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P.O.Box 196
info@uog.edu.et
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Editorial

Bridging the Research–Practice Gap in Rehabilitation: A Crisis of Values

Zelalem Dessalegn Demeke

Department of Occupational Therapy, University of Gondar, Country Representative for Ethiopia, Enablement Foundation

Correspondence: zelalemzdemeke@queensu.ca

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EDITORIAL

Working in rehabilitation in Ethiopia, I am repeatedly confronted by a troubling paradox: evidence for effective rehabilitation interventions continues to grow, yet everyday practice in many low- and middle-income countries (LMICs) remains largely unchanged. Despite decades of research, much of what happens in clinics and communities still reflects outdated approaches that are poorly aligned with current evidence. This gap between research and practice is not merely a technical problem. It represents a systemic failure that limits access, participation, and dignity. Knowledge exists, yet it does not consistently reach those who need it most.

Let us consider pediatric rehabilitation as an example. Systematic reviews have demonstrated the effectiveness of goal-directed, family-centered, and activity-based interventions for children with cerebral palsy. These approaches emphasize learning through daily activities and play, and they prioritize meaningful participation over isolated skill training (Novak et al., 2020). Yet in many settings, therapy continues to focus primarily on impairment-based "fixing," with limited attention to functional goals, family priorities, or participation in everyday life.

This persistence raises critical questions about the relevance of professional training curricula, the quality and consistency of clinical supervision, and the capacity of health systems to support contemporary, evidence-informed practice. In the absence of ongoing mentorship and reflective learning environments, practitioners often rely on familiar routines rather than evolving evidence, even when those routines yield limited long-term benefits. As a result, promising research findings remain disconnected from everyday clinical decision-making, and children are denied opportunities to develop skills in ways that are meaningful, motivating, and contextually relevant. Bridging this divide requires more than improved access to research; it demands practical support for clinicians to adapt evidence-based approaches to local realities. Without such support, evidence remains theoretical rather than transformative.

Early identification and intervention follow a similar pattern. Research consistently demonstrates that timely screening and early support significantly improve long-term developmental outcomes for children with disabilities. Interventions delivered during critical periods of neurodevelopment can enhance motor, cognitive, and social functioning, while empowering families to support learning at home. Nevertheless, in many LMICs, children are identified late and enter services only after substantial delays. Studies from Bangladesh, for example, indicate that many children with cerebral palsy never receive rehabilitation, and those who do often begin services around four years of age, well after optimal windows for early developmental gains have narrowed (Al Imam

et al., 2021). Consequently, children miss crucial opportunities for early skill acquisition, and families are left without guidance during formative stages of development.

Community-based rehabilitation (CBR) and telerehabilitation models have demonstrated considerable potential to expand access in underserved areas (Karim et al., 2021; Al Imam et al., 2025). However, these approaches are frequently confined to short-term projects and pilot initiatives, with limited integration into national health systems and policies. Several interconnected factors sustain the research–practice gap. Training programmes are often outdated. Heavy workloads restrict opportunities for reflection and continuing professional development. Research agendas are frequently disconnected from frontline realities. Families and persons with disabilities are rarely meaningfully involved in service design and evaluation. In such contexts, routine becomes safer than innovation, and evidence remains abstract rather than actionable. Underlying these challenges is a deeper issue of power and politics. Decisions about what constitutes valid knowledge, which interventions receive funding, and how quality is defined are typically made by actors far removed from the communities served. This dynamic entrenches hierarchies that marginalize the very people rehabilitation is meant to empower.

Bridging this divide requires more than disseminating guidelines or publishing new studies. It requires stronger relationships between researchers, practitioners, families, and communities. It requires funding models that support long-term implementation, supervision, and learning. It requires leadership that values critical reflection alongside efficiency. Most importantly, it requires redefining success. Success should not be measured primarily by the number of publications produced or pilot projects completed, but by sustained improvements in access, participation, and quality of care. It should be judged by whether children, families, and persons with disabilities experience tangible improvements in their daily lives. Evidence must be treated not as an external authority imposed from above, but as a shared resource to be interpreted and applied collaboratively. If rehabilitation is to fulfil its promise of promoting inclusion and dignity, evidence must not remain confined to academic journals. It must become embedded in everyday practice, shaping how services are designed, delivered, and evaluated. Achieving this will require sustained commitment, institutional support, and collective learning. Only then can research truly serve the people it is intended to benefit.

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Original Research Article

Caregiving Together: Optimising the Involvement of Fathers of Children with Disabilities in India

Nicole Bishop[1], Raania Amaani[1], Deepthi N Shanbhag[2], Beena Koshy[3], Fairlene Soji[4], Kaaren Mathias[5], Lorane Scaria[6], Saju Madavanakadu Devassy[6], Francis Annunci[4], Shiva Mohan Rao[4], Suresh Karuppannan[1]*, Nathan Grills[1]

1 The University of Melbourne, Australia
2 St John's National Academy of Health Sciences, India
3 Christian Medical College Hospital, India
4 Christoffel Blinden Mission, India
5 University of Canterbury, New Zealand
6 Rajagiri College of Social Sciences, India
* Correspondence: Suresh.karuppannan@unimelb.edu.au

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ABSTRACT

Background: While mothers are often the default caregivers of children with disabilities in India, emerging evidence highlights the importance of fathers' engagement in caregiving, which may enhance child development and family wellbeing. However, paternal caregiving remains underexplored in low-resource settings.

Aim: This study explored the caregiving roles, perspectives, and barriers experienced by Indian fathers of children with disabilities, using a large qualitative dataset from diverse geographic and cultural contexts.

Method: This exploratory qualitative study involved 54 semi-structured interviews and 9 focus group discussions with fathers and other caregivers, conducted across eight sites in five Indian states. Participants were purposively sampled to capture a range of disability types (physical, sensory, intellectual, developmental, and mental health conditions) and caregiving experiences. Interviews were transcribed, translated, and analysed using inductive thematic analysis in NVivo 14. The large sample size allowed for thematic saturation across diverse subgroups and regions.

Result: Thematic analysis revealed three key themes: fathers' caregiving roles, the impact of caregiving, and support needs. Fathers' involvement ranged from providers and decision makers to occasional primary caregivers, influenced by cultural beliefs, availability, skills, and emotional bonds. Caregiving shaped fathers' self-perception, mental health, and family dynamics. Acceptance was higher when caregiving was viewed as purposeful. Barriers included stigma, rigid gender norms, limited inclusive infrastructure, and lack of tailored services. Fathers expressed the need for greater public awareness, emotional encouragement, and consistent, accessible disability services to support their roles and enhance outcomes for children and families.

Keywords: Paternal engagement, inclusive caregiving, cultural perceptions, gender dynamics, social inclusion, caregiver well-being.

INTRODUCTION

Background

According to the Census of India (2011a), 7.8 million children have disability in India; however, this likely underestimates the true prevalence. These children encounter significant barriers, including restricted availability and access to social welfare programs, social exclusion, educational non-enrolment, denial of property rights, insufficient awareness of available benefits and services, and limited employment opportunities (Gireesan, 2018; Janardhana et al., 2015; Miner et al., 2023). Caregivers can play a significant role in either mitigating or perpetuating such barriers.

The role of caregivers, particularly parents, is critical in shaping the developmental trajectories of these children with disabilities (Acar et al., 2021; Smythe et al., 2022). A nurturing, supportive, and positive family environment optimises developmental outcomes for children with disabilities (Tiengsomboon & Luvira, 2024). Parental involvement correlates with a child's emotional, social, linguistic, cognitive, and motor development (Hohlfeld et al., 2018; Lv et al., 2019) and plays a pivotal role in fostering school readiness, motivation, and academic achievement among children with disabilities (Bariroh, 2018; Guo & Keles, 2024).

Paternal involvement in caregiving is important for the well-being and developmental progress of children with disabilities (Lamb & Billings, 1991; Jeong et al., 2023). Studies have demonstrated that fathers' active participation positively influences developmental outcomes, including reductions in behavioural difficulties, improvements in socio-emotional skills, and enhanced academic performance (Rollè et al., 2019; Lopez et al., 2019; Panter-Brick et al., 2014). Moreover, paternal engagement in physical care, cognitively stimulating activities, and emotional warmth has been associated with a lower likelihood of cognitive delays in children with disabilities (Cabrera et al., 2018). However, the extent and nature of paternal involvement is not uniform and is influenced by factors such as socio-cultural norms, personal capacities, and the availability of external support (Dada et al., 2020).

Fathering in India

Traditionally, parental roles in India have been distinctly delineated. Although changing, fathers are still typically seen as income providers, moral guardians, protectors, and educators, whereas mothers tend to be viewed as primarily responsible for caregiving and nurturing (Navalkar, 2010; Isacc et al., 2013). Traditional gender roles can see fathers less involved during early childhood but taking on more active roles as children reach school age, particularly imparting specific skills and knowledge (Sriram & Sandhu, 2013; Varghese et al., 2015).

Parenting practices in India are also strongly influenced by the predominant religious values. Hindu concepts such as dharma, signifying one's ethical duty or moral righteousness, and moksha, refers to spiritual liberation, emphasise parents' moral responsibilities and highlight their duty of care and acceptance (Navalkar, 2010; Dickinson, 2018). In the context of children with disabilities, the faith of karma is often mentioned, attributing a child's condition to past actions. Nonetheless, fulfilling swadharma - the parental obligation or duty of care - is believed to bring virtues and merits to both parents and the child (Sriram & Sandhu, 2013; Dickinson, 2018).

In India, national policies and programs, supported by non-governmental organisations, provide assistance to children with disabilities (Government of India, 2016). However, accessing these services remains challenging for families, and paternal motivation plays a significant role in influencing their ability to advocate for and utilise available resources (Johnstone et al., 2022). Fathers' advocacy is essential in addressing systemic barriers within political, institutional, and broader sociocultural structures, ul-

timately enhancing the quality of care for children with disabilities (Bourke -Taylor et al., 2022; Sriram, 2011a).

Support for caregivers, especially fathers, remains very limited and differs between regions. Financial assistance is minimal, employment laws have minimal provisions for caregiving, and facilities offering respite care, emotional support, and social support are often scarce, inaccessible, or unaffordable compared to those available in high-income countries.

Most of the existing research on fathers' involvement in caregiving for children with disabilities has been conducted in high-income settings (Davies et al., 2024; Marsh et al., 2020). In India, scholarly research into this subject is scarce, with the most recent studies dating back over a decade (Navalkar, 2010; Sriram & Navalkar, 2013). Given the evolving socio-cultural landscape, it is imperative to understand the contemporary role of fathers in caregiving. This study, therefore, explores the lived experiences of fathers caring for children with disabilities in India, examining their roles and influencing factors, the impact of caregiving on paternal and family well-being, and the necessary support systems for enhancing their caregiving effectiveness.

METHOD

Study Design and Setting

This study employed a multi-site exploratory qualitative design, conducted across eight locations in five Indian states (Uttarakhand, Tamil Nadu, Kerala, Karnataka, and Gujarat). These regions were selected to reflect socio-cultural, linguistic, and service provision diversity across North, South, and Western India. The study used semi-structured interviews (SSIs) and focus group discussions (FGDs) to explore fathers' caregiving experiences. Local community workers from seven disability-focused organisations facilitated recruitment and data collection, ensuring cultural and contextual relevance as well as psychological safety during participation.

Study Population and Sampling

Eligible participants were parents aged 18 years and above who identified as primary caregivers of at least one child with a disability. The sample included 54 SSI participants (42 fathers and 12 mothers) and 9 FGDs (7 mixed-gender, 1 male-only, 1 female-only). The sample size allowed an exploration of caregiving approaches across India's heterogeneous regions and disability types. Purposive sampling was employed to ensure variation across gender, geographic location, disability type and religion, aiming for thematic saturation across subgroups (Carter et al., 2014; Creswell & Miller, 2000).

Participants were drawn from rural and semi-urban settings: 27 from Uttarakhand, 22 from Tamil Nadu, Kerala, and Karnataka, and 5 from Gujarat. Fathers represented various occupations including daily wage labourers (n = 15), company employees (n = 11), farmers (n = 8), self-employed (n = 5), and full-time caregivers (n = 3). Mothers were predominantly housewives (n = 4), farmers (n = 4), or company employees (n = 4). The children under their care ranged from 1 to 18 years in age and exhibited a broad spectrum of disabilities including physical, sensory, intellectual, mental health, and developmental impairments.

Data Collection

Interview and FGD guides were collaboratively developed with community partners to ensure linguistic and cultural congruence (Appendices 1 and 2). SSIs explored personal caregiving roles, emotional impacts, barriers, and familial relationships. FGDs addressed societal perceptions and norms regarding paternal caregiving. All sessions were conducted in participants' native languages, audio-recorded, transcribed verbatim,

translated into English by bilingual staff, and de-identified for confidentiality (Magaldi & Berler, 2020; Carter et al., 2014).

Data Analysis

The study employed an inductive interpretative thematic analysis approach to explore the roles, perspectives, and support needs of fathers of children with disabilities in India (Braun et al., 2019). NVivo 14 qualitative analysis software was used to facilitate systematic coding, theme development, and data management. An initial *a priori* coding framework was developed based on existing literature and the interview and focus group guides, focusing on dimensions such as caregiving roles, emotional responses, perceived barriers, and support systems (Saldaña, 2020). However, the coding process remained flexible and iterative, allowing emergent concepts and patterns to be inductively incorporated.

Two researchers (RA and NB) independently coded the full dataset, followed by reflexive team discussions to consolidate codes and refine thematic hierarchies. Through repeated reading and constant comparison, initial codes were collapsed into higher-order themes and subthemes. Discrepancies in interpretation were resolved through consensus with a third reviewer (NG), ensuring analytic integrity and intercoder reliability (Braun et al., 2019). Informed by grounded theory techniques and interpretative phenomenological analysis principles, the coding process also sought to capture the subjective emotional positioning of fathers, including how they made sense of their caregiving roles through religious beliefs, relational identity, and emotional recalibration.

The final thematic structure was reviewed by two external qualitative researchers to ensure credibility and confirmability (Isaacs, 2014). Additionally, triangulation was applied by comparing findings from fathers with supporting data from mothers and community stakeholders (Carter et al., 2014). Data saturation was achieved when no new codes emerged from the final transcripts, affirming thematic completeness. Verbatim quotes are used throughout the results to illustrate the nuanced experiences and meaning-making processes of participants.

Ethical Considerations

This study was approved by the Community Health Global Network (CHGN) Uttarakhand Cluster Ethics Committee in May 2023. Informed consent was obtained from all participants, with oral consent procedures used for participants with low literacy. Participants were provided with information sheets in their native language, and their right to withdraw at any time without consequences was emphasised. Confidentiality, anonymity, and voluntary participation were upheld throughout the study.

RESULT

Thematic analysis of the data revealed three major themes: the role of fathers, the impact of caregiving on them and their families, and the supports available to father-caregivers.

Role of fathers

The role of fathers in caregiving is multifaceted and shaped by various factors, including the identity they derive from their role, their physical and mental well-being, adherence to traditional beliefs and cultural practices, and their spatial and relational capacity.

Fathers' involvement in caregiving was observed along a spectrum, ranging from 'not involved', 'involved', 'maintaining contact from a distance', 'involved but not hands-on', to 'directly hands-on' and 'primary caregiver'. Notably, primary caregiving among Indian fathers was uncommon, with most assuming roles as providers, protectors, moral guardians, decision-makers, problem solvers, friends, or therapists.

As a primary caregiver, Father S stated, "I am actively involved in every aspect of my child's life. I am her primary carer", while Father B similarly expressed, "I take care of my son more than his mother." These accounts highlight the rare yet significant presence of fathers assuming primary caregiving roles in India.

In contrast, most fathers primarily identified as providers. For instance, Father N focused on "financial support, planning, and securing the future," while his wife managed daily caregiving responsibilities. Additionally, decision-making emerged as a central role among fathers, as illustrated by Father A, who stated, "The decision-making often depends on me. Everything that needs to be done for her is always on my mind." Similarly, Father T viewed himself as "the primary problem solver… for the most part, I can address and fix her challenges."

Fathers often acted as a 'therapist' or oversaw their child's therapy. This may involve taking their child to the hospital or disability services, managing paperwork for therapy, scheduling therapy sessions or acting as a therapist at home. For example, Father Y "trained [his son] in speech and followed up on his progress," and Father H "gave [his son] physical exercises to improve his fitness."

Fathers' Engagement in Caregiving: Influencing Factors and Perspectives

Our data showed that fathers' engagement in caregiving was largely shaped by their understanding of their child's disability in the context of socio-cultural and religious perspectives. Their involvement was often associated with finding deeper meaning, purpose or identity in fathering a child with a disability for example, Father C, a primary caregiver, stated, "I have embraced disability. God entrusted us with this child, so we must take care of him." When fathers perceived their caregiving role as having a higher purpose, it fostered acceptance and even joy. As Father Q expressed, "This child has brought joy to our family since he was born, and we don't worry all the time because we are in line with God's purpose."

Fathers who integrated their caregiving role into their worldview, faith or identity were inclined to experience a deep love and joy in their responsibilities. Father AG affirmed, "A disabled child means more love and care to me." Conversely, fathers who struggled to find meaning or joy in caregiving were more likely to perceive their child as a "burden" (Father L), a source of "trouble" (Father O), or even a "showstopper" (Father AL), disrupting their lives. Several factors influenced the extent of fathers' involvement in caregiving, including availability and necessity, their bond with the child, capacity (skills, knowledge, and health), and traditional beliefs regarding gender roles.

Availability and necessity: Fathers with flexible work schedules were more available to be involved in caregiving. As Father B observed, "Working from home for both men and women helps us care for the child with disability." Similarly, Father V noted, "More flexible work hours allow us to be more involved." Alternatively, fathers with structured work hours tried to integrate caregiving into their daily routines: "I take care of the child every evening after 6 p.m. until bedtime, and since Sunday is free, I spend more time with my child." (Father F).

Fathers typically did not assume primary responsibility for personal care in the presence of the mother. However, these tasks were undertaken when the mother was unavailable or unable to perform. Mother B remarked, "Although my husband helps out when I'm not around, he tends to avoid these tasks when I am present." Mother D reflected, "It was an eye-opening experience for me, realising that even in my absence, things would proceed smoothly. It also made me realise how effectively my husband could handle our child's needs."

Bonds with the child: A strong correlation was observed between the quantity and quality of care and the emotional bond between father and child. Fathers who were actively involved in caregiving reported their child was "most comfortable by my side"

(Father D) and "has a stronger bond with me than anyone else" (Father H). However, emotional bonding was often constrained by the child's communicative ability and gender. Fathers found it "challenging to engage with [their child with disability'] since he is unable to communicate and react" (Father O). Additionally, gender norms influenced caregiving involvement; for instance, Father AH, who cared for an adult female child, reported, "[Her gender] restricts me from getting too involved."

Capacity Factors: Caregiving skills and knowledge were closely associated with fathers' levels of involvement. Some fathers expressed a strong desire to be actively engaged but felt ill-equipped. Father G admitted, "I do want to do a lot of things for them, but I feel incapable. I do not have much knowledge." This challenge was particularly pronounced in cases requiring specialised care. The fathers' capacity to engage was also affected by their physical and mental health (e.g., age, physical strength) and unhealthy behaviour. Mother E commented "My husband is an alcoholic and also spends money betting on cotton lottery, losing his money and becoming depressed, which is why he doesn't spend much time with me and my children."

Traditional Beliefs: Societal, familial and gender expectations frequently constrained fathers' caregiving roles. The father's mother was often described as a "prominent barrier" (Father F), reinforcing traditional beliefs that "fathers should not be involved" (Father AE) or "shouldn't handle certain duties, notably washing their child" (Father M). Furthermore, cultural expectations dictated that fathers should prioritise income generation, which consequently limited their caregiving participation. As Father H stated, "It is challenging. My parents have always hoped I would pursue a job with a higher salary. They have questioned my current job choice, wondering if I am using caregiving as an excuse to stay home."

Impact - Factors Influencing the Effect of Caregiving on Fathers

Self-Perception and Appreciation

Our data indicate that the impact of caregiving on fathers, and consequently on those around them, is influenced by their self-perception (respect and appreciation), self-compassion (collaboration and quality time), and self-regulation (emotional control and rational expectations). Fathers often feel undervalued after having a child with a disability. Our study found that their self-perception and engagement were shaped by whether they felt respected and appreciated. One respondent in FGD 07 noted, "When the father receives respect from his wife, children, and family, it helps him continue his work." Appreciation from a spouse or other family members enhances a father's sense of self-worth. As Father H mentioned, "My family members praise me for taking good care of my child and say others would not have done the same".

Sacrifices and interdependence

Caring for a child with disabilities requires significant physical, mental, and financial sacrifices. Some caregivers become so selfless that they neglect their own well-being. As Father Z noted, they often fail to "take care of themselves," while Father E admitted to "feeling guilty about their own happiness." Father U added that some fathers "keep their troubles and anxieties to themselves," which can lead them to "feel trapped by this emotion" (Father AB). Clear communication, mutual respect and understanding between the caregivers allowed parents to understand the family role distribution, accept each other's contributions and limitations. As Father C explained, "The key for us has been clear communication and making adjustments where needed. This way, we ensure we are both involved in our commitments without compromising our son's care." Maintaining positive relationships and collaborating with family members was also critical, as illustrated by Father AG, who shared: "We depended on each other to take care of the child."

Quality Time and Family Bonding

Spending quality time together as a family, between husband and wife and father and child, was crucial for strengthening family bonds and alleviating the stress associated with parenting challenges. Father J, who reported that he and his wife "do not get much time for each other," felt a lack of opportunities for meaningful conversations and effective communication. In contrast, Father G emphasised, "We have always valued spending time as a family and have never let his presence make us feel uncomfortable or burdened. We travel, attend events, and live happily."

Paternal Acceptance and Adjustment

Some fathers of children with disabilities experienced periods of depression and fluctuating mental states, particularly when they first learned about their child's condition. As Father C recounted:

> *The early days after having him were intense and filled with mixed emotions. It was emotionally overwhelming as we came to terms with this new reality. It took a long time for us to realise and accept that this was something we as a family had to live with.*

This study illustrated that fathers' ability to think flexibly and adjust expectations significantly influenced their caregiving experience. When fathers could emotionally process their situation and focus on present circumstances they tended to cope better. For instance, Father R stated, "I don't let my child's disability control or depress me," while Father G stressed, "There is no place for stagnant reflection or pessimistic rumination." This was supported by Mother G, who noted, "Though my husband occasionally expressed worries about our child's future, he has learned to handle it and focus on today." Conversely, some fathers struggled to come to terms with their situation and experienced prolonged distress. As Father H stated, "I just couldn't process it, and I, in fact, fainted and fell." The father's ability to adjust and accept the situation was affected by the severity of his child's problem behaviours. .

Support - Fathers seeking supportive environments and services

Fathers in this study highlighted the essential support they require to better care for their children with disability, which can be categorised into three primary areas: addressing stigma, creating inclusive public spaces, and providing individualised disability services.

Addressing Stigma and Promoting Acceptance

Fathers expressed the need for encouragement, acceptance which underscores the importance of challenging the stigma associated with disabilities and traditional gender roles. As Father H stated, "One of the difficulties of raising a child with a disability is that not everyone fully understands our journey or the challenges we [fathers] encounter." He further emphasised the importance of actively encouraging fathers, stating:

> *Visiting the fathers of children with disabilities, chatting with them at their homes, empathising with them, acknowledging that our child and yours are alike, or saying, like 'we admire the activities you do with your children. You are doing a wonderful job for your children. Your child has a lot of potential'.*

In contrast, in certain regions of India, particularly the northern states, disability remains heavily stigmatised, and fathers experienced shame and exclusion. Some communities perceive childhood disabilities as "a curse" (Father AE), "an infectious disease" (Father AD), or "not worth taking care of" (Father Z). Furthermore, fathers who actively participate in caregiving are sometimes ridiculed, being labelled as "wife's slaves" (Father M), "hen-pecked" (Father O), or engaged in "lady's work like a woman" (Mother N). This societal stigma often discourages fathers from taking an active caregiving role. As Father Y mentioned in FGD 02, "Some fathers take a more active role in raising their children,

but when others make fun of them for providing too much care, they get embarrassed and stop caring for their children."

The respondents described hostility toward families with children with disabilities. In Uttarakhand, for example, they reported that people had set fire to crops and thrown stones at houses, believing that such children bring a curse to the community. Furthermore, children with disabilities often "encounter unkindness from other children or adults when they play. This hurts their feelings. All parents hope that their child will be welcomed by everyone" (Father AF).

In southern and western India, public awareness about disability was reportedly better but stigma still present. Intrusive questions and excessive, unsolicited advice were reported as making fathers uncomfortable. Father U similarly noted:

> *Some people excessively feel sorry for my child. This was more obvious during the initial times. There were times when I would easily lose my patience to questions like, 'Can she speak?' 'Can she walk?' and so on.*

Inclusive public spaces and services

Fathers emphasised the need to enhance public services for children with disabilities. As Father E noted, "Indian culture is more inclusive, but establishments such as hospitals, public utilities, and places of worship are not." For instance, Father Q faced challenges in finding inclusive restroom facilities for his daughter due to gender-related barriers, stating, "I find it difficult taking her to the restroom to change her clothes and diapers." Similarly, multiple fathers expressed concerns about the lack of inclusive public transport, which poses a significant mobility barrier for children with physical disabilities. As Father U explained, "I have to book my personal big vehicle, as … cannot travel on public transport, as it's not disability-friendly and it's crowded."

Access to individualised services

Many fathers stressed the importance of finding individualised services tailored to their children's specific needs. As Father Y stated, " every child is different and needs to get individualised care and treatment." Father N echoed this sentiment:

> *For a child, it's crucial to establish a rapport with the therapist. Every time we change to a new therapist, it feels like we are starting over. The therapeutic process would be beneficial only if a therapist could remain consistent for at least two years.*

Additionally, fathers advocated for improved support programmes, including increasing awareness, simplifying application processes, and expanding eligibility criteria. Father P pointed out, "Even though our government has several provisions and support structures in place, the fundamental problem is a need for more awareness. I wasn't even aware of insurance plans or compensatory schemes for treatments." Moreover, bureaucratic hurdles often made it difficult for families to access available services. Father U noted, "There is a lot of extensive paperwork to avail of these services, which makes things difficult." Accessing these resources was often contingent on personal connections, as described by Father H: "The process can be tedious, and you must stay on top of it. Fortunately, I was helped by a doctor I knew who worked at the hospital. Navigating the paperwork might not be easy for a parent without such connections."

DISCUSSION

Shifting role of fathers in caregiving of children with disability in India

The definition of caregiving ranges from narrow definitions to quite inclusive interpretations (Bowers, 1987; Riffin et al., 2017). Narrow definitions include a minimum of four hours per day and participation in at least one activity of daily living and the "primary caregiver" has been the "hands-on" provider of "direct care". Some definitions

simply describe a caregiver as someone who provides care to individuals who need assistance with daily activities (Kent et al., 2016). In this study, we adopted a broader definition, aiming to include all potential roles of fathers to determine whether their involvement remains limited to peripheral care or extends to substantial direct caregiving contributions.

Our findings indicate that the current roles of fathers in India are more diverse and extensive than previously documented. While fathers have typically been considered central as providers and supporting access to care, our data reveal that some fathers also fulfil roles as primary caregivers and are directly involved in personal care. Additionally, our research shows fathers can also act as friends or companions to their children, engaging in activities such as playing, spending time together, or sharing personal thoughts. This differs from the literature which documents emotional gap between fathers and their children with disability (Sriram, 2011a; Sriram & Sandhu, 2013).

This study also revealed that fathers take on therapeutic roles in their child's care, a responsibility that has been identified for example, in the mechanics of ensuring children have access to care. This role has not clearly been described in the literature. Their involvement as caregivers for young people with mental health problems was described as providing support for activities of daily living, improvising therapy and long-term rehabilitation. This is contrary to dominant gender norms in other studies set in North India (Mathias et al., 2019). We also found that fathers are also involved in arranging therapy sessions, managing paperwork, and directly implementing therapeutic interventions at home, effectively acting as informal therapists.

Any observed shift in the role of fathers is likely driven by changing societal norms which includes a growing move to less asymmetrical gender roles with fathers taking greater responsibility in household chores including cooking and cleaning as well as caregiving (Sriram, 2013; Mathias et al., 2022). Motwani (2024) highlights a noticeable evolution in both the practices and discourse surrounding child-rearing within urban middle-class Indian society. Consequently, traditional gender norms related to caregiving responsibilities are beginning to shift within Indian households and communities. (Sriram, 2018; Mathias et al., 2022). Our data reflect this change, particularly in the first theme on the roles of fathers of children with disability, and the third theme on societal perceptions. . Social norms play a pivotal role in shaping the gender-based distribution of childrearing responsibilities and are evolving in response to wider social and economic transformations (Motwani, 2024). Increased education and employment among urban upper-middle-class women has contributed to a redefinition of gender roles (Motwani, 2024). These changes are reshaping societal expectations and perceptions of paternal involvement more broadly and are likely applicable to fathers of children with disability (Dada et al., 2020; Saraff & Srivastava, 2010).

Furthermore, our analysis in the third category reveals that perceptions of disability and paternal involvement vary across different regions of India, a pattern supported by previous studies (Isaac et al., 2013). Compared to the southern and western sites, the northern sites tend to uphold more traditional views regarding disability and the role of fathers. Consistent with earlier findings, disabilities in the northern states are often perceived as a curse or even contagious. In such contexts, fathers who engage in caregiving are sometimes viewed as inappropriately subordinate to their wives (Varghese et al., 2015; Mathias et al., 2022). These regional differences align with broader demographic and health indicators, with southern and western states demonstrating more favourable outcomes in education, employment, health, and economic development (Census of India, 2011b). Data from the National Family Health Survey (NFHS-5) 2019-21 also suggest a shift in these more developed states toward progressive attitudes regarding the role of fathers and the understanding of disability (IIPS, 2021; Pattnaik et al., 2023; Motwani,

2024). Existing policies, programs, and awareness campaigns probably also contribute to transforming social norms around expectations and perceptions of paternal involvement and disability (Dada et al., 2020; Saraff & Srivastava, 2010).

Optimising Father Involvement in Caregiving for Children with Disabilities

Our findings indicate that paternal involvement is positively associated with the wellbeing of fathers, in addition to that of the child and the broader family. Qualitative studies from other countries have shown a strong correlation between the level of paternal engagement in caregiving and a range of positive outcomes for fathers, as well as improvements in the quality of care provided (Sato & Araki, 2022; Giannotti et al., 2022). While the direction of causation remains complex and difficult to establish definitively, caregiving has been linked to increased self-esteem, confidence, empathy, happiness, cooperation with one's spouse, attentiveness to the child's needs, and enhanced knowledge and skills in child-rearing (Bragiel & Kaniok, 2014; Glenn, 2007). Promoting paternal involvement in India is therefore likely to be beneficial not only for children and families, but also for fathers' own health and wellbeing.

In our study, religious engagment and spirituality emerged as significant coping mechanisms in the context of disability. This aligns with existing literature indicating that religious involvement supports both individuals and families in adjusting to disability and finding new meaning or direction. Evidence suggests that religious coping frameworks facilitate cognitive reappraisal, which has been associated with greater resilience in the face of adversity (Dolcos et al., 2021).

Recommendations for Existing and Future Programmes and Policies

Based on this study's findings, several key recommendations can enhance existing and future programmes and policies aimed at supporting fathers in caregiving roles.

Expanding Paternity Leave and Workplace Support

In India, few policies specifically support fathers in caregiving roles (Johnstone et al., 2022). Currently, paternity leave is limited to government employees, school staff, and university personnel, with a short duration of only 15 days. Expanding paternity leave to include fathers working in the private sector and extending the leave period, particularly for those caring for children with disabilities, would provide fathers with more time to adjust, cope, and actively engage in caregiving responsibilities (Angothu & Chatuvedi, 2016; Boyd et al., 2019; Purba & Simanjuntak, 2021; Richard, 2014; Simmerman et al., 2001). Additionally, workplace policies must evolve to accommodate caregiving responsibilities. Many fathers struggle to balance employment and caregiving due to rigid work structures. Increasing workplace flexibility, such as offering remote work options and flexible schedules, would enable fathers to participate more actively in their children's care without compromising their careers (Sriram, 2018; Uribe-Morales et al., 2021).

Simplifying Bureaucratic Processes and Increasing Awareness

The guardian certificate scheme is a critical policy mechanism that enables access to disability-related benefits, including pensions, concessions, and financial assistance. However, the application process remains complex and burdensome for families (DEPWD India, 2023). Streamlining this process would reduce administrative hurdles and ensure that eligible families can access the support they need without unnecessary delays.

In addition to simplifying procedures, broader awareness initiatives are essential to ensure that fathers are well-informed about the available programs and benefits. A significant number of caregivers remain unaware of the financial, medical, and social support services intended to assist them. Strengthening public education efforts and outreach strategies is necessary to bridge this gap and enhance access to these critical resources (Kumar & Singh, 2019; Grills et al., 2017; Srivastava et al., 2014).

Enhancing Public Services

Inclusive public services are essential for supporting families of children with disabilities. Enhancing accessibility in public transport, places of worship, public restrooms, and community spaces can reduce caregiving burdens and promote the active involvement of both mothers and fathers in their children's daily lives (Brien et al., 2023).

Strengthening Family-Centred Programmes

Family well-being is at the core of effective caregiving. Programmes specifically designed for fathers have demonstrated benefits for the entire family, including improved mental health, stronger parent-child relationships, and enhanced family cohesion (Irwin et al., 2019; Paswan & Kumar, 2024; Samadi et al., 2013). Initiatives that foster emotional connections between fathers and children, strengthen co-parenting relationships, and provide psychosocial support for fathers can create a more balanced caregiving dynamic (Altenburger, 2023; Allen & Hawkins, 1999; Richard, 2014).

Building Supportive Communities and Training Fathers

Social support networks are crucial for fathers navigating the complexities of raising children with disabilities. Community-driven initiatives such as the I'm-Perfect Fathers group in India have been successful in providing peer learning, promoting non-violent discipline strategies, and creating spaces for fathers to share experiences, access resources, and advocate for their role in caregiving (Shetty et al., 2017). Expanding such initiatives across different regions can further strengthen social support systems for fathers.

Additionally, structured training programmes are helpful to equip fathers with the skills and confidence needed for caregiving. Evidence suggests that skill-based interventions improve fathers' self-efficacy and ability to manage the challenges of disability caregiving (de Santis et al., 2020; Hohfeld et al., 2018). Individualised therapy and counselling services, led by professionals who adopt a holistic approach, can also help fathers better understand their children's unique needs and potential (Wiesel et al., 2024).

Raising Societal Awareness

Beyond individual and family-level interventions, broader societal change is needed to foster an environment that supports fathers in caregiving roles. Public awareness campaigns, educational workshops, and community engagement initiatives can help shift societal attitudes, reduce stigma, and encourage collective responsibility in supporting families of children with disabilities (Lindsay & Edwards, 2013; Scior, 2011).

CONCLUSION

This study yielded three major findings. First, Indian fathers are increasingly assuming diverse and extensive caregiving roles. Their level of involvement is shaped by their understanding of disability. It is further influenced by spatial, relational, and capacity factors within socio-cultural and religious perspectives, as well as by their own health status and redefined gender roles. Second, caregiving is associated with both positive and negative impacts, which are shaped by self-perception, self-compassion, and self-regulation. Finally, external factors and health conditions significantly influence fathers' participation in caregiving.

Policy can support and enhance fathers' caregiving roles through inclusive public services, community-based support and encouragement, enabling legislation, and individualised disability services. These findings underscore the importance of policies and programs that promote paternal well-being, strengthen family relationships, offer capability-building opportunities (e.g., parenting courses), foster supportive peer communities, and implement public awareness campaigns. Such initiatives may enhance paternal

engagement in caregiving and lead to better outcomes for fathers, their children with disabilities, and their families.

Limitations and Future Research Directions

While this study provides valuable insights into paternal caregiving in India, its findings are based on a small sample size and qualitative methodology, limiting their generalisability. Further research is needed to explore the applicability of these recommendations across different regions in India and internationally, ensuring that policies and interventions are responsive to diverse caregiving needs.

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Original Research Article

Using nominal group technique to develop a training model for community health workers in physical rehabilitation services: insights and perspectives from stakeholders

Miriam Mapulanga[1], Tafadzwa Dzinamarira[2], and Thembelihle Dlungwane[1]

1 Department of Physiotherapy, School of Health Sciences, University of Zambia, Zambia
2 ICAP at Columbia University, Zambia
* Correspondence: mapulanga2002@yahoo.com

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ABSTRACT

Background: Although some community health workers are already involved in the delivery of physical rehabilitation services, including physiotherapy, occupational therapy, communication support, and assistive device provision, there is currently no standardized training program to prepare them for these roles. In response to this gap, the present study sought to identify the training needs of community health workers in physical rehabilitation and to propose an appropriate training model to guide capacity development in this area.

Methods: A cross-sectional study employing the nominal group technique to collect data from purposively selected key stakeholders in community physical rehabilitation was conducted. The study consisted of phase 1, which focused on identifying training needs for community health workers delivering physical rehabilitation services, and phase 2, which aimed to determine the appropriate training model for these workers. Stakeholders used a 1–4 ranking for the training needs and the training model, and an overall ranking was calculated for each. Stakeholders were provided with the ranking results for their feedback. The qualitative data were analysed thematically.

Results: The stakeholders identified training needs in client assessment, basic case management, and health education encompassing disability awareness and client support at the community level for community health workers providing physical rehabilitation services. In addition, the stakeholders suggested adopting a decentralised training approach, with the ability to read and write as the entry requirement. The proposed training program could be delivered over three months using a blended approach that combines in-person and online instruction. In addition, stakeholders suggested the inclusion of both theoretical and practical summative assessments, with certification awarded upon successful completion of the training.

Conclusion: Leveraging the identified training needs and the proposed model to develop a standardised training programme for community health workers in the delivery of physical rehabilitation services in Zambia has the potential to improve both access to and the quality of physical rehabilitation services at the community level.

Implications: Standardised training for community health workers in physical rehabilitation could enhance service access, quality, and referral pathways, while addressing

workforce gaps. Competency-based, blended learning with certification may strengthen community health worker capacity and inform policy, supporting Zambia's obligations under the United Nations Convention on the Rights of Persons with Disabilities.

Keywords: Community health workers, training needs, training model, human resources for health in physical rehabilitation, physical rehabilitation services

INTRODUCTION

The World Health Organisation's "Rehabilitation 2030: A Call to Action" urges member states to strengthen rehabilitation services, focusing on expanding human resources for health in this field (World Health Organisation, 2017). However, despite the increasing demand for rehabilitation services driven by the shift from communicable to non-communicable diseases, implementing these recommendations has been challenging in resource-constrained settings like Zambia (Kamenov et al., 2019). This situation has been due to the chronic shortage of human resources for health in rehabilitation, particularly in physical rehabilitation, resulting in low service coverage (Jesus et al., 2017).

The Zambia 2022-2026 National Health Strategic Plan identifies physical rehabilitation services to include physiotherapy, occupational therapy, speech therapy, and prosthetics/orthotics (Ministry of Health, 2023a). While Zambia has made some improvements in the delivery of physical rehabilitation services, significant challenges persist, particularly at sub-national levels. Challenges stemming from a shortage of human resources for health in physical rehabilitation, with a ratio of 0.26 health workers to 10,000 population, have been compounded by a lack of multidisciplinary skills (Ministry of Health, 2023a). This crisis has led to inequities in physical rehabilitation service delivery, with most services concentrated in urban and hospital settings.

Community health workers are widely recognised as an effective solution to the human resources for health crises by enhancing health service coverage in underserved areas (Schneider & Lehmann, 2016). Their cultural competence and understanding of local social and cultural barriers make them natural links between health systems and communities (Sharma et al., 2019). In Zambia, Community health workers provide a broad range of services, including health education, health promotion, disease prevention, primary health care, and specialised services such as maternal and child health, tuberculosis, and malaria care (Ngoma-Hazemba & Ncama, 2018; Schuttner et al., 2014; Kapata et al., 2014; Ashton et al., 2023).

In Zambia, community health workers have contributed to a range of health interventions and have provided physical rehabilitation services for children with disabilities, in line with the objectives of non-governmental organisations that employ them (Mapulanga & Dlungwane, 2024). Evidence from some sub-Saharan African countries showed that community health workers can support physical rehabilitation services, with their roles and modes of operation varying across settings (Mapulanga et al., 2024). Their successful involvement has followed training or orientation in rehabilitation service delivery typically (Nesbit & Clark, 2019; Scheffler & Mash, 2020; Vancampfort et al., 2021). Still, the duration and focus of training has varied based on specific health interventions and funding objectives, leading to variations in community health workers' scopes of practice in physical rehabilitation.

While the Zambian National Community Health Worker Strategy 2022-2026 estimated that Zambia has about 90,016 community-based volunteers, the community health worker program in Zambia is fragmented, with various community health workers working under different implementing partners in vertical programmes (Ministry of

Health, 2023b; Tulenko et al., 2013). Therefore, training of community health workers in Zambia differs in content, length, and intensity depending on the programme goals of the implementing partners, with no standardised selection criteria, motivation guidelines, or working hours (Ministry of Health, 2021). This variation has led to the creation of various community health worker groups addressing different health needs, such as growth monitoring, HIV adherence support, and safe motherhood.

In Zambia, a few trained community health workers have been providing physical rehabilitation services, but their training is not standardised (Mapulanga & Dlungwane, 2024). Nonetheless, many community health workers not trained in physical rehabilitation still provide physical rehabilitation services at the community level without formal training (Mapulanga & Dlungwane, 2025a). While both service users and caregivers have valued services provided by these untrained community health workers, feedback indicates a need for formal training in the delivery of physical rehabilitation services. This need is further scored by the limited accessibility of physical rehabilitation in Zambia, particularly at community levels, as the majority of Zambia's human resources for health are concentrated in urban areas, are inequitably distributed, and often lack the appropriate skill mix to meet population needs (Ferrinho et al, 2011; Vledder & Campbell, 2022).

Standardising community health worker training in physical rehabilitation could help address the human resources for health gap and improve service coverage (Mapulanga & Dlungwane, 2025b; Kumurenzi et al., 2022). This study aimed to identify the training needs of community health workers in physical rehabilitation and propose a suitable training model.

METHOD

Study Setting

This study was conducted in landlocked Zambia, a sub-Saharan country, which shares borders with the Democratic Republic of Congo in the north, the Republic of Tanzania in the northeast, Malawi in the east, Mozambique in the southeast, Zimbabwe and Botswana in the south, Namibia in the southwest, and Angola in the west (Republic of Zambia, 2024). Zambia, with a population of about 19 million, has an estimated disability prevalence of 11%, while access to rehabilitation services remains limited to only 17% of those affected. (Republic of Zambia, 2024; Central Statistical Office / Ministry of Community Development & Social Services, 2018).

Study methodology

This study employed a cross-sectional design using the nominal group technique to generate community health workers ' training needs for physical rehabilitation service delivery and to propose a training model. On 24th April 2024, we held a three-hour in-person workshop with key stakeholders in the lecturer theatre at the University of Zambia in Lusaka, Zambia.

Stakeholders

We purposely selected our stakeholders based on their relevant expertise in physical rehabilitation and availability at the time of data collection, while ensuring representation of key functional roles within the rehabilitation and community health system in Zambia. We included two community physiotherapists, an occupational therapist and an occupational therapy technologist, a speech therapist and a communication supporter, two prosthetists and orthotist technologists, a community health manager, a community health worker trainer, and a community health worker who had a disability and was a user of rehabilitation. We used phone calls to invite eleven stakeholders to attend a physical workshop.

Eligibility criteria

Individuals who met the following criteria were included in the study
Health professionals in physical rehabilitation, namely physiotherapy, occupational therapy, speech therapy, prostheses, and orthoses.
Personnel involved in the management of community health.
Personnel involved in the training of community health workers.
Individuals who work as community health workers.
Persons with disabilities who are users of physical rehabilitation services.
Individuals who were able to communicate in the English language.

Exclusion Criteria

Personnel who lacked the mental capacity to consent to participate in the study.
Personnel who were not available at the time of data collection.

Data management and analysis

The principal investigator was responsible for data management. Collected data, facilitator session notes, and post-it note pads were stored in a lockable cabinet. The total importance score for each training need idea was calculated by summing the individual stakeholder's scores from the quantitative data gathered during the ranking step of phase 1 of the workshop, with ranking scores ranging from 1 to 4. Similarly, for phase 2, the total importance score for each training model idea was calculated by adding the stakeholders' individual scores, and the ranking scores ranged from 1 to 4. Qualitative data from the workshop discussion were analysed using thematic content analysis to identify emerging themes. Qualitative data from the recorded data, facilitator session notes, and post-it note pads were used to explain the scores. A draft report prepared by the principal investigator was circulated to the stakeholders within one week for review, comments, and verification. Stakeholders' feedback was incorporated into the final report.

Workshop programme

The data was gathered during the nominal group technique workshop on 24th April, 2024. The workshop was conducted in two phases. Phase 1 focused on identifying the training needs of community health workers in physical rehabilitation, while Phase 2 centred on developing a training model for community health workers in physical rehabilitation services. The workshop was facilitated by the principal investigator with the research assistant. The procedure for each phase is outlined as follows:

Phase 1

Objective- To determine the community health workers ' training needs in physical rehabilitation services.

Question: What should community health workers be trained in as regards to physical rehabilitation services?

Procedure—The stakeholders were asked to share the community health workers ' training needs based on their knowledge and expertise. The following pre-determined themes were used to reflect existing evidence, national policy priorities, and known gaps in community health worker training in Zambia (Mapulanga & Dlungwane, 2024; Mapulanga et al, 2024; Mapulanga & Dlungwane, 2025a).

Assessment
Case management
Health education
Community liaison with support services
Health system linkage
Administration

Ideas in the individual themes were voted on and ranked, with the most important idea receiving a score of 4 and the least important receiving a score of 1. Therefore, the idea with a score of 4 is ranked high, and the idea with a score of 1 is ranked lowest. With 11 stakeholders, the highest total score would be 44 (100%), and the lowest would be 11 (25%).

Phase 2

Objective- To develop a community health workers' training model in physical rehabilitation.

Question: What training model should be used for community health workers in physical rehabilitation?

Procedure: Stakeholders were asked to suggest a training model for community health workers in physical rehabilitation. The model responses were required for the following predetermined themes, as identified in the literature review (Scheffler & Mash, 2023; Komi et al., 2022).

Entry qualification
Duration of training
Mode of training
Training approach
Evaluation
Regulation
Certification

Again, the ideas in the individual themes were voted on and ranked, with the most significant idea receiving a score of 4 and the least a score of 1. Therefore, the idea with a score of 4 is ranked highest, and the idea with a score of 1 is ranked lowest. With 11 stakeholders, the highest total score would be 44 (100%), and the lowest would be 11 (25%).

Ethical clearance

This study was part of a larger study cleared by the University of KwaZulu-Natal Biomedical Research Ethics Committee (BREC 00000569/2019). The Zambia National Health Research Authority granted permission to conduct the study. Stakeholders gave consent to participate in the workshop.

RESULTS

Quantitative Findings

Demographic profile of the stakeholders

Eleven key stakeholders aged 30 to 65 participated in the workshop. The inclusion of stakeholders was guided by their direct involvement in community-based rehabilitation, training, and service delivery. In Zambia, the number of professionals working in rehabilitation services is limited; therefore, the selection of stakeholders was pragmatic. The characteristics of the stakeholders are presented in Table 1 below.

Table 1- Demographic profile of the stakeholders

Stakeholders	Age group	Gender	Occupation	Years in service
P1	30-35	Female	Community physiotherapist	14
P2	30-35	Male	Community physiotherapist	11
P3	60-65	Male	Occupational therapy technologist	Retired
P4	40-45	Male	Occupational therapist	17
P5	60-65	Female	Speech therapist	Retired

P6	30-35	Female	Communication supporter	5
P7	40-45	Female	Prosthetics and orthotics technologist	15
P8	35-40	Male	Prosthetics and orthotics technologist	12
P9	45-50	Female	Community health worker trainer	7
P10	45-50	Female	Community health worker with a disability	6
P11	45-50	Female	Community health worker manager	7

Training needs

Eleven stakeholders ranked the training needs of community health workers in physical rehabilitation across predefined themes (Table 2). In client assessment, assistive device needs and functional and physical abilities were ranked highest (44 scores, 100%), while biomechanics, gait, posture, balance, and proprioception were lowest (24 scores, 55%). In case management, assistive device provision and fitting, communication support, and functional activities and exercises ranked highest (44 scores, 100%), whereas prosthetic material selection ranked lowest (16 scores, 36%). For health and disability education, disability awareness ranked highest (44 scores, 100%), while disease-specific information ranked lowest (24 scores, 55%). In community liaison, inclusion, and support services, community liaison ranked highest (41 scores, 93%) and economic empowerment lowest (26 scores, 59%). For health system linkage, client identification ranked highest (41 scores, 93%) and community health sourcing lowest (24 scores, 55%). In *administration,* documentation ranked highest (40 scores, 91%) and filing lowest (29 scores, 66%).

Table 2- Community health workers' training need

Theme	Training needs	Summing by votes				Total score	Rank in percentage
		1	2	3	4	44	
CONCLUSION	Biomechanics, gait analysis, posture, balance, and proprioception	4	1	6		24	55
	Review of hearing, sight, movement, and mental status	4	1	6		24	55
	Cognitive abilities and inabilities	2	3	6		26	59
	Emotional abilities and inabilities	3	2	2	4	29	66
	Movement abilities and inabilities	2	2	2	5	32	73
	Activities of daily living and environmental barriers	1		4	6	37	84
	Case history taking		1	1	9	41	93
	Physical Observation			2	9	42	94
	Speech and language abilities and inabilities			1	10	43	98
	Identifying conditions requiring physical rehabilitation			1	10	43	98
	Physical abilities and inabilities				11	44	100
	Functional abilities and inabilities				11	44	100
Assessment	Orthotic and prosthetic requirements				11	44	100
	Prosthetic material selection	5	5		1	16	36
	Articulation	6	4		1	18	41
	Social skills	4	6		1	22	50
	Patient care		1	4	6	38	86
	Exercise provision				11	44	100
	Functional exercises				11	44	100
	Functional activities				11	44	100
	Communication support				11	44	100
Case management	Essential assistive device provision and fitting				11	44	100
	Provision of information about diseases	4	1	6		24	55
	Demystifying physical illness and disability		2	4	5	36	82
	Provision of information about physical disabilities			5	6	39	89
Health education	Disability awareness				11	44	100
	Economic empowerment	3	1	7		26	59
	Clients' support and empowerment		3	3	5	31	71
	Support clients in community participation.		2	3	6	37	84
	Community client integration	1		1	9	40	91
Community liaison with support services	Community liaison		1	1	9	41	93
	Community health sourcing	4	1	6		24	55
	Linking clients to health facilities	1	2		8	37	84
	Making referrals		2		9	40	91
Health system linkage	Clients identification		1	1	9	41	93
	Filling	3	3		5	29	66
	Record keeping		1	2	8	39	89
Administration	Documentation			3	8	41	91

Training model

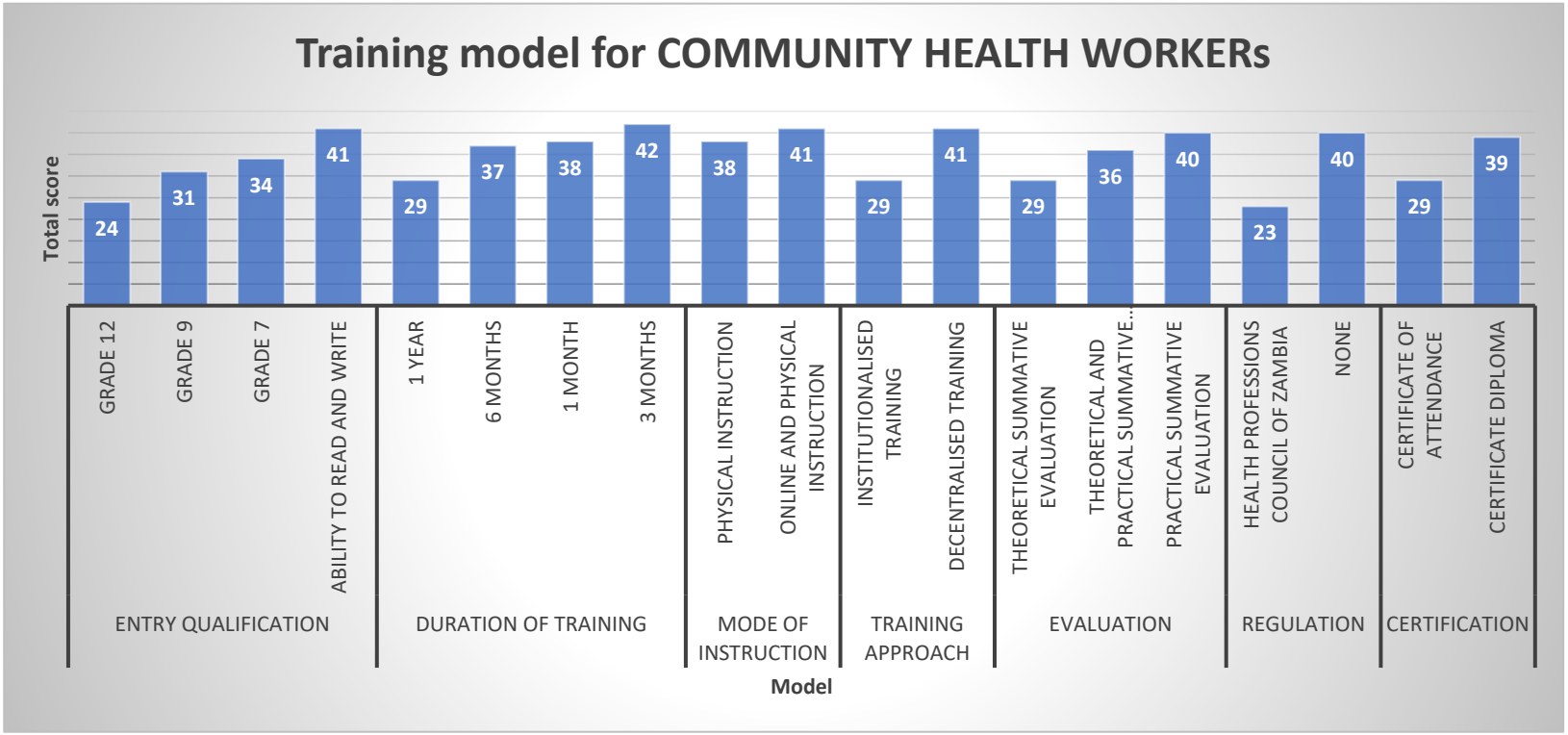

Figure 1- Proposed training model for community health workers in physical rehabilitation

Stakeholders also scored their preferred training model for community health workers in physical rehabilitation across predefined themes (Figure 1). For *entry qualifications*, basic literacy (93%) was rated the highest, while Grade 12 was rated the lowest (55%). Regarding *duration*, three months of training was preferred (96%), while one year was the least preferred option. As regards to the *mode of training*, blended mode of instruction (a combination of face-to-face and online) was rated higher (93%) than face-to-face instruction only (86%). A decentralised training *approach* was preferred (93%) over a centralised model. For *evaluation*, the practical summative assessment ranked highest (91%), followed by a combined theoretical and practical assessment, while the theoretical-only assessment

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ranked lowest. Most stakeholders indicated that *regulation* was not necessary (91%) and that *certification* should be awarded upon completion (87%).

Qualitative Findings

Training needs

Client assessment

The stakeholders pointed out that assessing physical abilities would help the community health worker identify clients' physical capacity to perform activities, such as elbow flexion. Assessing functional abilities helps them identify shortcomings in the capacity to perform meaningful functions.

"Being equipped with the skill set to assess functional and physical inabilities will help them plan strategy to help the clients." (P4)

According to the stakeholders, assessing the clients' assistive device requirements equips community health workers to understand community needs.

"It is very important that they know how to assess assistive devices requirements in the community. This will help them know who needs what assistive device." (P7)

Learning to identify conditions requiring physical rehabilitation, including speech impairments, would help them understand which conditions require intervention by community health workers. The statement below from the stakeholder underscored the need to train community health workers in physical observation.

"It will be prudent for them to understand conditions which require physical modalities because this is what they will be offering. "(P10)

"Knowing the clients' speech abilities and inabilities will help them plan support or refer the clients. "(P5)

"They need to differentiate the abnormal from normal by looking at clients which will lead to physical examination." (P9)

The stakeholder explained that community health workers needed to understand history taking in their training as well.

"The skillset to relate a condition to past incidence is needed in their practice." (P8)

The stakeholders reasoned that training the community health workers in the assessment of activities of daily living and environmental barriers would enhance their service delivery. The epitome of health services delivered by community health workers in the community or to clients is the enhanced activities of daily living and overcoming environmental barriers.

"Observing how the clients goes about daily activities is needed so that they understand what barriers are common in their environment and provide help. This will help them provide appropriate devices which are functional in the clients' space." (P11)

The stakeholders thought that since physical rehabilitation is centred on propulsion, the community health workers needed to learn movement abilities and inabilities in their client assessment.

"Movement is the core business of physical rehabilitation. Improving movement abilities is an important outcome for many clients." (P2)

Case management

Regarding the provision and fitting of assistive devices, stakeholders suggest training community health workers in basic assistive device provision and fitting so clients can be assisted at the community level.

"These community health workers will need to know basic assistive devices provision and fitting. The devices need to be basic like supportive seating or wheelchairs. They will also need to know how to just fit some devices like artificial limb. If there is a client having a problem in the

community with some devices, the community health workers should be able to help or make a referral." (P8)

In the absence of speech therapy, the stakeholders suggested simple communication support for clients who cannot access services.

"A lot of cases are left unattended to, but the community health workers should be able to offer communication support so that the clients can express themselves through other activities like eye contact." (P5)

It was also suggested that the community health workers be able to teach functional activities and, hence, be trained in this area.

"They will need to know how to teach functional activities to help improve the function of their clients. The goal is to improve the client's independence in daily living." (P3)

Improving functional performance was identified as the ultimate aim of community health workers, hence the stakeholders suggested training them in functional exercises.

"For functional performance to improve, they need to know how to conduct the very functional exercises for the clients." (P1)

Unique to physical rehabilitation, the stakeholders suggested that community health workers be trained in general exercise provision, including the type, timing, and client needs.

"In physical rehabilitation, exercise provision is key. They need to understand this…what type of exercises, when to exercises and who to give exercises." (P1)

The stakeholders suggested that patient care be included as a training needs of community health workers in case management, as they would be working independently at the community level.

"Because they will be operating at community level, they need to be equipped with skills in patient care like blood pressure monitoring." (P9)

Health and disability education

The stakeholders reasoned that one of the community health workers' duties should be providing disability awareness.

"One of their important roles should be to increase disability awareness to communities. Disability awareness is still low and these should be agents to increase the awareness to communities." (P2)

Due to a lack of information regarding disabilities, the stakeholders suggested that community health workers should be able to provide this information to the communities. The stakeholders suggested that, in health and disability education, community health workers should also be trained to demystify physical illness and disability.

"Many people do not have information regarding physical debilities as in what they are and the possible causes. The community health workers need to know how to provide the information regarding physical debilities." (P4)

"There are of myths concerning physical illness. The community health workers should be trained in demystifying physical illness and disability myths through health education." (P11)

Community liaison, inclusion, and support services

The stakeholders reasoned that training community health workers in community liaison would be highly beneficial for service delivery, as they are well-positioned in the communities and are rich in cultural competence.

"The community health workers need to be trained in community liaison because they understand the communities better and have a bigger voice as compared to ordinary community members." (P10)

Since they are to operate at the community level, the stakeholders suggested that community health workers be trained in client integration because they are better placed among human resources for health to integrate clients in the community.

"Community health workers are members of the community and work in the community, therefore training them to integrate clients in the community will be necessary. "(P11)

Given their proximity to clients and the community, client support in community participation was suggested as part of the training for community health workers in physical rehabilitation.

"Community participation by clients is vital to achieve good community health outcomes and for this to be possible, community health workers will need to support clients in community participation." (P4)

The stakeholders also suggested client support and empowerment through community-level activities or education as part of the training needs for community health workers.

"Clients need to be supported and empowered in terms of rehabilitation. This can be in form in activities or education at community level and this will be done by the community health workers. They need to be trained in this regard." (P5)

Health system linkage

Training in client identification at the community level.was suggested as a training need as community health workers are the first-line workers in health systems.

"Clients' identification is a very important training need for community health workers. They are the first front-liners in health care. They need to be equipped with skills to identify those in need of services at community level." (P11)

In the health system linkage, it was also suggested that they need to be trained to make referrals to other levels of care.

"Their training should equip them with tools to make referrals to other providers or higher level." (P10)

Aside from making referrals, the stakeholders also suggested that community health workers be trained to link the identified clients to health facilities.

"The essence of community health workers is linking clients to health facilities. They need these skills." (P9)

Administration

As part of the service administration, the stakeholders suggested that the community health workers be trained to document and manage data.

"Data management is a skill they should learn like any other worker. Documenting their activities will help in making progress reports." (P11)

Equally, the need to keep records at the community level was emphasized as a training need in administration.

"Record keeping is very important for all health workers especially these will be at community level. Records will be required for evaluating services and make improvement where necessary." (P8)

Training model

Entry qualification

The stakeholders suggested that interest in community health work be a prerequisite for entry. They also considered reading and writing very important, as instruction comprehension is required during the training.

"A qualification need not be attached, as long as one can read and write, they can be taken up. If a person is able to read and write then, they can well comprehend the instruction in the training. What matters is one has a heart for the work." (P9)

Regarding academic qualifications, settling for as low as the seventh grade was thought of as ideal, as long as the candidate could understand instruction.

"Just grade seven is necessary. Nothing much. They just need to understand what is being taught. What is important is the passion for the work." (P2)

Meanwhile, a twelfth grade was not considered as a good requirement, as it was thought to lead to a high attrition rate, because then candidates also qualified for other programmes.

"Taking those with grade 12 qualification is not the best idea. They may not really be interested in the work. But just because there is a programme, they will enrol and later migrate to work of their interest." (P4)

Duration

Three months of training for community health workers in physical rehabilitation was highly favoured to cover both theory and practice while accounting for other personal activities in candidates' lives.

"Three months is good period to cover basic training needs both the theoretical and practical aspect. These are people who have other activities going on in their lives." (P9)

Although one month also scored high, the stakeholders reasoned that a one-month period could be too short to instill the practical aspect.

"One month may not be long enough to coverthe practical aspect" (P5)

The longest, which was suggested and scored higher, was 6 months, including both theory and practical.

"Physical rehabilitation has four components which they can cover in six months including both theory and practical." (P7)

Mode of instruction

The hybrid mode, a combination of physical and online instruction, was highly favoured.

"Health service delivery is physical. But the combination of both physical and online instruction would be ideal. While physical instruction is best, follow up can be done online especially where distance is an issue. The world is moving in this direction." (P5)

The suggestion for physical instruction was also favoured because physical rehabilitation is hands-on, and this would yield better results.

"Physical rehabilitation is hands on. Even the training need to be tailored in this way. Hence physical instruction would bring out the best results. "(P9)

Training approach

The stakeholders suggested a decentralised approach to training as they felt community health workers should be trained in their natural environment.

"Community health workers need to be trained in the environment where they will operate from which is the community. So the training need to take a decentralised approach." (P9)

Evaluation

Physical rehabilitation, being practical, a practical, summative evaluation to bring out practical skills was suggested.

"Practical summative evaluation will bring out the skills achieved by the community health workers. Community health is practical and the objective should be to bring it out." (P9)

However, a theoretical and practical summative evaluation scored higher, to bring out both the theory and the practical know-how was highly favoured.

"It will necessary to bring out what the theory as well practical knowledge. They will not only be delivering practical services. They will also have engaged in health education. How do we know what they know about conditions?" (P11)

Regulation

The stakeholders suggested that the regulation of community health workers be left out. They reasoned that all community health workers are non-regulated and that, after training, they will be supervised by qualified health workers.

"All community health workers are unregulated in Zambia. It should be the same for these ones." (P11)

"There is no need of regulating these community health workers because they will be supervised by a qualified health provider." (P9)

Equally, the Health Professions Council of Zambia requires a full grade 12 certificate for professional registration, which, in this case, is not a mandatory qualification for entry into the community health worker programme.

"Health Professions Council of Zambia requires regulating professions with a full grade 12 certificate, which these one may not have." (P1)

Certification

The stakeholders highly favoured issuing a qualification certificate to community health workers upon completion of training.

"It is only fair to give a certificate to one who has been trained longer than a month." (P11)

"A certificate can be used to get employment because the time is longer. It is a way of motivating them"(P9.

DISCUSSION

This study, conducted through collaboration with key stakeholders, identifies the training needs and training model for consideration when training community health workers to render physical rehabilitation services. The stakeholders emphasised the importance of detailed client assessment and case management for community health workers rendering rehabilitation services. In addition, the stakeholders suggested adopting a decentralised approach to training, with the ability to read and write as the entry requirement, and a duration of three months, with a combination of physical and online modes of instruction. Furthermore, a theoretical and practical summative evaluation was emphasised, and a certificate was to be issued upon completion of the training. These study findings echo the World Health Organisation guideline on health policy and system support to optimise community health workers' programmes (World Health Organization, 2018).

Patient assessment and case management are integral to delivering quality physical rehabilitation services. Community health workers are important health front-liners. Therefore, adequate assessment skills and case management empower them to operate independently at the community level (Glenton et al, 2012). While the current study suggested a detailed physical rehabilitation patient assessment and case management, the included components are actually basic components of physical rehabilitation practice at the lowest level. This leaves individual trained human resources for health in physical rehabilitation to provide the detailed, specific service.

Meanwhile, other community health workers ' training programmes in physical rehabilitation services vary in how they incorporate patient assessment and case management (Nesbit & Clark, 2019). In health education, community health workers serve as the primary source of health information at the community level; therefore, equipping them with appropriate health education tools has the potential to enhance disability awareness (Jansen-van Vuuren & Aldersey, 2018). Community health workers should also be empowered to strengthen, liaise with, and integrate clients. They should support clients in community participation as they are considered health pillars of the community (Hartzler et al, 2018). The current study also highlighted this.

Training community health workers in general skills such as health education, health system linkages, community liaison, disability awareness, and administration has potential to strengthen currently fragile community health systems in Zambia. Such capacity building may facilitate the development of effective rehabilitation referral and care pathways, thereby improving access to and delivery of physical rehabilitation services (LeBan et al., 2021). Furthermore, strengthening community health systems and expanding access to physical rehabilitation services constitute a disability right to which persons with disabilities are entitled to, particularly in light of Zambia's ratification of the United Nations Convention on the Rights of Persons with Disabilities (United Nations High Commissioner for Human Rights, 2025). The provision of appropriate physical rehabilitation services is therefore integral to advancing health equity, social justice, and the realisation of human rights (Guide, 2014).

While community health workers are recruited from local communities, their training varies across settings (Lehman & Sanders, 2007). In the current study, stakeholders argued that, in addition to being from local communities, entry requirements should be based on the candidate's ability to read and write. Evidence shows that the experience and practical training of community health workers outperform their literacy and formal education and predict increased knowledge and performance (Rogers et al., 2023). In contrast, in South Africa, the community health workers should at least have completed high school with some basic literacy and numeracy (Scheffler & Mash 2023). Regarding training duration, the existing literature indicates that community health worker training programmes in physical rehabilitation may range from 21 hours to 3 days (Scheffler & Mash, 2023; Nesbit & Clark, 2019). However, the stakeholders in the present study perceived a three-month training period to be sufficient for community health workers to acquire the knowledge and skills in physical rehabilitation. While the training duration depends on the content and depth of what has been considered essential, the stakeholders in this current study felt that three month's duration would be sufficient for community health workers to gain both theoretical and practical skills across all four components of physical rehabilitation. Without national standards for training community health workers in Zambia, exploring the entry requirements underscores the need to understand whether they can be trained effectively.

A decentralised training approach was recommended as suitable for community health worker training to ensure that practical and theoretical training are adequately integrated (Scheffler & Mash, 2023; Nesbit & Clark, 2019; De Villiers et al., 2017). Additionally, the current study suggested a hybrid approach as a teaching and learning strategy. While online instruction would make training more accessible in other settings, it might pose challenges in some regions of Zambia with inadequate technological infrastructure (Zambia Information and Communications Technology Authority, 2022). With appropriate logistics in place, in-person instruction yields positive results in community health worker training (Shireman et al., 2020). However, securing time for in-person instruction for community health workers may be challenging, as adult students may have other responsibilities. A theoretical and practical summative evaluation is widely used in most community health worker training programs (Galvez et al., 2021; Scheffler & Mash, 2023). The same was also suggested in the current study. Given the independent operation of community health workers, a theoretical and practical summative evaluation would ensure that knowledge and skills are properly assessed. Community health workers face various challenges in their service delivery, including unrealistic expectations and limited resources. With a standardised training model and certification, a path could be paved for integration into the national health system, thereby minimising challenges.

This proposed training model for community health workers, therefore, offers a valuable solution to improve rehabilitation service delivery in Zambia and similar low-resource settings. To further increase community health workers' effectiveness after training, their role should focus on specific, well-defined tasks under a task-sharing approach, as they will not be able to manage all conditions independently (Yankam et al, 2023). It is therefore recommended that community health workers be competency-based trained, delivered by specific human resources for health in physical rehabilitation, with ongoing supervision and mentorship. For further effective implementation, the model must be supported by national health policies, integrated into existing health systems, and supported by academic and professional institutions.

Strengths and limitations of the study

The study used a mixed-methods approach, specifically the nominal group technique, to gather input from various stakeholders in physical rehabilitation, including professionals in physiotherapy, occupational therapy, and speech therapy with expertise in prosthetics and orthotics. This approach generated ideas for the training needs and a model for community health workers in physical rehabilitation. However, a fundamental limitation was the difficulty in assembling stakeholders due to Zambia's shortage of physical rehabilitation professionals. To address this, the study included a retired speech therapist and occupational therapy technologists.

CONCLUSION

Community health workers offer a solution to the ongoing human resources crisis in health within resource-constrained settings. Their roles vary, but they can support physical rehabilitation services. Training community health workers in this area could help fill the human resources for health gap and improve service distribution, especially in resource-constrained settings. The results emphasised the importance of standardised training programmes to enhance competencies and ensure equitable service distribution.

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Authors contribution

MM conceptualised the study, conducted data collection and initial analysis, and wrote the first draft of the manuscript. TD[3] assisted in conceptualising the study and data collection and reviewed the manuscript. TD[1] guided the study's conceptualisation and data analysis, reviewed the manuscript, and provided intellectual insight. All the authors approved the manuscript for publication.

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Review Article

The Current State of Ghana's Disability Policy

Afua Ntoaduro[1*], Douglas Fofie[2], Grace Yeboah[1], Adu Gyamfi Benjamin[2], Sarah Takyi[3]

1 Department of Interdisciplinary Studies, Akenten Appiah-Menka University of Skills, Training and Entrepreneurial Development, Kumasi, Ghana
2 Department of Educational Studies, Akrokerri College of Education, Akrokerri, Asanti Region, Ghana
3 Department of Education and Psychology, University of Cape Coast, Cape Coast, Ghana
* Correspondence: antoaduro@aamusted.edu.gh

ABSTRACT

This article contributes significantly to the practices in Ghana that aim to alleviate the systemic challenges and opportunities for improving the lives of persons with disabilities (PWDs). After an extensive online search (on Google Scholar, ProQuest, etc.) for articles on current disability programmes and policy, more than 76 articles were downloaded. These included 52 journal articles, 6 book chapters, 7 reports, 1 conference paper, 6 web-based papers, and 2 policy documents. After a careful review, some of them were discarded. The criteria used were that the article must be about disability policy, programmes, and activities in Ghana, either by the central government, non-governmental organisation agencies, or civil society groups. During the analyses, the papers were grouped under the headings presented in this paper. The reviewed studies revealed that disability inclusion in Ghana is hindered by structural, cultural and policy barriers, including stigma, inaccessible infrastructure, weak policy enforcement and limited data. Despite the existence of supportive legislation such as the Persons with Disability Act (2006), implementation remains poor and representation of persons with disabilities is inadequate. Nonetheless, community-driven initiatives and non-traditional service providers offer promising approaches by promoting local participation, cultural sensitivity, and grassroots advocacy. Some recommendations are the need for stronger policy enforcement, adequate funding and transparent evaluation to translate the goals of the Persons with Disability Act (2006) into tangible outcomes.

Keywords: Challenges, Disability policy, discrimination, insurance, physical environment

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INTRODUCTION

Ghana's disability policy landscape is anchored by the National Disability Policy (1996), the Persons with Disability Act (2006/2007), and the National Social Protection Policy (2015). Additional relevant policies such as the National Health Insurance Act (Act 650, 2003), with its legislative instrument (LI 1809), provides for free health insurance enrollment for persons with disabilities, though implementation challenges persist. Ghana's disability policy indicates that, while significant legislative frameworks exist, enforcement remains a critical gap, especially concerning accessibility and social inclusion. The current Ghana's *Persons with Disabilities Act* (Act 715) of 2006 was intended to facilitate the rights and participation of PWDs. This has been limited in its effectiveness

due to the low enforcement of necessary legislative instruments and consistent monitoring mechanisms (Naami et al., 2023). Calls from stakeholders, including the Ghana Federation of Disability Organisations, emphasised aligning the Act with the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD), highlighting that without such an alignment, PWDs continue to face obstacles in public and social domains (Naami et al., 2023; Ghana Somubi Dwumadie, 2024).

Social protection interventions, including the *Livelihood Empowerment Against Poverty* (LEAP) Program and the *National Health Insurance Scheme* (NHIS), offer targeted support to PWDs. However, the criteria for accessing these programs are often ambiguous, leading to inconsistent eligibility assessments and limitations on actual accessibility (Naami et al., 2023). The *District Assembly Common Fund*, another support mechanism designated for PWDs, is often underfunded, restricting its reach and impact on those who need it most (Naami et al., 2023; Ghana Somubi Dwumadie, 2024).

Ghana Somubi Dwumadie is a disability-focused programme that aims to improve the wellbeing of people with disabilities in Ghana, particularly through supporting disability policy implementation and promoting inclusive practices. The link between Ghana Somubi Dwumadie and disability policy is that the programme acts as a catalyst for policy reform, capacity building, and practical implementation of Ghana's disability laws and social protection initiatives.

Ghana's disability policy framework includes the Persons with Disability Act (Act 715), the National Disability Policy, and targeted social protection schemes like the Disability Fund and free health insurance for persons with disabilities. However, research shows that implementation gaps persist, with barriers such as bureaucratic delays, lack of information, and insufficient funding limiting the effectiveness of these policies (Agbelie, 2023; Karimu et al., 2024; Opoku et al., 2019). Programmes like Ghana Somubi Dwumadie are designed to address these gaps by supporting government and civil society efforts to make disability policies more effective and accessible.

A key component of Ghana Somubi Dwumadie is disability training for health workers and community leaders, which has been shown to improve attitudes, reduce stigma, and empower stakeholders to advocate for the rights of people with disabilities (Rotenberg et al., 2024). These interventions align with policy goals by fostering a more inclusive environment and ensuring that disability rights are respected in practice.

Since 2020, Ghana Somubi Dwumadie has promoted disability-inclusive policies and public awareness. Funded by UK aid, this program focuses on policy advocacy, addressing stigma, and expanding accessible mental health services through collaborations with the Ghanaian government and community organizations. This initiative has demonstrated the importance of user-led advocacy in shifting perspectives on disability and reinforcing the rights and needs of PWDs in Ghana (Ghana Somubi Dwumadie, 2024). Similarly, research on older adults using the Ghana 2021 Population and Housing Census found that 38.4% of those over 60 have at least one disability, with prevalence linked to socioeconomic factors such as gender, education, and rural residency (Agyekum et al., 2024).

Challenges and Barriers

Environment and Transportation

Physical environments, infrustructures, and medical equipment in Ghana are often inaccessible to students with disabilities (SWDs), leading to significant barriers in accessing health care services. Challenges include geographical proximity to facilities, travelling time, and transportation difficulties (Ador, 2019). Bezyak et al. (2017) identify significant obstacles in public transportation systems, emphasising the need for improved services to accommodate individuals with disabilities. The organisation of health care services is highlighted as inadequate, failing to accommodate the specific needs of

SWDs (Vincent & Chiwandire, 2019). There is a lack of supportive logistics and services such as directional signs, tactile or braille materials, and sign language interpreters, which are crucial for facilitating access.

Finance

Financial barriers are noted, particularly relating to health insurance coverage. SWDs often face difficulties in obtaining necessary consultation records and encounter limitations in benefit coverage from existing health insurance schemes (Abodey et al., 2020).

Systemic weaknesses within healthcare frameworks, limited prioritisation of disability issues within health policies, and poor monitoring and evaluation of existing disability policies are factors that contribute to the challenges SWDs face in accessing healthcare (Hamilton et al., 2019).

Employment

Employment also remains an obstacle, as employers generally view PWDs as unproductive, and accessible workplaces are rare (Naami, 2015), which denies them the means of earning incomes to support themselves and their families. Many healthcare facilities lack necessary accommodations, and healthcare providers often display discriminatory attitudes due to limited training on disability care (Dassah et al., 2018; Badu et al., 2016).

PWDs often face exclusion from education, employment, and healthcare, contributing to diminished income levels and reduced quality of life (Asuman et al., 2021). This situation is compounded by what is termed a "conversion handicap," where households with disabled members incur additional costs to maintain a similar standard of living as those without PWDs (Asuman et al., 2021). This contextualises Ghana's experience, showing that international studies support the correlation between disability and poverty, especially in resource-limited settings (Asuman et al., 2021; Mitra et al., 2013).

PWDs globally and in Ghana are among the most marginalised, often facing financial hardship due to limited access to education and employment (Wiredu et al., 2021). PWDs in Ghana experience higher healthcare costs compared to the general population, which can make healthcare less affordable and accessible without social protection measures like National Health Insurance Scheme (NHIS) enrollment. This issue aligns with broader research findings indicating that healthcare utilisation improves when individuals are enrolled in health insurance, especially among vulnerable populations (World Health Organization, 2015; Badu et al., 2016). Factors like gender, income, and education level are significant predictors of NHIS enrollment among PWDs, with female individuals with lower incomes, and those with minimal education levels being more likely to participate in the scheme (Wiredu et al., 2021).

Despite the passage of the *Persons with Disabilities Act, 2006*, and other legislative efforts, barriers to accessibility, stigma, and discrimination persist (Mfoafo-M'Carthy, Grischow et al., 2020 a). For example, traditional beliefs often associate disability with spiritual or moral failures, resulting in discrimination in areas like marriage, employment, and healthcare (Kassah, 1998; Naami et al., 2012). This stigma reinforces exclusion from education, where inadequate resources and negative perceptions discourage many families from supporting the schooling of children with disabilities (Opoku et al., 2017).

Many media organisations view disability issues as unprofitable, which leads to a lack of coverage and support for programs aimed at improving the lives of PWDs (Amoako et al., 2020). This perception is influenced by the overarching goal of profit maximisation in a neo-liberal environment (Amoako et al., 2020). There is a significant underemployment of PWDs in the media sector, which is compounded by societal attitudes and the prioritisation of meritocracy and competition over inclusivity (Abdallah,

2023). Media organisations often cite resource limitations as a reason for not prioritising disability issues. They struggle to cover the costs associated with disability programs, which are seen as less profitable compared to other content (Andrews et al., 2021). The study found that disability issues receive minimal media coverage, which perpetuates the marginalisation of PWDs in society. This lack of coverage is attributed to the media's focus on profitability and competition rather than social responsibility.

Additionally, Darcy and Taylor (2009) analyse disability citizenship in the context of cultural industries, suggesting that societal attitudes and policies significantly impact the experiences of PWDs. A study on the campus shuttle experience and mobility concerns of SWDs at the University of Cape Coast, Ghana, reveals that the floor height of shuttles ranged from 320 to 520 mm, exceeding the recommended maximum of 230 mm for accessibility (Odame et al., 2020). While students with visual impairments could manage boarding using white canes, wheelchair users faced significant difficulties due to the absence of boarding platforms, often needing to fold their wheelchairs or crawl into the shuttles.

Special education initiatives have been in place since 1936, but they have often been inconsistent and poorly coordinated, failing to adequately address the needs of children with disabilities. Infrastructural challenges that hinder access to schools; socio-cultural discrimination and stigmatisation of persons with disabilities (PWDs); and inadequate policy frameworks and funding, with the Special Education Division receiving minimal educational allocations (0.7% in 2010, 0.5% in 2011, and 0.4% in 2012).

There is a strong correlation between educational attainment and employment opportunities for PWDs, with higher education leading to better job prospects (Morgan, 2023).

Nsenkyire et al. (2023) highlight the intersection of energy poverty and functional disabilities, showing that rural and female-headed households experience greater multidimensional energy poverty, which exacerbates disability conditions, suggesting a need for integrative policy approaches.

Education

In education, Duorinaah (2023) demonstrates the role of community-driven initiatives in enrolling children with disabilities in schools, with practices like mapping and sensitisation forums mitigating stigma and increasing participation in inclusive education. Meanwhile, Opoku et al. (2021) critique barriers to inclusive education, identifying insufficient teacher training and systemic issues as impediments, calling for better resources and institutional commitment. Employment studies reveal that while legislation aims to create equal opportunities, disparities persist based on disability type and lack of vocational training, further complicating access to the labour market for PWDs (Equal Opportunity Study, 2023). Together, these findings advocate for holistic policies integrating socioeconomic, educational, and employment considerations for PWDs in Ghana.

METHODS

Systematic Review

A systematic review is a research method used to collect, evaluate, and synthesize existing literature in a structured and transparent manner (Tran et al., 2021). The primary goal of this systematic review was to synthesize the findings of existing research to understand the challenges and opportunities within Ghana's disability policy framework. By reviewing peer-reviewed articles, policy documents, reports, and other scholarly sources, this methodology identifies key themes and barriers that influence the implementation of disability policies while highlighting opportunities for improvement (Naami et al., 2023; Wylie et al., 2020). This review followed several stages, including a

literature search, inclusion and exclusion criteria application, quality assessment, and thematic analysis. These steps ensured a rigorous and comprehensive understanding of Ghana's disability policy landscape and its implications for PWDs.

Data Collection Process

The literature collection process involved searching for scholarly articles and other publications from multiple academic databases, including Google Scholar, ProQuest and relevant institutional repositories. These platforms were selected because they host a wide range of studies on social policy, disability rights, and advocacy in Ghana and similar contexts.

Inclusion Criteria

1. The inclusion criteria were carefully defined to ensure the relevance and quality of the selected studies. Articles and publications were included if they:
2. Focused on Ghana's disability policies and programs or related disability initiatives.
3. Explored themes such as accessibility, social inclusion, education, healthcare, or employment of PWDs.
4. Included empirical data, case studies, or theoretical analyses on the effectiveness of disability policies in Ghana.
5. Were peer-reviewed journal articles, book chapters, policy documents, or high-quality reports.

Exclusion Criteria

1. Studies were excluded if they:
2. Focused on disability policies outside the Ghanaian context without relevance to this study.
3. Were non-empirical sources such as opinion pieces or news articles unless they provided critical theoretical insights.
4. Failed to explore policy impacts or the lived experiences of PWDs.

Quality Assessment

Each selected article was assessed for methodological quality using standard quality assessment tools, such as the Critical Appraisal Skills Programme (CASP) checklist for systematic reviews. This ensured that only rigorous and credible evidence informed the conclusions drawn in this review (Johnson & Taylor, 2023).

Thematic Analysis

Once relevant data were extracted, a thematic analysis was conducted to identify recurring patterns and key themes. Thematic analysis is an approach to analyzing qualitative data that involves systematically identifying and interpreting patterns within the data (Braun & Clarke, 2022).

The initial phase involved a thorough review of all selected articles to familiarise the researcher/s with the content. After coding the data, the codes were grouped into themes. Key themes identified included policy enforcement gaps, socio-cultural stigmas, barriers in healthcare and education, and the role of community engagement in advancing disability rights. The findings from the thematic analysis provide actionable insights into the systemic barriers faced by PWDs in Ghana and potential strategies to improve the inclusiveness and effectiveness of disability policies (Naami et al., 2023; Wylie et al., 2020).

Stigma, Infrastructure Gaps, and Policy Enforcement

Empirical evidence from Ghana demonstrates that stigma, infrastructural limitations, and weak policy enforcement continue to undermine disability inclusion. Tetteh et al. (2023) highlight that "there is a paucity of empirical data on the outcomes of Ghana's disability policy," noting that despite ratification of international frameworks, imple-

mentation remains fragmented. Agbenyega (2003) observed that labelling within schools and communities "constructs negative identities around disability," reinforcing societal stigma and policy ineffectiveness.

Barriers in Education

In the education sector, Anthony (2010) and Nketsia (2018) found that cultural beliefs about disability significantly shaped how inclusive policies were applied, leading to what Nketsia (2018) calls "a mismatch between policy rhetoric and classroom realities." Similarly, Owusu-Ansah and Agyei-Baffour (2012) report that SWDs in tertiary institutions face "unmet needs in learning environments," despite the mandates of the Persons with Disability Act (Act 715). Tudzi et al. (2017) quantify this problem, revealing that "less than 30% of university buildings in Ghana are accessible to wheelchair users."

Barriers in Healthcare

Healthcare also reflects these inequalities: Badu et al. (2016) documented that "physical access and staff attitudes remain the two biggest barriers to healthcare in Kumasi," while Ganle et al. (2016) showed that women with disabilities face "double discrimination" in maternal healthcare. Opoku et al. (2019) emphasise that though progress has been made, "resource constraints and poor monitoring systems continue to hinder success." Collectively, these findings confirm Mantey's (2014) and Vanderpuye et al.'s (2020) assertion that evidence-based frameworks are essential to scale up disability-inclusive practices nationwide.

The Need for Comprehensive, Inclusive, and Effectively Implemented Policies

Despite significant legal frameworks, including the Persons with Disabilities Act (2006), implementation gaps persist. Dziwornu (2023) observed that "policies are beautifully written but poorly executed," leaving most PWDs without tangible benefits (p. 152). The study advocates for "enforcement of disability rights, employment quotas, and anti-stigma initiatives" (p. 153). Odoi (2022) links these efforts to the UN Sustainable Development Goals, urging Ghana to "use SDG 10 and SDG 16 as leverage points" for enhancing inclusivity and democratic participation. Asuman et al. (2020) estimate that "households with disabled members incur additional costs equivalent to 26% of total annual consumption," pushing them deeper into poverty. Seidu et al. (2021) reviewed 15 national health policies and found that "only 53% incorporated any disability-specific considerations," a figure corroborated by Gyimah et al. (2024), who noted that adolescents with disabilities still face "systemic exclusion in healthcare access." Naami et al. (2023) critique Ghana's National Social Protection Policy, recommending "a twin-track approach and representation of PWDs in all decision-making bodies." Likewise, Opoku and Nketsia (2021) found that less than 10% of disability fund managers are persons with disabilities, revealing governance inequities.

The London School of Hygiene & Tropical Medicine (2024) similarly reported that "PWDs in Ghana experience poorer educational and economic outcomes," aligning with Grischow's (2021) claim that weak activism and political inertia contribute to the "non-enforcement" of disability laws. With the Ghana Statistical Service (2021) estimating that 8% of the population live with PWDs mostly in rural areas, these studies underscore the pressing need for comprehensive, inclusive, and enforceable disability policies.

Community-Driven Approaches in Enhancing Policy Implementation

Community participation has proven to be a powerful mechanism for improving disability inclusion in Ghana. Wickenden et al. (2012) demonstrated how "community-based rehabilitation (CBR) guidelines co-designed with local actors produced contextually relevant interventions." Such participatory methods ensured that "global disability frameworks were adapted to local cultural realities." Similarly, Wylie et al. (2020) highlight the contribution of "pastors, herbalists, and local doctors" who "fill critical gaps

in rehabilitation services," providing psychosocial and spiritual support that complements formal systems.

In education, Nketsia et al. (2016) found that "teacher advocacy and community engagement increased classroom inclusivity," while Mensah et al. (2022) reported that community awareness around Universal Design "significantly enhanced accessibility for students with disabilities in higher education." Conversely, Babik and Gardener (2021) reveal that "some communities reject PWDs from mainstream schools," demonstrating how social exclusion undermines inclusion. Masse et al. (2012) noted that such rejection "lowers self-esteem and increases suicidal ideation among affected individuals." Abodey et al. (2020) add that many communities still "exclude PWDs from local decision-making processes," resulting in low representation and alienation. Altogether, these findings affirm that community-driven and culturally sensitive initiatives are key to advancing inclusive development.

Role of Non-Traditional Service Providers in Disability Support Systems

Beyond formal healthcare and education systems, non-traditional service providers have become central actors in disability support. Wylie et al. (2020) documented how "faith healers, herbalists and community doctors offer pluralistic care that blends physical, psychosocial and spiritual dimensions." Their work reveals how "collaboration between formal and informal systems can create culturally resonant disability care." Dassah et al. (2022) provide complementary evidence from northern Ghana, showing that local health practitioners "navigate poor infrastructure and limited resources to improve primary healthcare for PWDs." Their recommendations include "making services more affordable and physically accessible."

Similarly, Yekple (2014) investigated traditional beliefs about intellectual disabilities, revealing that "when teachers and parents work with community leaders to challenge stigma, enrolment rates of children with disabilities rise." This suggests that traditional actors not only influence community beliefs but also contribute to advocacy and inclusive reform. Collectively, these studies affirm that non-traditional service providers play dual roles as caregivers and as advocates for social inclusion bridging cultural norms with formal disability policy efforts.

CONCLUSIONS

Across the reviewed studies, disability inclusion in Ghana is constrained by intersecting structural, cultural and policy challenges. Persistent stigma and infrastructural inaccessibility intersect with weak policy enforcement and limited data for informed decision-making. Although Ghana's legislative and policy landscape such as the Persons with Disability Act (2006) demonstrates formal commitment, poor implementation and insufficient representation of PWDs continue to impede progress. However, community-driven initiatives and the contributions of non-traditional service providers reveal pathways toward sustainable inclusion by integrating local participation, cultural sensitivity and grassroots advocacy. Together, these findings underscore that achieving disability equity in Ghana requires not only stronger policy enforcement but also the empowerment of communities and traditional actors as co-creators of inclusive systems.

Implications of the Study

The findings of the study underscore the urgent need for strengthened policy enforcement mechanisms to ensure that the objectives of the Persons with Disability Act (2006) and related frameworks are translated into measurable outcomes. This requires consistent government monitoring, adequate funding allocations and transparent evaluation systems to bridge the gap between legislative intent and lived experiences of PWDs.

The study highlights the importance of mainstreaming disability issues across all sectors, including education, health, employment, and infrastructure development. Policymakers should adopt an intersectional and rights-based approach that addresses the compounded effects of stigma, poverty and gender disparities among PWDs. Integrating disability considerations into national development plans and the Sustainable Development Goals (SDGs) will help promote inclusivity and equity.

The findings suggest that community participation and cultural sensitivity are essential for the success of disability policies. Engaging local leaders, traditional healers, faith-based institutions and community-based organisations in awareness campaigns and service delivery can foster positive social attitudes and improve accessibility. Strengthening partnerships between formal and non-traditional service providers would enhance culturally relevant interventions that reflect local realities.

Contributions of this paper

This paper contributes significantly to education and practice by highlighting the systemic challenges and opportunities for improving the inclusion of persons with disabilities (PWDs) in Ghana. It provides a comprehensive analysis of the barriers faced by PWDs in accessing education, emphasising the impact of infrastructure gaps, socio-cultural stigmas, and insufficient policy implementation.

The findings stress the need for inclusive education practices, such as adaptive teaching methods and specialised support systems, to accommodate the diverse needs of students with disabilities. By addressing these gaps, the study advocates for more equitable access to education, which is vital for the personal and professional development of PWDs and for fostering their full participation in society. Furthermore, the study underscores the critical role of teacher training and curriculum development in building an inclusive educational environment, encouraging the integration of disability-focused modules into training programs for educators.

In terms of practice, the paper contributes by identifying the importance of aligning disability policies with international frameworks like the UN Convention on the Rights of Persons with Disabilities (UNCRPD). It calls for stronger enforcement mechanisms and monitoring systems to ensure compliance with these standards. The study also highlights the role of community-driven initiatives, such as Ghana Somubi Dwumadie, which promote disability advocacy and public awareness. These initiatives demonstrate the transformative potential of involving local organisations and stakeholders in addressing stigma and providing culturally sensitive support for PWDs.

Additionally, the study's insights into healthcare accessibility for PWDs inform practice by advocating for the integration of disability-friendly infrastructure, equipment, and services in healthcare systems. It also calls for tailored social protection measures, such as expanded health insurance coverage and financial support, to mitigate the economic burden on PWDs. Together, these contributions provide a roadmap for policymakers, educators, and practitioners to create a more inclusive society that values and supports the rights and needs of persons with disabilities.

Suggestions for Future Research

Future research on disability inclusion in Ghana should focus on longitudinal studies that assess the long-term impact of the Persons with Disability Act (2006) and related social protection programmes. Such studies would provide insight into whether legislative commitments have translated into measurable improvements in education, healthcare and employment outcomes for persons with disabilities (PWDs).

Researchers should explore regional and intersectional disparities in disability experiences. Comparative studies between urban and rural areas or among different gender and age groups would help uncover the unique challenges faced by subpopulations,

especially women and children with disabilities, who often face multiple layers of exclusion.

Future studies should examine the effectiveness of intersectoral collaborations between government institutions, NGOs, and traditional actors in implementing disability policies. Evaluating these partnerships can reveal best practices for scaling up community-driven and culturally sensitive interventions.

There is a need for quantitative data collection and impact evaluation studies to fill existing empirical gaps identified. Generating reliable national data on accessibility, resource allocation, and policy outcomes would be vital for evidence-based decision-making and monitoring Ghana's progress toward disability equity and inclusion.

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Review Article

Experiences of People with Disabilities and Chronic Illnesses Accessing Healthcare in Rural and Remote Communities: A Scoping Review

Stephanie Quon[1*], Brandon Sum[1], Isabel Truong[1], Katherine Zheng[1]

[1] University of British Columbia, Vancouver, Canada
* Correspondence: quons@student.ubc.ca

ABSTRACT

Background: Rural and remote communities face well-documented challenges in healthcare access, including workforce shortages and long travel distances. For people with disabilities and people with chronic illnesses, these challenges are compounded by accessibility barriers, fragmented services, and heightened dependence on accommodation, support, and continuity of care.

Objective: This scoping review aimed to map the literature on how people with disabilities and people with chronic illness experience accessing healthcare in rural and remote settings, with attention to barriers, facilitators, care pathways, and patient-identified priorities for improvement.

Method: Following the PRISMA-ScR framework, we systematically searched MEDLINE, Embase, CINAHL, PsycINFO, and Scopus from inception to July 2025. Eligible studies included qualitative, quantitative, and mixed-methods research describing healthcare access experiences among people with disabilities and people with chronic illness living in rural or remote regions. Data were charted on population, geography, care setting, access dimensions, and reported outcomes, and were synthesized using descriptive and thematic analysis.

Result: Twenty-five studies were included, spanning primary care, specialty care, rehabilitation, home care, and emergency services across rural and remote regions in high-, middle-, and selected low-income settings. Four themes emerged: (1) distance, transportation, and the "time tax" of care; (2) service scarcity and discontinuity across the care journey; (3) accessibility and accommodation gaps within rural health systems; and (4) relational, cultural, and privacy dynamics shaping care-seeking and trust. Across studies, telehealth and local "wraparound" relationships were frequently described as partial mitigations, but often limited by broadband access, disability-related communication needs, and reduced opportunities for hands-on assessment.

Conclusion: People with disabilities and chronic illnesses in rural and remote communities face layered access barriers that extend beyond geography to include accessibility, continuity, and the social realities of rural life. Future research should evaluate interventions that combine accessible transportation supports, strengthened local interdisciplinary capacity, disability-competent telehealth, and coordinated pathways for specialty and rehabilitation care.

Keywords: rural health, remote health, disability, chronic illness, healthcare access, accessibility

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INTRODUCTION

Healthcare access in rural and remote regions is shaped by structural conditions that consistently disadvantage residents, including geographic isolation, limited infrastructure, and uneven workforce distribution [1–3]. Long travel distances to primary care, specialty services, and diagnostic testing are common in rural settings and are associated with delays in seeking care and lower uptake of preventive services [1,3]. Sparse healthcare infrastructure further compounds these challenges, with fewer clinics, limited on-site diagnostics, and constrained outpatient capacity contributing to higher reliance on emergency departments for conditions typically managed in ambulatory settings [4,5]. These structural barriers have measurable clinical consequences, including delayed diagnoses, preventable hospitalizations, and progression of otherwise manageable chronic conditions [4,5].

Workforce maldistribution intensifies these access gaps, as rural regions experience persistent shortages of physicians, specialists, nurses, and allied health professionals [6,7]. Recruitment and retention challenges have been documented across decades, with shortages particularly pronounced in rehabilitation and allied health services that are essential for individuals with chronic illness or functional limitations [8,9]. Limited local availability of these services contributes to long wait times, fragmented care, and increased dependence on informal or family caregivers, especially among older adults and those with complex health needs [8,9]. Financial barriers further compound these challenges, as rural residents face higher rates of uninsurance, underinsurance, and medical debt compared with urban populations, disproportionately affecting marginalized and racially minoritized groups [10–12].

For people with disabilities and people with chronic illness, healthcare access encompasses more than proximity to services and includes the ability to physically enter and navigate care environments, communicate effectively with clinicians, receive appropriate accommodations, and obtain coordinated care across multiple settings [13–15]. Professional guidelines emphasize that accessible built environments, such as automatic doors, accessible exam rooms, height-adjustable examination tables, and adaptive equipment, are foundational to equitable care delivery [16,17]. Communication accessibility is equally essential and may include sign-language interpreters, assistive listening systems, accessible written materials, and the involvement of support persons, particularly for individuals with sensory or cognitive disabilities [13,14]. Effective access requires reliable documentation of accommodation needs and proactive adaptation of both administrative and clinical processes, which remain inconsistently implemented across healthcare systems [15,18].

In rural and remote contexts, disability-related access needs intersect with existing structural constraints, amplifying barriers to care [19–22]. Rural regions often have fewer accessible healthcare facilities, limited home-care capacity, reduced availability of adaptive equipment, and fewer accessible transportation options, increasing reliance on informal caregiving networks [19,20,22]. Disability status further increases the likelihood of delaying or forgoing care due to transportation challenges, clinic hours, and travel burden, particularly when specialty services are concentrated in distant urban centers [22–24]. Rurality also carries distinct social and cultural dimensions, including reduced privacy in small communities, heightened stigma related to disability or chronic illness, and complex relationships with local providers that can be simultaneously supportive and limiting when disability-specific expertise is lacking [24–26].

Despite extensive rural health research examining distance, workforce shortages, and population-level outcomes such as hospitalization and mortality, the lived experiences of people with disabilities and chronic illnesses navigating healthcare in rural and remote settings remain fragmented across conditions, regions, and care contexts [23–25].

Disability and chronic illness introduce distinct mechanisms of inequity, such as inaccessible built environments, limited availability of assistive technologies, lack of disability-informed clinical practices, and the cumulative burden of frequent long-distance travel, that are not fully captured by traditional rural health frameworks [13,24]. A scoping review is therefore well-suited to map the breadth of existing evidence, synthesize patient-reported experiences, identify recurring barriers and facilitators, and highlight gaps in knowledge that can inform future research, policy, and intervention design. Accordingly, this review synthesizes literature on the experiences of individuals with disabilities and chronic illnesses accessing healthcare in rural and remote communities, with particular attention to structural, relational, and systemic factors shaping access, care quality, and equity.

METHOD

Protocol and Reporting

This scoping review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines [27]. Methodological conduct was guided by established scoping review frameworks to support systematic mapping of a heterogeneous evidence base. An a priori protocol defined the research questions, eligibility criteria, search strategy, and data charting plan. The protocol emphasized breadth of inclusion and conceptual exploration of access experiences rather than formal assessment of intervention effectiveness or study quality.

Search Strategy

We searched MEDLINE (Ovid), Embase, CINAHL, PsycINFO, and Scopus from inception to July 15, 2025. Searches combined terms related to (1) rural and remote contexts, (2) disability and chronic illness, and (3) healthcare access and patient experience. Controlled vocabulary and free-text terms were adapted for each database to maximize sensitivity. Reference lists of included studies were screened, and targeted grey literature searches were conducted across rural health agencies and disability advocacy organizations, recognizing that experiential and community-based evidence is often underrepresented in indexed academic databases.

Eligibility Criteria

Studies were included if they: (1) reported empirical data (qualitative, quantitative, or mixed-methods); (2) focused on people with disabilities and people with chronic illness living in rural or remote communities; and (3) described experiences accessing healthcare services, including primary care, specialty care, rehabilitation, home care, emergency care, or telehealth. Studies capturing patient, family caregiver, or community perspectives were all eligible for inclusion. Studies were excluded if they focused solely on urban populations, did not report patient or caregiver experiences, or addressed rural health generally without disability- or chronic illness-specific findings. No restrictions were placed on geographic region, healthcare system, or study design, consistent with scoping review methodology.

Selection Process

Two reviewers independently screened titles and abstracts and assessed full texts for inclusion. Screening was conducted using predefined inclusion and exclusion criteria to promote consistency and reduce selection bias. Disagreements were resolved through consensus. Reasons for exclusion at the full-text stage were documented to enhance transparency in study selection.

Data Charting and Synthesis

A standardized charting form captured study characteristics (country, rurality definition, population, condition or disability type, care setting), access barriers and facilitators, and reported outcomes. The charting form was piloted on a subset of included studies and iteratively refined as needed. Findings were synthesized descriptively and through inductive thematic analysis. Themes were developed iteratively to capture cross-cutting patterns in access, accommodation, and structural constraints across diverse rural contexts, without privileging any single healthcare model or outcome framework.

RESULTS

Study Selection and Characteristics

A total of 3,112 unique records were identified through database searching. Following title and abstract screening, 117 full-text articles were assessed for eligibility, of which 21 studies met inclusion criteria. Across studies, participant populations included individuals with mobility, sensory, and intellectual or developmental disabilities, as well as people living with chronic conditions such as diabetes, chronic obstructive pulmonary disease, heart failure, chronic pain, autoimmune disease, and complex multimorbidity. Care settings examined most frequently included primary care, specialty referral pathways, rehabilitation and therapy services, and home- and community-based care. Four interrelated themes emerged from the synthesis (Figure 1).

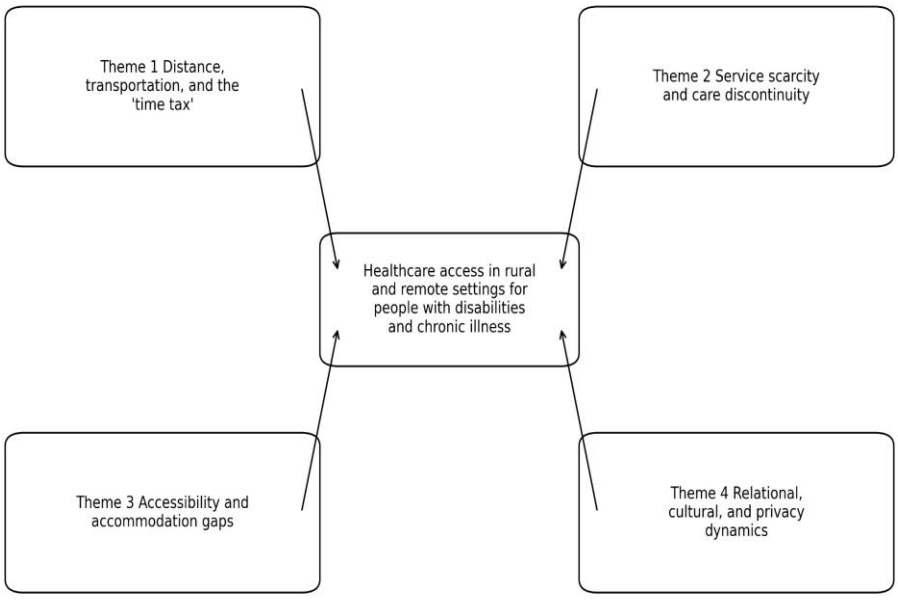

Figure 1: Schematic of identified themes.

Theme 1: Distance, Transportation, and the "Time Tax" of Care

Across studies, distance was not experienced as a simple geographic barrier but as a compounding logistical burden that shaped whether care was feasible at all. Participants described lengthy travel for specialty visits, diagnostics, or rehabilitation that often required early departures, overnight accommodation, missed work, and extensive coordination with caregivers, particularly for individuals using mobility devices or requiring assistance with transfers. These burdens were intensified by inaccessible vehicles, limited accessible public transit, and reliance on informal transportation arrangements in rural

contexts, consistent with prior findings on transportation barriers among rural residents and people with disabilities [19,22].

Transportation systems, when available, were frequently described as unreliable, inflexible, or poorly aligned with appointment schedules. Even dedicated rural shuttle programs were often inaccessible or impractical due to limited hours, physical barriers, or long wait times, echoing prior evidence that transportation availability alone does not ensure meaningful access [28–30]. For participants with fluctuating conditions such as fatigue, pain, or autonomic symptoms, travel itself was reported to exacerbate illness and reduce the perceived value of routine or preventive care, reinforcing patterns of delayed follow-up [19,22].

Participants consistently described these burdens as a "time tax" or "energy tax" that their urban or peers without disabilities did not face, encompassing lost wages, physical exhaustion, emotional strain, and caregiver coordination. As documented in prior rural and disability-focused research, this cumulative burden led many individuals to postpone appointments, reduce preventive care, or "save up" health concerns until multiple issues could be addressed in a single visit [19,22,31].

Theme 2: Service Scarcity and Discontinuity Across the Care Journey

Many studies described a persistent mismatch between high healthcare needs and limited local service capacity. Participants reported restricted access to specialists, rehabilitation providers, mental health services, and diagnostic testing, with long waitlists and fragile referral pathways that were often dependent on visiting specialists or rotating locum clinicians. These patterns are consistent with broader evidence of service scarcity in rural healthcare systems, particularly for people with complex or long-term care needs [32,33].

Discontinuity of care emerged as a central mechanism of harm. Participants described repeatedly "restarting the story," inconsistent medication management, and fragmented follow-up after hospital discharge due to under-resourced home care services and limited local capacity for coordination. Similar patterns of poor informational and relational continuity have been associated with increased risk of inappropriate medication use, adverse events, and mortality in populations with multimorbidity [34,35]. Caregivers were frequently described as assuming informal care coordination roles, navigating opaque systems and compensating for gaps between acute, community, and social care sectors, consistent with prior caregiver-focused research [36,37].

Several studies described a recurring pattern of avoidable escalation, wherein the absence of timely, accessible early intervention led to worsening conditions that ultimately required emergency care. This pattern was particularly evident for pain crises, respiratory exacerbations, wound care needs, and mobility-related complications, reflecting prior evidence linking service fragmentation to increased emergency department use in rural settings [32,38].

Theme 3: Accessibility and Accommodation Gaps Within Rural Health Systems

Beyond service availability, many studies highlighted how healthcare environments and processes were not designed to accommodate people with disabilities or communication needs. Participants described inaccessible entrances, non-adjustable examination tables, limited accessible diagnostic equipment, inadequate transfer supports, and insufficient private space for caregiver-assisted communication. These findings align with established literature documenting persistent accessibility gaps in healthcare facilities, particularly in rural and smaller clinical settings [22,23].

Communication barriers were also prominent across studies. Deaf and hard-of-hearing participants reported limited interpreter availability, autistic participants described sensory overload and lack of sensory accommodations, and individuals

with cognitive or fatigue-related impairments reported appointment pacing and information delivery that did not meet their needs. These challenges were amplified in smaller facilities with limited staffing and training, reinforcing "one-size-fits-all" clinical processes that fail to account for disability-related needs [13,14,26].

Participants frequently described the need to self-advocate for accommodation, bring their own supports, or accept suboptimal examinations when accessible equipment or trained staff were unavailable. Professional guidance from organizations such as the American College of Obstetricians and Gynecologists emphasizes that accessible environments and proactive accommodation are essential components of equitable care, underscoring the gap between recommended practice and lived experience in rural settings [14].

Theme 4: Relational, Cultural, and Privacy Dynamics Shaping Care-Seeking and Trust

Rural healthcare experiences were strongly shaped by social context and interpersonal relationships. Several studies described the protective role of close relationships with local clinicians who knew patients' families, adapted care informally, and assisted with navigating referrals, fostering trust and continuity, particularly when clinicians acknowledged patient and caregiver expertise in disability-related care [12,25,26].

However, the same small-community context also created barriers. Participants described concerns about privacy, fear of community gossip, and heightened visibility when seeking care, especially for mental health services or when requesting accommodations. Stigma related to disability or being perceived as "high-needs" further discouraged care-seeking, with some participants expressing concern that complaints or advocacy could damage relationships in settings with few alternative providers [22,39–41].

Cultural norms of self-reliance emerged as an additional influence on care-seeking behavior. Participants described minimizing symptoms, avoiding "making a fuss," and delaying care to reduce burden on family members or local services. These patterns contribute to late presentation and crisis-driven care. These norms interacted with structural barriers such as distance, transportation limitations, and service scarcity, amplifying disparities for rural residents with chronic illness or disability [22,42–44].

DISCUSSION

This scoping review synthesizes a growing and diverse body of literature examining how people with disabilities and chronic illness experience healthcare access in rural and remote communities. Across conditions, regions, and care settings, the findings demonstrate that access barriers operate through layered and interacting mechanisms rather than a single dimension of distance. Geographic isolation, transportation constraints, service scarcity, disability-related accessibility gaps, and the social realities of rural life collectively shape whether care is feasible, timely, and effective. This multidimensional framing aligns with and extends prior rural health research, which has increasingly moved beyond distance-based models of access toward more holistic understandings of burden and inequity [10,24,41].

A central contribution of the literature is the reframing of rural healthcare access as a cumulative "time," "energy," and "coordination" burden rather than a simple travel problem. Participants consistently described the compounding demands of long-distance travel, appointment coordination, caregiver involvement, and physical or cognitive exertion, particularly for those requiring frequent follow-up, rehabilitation, or interdisciplinary care. These findings are consistent with prior qualitative work demonstrating that rural residents with complex needs experience disproportionate opportunity costs and fatigue associated with care-seeking, often leading to delayed or foregone care [10,24,41]. Importantly, this burden was not evenly distributed, falling most heavily on

individuals with disabilities, fluctuating conditions, or limited financial and caregiving resources.

The review also highlights that geographic proximity alone does not guarantee meaningful access when healthcare environments and processes remain disability inaccessible. Across studies, participants described barriers related to inaccessible entrances, non-adjustable examination tables, limited diagnostic equipment, and inadequate accommodation of communication or sensory needs. These findings reinforce prior evidence that rural facilities often lack the infrastructure, equipment, and training required to deliver disability-inclusive care, even when services are technically available [24,45]. This distinction has important policy implications: efforts to expand rural service availability without parallel investments in accessibility standards, disability-inclusive training, and adaptive equipment risk reproducing inequities rather than alleviating them.

Telehealth emerged across literature as a frequently proposed partial solution, particularly for follow-up visits, medication management, and select specialty consultations. Consistent with prior studies, telehealth was valued for reducing travel burden and increasing flexibility for individuals facing mobility, fatigue, or transportation barriers [46–49]. However, the evidence also underscores substantial limitations, including inadequate broadband access, lack of appropriate devices, reduced capacity for hands-on assessment, and challenges meeting disability-related communication needs [46,48,50–53]. These findings align with guidance from professional organizations emphasizing that telehealth expansion must incorporate accessible platform design, interpreter integration, flexible pacing, and clear escalation pathways to in-person care to avoid worsening disparities [53–55].

Finally, the review highlights the importance of relational, cultural, and privacy dynamics in shaping rural healthcare experiences. Trusting relationships with local clinicians were often described as protective, facilitating continuity and informal adaptation of care, particularly in settings with limited provider options. At the same time, small-community contexts introduced unique challenges, including privacy concerns, heightened stigma, and reluctance to seek care or request accommodations for fear of damaging relationships. Cultural norms of self-reliance further influenced care-seeking behaviors, interacting with structural barriers to produce delayed presentation and crisis-driven care. These findings are consistent with prior rural health research emphasizing the dual role of social closeness as both a facilitator and barrier to equitable care [41–44].

This review has several strengths, including its focus on lived experiences across disability types, chronic conditions, and care settings, and its synthesis of evidence spanning multiple rural contexts. However, the evidence base remains uneven. Many included studies were qualitative and condition-specific, with limited comparative evaluation of interventions or standardized outcome measures. Definitions of rurality varied widely, and few studies examined outcomes beyond patient experience, such as missed appointments, emergency department use, or preventable hospitalizations. Future research would benefit from implementation-focused designs evaluating bundled interventions, such as accessible transportation supports, mobile or visiting accessible clinics, integrated rural rehabilitation capacity, and coordinated specialty pathways, using outcomes that capture both experiential and clinical impact. Greater attention to intersectionality, including socioeconomic status, race, and Indigenous identity, is also needed to fully understand how rural disability-related inequities are produced and sustained.

CONCLUSION

In summary, this scoping review demonstrates that healthcare access for people with disabilities and chronic illnesses in rural and remote communities is shaped by cumulative, intersecting barriers that extend far beyond geographic distance. Effective responses must move beyond singular solutions toward integrated strategies that address transportation, service continuity, physical and communication accessibility, and the relational realities of rural care. Without deliberate investment in disability-inclusive design, training, and infrastructure, efforts to expand rural healthcare risk reinforcing existing inequities. Addressing these gaps is essential to advancing equitable, person-centered care for rural populations with disabilities and chronic illness.

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Review Article

Disability Prevention Initiatives in Rural India: Assessing Adequacy

Ronojoy Banerjee[1], Nandini Ghosh[1*]

1 Institute of Development Studies Kolkata, India
* Correspondence: nandinighosh@gmail.com

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ABSTRACT

Background: Primary healthcare is a central feature of all national health care systems seeking to establish equity in access to healthcare by expanding the reach of quality care at an affordable cost. Although the National Rural Health Mission launched by the Government of India in 2005, aimed to expand access to healthcare to the rural poor, it had little to offer to persons with disabilities in terms of access to health facilities. The Primary Health Care system in India remains unresponsive to both establishing an uniform and effective policy for prevention of disabilities as well as meeting the specific health requirements of disabled people, whether it be general health needs or impairment specific issues.

Objective: This paper attempts to explore the ways in which the primary health system in rural areas addresses prevention of disability both during pregnancy and after the birth of a newborn and in early childhood in 2 states of India, West Bengal and Odisha.

Method: West Bengal is at 13th position at the border of low-middle level of the Human Development Index 2007-08 and Odisha is at 22nd position with very poor status of human development. Data analysis based on secondary data compiled from Census reports 2011, District Census Handbooks and National Rural Health Mission Data allowed for drawing up a picture of availability of services that can help reduce or mitigate the incidence of disability.

Conclusion: The study reveals that the overall condition of the primary healthcare system in the two states has shown little improvement in terms of general health interventions that prevent disability both in ante-natal phase or post-natal care with policies lacking adequate implementation.

Keywords: Primary Healthcare, Persons with Disabilities, Prevention of Disabilities, Access to Healthcare, Rural Healthcare, India.

INTRODUCTION

Primary healthcare is a central feature of all national health care systems delivering high quality care at affordable cost. Primary health care has been defined as the provision of first contact, person-focused, ongoing care over time that meets the health-related needs of people, referring [to hospital] only those problems too uncommon to maintain competence. The World Health Organization (WHO) emphasizes the importance of de-

livering care locally, without requiring people to travel long distances. WHO strongly endorses the primary care principles enshrined in the 1978 Alma-Ata declaration, recommending equity, inter-sectoral collaboration, access to essential drugs, appropriate health technology, and comprehensive care in all countries, especially in the developing world.

Even before India achieved its independence, the Bhore Committee Report (1946) highlighted the need to assert administrative focus on establishing an elaborate, efficient, and effective system of primary healthcare that would contribute to the creation of a healthy and productive nation-state vital for the future development of the country After independence in 1947, the Constituent Assembly debates preceding the formal adoption of the Constitution of India in 1949 included lengthy discussions on the importance of prioritizing public health and developing rural health infrastructure in the newly independent nation-state. The constitutional directive enshrined under Article 47 of the Indian Constitution and the Supreme Court of India's subsequent interpretation of the Fundamental Right to Life under Article 21 both placed access to healthcare as an important responsibility of the state. However, it was only after the launch of the National Rural Health Mission in 2005 that a concerted effort was made by the Indian state to focus on the creation of a universally accessible healthcare system, which gave special attention to expanding outreach at the rural level. The goal was to not only cater to the health needs of the rural population where the majority of the population resided but also address the disadvantageous position that the rural population held about access to affordable healthcare. Moreover, expanding outreach was also envisaged as necessary to achieve better success in running programs of immunization, disease prevention, and general awareness. India's 11th 5-year Plan (2007-12) subsequently prioritized improving access to health care and the primary health care system as part of its objective of achieving 'inclusive growth.

The National Sample Survey Report of (NSS 2018) found that 2.2 % of the total population in India fell under the disability category, out of which 2.3% of the total rural population and 2.0% of the total urban population were identified as persons with disabilities. The National Sample Survey report is in concurrence with the last Census report 2011, where it was calculated that persons with disabilities form 2.21% of the total population, which roughly estimates to around 2.68 crore people of which 1.49 crores are male, and 1.18 crores are female. The National Policy for Empowerment of Persons with Disabilities (NPEPD 2006) lists programmes to be taken up and intensified for a) prevention of diseases, which result in disability, and b) the creation of awareness regarding measures to be taken for the prevention of disabilities during the period of pregnancy. The National Rural Health Mission's goal in making healthcare accessible and affordable is aimed at improving quality and equity of care by ensuring healthcare delivery and synergy between health and determinants of good health. Yet the National Rural Health Mission, which has been revamped and modified several times over the last few years, has little to offer to persons with disabilities in terms of access to health facilities. The Primary Health Care system in India remains unresponsive to the requirements of disabled people, whether it is general health needs or impairment-specific issues.

Systematic research into the prevalence and determinants of disability has been scanty from India, although it is an important public health issue (Kumar et al. 2012). The draft National Policy for Persons with Disabilities 2021 highlights the specific measures and programmes the state undertakes for the 'prevention' of certain types of disabilities like leprosy, polio, mental disorders, or blindness through improvement of nutritional intake of the poor, as well as running immunization programmes for preventing the same or the need to make facilities 'disabled friendly'. Health for people with disabilities is either analyzed as a separate document to be addressed by a specialized committee

recommendation or mentioned as empty statements under 'rights' that people with disabilities are entitled to. The Commission on the Social Determinants of Health (CSDH) remarked that health inequities arise due to a toxic combination of inadequate social policies, unfair economic arrangements, and bad politics, which disable the majority of the poor in developing countries from being in 'good health' (CSDH 2008, Lang et al. 2011). What makes people with disabilities vulnerable is not their disability but the lack of access, information, and support, which makes them truly vulnerable. The commission report also acknowledges that the poor, socially excluded, and marginalized section of the population would face the most difficulties in accessing quality healthcare.

Global initiatives from the 1980s, including the World Programme of Action Concerning Disabled Persons (United Nations, 1982), have stressed three things that are necessary for the state to perform with regard to disabilities, to safeguard the rights of disabled persons and ensure their wellbeing. These fall under the broad headings of prevention, rehabilitation, and equalization of opportunities. This paper, therefore, uses the data generated by different departments of the Indian state to explore the extent to which the global mandates have been fulfilled in terms of the prevention of disability and accessibility of health and medical services, which enable the prevention of disabilities during pregnancy and at childbirth.

METHOD

This paper attempts to explore the ways in which the primary health system in rural areas addresses the prevention of disability in 2 states of India, West Bengal, and Odisha. The analysis is based on a mixed approach to the question, utilizing both secondary data on healthcare and health infrastructure made available by the government of India and respective state governments, and validating the trends shown in data with primary fieldwork undertaken in two administrative blocks in West Bengal and Odisha, respectively. The secondary health data sources mostly include data published by the Ministry of Health and Family Welfare, Government of India, Census Data 2011, and the National Health Mission reports published until 2018-19 (NHM 2019). Data up to 2019–2020 were utilized because they provide important context for the primary survey undertaken in West Bengal and Odisha in 2020–21. More recent state-generated reports on the status of the healthcare system have not yet been made public (as of 2025–26). The primary objective behind such an analysis was to study the extent to which the health services provide for the prevention of disabilities, both during pregnancy and after the birth of a newborn, and in early childhood. Data analysis based on secondary data also allows the paper to draw a picture of the availability of services that can help reduce or mitigate the incidence of disability.

The focus on West Bengal and Odisha derives justification from them being two of the worst-performing states in accordance with the Human Development Index 2017-18. According to the Human Development Index of 2017-18, West Bengal is at 27th position amongst all states and Union Territories in India, and Odisha is at 30th position with a poor status of human development.

For the primary analysis, one district from each state was selected for the collection of micro-level data, 24 Parganas (S) in West Bengal and Mayurbhanj in Odisha, and in each district, 2 blocks were randomly selected, Bishnupur I and Bishnupur II in West Bengal and Baripada and Suliapada in Odisha, where primary health care services at sub-center, PHC, and CHC levels were examined to ascertain the actual availability of services and facilities to understand availability of services within the Primary Healthcare system.

Status of Primary Health Care System in India

The Primary Health Care System forms the first level of contact between the rural population and the healthcare system and includes the Sub Centers (SCs) at the community of village level, Primary Health Care Centers (PHCs), and Community Health Centers (CHCs) as mentioned in Health and Family Welfare Statistics (2013). The SC is the first point of interaction between the people of a particular area and the healthcare system, with a focus on preventive and basic curative care, manned by one ANM (Auxiliary Nurse Midwife), a female health worker, and a male health worker. It forms the first nodal point through which immunization programmes are conducted, pregnant women are assisted in safe delivery, general awareness on health is made available to the local people, and primary medical care is provided to the patient.

Primary Health Centre (PHC) provides integrated curative and preventive healthcare to the rural people with promotional and family welfare services and schemes. All PHCs, manned by a medical officer supported by 14 paramedical and other staff, provide outpatient services, and the majority of PHCs have four to six beds for patients. Primary Health Center (PHC) is the first referral unit for six Sub-centers. Community health centers (CHCs) are the first referral unit for PHCs and are established and maintained by the state government. While states are responsible for the functioning of the health care delivery system, the central government also has a responsibility towards the state's health care system in the form of policy making, planning, assisting, and providing adequate funds to various provincial health authorities to implement national programmes. The National Rural Health Mission, launched in 2005, had the objective of modernizing and upgrading the rural healthcare system and providing 'equitable, affordable, and quality health care to the rural population.' However, the status of our rural health care system in terms of catering to the health care requirements of most rural people, especially the poor and marginalized people who cannot afford private healthcare, is far from satisfactory.

The dismal condition of India's public health system itself has been well documented by different research studies. In India, individuals with the greatest need for health care have the greatest difficulty in accessing health services and are least likely to have their health needs met (Balaranjan et al 2011). India's healthcare system tends to be biased towards those who can afford it. Provisioning curative public healthcare is significantly biased towards urban areas than rural areas (Mahal et al. 2001). Baru et al. (2010) in their study on the inequities in access to healthcare services between states and rural-urban populations, identified social and economic status as one of the key determinants for access to quality healthcare. Especially in rural areas, the poor were worst affected in places where a functioning primary healthcare system was absent. Naveentham and Dharmalingam (2002), in an earlier study on the utilization of maternal healthcare services in the southern states of India, came to a similar inference linking poor access to healthcare with both socio-economic factors and unavailability of services and poor health infrastructure. According to Iyengar and Dholakia (2012), the absence of an accessible and functioning primary healthcare system has a significant impact on the poorest sections of society, especially those living in rural areas.

India's healthcare spending has been consistently lower than that of other developing countries, with public health expenditure forming only 1.28 % of GDP as of 2018. The Public Health Expenditure as a percentage of GDP in India from the period 2009-2010 to 2017-2018(Table 1) reveals that average spending by the state on health has been consistently low at an average of 1.09 percent of GDP in the past decade.

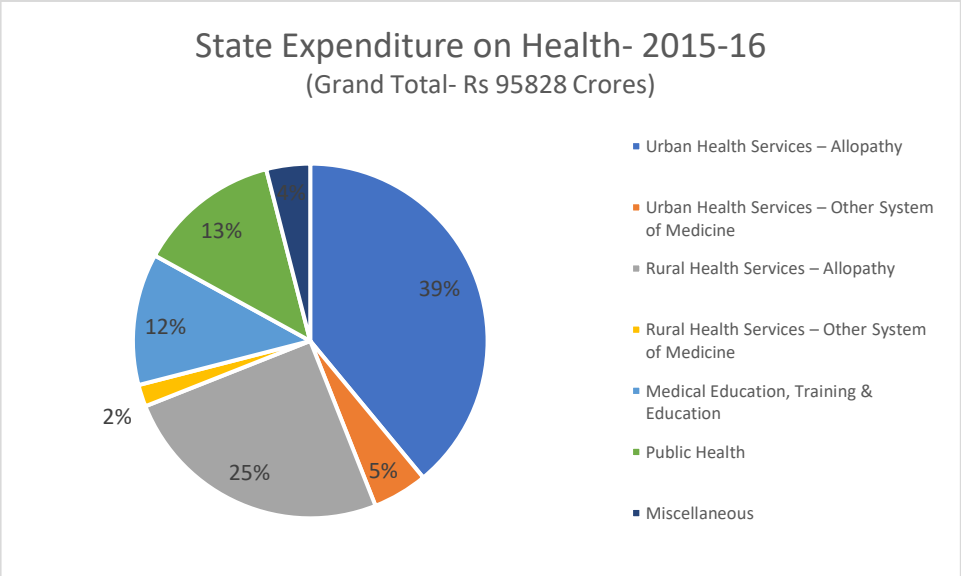
Table 1: Public Expenditure on Health as a Percentage of GDP

Year	Public Expenditure on Health	Population in Crores	GDP	Per Capita Exp. on Health	% Per Capita Exp. On Health
2009-10	72,536	117	6,477,827	621	1.12
2010-11	83,101	118	7,784,115	701	1.07
2011-12	96,221	120	8,736,039	802	1.1
2012-13	108,236	122	9,951,344	890	1.09
2013-14	112,270	123	11,272,764	913	1
2014-15	121,600.23	125	12,433,749	973	0.98
2015-16	140,054.55	126	13,764,037	1112	1.02
2016-17	178,875.63	128	15,253,714	1397	1.17
2017-18	213,719.58	129	16,751,688	1657	1.28

(*Source: Ministry of Health and Family Welfare, illustrated in the National Health Profile report 2019).

Out of this, the division of spending on healthcare between urban and rural by state is dismally skewed. Fig 1 illustrates that the total public expenditure on health in urban areas by states is significantly higher despite most of India's population living in rural areas. If we combine the urban health services, it is evident that state spending for urban healthcare is 44%, while the combined spending on rural health is only 27%.

Figure 1: State Public Health Expenditure in 2015-16



*Source: Ministry of Health and Family Welfare, illustrated in the National Health Profile report 2019.

According to World Bank data of 2016, the average public expenditure of High-income countries on health is 5.61% of GDP, while the average public expenditure of Low-Income countries on health is 1.57% of GDP. India fares even lower in public expenditure on health than Lower Income Countries at only 1.17% of GDP as of 2016. Comparing with other Asian countries, despite being significantly larger in size and

more economically powerful, India is located in the bottom half of the list of Asian countries in terms of per capita public expenditure on health. India is only better off than Bangladesh, Nepal, and Myanmar in terms of per capita expenditure on health by the government. According to the Niti Aayog ranking of states and union territories in India based on their performance in 5 rounds of assessments starting from the year 2014-15 to 2019-20 in 23+ health indicators, West Bengal did not feature in the later rounds of assessment due to the non-submission of required data. Odisha remains one of the worst-performing states in the Health Index score. These indicators are divided into 3 broad domains, namely Health Outcomes (Key Outcomes and Intermediate outcomes in Health for individual states), Governance and Information (Governance of Health Institutions, Health Monitoring and Data Integrity), and Key Inputs and Processes (Health Systems and their Service Delivery).

The dismal state of India's Rural Health care system is evident from the fact that only 13 states maintain the stipulated balance set by the Ministry of Health and Family Welfare between rural government health service providers and people in the community they serve. A considerable number of states, especially larger states with more population density, have rural health care institutions that serve populations far beyond their capacity. Similarly, there has been a significant increase in the number of inactive health facilities over the last 5 years across India. Data also reveals that around 13-14 states in India have a shortfall in either of the three levels of rural health infrastructure, and may have a shortfall in more than one type of health infrastructure (NHM 2018)

Health Facilities at District and Block Level

An analysis of the state of health services in Mayurbhanj district in Odisha and 24 Parganas (S)district in West Bengal gives a general idea of the overall status of the health system in these two states. Bishnupur Block I and Bishnupur Block II are part of the South 24 Parganas District of West Bengal. Bishnupur Block I is overwhelmingly rural, with 93.46% of its total geographical area falling under the rural category, while only 6.54% falling under urban areas. It has 11 Gram Panchayats and 84 villages falling under the block administration. Bishnupur Block II, however, has almost 1/third of its total area falling under the urban category; the major portion of its total geographical area falls under rural. Bishnupur II has 11 Gram Panchayats and 52 villages under its jurisdiction. Suliapada and Baripada are two adjacent blocks in the Mayurbhanj District of Odisha. Both the blocks are overwhelmingly rural, with Suliapada having a 100% rural geographical area and Baripada having just 14.74% of its geographical area falling under the urban category. Suliapada has 15 Gram Panchayats and 193 villages under its jurisdiction, while Baripada has 11-gram panchayats and 104 villages under its jurisdiction.

Before we go into the data regarding disability in the 4 Blocks under study, it is important to have a general overview of the demographic composition of the blocks being studied. Both blocks in Odisha, i.e., Suliapada and Baripada, are significantly less populated than Bishnupur –I and Bishnupur –II in West Bengal. For Bishnupur I and II most of the population live in rural areas, though Bishnupur-II has a considerable number of people residing in the urban areas. While Bishnupur-I and Bishnupur-II have a greater population of Scheduled castles, Suliapada and Baripada have a significant Scheduled Tribe population, living in the rural areas. Most of the population of all blocks under study, both in West Bengal and Odisha are Hindu. The blocks under study in West Bengal, i.e., Bishnupur –I and Bishnupur-II, have a significant Muslim population, whereas the Muslim population in Suliapada and Baripada is negligible. The Christian population in all blocks is negligible, although Bishnupur –I has a 5.26% Christian population.

In terms of the disabled population in the study areas, Census data of 2011 (Table 2) shows that both Odisha and West Bengal, and the respective districts under study have a

sizeable population of persons with disabilities. Interestingly, it can be seen that South 24 Parganas in West Bengal has a significantly larger population of disabled people than Mayurbhanj in Odisha. In South 24 Parganas, there is a high number of people with visual impairment, followed by people with other impairments. In Mayurbhanj, there is almost an equal number of people with hearing impairment and locomotor disability, followed by visual impairment, other disability, and multiple disabilities.

Table 2: Distribution of disabled population in Mayurbhanj, Odisha, and South 24 Parganas, West Bengal

Name of the District	Total PWDs (count)	In Seeing	In Hearing	In Speech	In Move-ment	Mental Retardation	Mental Illness	Any Other	Multiple Disability
Mayurbhanj (Odisha)	68,387	18.8	21.1	4.5	21.9	5.6	4.1	13.2	10.8
Odisha	1,244,402	21.2	19.1	5.5	20.9	5.8	3.4	13.9	10.1
South 24 Parganas (West Ben-gal)	227,129	26.7	14.5	6	13.1	6.3	2.9	21.7	8.9
West Ben-gal	2,017,406	21.1	15.6	7.3	16	6.8	3.5	20	9.7

Source: Census of India 2011

According to Goerdt (1995), the occurrence of disability itself calls for prevention and rehabilitation. WHO (2010) has highlighted the need for primary, secondary, and tertiary measures for the prevention of disability. Primary prevention consists of the measures aimed at the prevention of diseases and injuries, that can cause disabilities, which include immunization, particularly against poliomyelitis, measles, rubella and tuberculosis; prenatal care to ensure the healthy development and delivery of babies; appropriate nutrition, especially iron, iodine and vitamin A, for mothers and children; and sanitary measures to prevent eye diseases, such as infections and trachoma. Secondary prevention includes interventions used to treat diseases or injuries to prevent impairments. Secondary prevention includes the multidrug treatment of leprosy; the medical treatment of infectious diseases affecting the eye, ear, spinal cord, and brain; provision of appropriate nutrients against malnutrition; and medical and other treatment for mental disorders. Tertiary prevention consists of a variety of measures aimed at eliminating or reducing impairments or disabilities, such as difficulty in seeing, hearing, or walking. When disabilities occur, measures aimed specifically at the limited function that a disabled person experiences can also be taken to reduce or to limit the progression of the disability. Addressing the functional limitations of disabled people may also reduce the handicaps confronting them in their interactions with society.

Thus, as per WHO's guidelines (WHO 2010), primary and secondary disability prevention should be addressed at community levels, through immunization programmes for pregnant mothers and children, and disability specific medication, physiotherapy, or regular checkups with doctors for children and persons with disabilities. Since an overwhelming majority of disabled people live in rural areas in India, it becomes important to have a well-staffed, well-equipped, and efficiently running rural health care system that not only caters to the healthcare needs of disabled people but can aid in both early detection and prevention of disabilities.

Health Infrastructure and Access for Persons with Disabilities

The shortfall in health institutions, starting from the sub-center level to the level of the District Hospital, in the selected districts of Odisha and West Bengal shows that for the year 2015-16, West Bengal already had a significant shortfall across all levels of institutions compared to Odisha. South 24 Parganas also had a comparatively greater shortfall in the number of functional health institutions than Mayurbhanj. In 2019-20, the total shortfall of health institutions in Odisha rose more than three times from 11 in 2015-16 to 37 in 2019-20, while in West Bengal, the total shortfall rose from 106 to 148. In South 24 Parganas, the shortfall increased from 20 to 25, while Mayurbhanj remained constant with no shortfall. The major shortfall is at the PHC and CHC level for both states, although West Bengal exhibits a notable shortfall at the level of SCs, SDHs, and DHs as well.

However, our field data revealed that in Baripada and Suliapada blocks of Mayurbhanj, the majority of the respondents, which include both disabled people and their families as well as local people, reported that the sub-centers remained largely dysfunctional in their areas and ANM workers made rounds once a week to give medicines only to pregnant women and lactating mothers. No form of medical help was available at the sub-center level, even for people with general ailments.

The Rural Health Statistics report 2019-20, published as part of the National Health Mission, reveals much about the way in which the Rural Health system of the two states fares, both generally and with respect to each other. While both states have an adequate number of female Health workers, the shortage in male health workers at the sub-center level is concerning in both states. West Bengal has a 97.19% shortfall in male health workers, and Odisha has a shortfall of 50.22%. At the sub-center level, West Bengal has virtually no appointment of male health workers, while Odisha appoints only half of the total number of male health workers required. Looking at the percentage shortfall of female health workers in PHCs in West Bengal and Odisha in 2019-20, it is evident that in West Bengal, there are no female health workers at the PHC level, while in Odisha, the shortfall of female health workers at the PHC level lies in the tune of 34.32%. Similarly, the data for the same period in both states shows that for both West Bengal and Odisha, no appointment of Health Assistants (Male and Female) at the PHC Level was reported. This means that most women who depend on government primary health care services lack access to trained personnel who can guide them through pregnancy, delivery, and post-delivery complications.

Data published by the Ministry of Health and Family Welfare, Government of India, also shows that West Bengal has a surplus of doctors at the PHC level, while Odisha has a shortfall by 35.79%. This could be one of the factors explaining the high prevalence of Quacks and unqualified doctors in rural Odisha. For obstetricians and gynecologists, the shortfall in West Bengal (16%) is significantly less than in Odisha (68%). The presence of Obstetricians and Gynecologists is of vital importance for the healthy birth of a child, and a dearth of such doctors can lead to complications in pregnancy, which, if undetected, may result in increasing the probability of the birth of a disabled child. In the case of surgeons appointed at the CHC level for West Bengal and Odisha, we can see that both Odisha and West Bengal have a significant shortfall at 75.06% and 69.25 %, respectively. Thus, for disabled people who may require surgery to prevent secondary disability, this creates problems in terms of accessing interventions to mitigate their condition and requires additional costs for travel to urban centers and seeking private health care.

Similarly, the data also reveals that health care for children at the level of the Community Health Centers in Odisha has a significantly higher shortfall of pediatricians than in West Bengal. This means that a significant percentage of rural children are de-

prived of health care interventions that could prevent disability or lessen its impact with timely interventions.

Hence, it can be seen that the condition of the primary health care system in most of the indicators mentioned above is quite alarming in both Odisha and West Bengal. If these figures published by the national government are true, it will require serious efforts and investment by the states to lessen the wide gap in the medical personnel required and in the medical personnel in position across all the tables above.

Table 3 reveals that PHCs in both Odisha and West Bengal are below the national average in terms of operation. Only 9.8% of the PHCs in Odisha and 25.1% in West Bengal function round the clock, which makes it difficult for rural people to access healthcare in times of emergency. Also, only 49.8 % and 47.1% of the total PHCS in the two states function with an operating theatre. Furthermore, only 8% PHCs in Odisha and 28.7% PHCs in West Bengal function with at least 4 beds for inpatients.

Table 3: Total % of PHCs Functioning 24x7, with OT and At least 4 Beds

State/UT	% of PHCs Functioning 24x7	% of PHCs with OT	% of PHCs with at least 4 Beds
Odisha	9.8	49.8	8
West Bengal	25.1	47.1	28.7
India	34.2	72.4	66.9

Source: Ministry of Health and Family Welfare

Both states, however, fare pretty well in the functioning of CHCs. West Bengal has an average far above the national average (5.87%) in this indicator, even if the percentage is low (16.09%). In terms of % CHCs functioning with at least 30 beds, West Bengal fares better (77.59%) at par with the national average (77.68%), while Odisha has a gross deficiency with only 17.24% of the CHCs functioning with at least 30 beds.

However, in terms of physical infrastructure (Table 4), Odisha fares better than West Bengal in terms of access to regular electricity and supply, telephone connection and digital record keeping as well as physical access through motorable roads.

Table 4: Percentage of PHCs with Physical Infrastructure

State/UT	% PHCs without Regular Electric Supply	% PHCs without Water Supply	% PHCs Without Motorable Road	% PHCs with Telephone	% PHCs with Computer
Odisha	1.9	2.9	0.3	100	64.2
West Bengal	4.4	4.8	14.2	9.9	10.1
India (Average)	4.3	6.9	7.8	51.7	65

Source: Ministry of Health and Family Welfare

In both states, primary data collected at the block levels reveal that there are very few disability specific facilities available at the SC, PHC, or even at the CHC level, which would help persons with disabilities with their health and medical needs. No type of disability specific medication was available with the SC/PHC/CHCs in both states. Disability-specific doctors, such as neurologists, psychiatrists, ENT specialists, and physiotherapists, were not available in any of the PHCs or CHCs from which data were collected in South 24 Parganas or Mayurbhanj district. Although the CHCs in the Bishnupur blocks had appointed eye specialists, they visit only once a week to see patients. The nearest facilities where people with disabilities could access disability-specific public healthcare services, such as medication or checkups, were usually sub-district or district hospitals, which were often far away, thereby discouraging them from accessing these services.

Prevention of Disabilities: Immunization and Healthcare

The birth of a child with a disability can be the result of many factors. Deformities or complications may result from genetic predisposition, emotional and mental status of the pregnant woman, as well as nutritional and health support available to the pregnant woman. Both the central and the state governments, over the years, have made serious efforts to conduct immunization drives for children to reduce the risk of disability causing diseases, provide basic antenatal care to pregnant women, and spread awareness amongst the rural population to reduce the risk of disability. Hence, one of the key objectives of the National Health Mission is to try to ensure a healthy population of citizens who, by availing the benefits of the affordable health care system, can live a healthy and productive life. The data on immunization from 2015-16 over a five-year period till 2019-20 of both pregnant women and children in both the states and the districts under focus, reveals the extent of coverage and hence the risk of disability.

Table 5 reveals that in terms of ANC checkups during the time of pregnancy, both the states and the respective districts and blocks fared well. However, in comparison to 2015-16, there is a slight decline in the figures for Odisha and West Bengal, with a sharper decline in Mayurbhanj district, especially in Suliapada.

Table 5: % Pregnant Women received All ANC checkups to Total ANC Registrations

Percentage Of Woman Who Received All ANC Checkups To Total ANC Registrations				
Year	State/District	Percentage	State/District	Percentage
	Odisha (S)	87	West Bengal (State)	87.6
	Mayurbhanj (D)	88.7	South 24 Parganas (D)	82.4
	Baripada (D)	85.7	Bishnupur I (D)	77.4
2015-16	Suliapada (D)	91.2	Bishnupur II (D)	88.2
	Odisha (S)	81.4	West Bengal (S)	84.5
	Mayurbhanj (D)	79.7	South 24 Parganas (D)	87
	Baripada (D)	79.5	Bishnupur I (D)	82.6
2019-20	Suliapada (D)	78.8	Bishnupur II (D)	81.4

Source: Ministry of Health and Family Welfare

From the years 2015-16 to 2019-20, there was an improvement in the number of women who received Tetanus Toxoid Vaccine during pregnancy, both at the state level and District and Block level, barring Suliapada, where there seems to be a 7.9% decline.

According to the WHO, a daily dose of iron and folic supplementation is recommended for pregnant women to prevent maternal anemia, puerperal sepsis, low birth weight, and preterm birth, to prevent birth complications, and reduce the risk of giving birth to a child with disability. The data also shows that West Bengal had a higher percentage of women receiving the full dose of IFA tablets in comparison to Odisha. However, the data for 2019-20 shows that the percentage of pregnant women receive full dose of IFA tablets improved for Odisha in 2019-20, while it declined for West Bengal. Yet, in the districts under study, there was a significant improvement in South 24 Parganas and a slight decline in Mayurbhanj.

Pregnant women having severe anemia are at a risk of getting birth complications, which include result in low weight babies, deformities in the fetus, or premature birth. Women having severe anemia should have higher doses of IFA supplements, a proper diet, and regular checkups and monitoring to reduce the risk of complications during pregnancy. From the year 2015-16 to 2019-20, the number of women with severe anemia treated at a healthcare center increased in both Odisha and West Bengal, although the rise in West Bengal is pretty steep. The rise in severe anemic patients in South 24 Parganas was also pretty steep, though there were no cases of severe anemia in the chosen districts of Mayurbhanj and South 24 Parganas.

The number of women with obstetric complications decreased overall in the five years (2015-16 to 2019-20) in Odisha and West Bengal. However, a more detailed study reveals that while in Mayurbhanj it decreased from 14.4 to 7%, the number of obstetric complications increased in South 24 Parganas from 8.5% to 13.9%. At the block level, only Suliapada in Odisha showed a significant increase in women with obstetric complications from 2.1 % to 12.9%.

Low-birth-weight babies run the highest risk of developing some form of disability. Low Birth weight babies can develop serious respiratory, neural, and heart complications, which may result in Cerebral Palsy, Blindness, Deafness, or stunted growth eventually. Data shows that 19.1% of newborns in Odisha and 16.6% of newborns in West Bengal in 2015-16 were born as Low-Birth-weight babies. This changed to 18.7% in Odisha and 22% in West Bengal in 2019-2020. Mayurbhanj had a significantly higher percentage of Low-birth-weight babies compared to South 24 Parganas, and both Baripada and Suliapada have a sufficiently high percentage of low-birth-weight babies compared to Bishnupur I and II, where the percentage of low-birth-weight babies oscillated between high and low over the 5-year period.

Both Odisha and West Bengal and the target districts and blocks, have a good percentage of newborns who received the OPV Birth dose and the BCG Vaccine. However, for the OPV0 dose, which should be administered to all newborns, both states show a 12–15% gap in the number of infants receiving the polio birth dose. Although this percentage increased in both states in 2019-20, in South 24 Parganas, the gap in the birth dose numbers was at 13%, and at the Baripada Block level, at 17%, thereby increasing the risk of these infants contracting Polio. The numbers given for the BCG (tuberculosis prevention) vaccine is however, satisfactory in both states. Regarding Hepatitis Birth Dose, Odisha reports a slight decline in its administering of the vaccine, while West Bengal has shown a slight improvement.

Most of the vaccination records under the National Health Mission Programme indicate a significant gap between the number of vaccines that should be administered and the number that reach children. Some of these vaccines administered in Odisha and West Bengal in the last 5 years are:

a. In the case of BCG Vaccines, there is a gap of almost 40% in Odisha and 30% in West Bengal in terms of administering BCG Vaccines.
b. For the DPT3 vaccine, the gaps are similar, though there has been a significant rise in the number of Vaccines administered in West Bengal from 8.8 to 71% over the 5 years. For DPT5, there was a noticeable shortfall in the number of vaccines successfully administered over the five years in Odisha, while in West Bengal, there was a marginal rise.
c. The number of Polio Vaccines successfully administered marginally declined in Odisha from 63.7% to 61.9% and marginally increased from 70% to 71% in West Bengal.
d. In the case of Tetanus Toxoid administered to children below 10 years of age and children under 16 years of age, West Bengal shows very dismal figures compared to Odisha. While 90% of the children below 10 years and 76.5% of the children below 16 years obtained the tetanus toxoid vaccine in Odisha in 2019-20, the figure for West Bengal was a mere 35% and 21.9%, respectively, for West Bengal for the same year. This shows a lack of awareness amongst the older children and their parents in Bengal regarding the importance of the tetanus vaccine.
e. The total number of women who received antenatal care and opted for institutional deliveries is also low in both states.

CONCLUSION

From the national level health data, it is evident that the rural population is underserved by the existing health care system, with larger states with more population density having rural health care institutions that serve populations far beyond their capacity. The data clearly indicates that health infrastructure in both West Bengal and Odisha has improved, along with an increase in the number of users of these services. The data has also revealed that over the last 5 years across India, there has been a significant increase in the number of inactive facilities across all states, more significantly in rural areas. In the states under study, i.e., West Bengal and Odisha, and in the specific districts, South 24 Parganas had a comparatively more shortfall in the number of functional health institutions than Mayurbhanj. From the data of 2019-20, the total shortfall of health institutions in Odisha rose more than three times from 11 in 2015-16 to 37 in 2019-20, while in West Bengal, the total shortfall increased from 106 to 148. Thus, the condition of the primary health care system in most of the indicators mentioned above is quite alarming in both Odisha and West Bengal.

General health interventions that can prevent disability, both at the level of the pregnant mother and the newborn child, have been made robust but are lacking in terms of implementation and access. In terms of the prevention of disability, an examination of the data on vaccination also revealed the decreasing reach to pregnant women in terms of initiatives that can help reduce the risk of disability in the unborn child. For children, too, the immunization programmes have performed poorly in both the states under consideration. Thus, both states are seriously lagging in their efforts to increase the percentage of children successfully received the vaccines vital for the good health of children. The gap in immunization suggests that there is a risk of other disabilities coming up. Both states need to acknowledge the risks that unimmunized children face of contracting deadly diseases and step up their efforts to spread awareness and immunize all children, especially in rural areas. The shortfall in the services required and their consequent accomplishment brings to light the necessity to strengthen the rural healthcare system, both for the use of the general rural public and, more importantly, for people with disabilities.

A study of 2 CHCs and 2 PHCs in Odisha and 2 CHCs in West Bengal revealed that there was a lack of uniformity in the data maintained in the two states and even within two CHCs within the same district. Neither of the states maintains any separate record on the number of disabled people who seek treatment at their facility, the number of people who were referred to higher institutions with suspected disability, or the procedures the institution follows for early detection of disabilities. Access to healthcare institutions for disability-specific services is influenced by several factors, including awareness of available services, availability of resources and facilities, and the family's circumstances. Lack of early screening and appropriate interventions means that children born prematurely or with anemia find little support at the community-level health centers. In-depth interviews with disabled people and their families in both states revealed the dearth of services for disability screening and interventions within communities. Poor access to government hospitals meant that no one sought proper medical support, and it all ended up with some form of disability. Only those with connections in urban centers make it to the government hospitals at the district level or to private hospitals. While the local government health institutions are the first line of approach, the government health facilities are inadequate in terms of provision for early identification and immediate interventions required by disabled people, both in Bengal and Odisha. The lack of adequate health care facilities at the community level has led to a wide prevalence of Quack Doctors and traditional healers who fill this void in health care facilities within the villages by offering diagnosis at the doorstep or in the vicinity of the patients. The majority of the persons with disabilities preferred to seek treatment from such doctors and healers, as they were close, cheap, and provided medicines at the doorstep.

There is a need for the states to acknowledge the risks that unimmunized children face of contracting deadly, disability causing diseases and step up their efforts to spread awareness and immunize all children, especially in rural areas. There must also be concerted efforts to enhance the reach of immunization programmes at health institutions as well by raising awareness amongst rural people to reduce the risk of disabilities. Overall, the need for a primary health care system that has both disability friendly infrastructure and disability specific medicine and treatment is of paramount importance and should be adequately addressed by all states and the union. Only then can people with disabilities live a better, healthier, and more dignified life.

Data Availability

Most of the secondary data used in this paper is available online at: https://www.data.gov.in/keywords/NRHM, which is a government-maintained website publishing Health Data. Apart from this, the Ministry of Health and Family Welfare Data in its raw form, is available on Indiastat.com, which is a legitimate data source compiling government data. Census reports can be accessed directly from the census website maintained by the Government of India.

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Review Article

A Decade Without Audiologists: Persistent Non-Recruitment in Indian Public Health

Yogesh Mahajan

Independent Researcher, India
* **Correspondence:** yogeshmahajanresearch@gmail.com

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ABSTRACT

The National Programme for Prevention and Control of Deafness (NPPCD) was introduced in India to provide early hearing detection and intervention services at district and tertiary healthcare levels. Although the programme plans for a qualified audiologist to be posted at each district facility, our research shows that this has not happened in most public hospitals across India. This finding comes from our review of policy records and Right to Information (RTI) responses covering the years 2014–2024. Instead, Audiometric Assistants and Technicians are routinely substituted, despite lacking statutory recognition or registration.

Under the Rehabilitation Council of India (RCI) Act, 1992, only RCI-registered professionals may practice as Audiologists. In 2021, RCI issued Model Recruitment Rules (MRRs) to standardize qualifications, pay scales, and designation. Yet, no central or state institution has adopted them to date.

This paper analyzes a decade of non-compliance and institutional neglect using legal provisions, budget allocations, and government admissions obtained through RTIs. It concludes that continued misclassification of roles and failure to recruit qualified Audiologists represent violations of statutory, ethical, and programmatic obligations, undermining the rights of persons with hearing disabilities and misusing public funds.

We call for mandatory implementation of RCI's MRRs, audit of NPPCD-compliant staffing, and legal accountability for healthcare providers violating rehabilitation laws. This study is the first to systematically document, through government-verified RTI data, a decade-long administrative failure to implement NPPCD's mandated recruitment of Audiologists, highlighting the policy and rights implications of this neglect

Keywords: Audiologist recruitment, NPPCD, Rehabilitation Council of India, Public health policy India, Disability rights, RCI Act 1992, Healthcare human resources, Misuse of professional titles.

INTRODUCTION

The National Programme for Prevention and Control of Deafness (NPPCD) was introduced by the Ministry of Health & Family Welfare (Ministry of Health and Family Welfare, 2015) to reduce the burden of hearing impairment in India. A critical component of

this program is the deployment of qualified Audiologists, as recognized under the RCI Act, 1992, to ensure early diagnosis, intervention, and rehabilitative services. This aligns with global frameworks such as the World Health Organization's World Report on Hearing (2021) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006), which emphasize the right to accessible hearing care and qualified rehabilitation personnel (World Health Organization, 2021;United Nations, 2006). However, more than a decade after the NPPCD's implementation, Audiologists remain systematically absent from institutional frameworks, reflecting a gap between program intent and human resource implementation

This institutional failure directly affects the developmental outcomes of children with hearing impairment, delaying speech-language acquisition, literacy, and cognitive development, and thereby reducing long-term educational and social inclusion opportunities.

This paper draws upon official RTI responses from government hospitals and ministries (2014–2015), reinforced with findings as of 2024, and argues that this longstanding pattern of non-recruitment is not due to administrative delays but reflects a deeper institutional apathy and systemic disregard for both legal mandates and healthcare outcomes.

METHOD

This study adopts a documentary and legal analysis approach. Data were obtained through multiple Right to Information (RTI) applications filed between 2014 and 2015 with government hospitals, ministries, and statutory bodies, including the Directorate General of Health Services (DGHS), the Ministry of Health and Family Welfare (MoHFW), and the Rehabilitation Council of India (RCI). The responses were examined both for factual content and for their administrative language, which reflected administrative positions toward professional recruitment. Particular attention was given to how bureaucratic phrasing in RTI replies revealed implicit resistance to implementing professional standards. These RTI data were complemented by policy documents and follow-up communications up to 2024. This qualitative evidence base provides insight into the systemic neglect of audiological human resources in India's public health sector.

RTI responses were chosen as they are official, legally verifiable documents that represent institutional positions rather than personal opinions, thereby providing a reliable evidentiary base for policy analysis. Despite these clear statutory provisions, most government hospitals continue to appoint or deploy unregistered personnel in violation of the Act, undermining both legal accountability and professional standards

FINDINGS

Background and Literature Context

Previous studies have highlighted the acute shortage of rehabilitation professionals in India and the challenges this poses to inclusive service delivery (Narayan & Deepthi, 2013; RCI, 2021). The World Health Organization's World Report on Hearing (2021) emphasizes that unaddressed hearing loss affects education, employment, and social participation, particularly in low- and middle-income countries. Studies on health workforce planning have also shown that the absence of qualified personnel directly limits program effectiveness (WHO, 2016). In the Indian context, few published works have empirically documented the administrative gaps and regulatory failures affecting audiology practice in public institutions. This study addresses this gap by analyzing RTI evidence and policy responses to examine how the persistent non-recruitment of Audiologists undermines disability-inclusive health systems.

Legal Framework: RCI Act and Professional Scope

As mentioned before, in spite of clear statutory provisions, most government hospitals continue to appoint or deploy unregistered personnel in violation of the Act, undermining both legal accountability and professional standards. The relevance of the RCI Act, therefore, lies in its potential to ensure lawful recruitment and safeguard the quality of audiological services under public health programmes.

The Rehabilitation Council of India Act, 1992, is the primary statute governing the education, licensing, and ethical practice of Audiologists in India. It mandates that:

Only those registered with the RCI may practice as an Audiologist (Section 13).

Unauthorized use of professional titles is punishable by law (Section 14).

The Council can recommend minimum standards for employment and training.

The continuing absence of RCI-registered professionals within public hospitals demonstrates the current relevance of this Act. However, the lack of its implementation and the reluctance of government to control and safeguard competent and ethical audiological services weakens its expected impact.The Act provides both individual protection for professionals and structural safeguards for service quality — both of which are currently being bypassed.

The absence of adherence to these statutory requirements directly affects the design and implementation of national programmes such as the NPPCD. Although the legal framework clearly establishes professional standards and accountability mechanisms, these have not been integrated into operational planning or recruitment procedures. The next section reviews how the NPPCD's policy commitments and financial allocations failed to translate into actual appointments of qualified Audiologists across India.

NPPCD Guidelines and The 12th Five-Year Plan

In its reply dated 27 July 2015, the Directorate General of Health Services (Government of India, 2014) confirmed that under the 12th Five-Year Plan, each implementing district was sanctioned contractual posts for:

1 ENT Surgeon

1 Audiologist

1 Audiometric Assistant

1 Instructor for Hearing Impaired

Funds were allocated and guidelines issued. Despite this, implementation remains minimal. In fact, RTI responses from hospitals in 2015 confirmed (Government of India, 2015) the absence of Audiologist posts(Government of India, 2015) and a follow-up check in 2024 reveals no progress in recruitment, posting, or service delivery.

Institutional Responses: Then and Now

The Right to Information (RTI) mechanism was used as a documentary research tool because it provides authenticated, government-verified responses, ensuring reliability and traceability of data across institutions.

To assess institutional adherence to NPPCD mandates, RTI responses were collected from key government hospitals in 2014–2015 and were followed up with status checks in 2024. These institutions included RML Hospital, Kalawati Saran Hospital, Lady Hardinge Medical College (LHMC), Safdarjung Hospital, VMMC, JIPMER, and PGIMER. Despite policy directives and sanctioned posts, no significant recruitment or reclassification has occurred.

For a comparative summary of institutional responses in 2015 versus 2024, please refer to Table 1 under the "Tables and Figures" section at the end of this manuscript.

These findings confirm that no corrective action has been taken over 10 years, despite repeated RTIs, complaints, and policy recommendations.

This sustained lack of progress reflects system inertia within the NPPCD framework, where administrative approvals exist on paper but execution remains stagnant across institutions.

This institutional silence reflects a deeper pattern of bureaucratic neglect and a lack of accountability toward disability-inclusive public health policy

Rci's Position: Audiologist Must Be Appointed

In continuation with the findings above, it is important to note that the Rehabilitation Council of India (RCI), the statutory regulatory authority, has consistently emphasized the need for employing qualified Audiologists.

In its letter dated 23 November 2015, the Rehabilitation Council of India (RCI) wrote to the Chief Commissioner for Persons with Disabilities (Chief Commissioner for Persons with Disabilities, 2015):

> *"The Council is of the view that qualified Audiologists should be employed by hospitals and healthcare providers — government or private — for providing quality services to persons with hearing impairment and optimal utilization of audiological infrastructure."*

This unambiguous position from a statutory authority makes non-recruitment legally untenable.

The Ministry Of Health & Family Welfare's Evasive Reply

In response to both NHRC and the Chief Commissioner for Persons with Disabilities, the Ministry of Health & Family Welfare (MoHFW) replied on 23 November 2015 that (Government of India, 2015):

To overcome shortage, a DHLS course (Diploma in Hearing Language & Speech) had been launched.

Appointment of Audiologists in district hospitals is state subject.

These responses appear administratively insufficient and misleading:

DHLS holders are not equivalent to Audiologists.

Central hospitals like RML and Safdarjung are under MoHFW, not state.

The same evasive argument continues even in 2024, with no recruitment drives, no amendments to hospital recruitment rules, and no enforcement of standards. Such administrative evasions indicate systemic disregard for statutory compliance and ethical responsibility, as the Ministry continues to deflect its obligations under national law.

Model Recruitment Rules (2021): Ignored Blueprint

The RCI released revised Model Recruitment Rules in 2021, which:

Classify Audiologists and SLPs as Group B Gazetted posts

Mandate RCI registration for appointments

Outline career progression (Grade II → Grade I)

Propose transition rules for existing staff

The non-implementation of these rules appears linked to bureaucratic fragmentation between central and state authorities, unclear jurisdiction over health-care staffing, and limited political priority accorded to rehabilitation services.

As of 2024, not a single government hospital or public health institution has implemented these Model Rules (Rehabilitation Council of India, 2021), making them effectively defunct, despite being released by a statutory regulator.

Legal And Policy Violations

The situation today constitutes clear violations of:
RCI Act, 1992 – misuse of titles, unregistered practice
RPwD Act, 2016 – denial of rehabilitation services to persons with disabilities
Article 41 of the Constitution – right to public assistance in case of disability

Budgetary mismanagement – costly equipment (Government of India, 2014) purchased without professionals to operate it

Public funds have been spent, infrastructure created, and guidelines issued — but without qualified professionals, the system remains functionally incomplete. Taken together, these correspondences reveal a pattern of denial that transcends administrative excuses and enters the domain of legal non-compliance.

DISCUSSION

The findings of this study reveal more than administrative delay; they demonstrate a persistent structural disconnect between statutory mandates and public health implementation. Despite sanctioned posts, budget allocations, and clearly defined professional standards under the RCI Act (1992), institutional responses over a ten-year period show no meaningful movement toward compliance. The RTI evidence confirms that non-recruitment is not episodic but systemic.

A key pattern emerging from the RTI replies is bureaucratic deflection. Repeated references to "health being a state subject" and reliance on substitute cadres such as DHLS-trained personnel indicate an administrative strategy of responsibility shifting rather than resolution. This suggests that policy commitments under NPPCD operate symbolically at the guideline level but lack enforcement mechanisms at the operational level. Such fragmentation between central policy design and institutional execution weakens programme credibility.

From a developmental perspective, the consequences are significant. Early childhood hearing loss requires timely, specialised intervention to prevent long-term speech, language, and cognitive delays. The absence of qualified Audiologists within district and tertiary hospitals delays diagnosis, reduces rehabilitation quality, and increases the likelihood of preventable educational exclusion. The World Health Organization (2021) emphasises that early hearing care yields substantial long-term social and economic returns; therefore, prolonged non-recruitment represents not only a rights violation but also a loss of human capital.

The findings also illustrate broader governance challenges within India's disability sector. While the RCI regulates professional standards and the RPwD Act (2016) guarantees rehabilitation rights, health workforce planning remains administratively disconnected from disability legislation. This institutional fragmentation allows statutory provisions to exist without enforcement. The decade-long persistence of this gap indicates that the issue is structural rather than procedural.

Comparatively, countries that have integrated audiologists into community-level hearing programmes demonstrate improved early detection and intervention outcomes. The absence of similar integration within NPPCD suggests that the programme's design has not translated into accountable human-resource planning. Without clear monitoring mechanisms and mandatory staffing audits, sanctioned posts risk remaining nominal commitments.

Taken together, these findings suggest that the non-recruitment of Audiologists is not merely a human-resource shortage but a governance failure affecting disability justice, health equity, and inclusive development. Addressing this gap requires structural

alignment between policy mandates, statutory regulation, and institutional accountability mechanisms.

CONCLUSION

Ten years after formal complaints were lodged and RTIs submitted, nothing has changed. The same hospitals (Government of India, 2015), the same ministries, and the same statutory silence continues. This is no longer a bureaucratic lapse, it is a systemic defiance of the law, a betrayal of professionals, and a disservice to citizens who depend on public health systems. . The persistence of these patterns over a decade underscores not merely administrative inertia but a structural indifference toward the rights of persons with hearing disabilities. Without immediate structural reform and statutory enforcement, Audiology in India will continue to operate in a legal vacuum and professional neglect.

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RECOMMENDATION

1. Mandatory enforcement of the 2021 RCI Model Recruitment Rules in all government institutions.
2. Central MoHFW directive to all hospitals receiving NPPCD funding to appoint RCI-registered Audiologists.
3. Immediate reclassification of qualified assistants into proper grades under a one-time transition rule.
4. Judicial or quasi-judicial oversight through CCCPwD or writ petitions in High Courts.
5. Audit of NPPCD implementation to assess recruitment compliance and equipment usage.

DATA AVAILABILITY STATEMENT

The data supporting this study consist of publicly available Right to Information (RTI) responses and official communications with ministries and statutory bodies. Copies of RTI replies and related documents are available from the author upon reasonable request.

Table 1: RTI Findings (2014–2015) and Current Status (2024)

Institution	2015 Status	2024 Status	Change?
RML Hospital, New Delhi	No Audiologist; Technician employed	Same situation persists	❌ No Change
Kalawati Saran Hospital	Assistant with Audiology degree; no Audiologist	Same; assistant with Audiology degree	❌ No Change
Lady Hardinge (LHMC)	No sanctioned post	Still vacant	❌ No Change
Safdarjung & VMMC	No sanctioned post	Still none	❌ No Change
JIPMER /PGIMER[7]	Awaiting recruitment rules	Still pending	❌ No Change

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Review Article

Towards More Inclusive Elections: State of the Art and Challenges of Electronic Voting for People with Disabilities in Developing Countries

Jomark Pablo Noriega Zapata[1*], Ana Vargas[2], Jorge Castañeda[3], Augusto Bernuy[1]

1 Departamento de Postgrado, Programa DISI, Universidad Nacional Mayor de San Marcos. Universidad del Perú. Decana de América. Lima, Perú
2 Departamento Académico de Estadística e Informática, Universidad Nacional Agraria La Molina. Lima, Perú
3 Facultad de Ingeniería, Escuela de Ingeniería Informática, Universidad San Ignacio de Loyola. Lima, Perú
* Correspondence: jomark.noriega@unmsm.edu.pe

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ABSTRACT

Aim: This study examines the current state of electronic voting (e-voting) technologies and their implications for accessibility for people with disabilities, with particular attention to developing countries. It aims to identify key technological approaches, structural barriers, and design gaps affecting inclusive electoral participation.

Method: A systematic review was conducted using the *PRISMA* methodology, analyzing publications from 2018 to 2023 in databases such as Scopus, Web of Science, Science Direct, Wiley, and IEEE. The review focused on studies addressing e-voting technologies explicitly linked to accessibility and disability inclusion, excluding works that discussed electronic voting without reference to people with disabilities.

Results: The findings highlight *blockchain* technology as a promising solution due to its security and transparency features. However, major barriers remain, including the digital divide, lack of inclusive design, and absence of legal frameworks supporting electronic voting for people with disabilities. While some countries, such as Estonia, have successfully implemented remote voting, there are still no widespread solutions tailored to people with disabilities in developing regions.

Conclusions: The findings highlight the need for e-voting systems that integrate accessibility requirements from the design stage, ensuring usability, autonomy, and non-stigmatizing participation. Future research should advance toward pilot implementations of accessible e-voting systems in developing countries, combining biometric authentication and assistive technologies within inclusive public policy frameworks.

Keywords: Electronic voting, accessibility, blockchain, disability inclusion, developing countries.

INTRODUCTION

In the context of a globalized world where democracy stands as the cornerstone of

most nations, the right to vote emerges as an incontrovertible principle. States are mandated to ensure the participation of all citizens, as this constitutes the foundation of any democratic regime. However, despite efforts to deploy resources and logistics, not all nations succeed in securing the inclusive participation of their electorate. This problem is particularly evident in the case of individuals with disabilities or those with conditions that prevent them from moving to exercise their right to vote.

The gap in inclusive suffrage highlights a significant issue: equitable access to voting. Although technological advancements have suggested that the development of electronic voting systems could facilitate the exercise of the right to vote for those unable to move, there are still considerable limitations and gaps in the current solutions.

To address this gap, the present work conducts a systematic review of contemporary literature worldwide, with the goal of identifying advanced technologies available in electronic voting for people with disabilities. This analysis aims to answer two critical questions: What are the advanced technologies in electronic voting available to people with disabilities? And what are the limitations and gaps existing in the advanced technological solutions for electronic voting targeted at this group? Through this approach, the study seeks to contribute to narrowing the gap in access to suffrage, promoting more inclusive participation in democratic processes globally.

METHOD

This study represents a systematic review that follows the *PRISMA* method (Moher et al., 2019). The search strategy covered several databases, including Google Scholar, Scopus, Science Direct, Web of Science, Wiley, and IEEE.

The specified inclusion criteria were articles published between 2018 and March 2023, in English or Spanish, with full text access. Exclusion criteria were applied to previous reviews, duplicate articles, and those without a relevant technological component. The search terms used were: "E-VOTING" AND (SYSTEM OR SCHEMES) AND ONLINE AND DISABLED PEOPLE.

The initial search resulted in 155 articles. Applying the *PRISMA* (Preferred Reporting Items for Systematic reviews and Meta-Analyses) method, 99 articles were excluded after a title review due to a lack of coherence with the topics of interest. An additional 14 articles were discarded after reviewing the abstracts for not adequately addressing technologies for electronic voting (e-voting)or technologies intended for people with disabilities. Then, 18 articles were excluded after full reading for focusing on medical or psychological aspects.

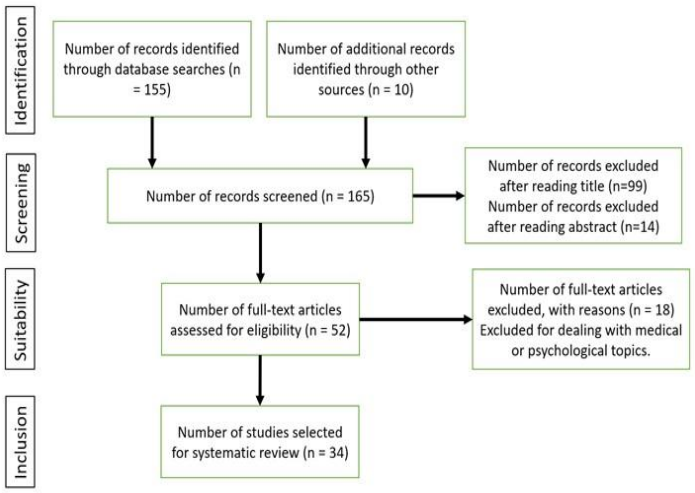

Figure 1: PRISMA Method

Furthermore, 10 references were manually added that were considered relevant due to their formality or because they were cited by the reviewed articles, focused on research about conditions for *e-voting*. This process is summarized in the *PRISMA* flow diagram (see Figure 1). Within this discussion, an *e-voting* model adapted for people with disabilities is proposed, focused on the context of the Peruvian state, but that could be adapted to other realities. This proposal takes into consideration both access to information and detailed knowledge of the electoral process by the authors. It is important to recognize that the development of this research could be influenced by the personal experiences and academic background of the authors. However, the importance of maintaining objectivity and impartiality in the study will be emphasized. To this end, the *PRISMA* method will be applied rigorously, with the goal of minimizing possible biases and ensuring the quality and relevance of the results obtained.

CURRENT RESEARCH

The right to free, direct, universal, secret, honest, and in certain cases, compulsory voting is fundamental in the constitutions of democratic governments, as evidenced in various legislations and international studies (Arshad et al., 2021; Fahri and Hardianto, 2022; Cámara de Diputados del Honorable Congreso de la Unión, 2021; Presidencia de la República de Ecuador, 1998; Rathore, 2022). Similarly, the Political Constitution of Peru establishes that votes must reflect "the authentic, free, and spontaneous expression of citizens," ensuring that results are an exact and timely reflection of the voters' will (Presidencia de la República del Perú, 1993). In Colombia, the Constitution emphasizes the state's obligation to guarantee coercion-free, secret voting in individual booths, also facilitating the use of electronic or computer means for this purpose (Presidencia de la República de Colombia, 2011).

Defensoría del Pueblo del Perú (2018) has identified that the main difficulties for people with disabilities in voting relate to the transfer and access to polling places, as well as a lack of knowledge by electoral personnel about the specific needs for attention. According to the Instituto Nacional de Estadística e Informática (2019), the 2017 census revealed that 10.3% of the population has some type of permanent disability that affects their daily activities, with this percentage being 11.5% for women and 9% for men. Figure 2 illustrates the different degrees of disability and their distribution by age range, highlighting that 82.6% are of legal age and 57.1% are in the age group obliged to participate in electoral processes (Consejo Nacional de Discapacidad [CONADIS], 2022). Although people registered with CONADIS can request exemption from electoral fines due to their condition (Organismo Nacional de Procesos Electorales, 2021), this does not exempt them from the right to vote.

Table 1: Development of electronic voting in the World Last election or experience(years)

Status	<5	6-10	>10	Total
Implemented	6	-	3	9
Under study or partially implemented	11	3	5	19
Legally prohibited or halted	-	6	1	7
Total	17	9	9	35

Source: Department of Security of the Basque Government. (August 7, 2022)

However, cross-country comparisons regarding the electoral participation of persons with disabilities are constrained by significant variability in the availability and quality of official data. Differences in legal definitions of disability, civil registration systems, and national census methodologies affect the identification of eligible

voters with disabilities and limit the comparability of participation figures across jurisdictions. According to the Voto electrónico en el mundo. (https://www.euskadi.eus/informacion/votoelectronico-voto-electronico-en-el-mundo/web01a2haukon/es/), electronic voting has experienced significant evolution worldwide. To date, it has been officially implemented in nine countries, while seven have chosen to legally ban or suspend its use. In addition, there are studies and partial implementations ongoing in another 19 countries (see Table 1). Among the countries that have adopted this technology, Estonia stands out as the most advanced in terms of development and electoral participation through electronic voting.

Sreekanth et al. (2022) emphasize that in democratic societies, the constitutional right to vote is granted, allowing citizens to choose their representatives and thereby influence the destiny of their country. Despite the perception that a single vote may seem insignificant, history has shown that a small number of votes can induce significant changes. Thangavel et al. (2022) highlight that one of the purposes of electronic voting is to improve accessibility for people with disabilities. In this sense, De Silva et al. (2021) argue that the traditional voting method, in which visually impaired people are assisted, compromises their right to a secret vote. Pethig and Kroenung (2019) point out that approximately 15% of the world's population has some disability, a figure that increases with aging. They identify two critical factors in the adoption of technologies: the perception of their usefulness and the awareness of the status acquired by using them. They emphasize the importance of evaluating any initiative aimed at people with disabilities to avoid stigmatization and potential rejection. According to Thangavel et al. (2022), the electoral process consists of four stages: composition, issuance, registration, and tabulation. The main challenge is "to maintain confidentiality, verify integrity, and ensure authenticity throughout the process." They argue that *blockchain* technology could meet these requirements, treating each vote as a link in the chain with a unique cryptographic identity, and if the information of a link is altered, the chain would break, evidencing any attempt at fraud (Giraldo et al., 2021; Thangavel et al., 2022). Additionally, they propose that this model is scalable and its capacity can be increased using specialized tools such as Ethereum Mainnet, IBM's Hyperledger Fabric, ReactJS, and ExpressJS. They suggest integrating facial recognition technologies through artificial intelligence and convolutional neural networks (CNN), retina and iris scanning for identity authentication, complemented with voice assistants, to improve the accessibility and security of the electoral process (Braz, 2021; Parihar et al., 2021; Sreekanth et al., 2022).

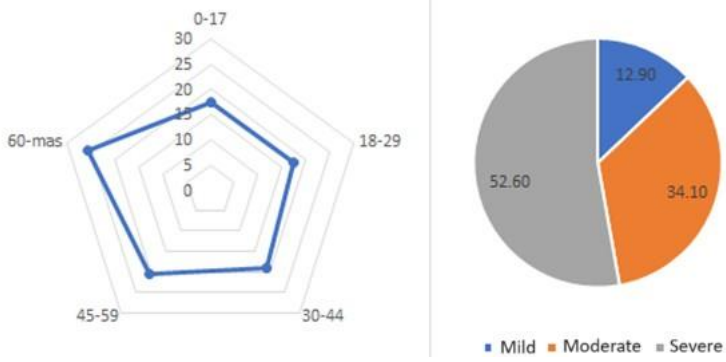

Figure 2: Percentage by Age and Degree of Disability Source: CONADIS Statistical Report April 2022

Rathore (2022) underscores the urgency of implementing electronic voting solutions in countries with large electoral populations, such as India, identifying high costs and potential manipulation risks as the main challenges of current systems, citing Ar-

shad et al. (2021) and Chima (2022). He proposes identity verification through one-time passwords (OTP) sent to registered mobile phones and suggests improving accessibility through audio interfaces for the illiterate.

Mamokhere and Mabeba (2022) contrast manual and electronic voting systems, noting that problems observed in the manual system during South Africa's national elections, such as multiple voting, could be mitigated with the adoption of electronic systems. They recommend conducting pilot tests based on experiences from the United Kingdom, which include internet, telephone, machine, and SMS (Short Message Service) voting, to assess limitations and advantages. Chigona et al. (2009) explored whether mobile internet could reduce social exclusion, including people with disabilities in developing countries. They found limited use of mobile internet among the most excluded, attributed to a lack of awareness about its possibilities, limiting its impact on economic and political aspects. Goodman et al. (2018) investigated the effects of eliminating paper voting, finding that exclusively electronic voting predominantly attracts voters with high technological knowledge. They suggest that dispensing with paper votes could marginalize those without technological skills. Hassan et al. (2022) argue that in emerging democracies, manual voting systems can be plagued by electoral fraud. For voting by people with disabilities, they propose the use of audio interfaces and highlight preliminary steps such as the electronic registration of voters, fingerprint validation systems, and the use of smart cards. They suggest starting with tests in non-public elections, gradually scaling up to broader adoption in Nigeria, which would facilitate citizen participation, identification of gaps, technological validation, and the development of governmental capacities.

Germann and Serdu¨lt (2017) explored whether the validation of the electronic voting system could increase electoral participation. Through an experiment conducted in cantons of two Swiss cities, they compared the online electronic voting system with other methods, without finding significant differences. However, they underlined the importance of considering factors such as culture, previous experiences, and the efficiency of the postal service in Switzerland. They recommended focusing future efforts on strengthening the training of electoral personnel, keeping the electoral register updated, constantly implementing and updating cutting-edge technology, and permanently validating the process through controlled and incremental pilots before national implementation. They also suggested initiating studies in specific groups of voters, such as people with reduced mobility, military stationed abroad, and expatriates. Toapanta et al. (2022) indicated that for an electronic voting process to be acceptable according to international standards, it is necessary to invest in technology, train those involved in the process, establish agreements with telecommunications companies, use 128-bit encryption mechanisms, and security measures that mitigate cyber-attacks. They highlighted that access through mobile devices or computers connected to the internet could benefit people with limited mobility, those far from their polling place, or those deprived of freedom. Ehin et al. (2022) examined the electoral process in Estonia for nearly two decades, highlighting that internet voting in this country is part of a digitally advanced society, which is the key to its success. Almost half of all votes in recent elections were cast via the Internet, and digital gaps do not represent a major concern, as sociodemographic differences do not affect the use of the system. Although there is confidence in the system among voters, there is perceived risk of polarization. The authors presented five conclusions about the electronic electoral process in Estonia, detailed in Table 2. According to Braz (2021), the electoral process in Estonia begins with the identification of the voter through their digital ID card and security pins, using HSM (Hardware Security Module) encryption services and QR (Quick Response) codes to notify citizens. Although there have been political

conflicts related to electronic voting, these have decreased as citizen participation increased, to the point that abandoning the system would be very costly (Ehin et al., 2022).

Table 2: Conclusions from the analysis on electronic voting in Estonia.

Inference	Sustentation
Advanced and solid infrastructure and digital identity	Regular use of secure digital services in e-government means there's no need for special voting systems.
E-voting, it is not a simplification for the processes electoral	The ongoing task is to refine technologies and legal structures, manage resources, and tackle disinformation, which complicates election management.
E-voting does not influence voter participation.	Voter turnout in Estonia's 11 elections has been stable; ease of electronic voting engages willing participants but doesn't necessarily motivate the disinterested.
Adoption of E-voting must be gradual.	Effective promotion and gradual adoption are essential. In Estonia, electronic voting uptake isn't affected by demographics like wealth, location, or gender.
Confidence in the use of new technologies.	Estonia's efficient digital governance ecosystem fosters familiarity with secure digital ID use, aiding in everyday tasks, including voting.

Source: Ehin et al. (2022)

Essex and Goodman (2020) argue that while there is a trend toward adopting electronic voting, it is imperative to establish regulations and security standards specific to each country. The lack of regulation in Canada has left municipalities to implement these processes. This regulatory gap, with respect to integrity, auditing, and transparency, could compromise citizen representativeness. Municipalities, in their effort to optimize budgets through electronic voting, and the absence of clear regulations, have developed solutions that vary significantly in design, architecture, and security mechanisms. Udhaya et al. (2019) suggest automating the electoral process through the use of Internet of Things (IoT) components and security mechanisms at each stage, from biometric validation with Aadhar card data, through the act of voting, to secure data storage in the cloud. They propose the use of an Arduino component, a radio frequency module, Raspberry Pi 3+, and a biometric reading module. Fahri and Hardianto (2022) note that the COVID-19 pandemic has posed additional challenges for electoral processes, as the in-person format of elections encouraged gatherings and, as a result, an increase in infections and in the number of fatalities. They propose electronic voting as a viable alternative in pandemic scenarios or similar situations, arguing that, from a constitutional perspective, the protocol for implementing electronic voting is consistent with the principles of direct, general, free, confidential, honest, and fair elections, and could serve as an alternative electoral policy in the future. Electronic voting offers potential benefits for making the electoral system more democratic, efficient, and secure, adapting to the current pandemic situation and facilitating access for people with disabilities. However, in Indonesia, it faces significant obstacles to its implementation due to systemic failures that prevent guaranteeing a secure and reliable system, in addition to limitations in infrastructure development and the digital divide among voters.

Okediran (2019) develops a technological architecture proposal aimed at facilitating electronic voting. This architecture allows the voter to register in advance and

receive a security code on their SIM (Subscriber Identity Module) card, which is exclusively linked to that user.

To vote, the voter can access a web portal from a PC and validate their identity through biometric recognition or vote remotely using a mobile phone to send an SMS with an image of their fingerprint. It is important to highlight that the data collected are centrally stored and transmitted through tunnels encrypted with SSL (Secure Sockets Layer) or TLS (Transport Layer Security), ensuring the protection of information through the RSA cryptographic algorithm. This mode of remote voting offers significant advantages for those voters who, due to disability or other reasons, cannot physically present themselves at polling centers. Muhammad and Ahmad (2021) highlight that in Indonesia, the use of ballots in elections represents high economic and human costs for the country. They mention that in the 2019 elections, there were approximately 527 deaths of officials due to exhaustion, and the prolonged scrutiny process opens doors to electoral fraud. They note that there have been some regional electronic voting pilots with moderate success and advocate for their expansion. They propose a model of in-person electronic voting with identity validation through biometric devices, seeking benefits such as speeding up the scrutiny, optimizing the budget, and improving the security, integrity, confidentiality, and transparency of the electoral process. De Silva et al. (2021) examine the needs of voters with visual disabilities in Sri Lanka, who traditionally required assistance to vote, limiting their constitutional right. They developed two adaptive devices: one with a button interface and another with a touchscreen, allowing the voter to operate them independently. Additionally, they incorporated audio functionality to facilitate their use. After testing with people with and without visual impairments, both devices were well-received, although the button interface showed a slight preference. Nonetheless, the need to improve the resolution of erroneous selections in the touchscreen interface and audio assistance was identified.

DISCUSSION

Electronic voting has not been widely implemented globally, with only a few countries in the process of adopting it. Estonia is the most emblematic case of its implementation (Braz, 2021; Ehin et al., 2022). Outside of Europe, municipal initiatives in Canada and local experiences in Australia, the United States, Indonesia, India, Pakistan, and Sri Lanka have been carried out (De Silva et al., 2021; Ehin et al., 2022; Goodman et al., 2018; Muhammad and Ahmad, 2021). Studies have focused on proposing technological alternatives for future projects and discussing, based on documented experience, how to conduct electronic electoral processes, considering the necessary conditions and aspects. However, specific e-voting proposals for people with disabilities are scarce, except for the blind, for whom mechanisms that include audio in the process have been suggested (De Silva et al., 2021). Despite this, various authors agree that non-presential electronic voting would especially benefit people with disabilities (Chigona et al., 2009; Chima, 2022; Fahri and Hardianto, 2022; Hassan et al., 2022; Parihar et al., 2021; Okediran, 2019; Sreekanth et al., 2022; Thangavel et al., 2022).

The advanced technologies implemented so far in *e-voting* processes focus mainly on *blockchain*, recommending not to include the voter's public key to preserve the secrecy of the vote (Giraldo et al., 2021). Processes of validation and identification have been proposed using facial recognition with artificial intelligence, deep learning, and convolutional neural networks (CNN) (Sreekanth et al., 2022), as well as fingerprint recognition (Arshad et al., 2021; Hassan et al., 2022; Okediran, 2019). In India, two-phase authentication based on the Aadhar number and OTP codes sent to mobile

phones is suggested, which must match to allow voting over the internet (Sreekanth et al., 2022; Rathore, 2022). The use of *IoT* in each stage of the electoral process has also been explored (Udhaya et al., 2019), promoting an architecture that assesses the performance of a multifaceted electronic vote (Okediran, 2019). Pethig and Kroenung (2019) emphasize the importance of integrating accessible functionalities from the system design, ensuring its usability for all and promoting true inclusion, thus avoiding the stigmatization of certain voter groups.

Among the identified limitations and gaps, Goodman et al. (2018) noted that the absence of paper ballots favors voters with greater technological knowledge. This finding coincides with that of Chigona et al. (2009), that the use of mobile internet is low among the most socially excluded sectors, widening the digital divide. Although both in-person voting and *e-voting* are constitutional (Fahri and Hardianto, 2022), both face constant threats, highlighting the need to invest in advanced technology, train participants in the electoral process, and establish robust security mechanisms (Toapanta et al., 2022). The practice of electronic government has simplified government administration, improving efficiency, transparency, and accountability, as demonstrated by the case of Estonia, which has promoted the development of *e-voting* in a highly digitized society (Ehin et al., 2022). The implementation of *e-voting* could reduce electoral fraud and citizen dissatisfaction, although it does not necessarily increase electoral participation, as observed in the Estonian elections (Germann and Serdu¨lt, 2017; Braz, 2021; Ehin et al., 2022).

IMPLEMENTATION PROPOSAL

Building on the mentioned background, we propose a model of non-presential electronic voting initially focused on specific segments that face mobility difficulties during electoral processes and would therefore significantly benefit from this system, encouraging them to participate more actively. These segments include individuals with motor disabilities and the elderly. In various countries, the registry of these groups may not be entirely accurate, so it is suggested to complement the information with data from formal entities such as health ministries, social security institutions, and foreign affairs ministries, or their equivalents, depending on the reality of each country.

It is recommended that online electronic voting system trials begin with small groups. From the planning and design stage, it is crucial to focus on the development of accessible functionalities, including user interface testing and other specific requirements for people with disabilities, so that the system can eventually be scaled up to a national level.

The proposal, detailed in Figure 3, suggests the use of a web interface that incorporates identity validation mechanisms through facial recognition. This would include access to the national identity registry, recording information on a private *blockchain*, components for generating block identity for each vote, chain nesting components, and replicas for auditing, scrutiny, and results presentation.

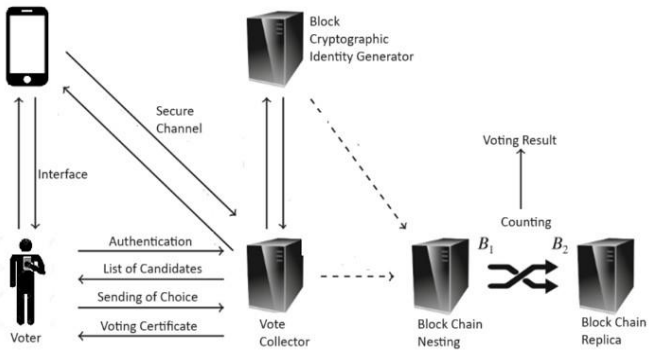

Figure 3: Pilot architecture proposal for non-presential election

The initial implementation phase of this model would target a sample ranging from 1000 to 5000 citizens with motor disabilities, who have sufficient ability to handle mobile devices, are duly accredited, and reside in major cities with adequate mobile communication services. The process is detailed as follows:

Before voting:

- *Registration:* Voters sign up using their identity document, disability certificate, and demonstrate their capacity to respond to online identity validation questions.
- *Registration confirmation:* Voters receive confirmation by email, an access PIN, and the link to the voting webpage.
- *Communicating the process to the voter:* A link to a digital-format voting tutorial is sent, along with recommendations on the conscious exercise of the right to vote, to be conducted on pre-established dates.

During voting:

- Voters access the web on voting day, within the established hours.
- They identify themselves on the platform using their username and security PIN.
- Facial biometric validation is performed, including a proof-of-life test, by comparing image sequences.
- The system presents the available list of candidates. Voters select their candidates and confirm their choice by re-entering their security PIN.
- A vote receipt is sent to the voter.

After voting:

- *Scrutiny:* The integrity of the cast votes is verified and counting proceeds.
- *Process review:* Agents and observers record any challenges.

This project assumes the development and widespread adoption of digital identity among citizens, promoting use cases that enhance interaction with both the public and private sectors, positioning it as a central pillar in the provision of institutional services. The results obtained would allow for the consideration of including new population segments or expanding the number of participants.

Limitations: This study is based exclusively on a systematic review of published literature and does not include empirical testing or field validation of the proposed *e-voting* solutions. While this approach allows for a comprehensive synthesis of existing knowledge, it limits the ability to assess real-world usability, institutional constraints, and user perceptions. Future empirical studies, including controlled pilots and user-centered evaluations, are necessary to validate the feasibility and inclusiveness of the identified technological approaches.

CONCLUSION AND FUTURE RESEARCH

Electronic voting has the potential to transform electoral accessibility for people with disabilities, particularly in developing countries where physical voting infrastructure may be inadequate. However, existing e-voting solutions are not designed with accessibility as a primary consideration, leaving people with disabilities excluded from digital electoral advancements.

The findings of this study highlight blockchain-based e-voting as a secure and transparent option, but its implementation faces key challenges, including technological accessibility, digital literacy, and legal adoption barriers. The lack of tailored solutions for individuals with disabilities further widens the gap in electoral participation.

To ensure a truly inclusive voting process, it is critical to:

1. Develop and test inclusive e-voting prototypes that integrate biometric authentication, assistive technologies, and voice-based interfaces.
2. Conduct pilot programs in developing countries to evaluate the feasibility of remote voting for individuals with disabilities.
3. Encourage legislative changes that promote the adoption of inclusive voting technologies.

Future research should prioritize empirical pilot studies in developing countries, involving people with disabilities as active participants in the design and evaluation of e-voting systems. Additionally, interdisciplinary collaboration between technologists, policymakers, and disability advocacy organizations is essential to translate technological innovation into inclusive public electoral policies.

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