebral palsy in the country is 2.95 per 1000 children surveyed(Sony et al, 2023).Due to this rising prevalence and increased awareness, comprehensive Cerebral palsy rehabilitation has become ubiquitous in India(Jindal et al, 2019). Children with Cerebral palsy undergo extended rehabilitation procedures which typically include muscle stretching and strengthening, massage, neurodevelopmental techniques, and gait training. These programmes often go on for several years(Heathcock, 2021). In addition, depending upon each child's needs, various other therapies are given to improve cognition, communication, behaviour, sensation and perception. While these are arguably done with the child's best interests at heart, are there checks and balances on how many hours of therapy the child requires? How do rehabilitation experiences balance with an enriching experience of childhood? Do we have any guidelines to follow? Are too many hours of shuttling between therapies an infringement on the quality of life for children?

IMPACT ON QUALITY OF LIFE

Physical examination and rehabilitation processes for children with Cerebral palsy start in infancy. Their childhood is moulded by pain and stress, not only because of the nature of their disorder but also because of the long hours of painful rehabilitation procedures, and from having to live in an environment generally created for the "typical" child(McKearnan et al, 2004; Dydyk & Givler, 2024). The repercussions of the long hours of therapy are severe and result in:

1. Chronic pain syndrome and central sensitisation(Van Der Slot et al, 2012; Verschuren et al, 2016)
2. Fatigue(Majnemer et al, 2008; Jarl & Alriksson-Schmidt, 2021)
3. Low academic performance(Parkes et al, 2008)
4. Caregiver fatigue leading to abuse or neglect of the child(Liu et al, 2023)
5. Behavioural problems(Parkes et al, 2008)
6. Anxiety and depression(Ramstad et al, 2012; Ullenhag et al, 2024).

The above-mentioned factors are interconnected and overlap. Chronic pain reduces the quality of life of children with Cerebral palsy as it negatively impacts their comfort levels, recreation and sleep patterns, and consequently hinders their involvement in activities of daily living while causing anxiety, fatigue, and depression(Majnemer et al, 2008; Parkes et al, 2008; Van Der Slot et al, 2012; Verschuren et al, 2016; Ullenhag et al, 2024). Caregiver fatigue is another inadequately acknowledged and challenging consequence. Parents, often the mothers, bear the brunt of caretaking responsibilities(Liu et al, 2023).They not only handle the child's activities of daily living but also provide emotional support, and attend appointments and therapy sessions, which can take a toll on their own quality of life. Often, these additional responsibilities hinder mothers' ability to manage routines, earn their livelihood, take care of other children, and engage in pleasurable activities. The toll on the caregiver's health has a direct effect on the well-being of the child, as has been reported in various studies(Liu et al, 2023).

These factors beg the questions:

- Are the long hours of rehabilitation necessary?
- Are rehabilitation professionals aware of the consequences?

Parental Expectations and Misconceptions

Rehabilitation professionals often do not give clear explanations to the parents of children with Cerebral palsy regarding the progression of the disease and the functional independence to be expected. This leads parents to believe that there is a cure and that their children may become normal if intensive and prolonged rehabilitation is undertaken. The health practitioners may imply that the children will improve faster if they undergo more hours of rehabilitation, but often the end point of improvement is unclear. The parents may construe the term 'improvement' to mean normalcy, so the children are forced to do things that are beyond their capability or may cause secondary problems like pain and anxiety; in consequence there is no time for enjoyment which, as per definition, equals neglect and abuse(Hutton, 2006; Ullenhag et al, 2024).In addition, unrealistic goals of parents put enormous pressure on the rehabilitation professionals, as they are afraid of the repercussions if their opinion is not similar to that of the referring doctors. From an economic perspective, professionals in private practice are concerned about 'therapist shopping' if they give contradictory opinions that do not satisfy the parents.

The aforementioned factors culminate in a cycle of long, and often, trial-and-error methods of formal therapy without much attempt at embedding therapy goals into routine activity. It is well- documented that therapeutic strategies must be part of the routine life of a child with Cerebral palsy as Cerebral palsy is a lifelong condition(Hutton, 2006; Moll & Cott, 2013). Sadly, this is not commonly practiced in India, due to lack of multidisciplinary teams and school-based rehab services. Samagra Shiksha Abhiyan (SSA), a government initiative, has a strong theoretical foundation but falls short in implementation for many reasons, including dependency on formal therapy which is rarely child-friendly. Anecdotal reports from professionals associated with SSA suggest that SSA has full-fledged multidisciplinary team services as the policy documents, but in actuality implementation is hindered by difficulties in staff hiring, high attrition rates, and inadequate individualisation of services and poor documentation. Occupational therapists, psychologists and speech pathologists are rarely present due to the dearth of professionals in these fields. Often the sole service providers are physiotherapists who visit the SSAs sporadically, and sometimes not at all. Block integrated education resource teachers (BIERT) often try to fill the gap and provide rehabilitation services within their abilities and expertise. Due to lack of training, the services may be erroneous and haphazard, potentially causing harm to the children. Furthermore, the assistive devices and mobility aids that the children receive from SSA are generic mass-produced devices that are not customised to the individual child. Another aspect of concern is the lack of adapted seating devices. Though the children are currently expected to sit in the school for more than 6 hours in a day, SSA fails to provide them with adaptive seating, resulting in bad posture and putting them at risk for the occurrence of deformities (Nagaraj / Santhosh / Sneha, via personal communication,2023), all of which are painful. In a nutshell, though the intention behind SSA is noteworthy, the implementation is not up to the mark.

Schooling and Educational Rights

What is happening with the schooling of children with Cerebral palsy? Are they allowed to go to school like other children? From our experience in working with parents of children with Cerebral palsy enrolled in the SSA programme, priority is given to the quality of walking as the outcome of rehabilitation, and the educational needs of the child are considered secondary to independent walking (Anagha / Vinay, via personal communication, 2023). This practice potentially affects the quality of education of children with Cerebral palsy. Either many children are enrolled in school only after an average age of 10 years or some are not going to school at all(Chiarello et al, 2010). On the other hand, though mainstream schools are mandated to admit children with Cerebral palsy, they often do not take them. School authorities advice parents not to send their children to school until they are able to walk and use the washroom independently. The following case illustrates this. Anitha (name changed to maintain confidentiality) is a 9-year-old with athetoid Cerebral palsy of GMFCS level IV, with associated moderately severe communication disability. She has above-average intelligence and problem-solving skills, and is eager to socialise and go to school. Unfortunately she was denied admission in a mainstream private school under the misconception that she was “intellectually disabled” because she could not walk, talk and write due to the involuntary movements (Rani, via personal communication, 2023). The child has the potential to excel in school if provided with adapted ways to learn and communicate, which are currently very feasible with Smartphone applications. The provision of a wheelchair would have allowed her to go to the washroom and the playground independently. Is this not against the child’s rights to education? Issues such as these often lead parents to force their children to walk, regardless of their ambulatory ability.

Another matter of concern is parents’ disinclination towards employing mobility aids and seating devices, which are essential to decrease secondary orthopaedic misalignment. Parents are reluctant to buy these because they think that the children with Cerebral palsy will eventually walk normally. They consider mobility aids to be therapeutic devices which need to be used only during therapy and can be discarded when the child attains “normal” ambulation or sitting balance. Therefore, they continue to allow children to adopt inappropriate postures and walk in non-optimal fashion out of therapy hours(Raja, 2006).Inappropriate seating, and non-use of orthotic and mobility devices are risk factors for chronic pain, fatigue, and anxiety. Together these lead to low academic performance and behavioural problems(Ireno et al, 2019; Jarl & Alriksson-Schmidt, 2021).Chronic pain, fatigue and anxiety in Cerebral palsy, although well-documented, are rarely acknowledged by health professionals in India. Parents are often not counselled regarding these factors(Verschuren et al, 2016; Dydyk & Givler, 2024).The secondary effects of this on the growing child manifest as orthopaedic deformities requiring repeated surgeries followed by ever longer periods of therapy. Long painful hours of therapy for years together (average of 10 years) flies in the face of child rights!

Then what is the way forward? Rehabilitation is a necessity for children with Cerebral palsy throughout their lives, but there should be checks and balances on the cumulative hours of formal rehabilitation and the methods adopted. A general consensus should be arrived at, between the medical practitioners and the rehabilitation professionals, regarding informing the parents about the level of improvement they can expect, based on the well-documented and well-known functional classification systems. Moreover, clear communication about therapeutic measures, assistive technology usage and the involvement of parents in therapeutic functions as part of daily life, is essential. Another solution is the improved focus of school-based rehabilitation programmes like SSA, so that the child’s educational and recreational needs are equally addressed. The key recommendations for the optimum performance of SSAs, keeping in mind staffing problems are:

- BIERTs should be trained adequately for triaging and referrals as well as for the provision of routine rehabilitation services.
- A health institution with a multidisciplinary team should be one of the stakeholders of each SSA. The professionals should visit the SSA at frequent intervals and guide and train the BIERTs.
- Adaptive physical education including traditional Indian folk games should be part of the SSA curriculum. A study conducted by Rahman et al (2024) reported the use of folk games which would increase the physical activity level of children with Cerebral palsy and are easy to implement as theyrequire minimum equipment and are widely accepted, being culturally embedded.
- Children should be guided adequately, and either sent to vocational training or continue with mainstream school based on their abilities after the completion of 10th standard, so that they can earn their livelihood in the future.

Let the parents have something to look forward to, so that children can enjoy their childhood regardless of their diagnosis.

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Reviews

Social Determinants of Health in the Lives of People with Disability

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ABSTRACT

Purpose: Health is socially produced through the acquisition of socioeconomic, cultural and environmental domains, known as Social Determinants of Health (SDH). It is noted that people with disability experience social inequalities in health, as they are denied rights involved in the production of health. Therefore, this study aimed to review the existing literature on the SDH of people with disability and to identify the gaps in knowledge and challenges in this field.

Method: An integrative review study was carried out in the Eric, PubMed and Science Direct databases. From 2013 to 2022, 1,252 articles were identified and 29 were selected for analysis. All the articles were in English and only one was based in Brazil. The studies were analyzed by categorization according to the layers of Dahlgren and Whitehead's SDH theoretical model.

Results: The results indicated a greater number of studies carried out with guardians of people with disabilities. People with disability tend to experience depression and engage in less physical activity. Their social participation is hampered, mainly by the lack of accessibility to transport and voting. Their friendships are limited due to negative disability stereotypes. Working contributed to a feeling of well-being and social belonging, although access to employment was negatively impacted by their disability. It was pointed out that access to education reinforces the possibilities of access to formal work.

Conclusion: People with disability face multiple and interrelated challenges to their health, which are influenced by the social determinants of health (SDH). Each sector involved in the provision of health services and social support has a role to play in addressing these challenges. Thus, public policies that promote the social and collective participation of people with disability, especially in the labour market, are essential.

Key words: social determinants of health, rights, access, health, people with disability

INTRODUCTION

It is conceived that the production of health is related to social determinants. In turn, the social determinants interact with subjects so as to influence their development process. These determinants are recognised throughout the life of individuals through the conditions in which people are born, grow up, live, learn, play, work, and age (WHO, 2008). In view of this, social inequalities in the field of health are generated among people, especially concerning people with disability (Skalinski & Praxedes, 2003; Comissão Nacional Sobre Determinantes Sociais da Saúde, 2008; Barata, 2009; UNICEF, 2018).

With regard to people with disability, it is known that deprivations of rights are experienced daily, although there is awareness of the social inequalities experienced by them (Wolbring, 2011). In particular, the socioeconomic and education levels are Social Determinants of Health (SDH) from which they are often excluded. The intersection of these deprivations sometimes acts on the Living Conditions and quality of life of people with disability (Vanegas-Sáenz et al, 2020). Another perspective on the understanding of SDH among people with disability also perceives the condition of disability as a determining factor, i.e., the experience of disability conditions the health relationships and productions of these individuals (Solvang et al, 2017).

The perception that people with disability are in precarious health merely because of their disability emphasises that the understanding is anchored in the medical model, which conceives such bodies as inadequate. Therefore, it is necessary to allude to the importance of disability being understood as a relationship of the body with the environment through the biopsychosocial model, manifested by the International Classification of Functioning, Disability, and Health (ICF) (Diniz, 2012). Understanding the importance of the relationships between the body and the environment will support policies regarding the implications of SDH on health production and people's quality of life (WHO, 2001; Green et al, 2020; Froehlich-Grobe et al, 2021).

Another very significant determinant in the lives of people with disability is access to work. Studies have shown that people with disability are more prone to unemployment and lower wages (Mikkonen & Raphael, 2010). They have also pointed out that neglect of salaried work compromises the health of this population (Kirsh et al, 2009), while the opportunity for access to work helps improve health and social participation (Mikkonen & Raphael, 2010; Goodman, 2015).

Given the above, it is possible to assume that the literature reveals concerns in understanding the SDH among people with disability (Froehlich-Grobe et al, 2021; WHO, 2015). In particular, studies have mainly addressed economic aspects and employability, to the detriment of education and social participation. Nevertheless, the gap in the literature is acknowledged regarding the understanding of all SDH related to people with disability globally so as to interfere with their Living Conditions. The insufficient findings on this theme serve to emphasise the fundamental importance of the current research dedicated to studying SDH and their relationships with people with disability. This study may lay the foundations for public powers to create policies linked to access networks to public health and education services, for example.

OBJECTIVE

This study therefore aimed to analyse the existing knowledge production about the Social Determinants of Health among people with disability.

METHOD

Study Design

This qualitative, exploratory, and descriptive review study was carried out using integrative review procedures to search and select scientific articles. The selection of studies followed the six steps described for this methodological design, which were: 1. elaboration of the guiding question; 2. search in the literature; 3. data collection; 4. critical analysis of the included studies; 5. discussion of the results; 6. presentation of the integrative review (Souza et al, 2010).

Data Collection

Data collection was carried out in three databases: PubMed, Eric, and Science Direct, from January to February 2022. The period of ten years (from 2013 to 2022) was considered as the time frame.

Inclusion criteria:

- Original scientific articles addressing SDH specifically among people with disability (physical, intellectual, auditory, or visual disabilities, autism spectrum disorder, and multiple disabilities)
- Articles available in full in Portuguese, English, or Spanish.

Non-inclusion criteria:

- Scientific articles that addressed other disabilities, such as nutritional deficiencies
- Articles that did not answer the guiding question.
- Books, book chapters, review articles, dissertations, and theses.

The following equation was used as a search strategy: ("People with Disability" OR "Persons with Disability" OR "Disability" or "Impairment") AND ("Social Conditions" or "Life condition" OR "Living Condition" OR "Social Determinants of Health" OR "Health Structural Determinant"), with the descriptors being selected in titles, abstracts, or keywords. The Boolean operators "AND" and "OR" were used to combine the descriptors, assisting in the search and extraction of the data.

After collection, the scientific articles were allocated into folders separated by the database. Initially, 1,252 studies potentially eligible for this review were identified. Of these, 1,223 were excluded because they failed to meet the inclusion criteria for this review, as described in Figure 1. The excluded studies were allocated into four groups: 1)Studies that did not thematise people with disability or addressed disabilities other than those included in this research; 2)Event reports; 3) Reviews or theses; 4) Studies that did not relate the SDH

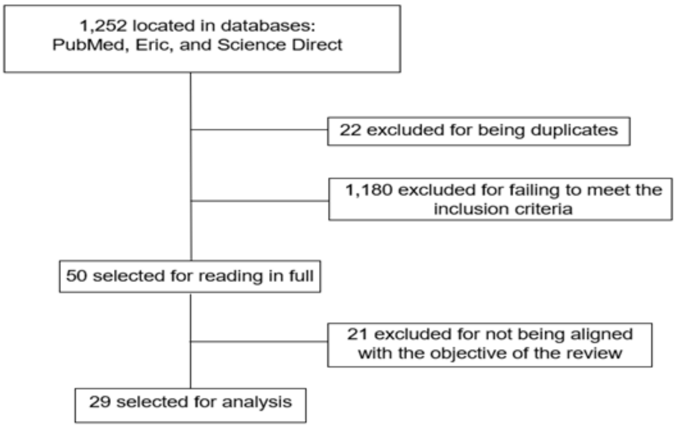

Figure 1: Selection of Scientific Articles

Data Analysis

For the analysis, the articles were categorised according to the representative layers of the SDH based on the understanding model proposed by Dahlgren and Whitehead (1991), as shown in Figure 2. The model exemplifies the determinants through micro, meso, and macro layers. Thus, it was identified that the studies selected for this review were related to the model through the thematisation of the domains present in it, which justifies its use as an organization for later discussion.

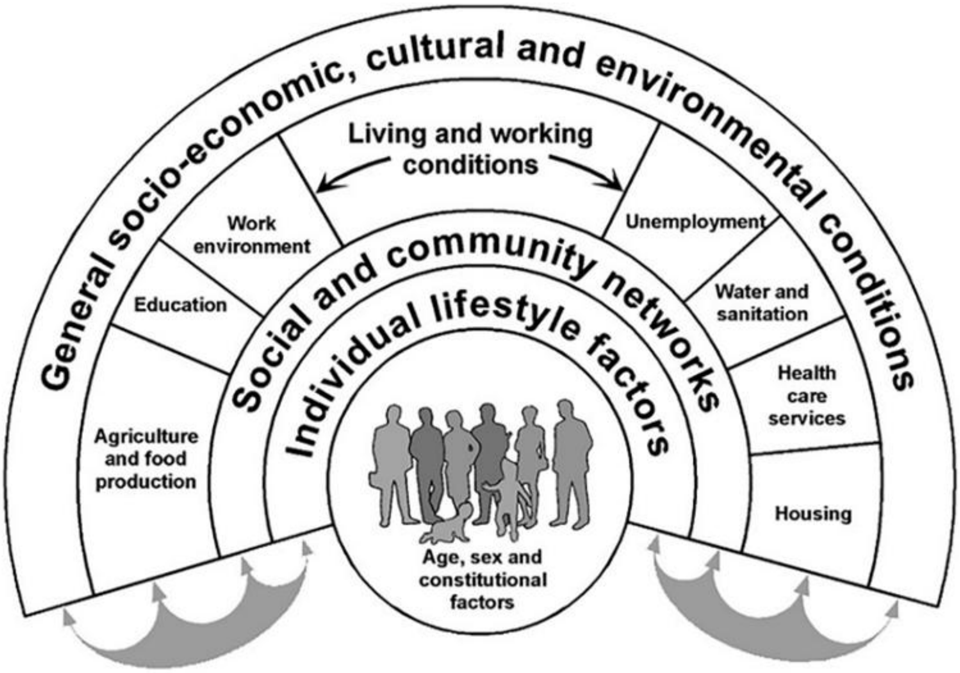

Figure 1: Social Determinants - Model by Dahlgren and Whitehead (1991). Source: Dahlgren and Whitehead (1991).

The analysis indicated that among the 29 selected studies, research conducted with people with intellectual disability predominated; in 8 studies the only participants were persons with intellectual disability and in 5 studies the participants were persons with intellectual disability coupled with other disability conditions (see Table 1).While 18 articles utilised interviews for data collection, it was generally parents and/or professionals who were interviewed; only 2 articles interviewed the people with disability and the interviews were monitored by family members and support professionals.

The current study identified the predominance of studies conducted with adult participants or even adults and senior citizens together. Only 4 studies included children or adolescents among the participants. It was observed that the studies under analysis presented the superiority of the United States, and only 1 was conducted and published in Brazil, in English.

Table 1: Characterisation of the Studies included in the Review

AUTHOR (YEAR)	LOCATION	TYPE OF DISABILITY	AGE	COLLECTION INSTRUMENT	SDH	MAIN RESULTS
Francis et al. 2013	United States	Disabilities – general	-	Questionnaire with family members, professionals, and people with disability	Living and Working Conditions	Awareness of the people with disability, family members, and support professionals about the importance of employment for people with disability
Kelly 2013	United States	Visual Impairment	16 – 64 years	Data from the Current Population Survey	Living and Working Conditions	People with visual impairments have lower employment rates than people without disability
Van Campen; Van Santvoort 2013	European Continent	Severe disabilities and without disabilities	+15 years	Interviews from the European Social Survey 2006/2007; Questionnaire	Lifestyle of the Individuals; Living and Working Conditions; General Socioeconomic, Cultural, and Environmental Conditions	People with disability report lower well-being than people without disability. Education level, work, and income were favourable for the increase in the subjective well-being of the participants
Bevan-Brown; Walker 2013	New Zealand	Visual Impairment	+17 years	Interviews with people with disability – 5 with family members together	Social and Community Networks; Living and Working Conditions	Indigenous people with visual impairments face general, educational, and cultural barriers
Anderson et al. 2013	United States	Intellectual and Developmental Disability	-	Theoretical study	Living and Working Conditions	People with disability experience health disparities such as lack of access, poverty, and non-inclusion of people with intellectual and developmental disability in public health
Agran; Hughes 2013	United States	Intellectual and Developmental Disability	-	Interviews with professionals	Social and Community Networks	People with disability receive little or no instruction on voting, resulting in their non-participation in the electoral process
Emerson; Brigham 2013	England	Intellectual Disability	-	Primary Care Trusts	General Socioeconomic, Cultural, and Environmental Conditions	Parents with Intellectual Disability are at higher risk of exposure to worse mental health and are more exposed to environmental adversities

Haider et al. 2013	Australia	Intellectual Disability	+18 years.	Telephone interview – people with disability; with support professionals/family members/friends.	Lifestyle of the Individuals; Social and Community Networks	People with intellectual disability report fewer SDH, such as social support, behavioural risks, obesity, depression, and diabetes
Anderson et al. 2014	-	Autistic Spectrum Disorder	13 – 16 years	Interviews with people with disability and their family members	Living and Working Conditions	Young adults with ASD are more likely to live with their parents after high school
Abbott; Carpenter 2015	England	Duchenne Muscular Dystrophy	+15 years	Questionnaire with family members Interviews with family members or young people with disability alone	Lifestyle of the Individuals; Social and Community Networks; Living and Working Conditions	Being a person with disability was associated with something bad. Resulting in worse health, leisure, and access to work
Lambert et al. 2015	United States	Disabilities – general	8 – 18 years	Medical evaluation; interviews with young people with disability and their parents or caregivers	Living and Working Conditions	People with disability use more medical services than people without disability
Jimenez-Corona et al. 2015	Mexico	Visual Impairment	+20 years	Interviews	Lifestyle of the Individuals; Social and Community Networks; Living and Working Conditions; General Socioeconomic, Cultural, and Environmental Conditions	People living in rural areas had a higher prevalence of visual impairment than urban residents. People with visual impairment were older, with lower education levels and unfavourable socioeconomic conditions
Fiorati; Elui 2015	Brazil	Disabilities – general	+18 years.	Open interviews about the life stories of the participants; observation	Social and Community Networks	The socio-family and community inclusion of people with disability is linked to the SDH, such as: inequalities in access to health, income, employment, education, culture, and transportation

Sandhu; Ibrahim; Chinn 2016	England	Intellectual Disability	Not specific (children)	Interviews with family members	Living and Working Conditions; General Socioeconomic, Cultural, and Environmental Conditions	Turkish families migrate to other countries in search of a better life due to their children with intellectual disability
Lysaght et al. 2016	Canada	Intellectual and Developmental Disability	21 – 59 years.	Interviews with family members and PWD	Living and Working Conditions	Access to formal or informal work presented positively for the social inclusion of people with disability
Agran; MacLean; Kitchen 2016	United States	Intellectual Disability	20 – 68 years	Interviews with 28 people with intellectual disability	Social and Community Networks	Voter participation of people with disability is low. However, they indicate an interest in participating in the democratic process
McConkey et al. 2016	Ireland	Intellectual Disability	40 – 55 years	Interviews with people with disability alone or with family members/supporters	Living and Working Conditions	People with disability residing alone or with friends require less support and are more likely to have a job and participate socially
Simões; Santos 2016	Portugal	Intellectual Disability	18 – 57 years	Interviews with people with intellectual disability, support team, and family members	Living and Working Conditions	People with disability perceive their quality of life more positively than support professionals perceive the quality of life of people with disability
Sanetti 2017	United States	Disabilities – general	-	Theoretical study	Living and Working Conditions	Educational progression is influenced by health needs
Cocks et al. 2018	Australia	Intellectual Disability	18 – 82 years	Interviews with people with disability or family member	Lifestyle of the Individuals; Social and Community Networks; Living and Working Conditions; General Socioeconomic, Cultural, and Environmental Conditions	Increasing age, physical inactivity, low socioeconomic status, and living in one's own home all increase the risk for worse subjective health
Tamayo; Besoaín; Rebolledo 2018	Chile	Disabilities – general	-	Theoretical study	Social and Community Networks	It is necessary to incorporate disability in SDH models as a structural determinant and producer of inclusion/exclusion
Gartrell et al. 2018	Solomon Islands	Disabilities – general	-	Theoretical study – observations and interviews with people	Social and Community Networks; General Socioeconomic, Cultural,	People with disability face the stigma of infantilisation and underestimation before society. In addition, they find it difficult to insert

				with disability, family members, and caregivers	and Environmental Conditions	themselves into the productive and social environment and experience physical barriers on a daily basis
Frier et al. 2018	Australia	Disability Neurological	29 – 65 years.	Interviews with people with disability and two caregivers.	Lifestyle of the Individuals; Living and Working Conditions; General Socioeconomic, Cultural, and Environmental Conditions	Acquiring the condition of disability caused negative changes in relation to income, employment, housing, transportation, and participation in everyday activities
McCausland et al. 2019	Ireland	Intellectual Disability	41 – 90 years	Interviews with people with intellectual disability only; people with intellectual disability with support from others; other people responding on behalf of the people with intellectual disability	Social and Community Networks	People with disability use transportation more with support. Public transportation is used more by people with disability with lower levels of disability severity and people with disability who live alone
Pérez-Hernández et al. 2019	European Continent	Disabilities – general	30 – 79 years	European Social Survey – interviews.	Lifestyle of the Individuals; Social and Community Networks; Living and Working Conditions	SDH influence the inequalities faced by people with disability. Thus, disability is superior among people living in poor conditions, with lower education and employment levels
Lancioni et al. 2020	-	Intellectual and Motor or Sensorimotor Disability	-	Leisure and communication intervention programme; Interviews with professionals	Social and Community Networks	The intervention programme showed that the use of technology proved positive in the communication and leisure of people with disability
Del Brutto et al. 2020	Ecuador	Disabilities – general	+60 years	SDH – Gijon Scale Measuring disability: Functional Activity Questionnaire (FAQ)	General Socioeconomic, Cultural, and Environmental Conditions	Worse support networks were the domains of the SDH most associated with disability, while the economic factor was the only one not associated
McDonnall; Tatch 2021	-	Visual Impairment	21 – 54 years	Interviews collected through the	Living and Working Conditions	The education level increases the chances of access to employment. However, even with higher education levels than people without

				American Community Survey		disability, people with disability are less likely to be admitted
Friedman 2021	United States	Intellectual and Developmental Disability	Mean age of 47.47 years.	Interviews	Lifestyle of the Individuals; Living and Working Conditions	Qualification of the SDH, such as education, employment, social and community participation, results in a decrease in emergency room visits

Source: Prepared by the authors (2023).

Caption: SDH – Social Determinants of Health; ASD –Autism Spectrum Disorder.

RESULTS AND DISCUSSION

According to the analyses, the studies did not use specific theoretical models to understand the Social Determinants of Health. The research was noticeably more focused on the Social and Community Networks and Living and Working Conditions of people with disability, the latter being the largest field of study among the articles analysed. Although in lower numbers than the others, the layers about the Lifestyles of the Individuals and the General Socioeconomic, Cultural, and Environmental Conditions were also presented as a field of research, with the focus mainly on the socioeconomic relationships of those researched. Moreover, 2 studies were concerned with thematising disability as an important domain in the SDH, pointing to it as a conditioner of the health production process. Therefore, for the discussion, the included studies were categorised according to the layers described in the model by Dahlgren and Whitehead (1991).

Lifestyle of the Individuals

Among the 29 articles selected for this review, 8 had articulation with the innermost layer according to the model by Dahlgren and Whitehead (1991). As for the phenomena related to the Lifestyles of the Individuals, a prevalence of studies that sought to research people with disability in adulthood or even senior citizens was noticed. Studies such as Jimenez-Corona et al (2015), Cocks et al (2018), and Pérez-Hernández et al (2019) pointed out that the increase in age presented itself as a factor of prevalence of disability, as well as a risk factor to the health of individuals with intellectual and visual disability. Moreover, the results revealed that impairments to subjective health and the presence of disability are associated with low physical activity levels and smoking (Cocks et al, 2018; Pérez-Hernández et al, 2019).

Living with a disability may impact the lives of individuals in a variety of ways. In a study conducted by Frier et al (2018) with people who acquired physical disability in the course of their lives, the authors identified, through the accounts of the study participants, changes in various spheres of life, primarily in economic, housing, and transportation contexts. Within the health-disease scope, these impacts are further accentuated by the severity of the disability condition. People with severe intellectual disability have more significant records of access to emergency rooms than people with mild intellectual disability, which may represent a favourable health-disease situation for them (Friedman, 2021).

However, one cannot ignore the fact that living with disability is sometimes reported as synonymous with physical and/or emotional pain. Children and youths with Duchenne Muscular Dystrophy point out that the condition of disability generates physical pain, which results in even more considerable difficulties in their social participation (Abbott & Carpenter, 2015). The relationship between the body and the environment in which the body is presented as a barrier causes possible emotional suffering (Abbott & Carpenter, 2015). As a result, studies such as that by Van Campen and Van Santvoort (2013) point out that people with disabilities identify their well-being at a disadvantage relative to people without disability.

Finally, with regard to the characteristics related to the lifestyles of the individuals, the study by Haider et al (2013), conducted with a representative number of the population of the state of Victoria, Australia, identified that people with intellectual disability report worse SDH indices. The authors pointed to deficits in the domains related to behavioural risk factors such as obesity and sedentary lifestyle, depression, diabetes, and poor or regular health in populations that experience disability compared to their peers without disability. It becomes evident that the layer referring to the lifestyles of individuals with disability represents an important phenomenon in the acquisition and production of health. Therefore, it is necessary to accommodate, listen, understand, and encourage people with disability to have healthy behavioural factors to ensure that they have qualified health.

Social and Community Networks

In the category of Social and Community Networks, 13 studies were identified that address the deprivation of social participation experienced by people with disability. In their study, Haider et al (2013) pointed out that people with disability have less social support, such as help from friends, than people without disability, with this being an important indicator for health risk exposure. In addition, the condition of disability is sometimes associated with negative stigmas, loaded with underestimation and infantilisation, leading to social exclusion (Bevan-Brown & Walker, 2013; Gartrell et al, 2018).

Recognising the disability loaded with negative stigmas indicates how much the medical model of understanding disability is still immersed in societies. Understood as exclusive to the person, the medical model understands disability through the bias of healing the body outside the norm, outside the standard expected for production in the social environment and for the search for capital (Diniz, 2012). Characterising the person solely by the disability condition causes limitations of life opportunities experienced through physical and attitudinal barriers expressed in everyday situations (Bevan-Brown & Walker, 2013; Gartrell et al, 2018).

However, the concern in other studies with identifying disability through the social model was also notable (Abbott & Carpenter, 2015; Fiorati & Elui 2015; Tamayo et al, 2018). Opposite to the medical model, the social model of disability understands it as a social production acquired by the environment in which the person lives, from the barriers encountered, which mark or diminish the experiences (Diniz, 2012; Ivanovich & Gesser, 2020). Hence, the architectural, attitudinal, and communication barriers experienced by people with disability intervene in their full social participation and must be faced as a collective responsibility (Silva Sampaio & Ferreira, 2019; Mota & Bousquat 2021).

Understanding the relational importance of the body to the environment, the study by Abbott and Carpenter (2015) identified the social model in the barriers to the participation of children and youths in life in society. The authors mainly pointed out, through the accounts of the research participants, the need for expansion of thinking, given that issues related to bodily experience, such as pain and sensations of the body as barriers to participation, should not be eliminated. That said, the condition of disability is recognised as a determinant for the production of health due to its social exclusion through the body (Tamayo et al, 2018).

Regarding the understanding of disability under the precepts of the social model, it is valuable to point out the responsibility of society and the understanding of the disadvantages and inequalities experienced by people with disability. Building society while taking into account universal access to all environments and decisions as a human right, ignites the demand for the creation of public policies that serve everyone with regard to health promotion (Fiorati & Elui, 2015; Tamayo et al, 2018).

Among the various deprivations, access to public transportation as a means of locomotion and habitual social activity appears as an obstacle in the lives of people with disability. People with physical disability acquired throughout life point out that the lack of this right minimises their participation in everyday tasks, such as going to the supermarket and participating in social activities, for example (Frier et al, 2018). Restricted mobility, such as inaccessible public transportation, is one of the most frequently reported causes impacting the low use of such transportation by people with disability (Bevan-Brown & Walker, 2013; McCausland et al, 2019).

However, the study by McCausland et al (2019) pointed out that the low use of this type of transportation is also caused by the level of severity of the disability condition and type of housing, given that people with mild intellectual disability or who lived alone had more reports of using public transportation. In contrast, people with severe intellectual disability who lived with family members or in institutions used other types of transportation more frequently. In addition, living in one's own home was also a predictor of worse health as reported by people with intellectual disability, in contrast to their peers who resided with family members or in care homes (Cocks et al,2018). This finding may be explained by the greater autonomy and functional capabilities that people living in their own homes may have.

Social participation through access to voting as a democratic right of any citizen has also been identified as a barrier for people with intellectual disability. According to reports, few individuals with intellectual disabilities practice this right, claiming insufficient or no knowledge, education, and instruction about the political process (Agran & Hughes, 2013; Agran et al, 2016). Denying the electoral participation of people with disability calls into question issues related to inclusion, contradicting ratifications that guide the rights of all people.

Friedman (2021) pointed out that encouraging the involvement of people with disabilities in social and community life by performing roles and interacting with the community was an important factor in reducing the frequency of visits of people with disability to emergency rooms. This finding corroborates the understanding that social relationships impact health production. In addition, Lancioni et al (2020) proved that the correct use of technology can help in the process of communication, participation, and leisure for people with disabilities.

All these reported data indicate and reinforce the significance of understanding the importance of the social and community networks in which people with disability are inserted. Denying rights of social participation and perceiving the person under the body-normative bias are still realities experienced by many people, realities that prevent the social involvement of people with disability (Gartrell et al, 2018). Thus, there is an urgent need for public awareness regarding social participation as a right of all people, regardless of their condition, recognising their merit in the fight for the non-production of inequalities in the field of health.

Living and Working Conditions

As meso-determinant, the category of Living and Working Conditions of people with disability was the one with the most significant representation in the literature included in this review, with 19 articles. Among the seven domains that are part of this layer, the studies were linked to four: unemployment, social health services, housing, and education. The first was thematised with supremacy relative to the others.

According to Anderson et al (2013), people with disability suffer inequalities in the field of health arising from various factors. Reports of worse quality of life are frequent among this population relative to people without disability, given that being conditioned to this experience is linked to something bad, in addition to living in precarious conditions and having lower education and job levels being associated with a higher prevalence of disability (Van Campen & Van Santvoort, 2013; Abbott & Carpenter, 2015; Pérez-Hernández et al, 2019). Additionally, the lag in health and medical interventions limits social participation and leisure (Abbott & Carpenter, 2015), even though people with disability use medical services more (Lambert et al, 2015).

In contrast, in a survey conducted with adults with intellectual disability and caregivers, Cocks et al (2018) identified that 243 (78%) participants recognised their health as good, even though it was impacted by other domains. In a comparative study between narratives of people with disability and their caregivers, Simões and Santos (2016) pointed out disagreements regarding health status since people with disability acknowledge their quality of life at a higher level than caregivers recognise the quality of life of people with disability. These findings reinforce the importance of validating the feelings of the participants, in addition to emphasising the significance of their presence and participation in the evaluations of their own qualities of life (Simões & Santos, 2016).

However, as mentioned, other domains influence the living conditions of the subjects, such as access to work. Having a job is associated with better life qualities, well-being, social involvement, and inclusion of people with disability (Van Campen & Van Santvoort, 2013; Lysaght et al, 2016; McConkey et al, 2016). In interviews with people with intellectual and developmental disabilities and/or their family members, Lysaght et al (2016) verified the feeling of belonging to society when linked to formal occupation.

The authors also pointed out barriers to their access, such as the lack of training, transportation, and attitudinal barriers, given the difficulty of finding services fit to hire people with disability. For this reason, unpaid work was mentioned, highlighting its importance for acquiring skills and social participation. There are different needs and interests regarding work, depending on the side one wants to perceive. Thus, people with disability continue to be more prone to unemployment than people without disability, and their lower productivity is one of the reasons pointed out (Haider et al, 2013; Kelly, 2013; Abbott & Carpenter, 2015; Lysaght et al, 2016).

Producing for the system, for profit, created what is known nowadays as ableism. Ableism, a form of oppression experienced by people with disability, arises as a project of capitalism based on the bias of the medical model. This mode of violence recognises the body as insufficient by emphasising disability through the productive capacities of the being, devaluing people with disability and recognising them as inherently negative (Campbell, 2009).

The study by Frier et al (2018), conducted with nine people who acquired physical disability in adulthood, pointed out that all participants reported a negative impact of the condition of disability on employment. Also, when relating formal trade and education, McDonnall and Tatch (2021) pointed out that people with disability with higher education are more prone to unemployment than people without disabilities with only a high school education. This puts back on the agenda the association regarding the prejudice related to the capacity of people with disability.

To reduce this social gap, it is important to raise awareness about work also on the part of the family as social support. In this sense, Francis et al (2013) proposed a training programme for family members and caregivers of people with disability, presenting the importance of regular work in the lives of this public. The intervention was successful, as the participants showed interest in encouraging access to salaried jobs for people with disability, recognising their social and individual importance.

Living in one's own home or with a friend was also a positive predictor of getting a job. In a comparative study with people with intellectual disability who lived in three different types of accommodation (living alone or with a friend; shared housing with groups of up to six people; support homes), McConkey et al (2016) identified that the first type of housing was more favourable to paid work, as well as the practice of physical activities and being engaged in the community. Thus, living alone or with a friend impacted the living condition of these subjects so as to qualify it and improve their health.

In research on young adults with ASD and other disability conditions, such as learning disabilities, intellectual disabilities, or emotional disorders, it was identified that people with ASD were more likely to live with their parents. One of the reasons pointed out was the need for continuous care related to parental care. In addition, young adults with ASD with higher functional abilities were more fit to live independently, in addition to having better incomes (Anderson et al, 2014).

The field of education, although little researched in the literature included in this review, also presented itself for the production of health. Sanetti (2017) pointed out that the educational progress of children and youths is influenced by health needs, such as health education, physical education and physical activity, environment and nutrition, access to health services, psychological services, and family and community engagement, for example. The author indicated that these accesses may impact the students' health and, consequently, their learning outcomes.

As noticed, the intersections that accompany the life of each subject further condition their experience. People with visual impairment and of indigenous origin report higher educational inequalities than those non-indigenous with visual impairment. These findings are related to educational and attitudinal barriers concerning the ability of the subject, as well as cultural knowledge about the condition of disability (Bevan-Brown & Walker, 2013).

Jimenez-Corona et al (2015) seeking to understand, in a comparative study, the prevalence of visual impairment and its associated risk factors in rural and urban populations in southern Mexico, identified that the experience of the disability condition is more frequent in rural populations. In addition, the predominance of moderate visual impairment was related to people with lower education levels, e.g., illiterate people, who experience economic marginalities, and indigenous people. In this way, it is made explicit that the SDH affect disability through economic, social, health, and educational conditions.

Friedman (2021) pointed out the influence of SDH in the field of health of people with intellectual disability, stating that with each improvement of the SDH, such as work, income, housing, and education, a decrease in hospital emergencies is identified. Thus, understanding the domains present in the construction of the living condition of the subjects, especially people with disability, and instigating their acquisition, will lead to the social production of their health.

General Socioeconomic, Cultural, and Environmental Conditions

The layer most distal to the subject according to the theoretical model used was presented in 8 studies, with a strong predominance of the socioeconomic field. According to Frier et al (2018) in a study conducted with people who acquired physical disability in adulthood, the participants reported that the socioeconomic conditions presented themselves as a central component of more significant impact after acquiring the disability condition. The authors concluded this by identifying the perceptible decrease in the prospects of access to employment, which converge to the decline in the income of the individuals.

People with disability point out that having a higher income directly intervenes in better subjective well-being compared to people without disability (Van Campen & Van Santvoort, 2013). In addition, when reporting that low socioeconomic conditions are linked to poor subjective health, people with intellectual disability indicate a direct association between economic factors and health (Cocks et al, 2018). Having said that, it is pointed out that financial stability before the disability experience influences the quality of life after the acquisition of the condition due to the decrease in access to social activities, which impacts the quality of life of the subjects (Frier et al, 2018).

Economic barriers affect several other health domains, such as access to education, for example, and life opportunities, such as fixed income. Consequently, without a formal occupation, social relations based on the feeling of being productive are broken, so as to perpetuate the stigma of exclusion and inability of people with disability to work. Thus, parental financial dependence is pointed out as an escape from the subsistence option (Gartrell et al, 2018).

With a greater maternal bond, situations of dependence permeate care relationships, indicating the strong influence of economic links drawn by people with disability and their family members. The authors question the experiences that people with disability will go through later, when their guardians die, pointing to the need to assume the role of the protagonist of their life in all aspects, including financially (Gartrell et al, 2018). Parents with intellectual disability reveal that the risk of exposure to health, such as poor mental health, may be related to their social position and environmental adversities (Emerson & Brigham, 2013).

Studies included in this review also showed a significant difference between the number of people with disability according to the context (Jimenez-Corona et al, 2015; Del Brutto et al,2020) since rural populations and those with unfavorable socioeconomic conditions obtained higher rates of disability than urban populations (Jimenez-Corona et al, 2015). Interestingly and in contrast, in the study by Del Brutto et al (2020), the only individual component not associated with disability was the economic factor. The authors justified this finding by highlighting the influence of social relationships on the condition of disability so that it can overcome other domains.

Moreover, the choices for general cultural and environmental relationships favourable to the condition of disability may prove significant. Sandhu et al (2016), in their research with Turkish families who experienced migration, highlighted the impact that cultural and environmental barriers may come to have on the experience of disability. Parents of children with intellectual disability point out the centrality, among the various reasons for migration, to the search for help for their children, such as opportunities for access to education, health, and social networks. However, although central to migration, none of the families surveyed reported active participation and involvement of children with intellectual disability in the decision-making.

The impact of SDH on health acquisition and production is evident in the literature reviewed. Concerning the general Socioeconomic, Cultural, and Environmental conditions, a prevalence of studies related to economic factors was noticed, given that this determinant is uniquely associated with the others (Frier et al, 2018).

CONCLUSION

It is noted that people with disability are neglected when it comes to health production, due to the lack of access to various sectors and rights that are essential to social life. According to the studies investigated, the lifestyles of people with disability are related to higher rates of depression and lower rates of physical activity, compared to people without disability. Furthermore, it was found that the social networks of people with disability are associated with deprivation of access, such as accessible transport and voting. It was also found that their social interactions are insufficient, friendships are limited, and are related to negative stigmas of disability. The social participation of people with disability had an inverse impact on the demand for emergency help.

Regarding the Living and Working Conditions, the layer with the greatest representation in the studies analysed, the concern with the field of work can be seen. It was identified that salaried work represented a means of inclusion and social participation of people with disability. Being employed proved to be a favourable factor in improving the subjective well-being of people with disability, as it generated a feeling of social belonging. However, it is recognised that people with disability have fewer employment opportunities than their peers without disability. At the same time, it was identified that the level of education increases the possibilities of access to employment.

The studies indicated that the layer of Socioeconomic, Cultural and Environmental Conditions was linked to the previous layer, being related to the field of work. It was found that acquiring a disability negatively impacted access to paid work. It is important to mention that, among the studies analysed, few were carried out specifically with people with disability, while preference was given to interviewing parents or caregivers. This data reveals the importance of action in the field of access for people with disability, and points to the urgent need for public policies that stimulate social life through social participation, with more public spaces for physical activity and better opportunities in the field of work. It also recognises that health is produced in a multidimensional way, as a right for everyone and a duty of the State.

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