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Health, Access, and Advocacy: Disabled People's Views on Rehabilitation in Guyana

Chavon Niles[a], Angela Colantonio[a], Nadeen Al Awamry[a]

[a] University of Toronto. Corresponding Author- Email: nadeen.alawamry@mail.utoronto.ca

Rehabilitation is a vital component of healthcare, yet disabled people in Guyana face persistent barriers to accessing these services. While existing literature focuses primarily on pediatric or clinical outcomes, little is known about how disabled adults experience and navigate rehabilitation services. This article is part of a broader qualitative study on rehabilitation in Guyana and builds on a companion paper that traced the structural evolution of rehabilitation services through provider perspectives. Using a narrative inquiry approach grounded in Critical Disability Studies, postcolonial theory, and Southern theory, we conducted semi-structured interviews with five disabled adults who have used/are using rehabilitation services in Guyana. Participants described a range of barriers to accessing services, including physical inaccessibility, provider attitudes, and a lack of public awareness about rehabilitation services and supports. Some did not know such services existed until they independently sought them out. However, once accessed, rehabilitation often offered relief and healing as well as meaningful relationships with physiotherapists. Their stories also reveal how disabled people are already co-creating caring structures through peer support, advocacy, and improvisation.

Keywords: rehabilitation, disability justice, Guyana, accessibility, patient narratives, structural barriers, Caribbean disability studies

Introduction and Background

Rehabilitation is increasingly recognized as a core component of health systems globally. According to the World Health Organization (WHO, 2017), rehabilitation should be available to anyone who needs it, delivered as part of universal health coverage, and integrated across all levels of healthcare. Importantly, rehabilitation is for anyone experiencing a reduction in their ability to function due to illness, injury, aging, or chronic conditions. This distinction between disability and functional limitation helps clarify that rehabilitation is for a wide spectrum of people, not just those traditionally labelled as disabled. Globally, over 2.4 billion people could benefit from rehabilitation, yet these services remain underfunded and unequally distributed, especially in low- and middle-income countries like Guyana (WHO, 2017).

Recent reports reinforce these gaps. According to the WHO's country profile for Guyana, a critical shortage of qualified rehabilitation professionals remains one of the biggest obstacles to service delivery (WHO, 2017). A submission to the Office of the United Nations High Commissioner for Human Rights (OHCHR) also highlights structural issues, including workforce shortages, poor infrastructure, lack of disability inclusion training, and limited coordination between agencies (OHCRC, 2023). The WHO and the United Nations International Children's Emergency Fund (UNICEF) (2023) identify an urgent need for inclusive and coordinated support for children with disabilities across health, education, and social services. Together, these findings paint a picture of systemic exclusion and fragmentation that undermines equitable access to healthcare.

Guyana is a small, multilingual country on the northern coast of South America, with a population of approximately 800,000 people. It is geographically bordered by Brazil, Suriname, and Venezuela, but is culturally and historically aligned with the English-speaking Caribbean. Guyana is marked by significant diversity, including Afro-Guyanese, Indo-Guyanese, Indigenous (Amerindian), and mixed-heritage populations, as well as growing urban-rural disparities. Most healthcare infrastructure and specialist services are concentrated in the capital, Georgetown, and coastal regions, leaving interior and rural communities under-resourced.

This geographic and demographic complexity translates into uneven access to rehabilitation. As documented in previous studies (Persaud, 2022; Ministry of Health, 2012; Pan American Health Organization (PAHO), 2017) and reflected in this study’s findings, disabled people in Guyana often travel long distances, pay out-of-pocket for transportation, and rely on family or informal networks to reach rehabilitation services. Services are often fragmented, disconnected from broader health systems, and delivered through informal or inconsistent referral pathways. In this context, physical rehabilitation, particularly physiotherapy and mobility-related support, is shaped by clinical need, social geography, stigma, and the enduring legacies of colonial health governance.

These structural barriers cannot be separated from Guyana’s colonial past. Persaud (2022) argues that colonialism shaped the country’s healthcare systems, legal infrastructure, and public narratives around disability. British colonial models embedded logics of exclusion into public health, especially through institutionalization, moral classifications of impairment, and racialized gatekeeping. These colonial residues persist today in architectural design, professional training, and policy frameworks that rarely reflect the lived realities of disabled people. While Persaud’s work focuses on mental health, similar institutional silos and gatekeeping logics influence how physical rehabilitation services are delivered and accessed.

This manuscript is the second paper from a larger qualitative study on rehabilitation in Guyana. The first paper traced the development of rehabilitation services from the perspectives of providers. This study shifts the focus to five disabled adults navigating physical rehabilitation systems such as physiotherapy, mobility aid access, and post-discharge support.

Despite increasing global attention to disability and health equity, there is limited empirical research on rehabilitation access and experiences in the Caribbean. Existing studies tend to focus on education, employment, or social protection (Stephenson & Persadie, 2023b; Stephenson et al., 2020; Gayle-Geddes, 2016; Harry, 2020), with far less attention to how disabled people navigate health systems, particularly rehabilitation. Narrative and participatory approaches are rare, even in work that engages lived experience, such as Tonge's (2023) study of spinal cord injury in the Eastern Caribbean. Where rehabilitation is examined, studies are often policy reviews or demographic reports rather than grounded, narrative-based accounts. In Guyana, these gaps are compounded by geographic inequities and limited rehabilitation infrastructure.

While some research has touched on rehabilitation in Guyana, most notably in pediatric contexts (O'Toole, 2003; 2006) or within broader regional assessments (Cieza et al., 2020), the focus has largely been on clinical outcomes, infrastructure, or child-specific interventions. These approaches provide little insight into how adults with physical disabilities experience, negotiate, or reshape rehabilitation services. This study addresses that gap by centering the narratives of disabled adults in Guyana, offering a critical account of how stigma, exclusion, and structural fragmentation are navigated, resisted, and redefined in everyday life. It affirms the importance of rehabilitation as clinical care and as a relational and rights-based practice and calls for earlier, more equitable access; investment in accessible infrastructure; and systems that treat disabled people as experts in their own care.

Literature Review

Critical disability studies, while primarily developed in the Global North, have been expanded and reshaped by scholars working in and with the Global South who are accountable to Southern epistemologies and grounded in local struggles. These scholars have increasingly challenged the dominance of Western biomedical models. Particularly scholars such as Erevelles (2000, 2005), Dossa (2005, 2006, 2009), El-Lahib (2015a, 2015b, 2016), Chataika (2012, 2018), and Ghai (2002, 2012) have worked to recenter disability as a condition fundamentally shaped by race, empire, poverty, and state power.

The work of Erevelles offers a foundational critique of how disability is shaped by material and ideological structures rooted in colonialism and global capitalism. She examines how disabled bodies are positioned at the intersection of race, class, and nation, especially in contexts marked by histories of exploitation and structural inequality. For Erevelles, education, institutionalization, and public discourse operate as disciplining mechanisms that render some lives legible and others disposable. Her call to engage the politics of location and to interrogate the geopolitical and historical conditions under which disability is produced remains crucial for scholars working in postcolonial and Global South contexts.

Together, these scholars insist that understanding disability in postcolonial settings requires more than applying Global North frameworks to new locations. Instead, it demands an epistemic shift that foregrounds plural ontologies, local resistance, and the embodied knowledge of disabled people navigating systems shaped by colonial legacies.

Building on this foundation, Grech (2009, 2011, 2012, 2013) has been instrumental in theorizing disability through the lens of postcolonialism and neocolonial development. His work critiques the continued marginalization of disabled people in the Global South by both academic theory and global development practices. Grech argues for situated understandings of disability rooted in everyday experience, shaped by structural violence, and informed by alternative ways of knowing and surviving. Recent work by Persaud (2022) in Guyana underscores the importance of centring spiritual, historical, and community-based understandings of disability. Her scholarship critiques imported rehabilitation and health service models, including hospital-based programs, policy frameworks, and professional practices that fail to reflect local cultural values or account for the ongoing effects of colonialism. These externally imposed models often replace or marginalize community-led and historically rooted approaches to supporting disabled people, limiting the relevance and sustainability of services in the Guyanese context. While Persaud's work focuses primarily on mental health and institutional care, it offers an important foundation for understanding how colonial-era logics of surveillance and control persist in contemporary health systems in Guyana. However, there remains a gap in empirical work on physical rehabilitation, particularly as experienced by disabled adults outside of psychiatric institutions.

Despite critical contributions to disability scholarship in the Caribbean, very few studies have examined how disabled people in Guyana experience rehabilitation or define and navigate healthcare in their own terms.[1] Existing research in the Caribbean has largely focused on education, family, and institutional policy related to disability (Harry, 2020; Stephenson & Persadie, 2023a), while rehabilitation studies continue to emphasize clinical outcomes, service efficiency, or delivery models shaped by Global North assumptions of health and independence.

Such approaches overlook the emotional, relational, and political dimensions of accessing rehabilitation in under-resourced and postcolonial contexts, as well as the ways disabled people advocate for access, create informal support networks, and challenge systemic exclusion. These gaps underscore the need for grounded, narrative-based accounts that capture both the systemic barriers and cultural meanings shaping rehabilitation in Guyana and across the wider Caribbean. Tonge's (2023) work on spinal cord injury in the Eastern Caribbean represents one of the few studies that draws on lived experience. Yet even this important contribution focuses primarily on the acute phase of recovery and does not examine long-term access or systemic barriers to rehabilitation.

This pilot study contributes to bridging that gap by documenting the lived experiences of five rehabilitation users in Guyana. All participants identified with a physical disability and described navigating physiotherapy, mobility supports, and related services across fragmented and often exclusionary systems. In doing so, this paper builds on existing scholarship while offering a distinct contribution: an empirically grounded, narrative-based account of rehabilitation access in postcolonial Guyana.

Theoretical Framework

This study is grounded in Critical Disability Studies (CDS) and informed by Southern and postcolonial scholarship. While CDS emerged in the Global North, scholars such as Erevelles (2000), Dossa (2009), El-Lahib (2016), and Grech (2009, 2012) have extended and challenged its boundaries, showing how disability in the Global South is shaped by colonial infrastructures, racialized hierarchies, and economic inequality. These approaches call for theorizing disability from the ground up, drawing on knowledge rooted in lived experience, local ontologies, and the socio-political contexts in which people navigate disability.

Southern theory shaped both the design and analysis of this study. The interview guide was constructed to reflect Guyanese realities of disability, support, and healing. Questions invited participants to speak about family networks, religious or spiritual resources, peer advocacy, and community-based interventions—pathways to rehabilitation that often exist outside formal health systems. Language avoided strictly biomedical terms, instead reflecting the ways participants themselves described their experiences, such as "getting help," "building strength," and "learning to move again." In interpreting the narratives, we treated them not as individual case histories but as critical commentaries on structural exclusion, drawing on local idioms and metaphors to understand meaning.

As a Guyanese researcher living in the diaspora, I, Chavon Niles. occupy a position that is both connected and removed. My cultural and familial ties to Guyana informed my awareness of the social and historical contexts shaping rehabilitation, yet my physical distance required reflexivity and humility. I did not assume full insider knowledge, instead relying on participants' framing of their own experiences to guide interview language and narrative interpretation. This positionality aligns with the epistemic commitments of Southern theory, which recognize the researcher's location as shaping what can be known and how it can be known.

We draw on Grech's (2009, 2012) concept of situated disability knowledge to understand rehabilitation not solely as a clinical intervention but as a contested terrain shaped by colonial legacies, the centralization of services in Georgetown, and persistent inequities across race, class, and geography. From this perspective, rehabilitation in Guyana involves more than physiotherapy sessions or functional outcomes. It includes navigating transport systems, negotiating with overstretched providers, relying on informal support networks, and advocating within bureaucracies not designed with disabled people in mind.

This framework positions the study as a deliberate departure from Global North rehabilitation models that prioritize individual recovery, functional independence, and "normalcy" as primary markers of success. The participants in this study resisted these assumptions, describing rehabilitation as relational, adaptive, and sustained through interdependence, persistence, and the creative use of scarce resources. By centering these accounts, we move away from deficit framings of disabled people as passive recipients and instead recognize them as co-theorists who generate knowledge about how rehabilitation is accessed, withheld, and transformed in postcolonial contexts. This theoretical grounding informed the methodological decisions outlined in the next section, shaping how participants were recruited, how data was generated, and how narratives were analyzed.

Methods

This study used a qualitative, narrative inquiry approach grounded in CDS and informed by decolonial and Global South methodologies. Narrative inquiry was chosen because it centers lived experience, values storytelling as a form of knowledge, and enables participants to speak in their own terms about structures that shape their lives (Riessman, 2008). This approach aligns with the political commitments of disability justice and the broader aim of this pilot study: to understand how disabled people in Guyana experience and navigate rehabilitation systems. Narrative inquiry was also suited to generating meaning across a small and heterogeneous group, since the focus was on the depth and specificity of each participant's account and the interpretive patterns that emerged across them rather than statistical generalization.

Participants were recruited through convenience sampling, with an open call shared via the Breadfruit Collective's networks and social media platforms. Interested individuals contacted the Principal Investigator (CN) via email. A brief pre-screening process was conducted by CN to assess eligibility based on the study's inclusion criteria: participants had to be (1) over the age of 18, (2) identify as disabled, and (3) have past or present experience using rehabilitation services in Guyana.

Five participants were selected, reflecting a diversity of experiences with disability and rehabilitation. Interviews were arranged at accessible locations in Guyana that were mutually agreed upon by the participants and the researcher. Four interviews were conducted in person, and one was conducted online based on the participant's preference and access needs.

Each interview was semi-structured, guided by open-ended questions designed to elicit reflections on participants' experiences with rehabilitation services, challenges in accessing healthcare, treatment by providers, and their strategies for survival and resistance. Questions were designed to invite discussion of both formal and informal pathways to rehabilitation, including family support, faith-based resources, and community-based initiatives, reflecting local understandings of disability, interdependence, and healing. Interviews lasted between 60 and 90 minutes and were conducted in English. All interviews were audio-recorded with informed consent, transcribed verbatim, and anonymized to protect participant confidentiality. Data was coded and analyzed through a process of close, iterative reading grounded in narrative and critical disability methodologies. After several rounds of reading the transcripts, an initial set of inductive codes based on recurring ideas, tensions, and expressions across participant narratives was developed. These codes emerged directly from the data. Codes were then organized into broader themes that reflected shared patterns, contradictions, and forms of resistance in how participants described their experiences with rehabilitation. Analytical saturation was assessed through iterative coding and review of transcripts until no new themes or subthemes were emerging, which was reached within this small sample due to the richness and depth of the narrative accounts. The analytical process was guided by the study's theoretical commitments to epistemic justice and situated knowledge, with special attention paid to how participants narrated exclusion, access to rehabilitation, and advocacy in relation to broader health, social, and community systems in Guyana. Thematic groupings were refined through reflexive engagement with the data to track interpretations, questions, and theoretical connections. Throughout the analytic process, participant stories were read as critical texts that offer insight, critique, and alternative frameworks for understanding how rehabilitation is delivered, adapted, and sustained- including formal clinical services, community-based initiatives, and informal support provided by family members, peers, and religious or social networks. Emphasis was placed on what was said, how stories were structured, what was emphasized or left unsaid, and what these narrative choices revealed about power, resistance, and support in everyday life. To align with the study's commitment to epistemic justice, transcripts were returned to participants for their review and correction prior to analysis. Participants were invited to clarify or elaborate on their accounts at that stage; however, they were not directly involved in co-analysis or in reviewing the thematic findings. This is acknowledged as a limitation of the study, as participant involvement in later stages of interpretation could have further enriched the analysis.

Ethical approval was granted by the University of Toronto Research Ethics Board. Informed consent was obtained from all participants and steps taken to ensure privacy, uphold participants' dignity, and provide accessible participation options, including offering interviews in participants' preferred locations.

Participant Characteristics

The five participants ranged in age from their early 20s to mid-50s and included one male and 4 females from urban and semi-rural areas in Guyana. They identified with a variety of disabilities, including mobility impairments, visual impairments, and chronic physical conditions. Each participant had interacted with at least one rehabilitation service, whether physical therapy, counselling, aqua therapy, or occupational therapy. Most described multiple points of entry and exit into the healthcare system. Below is a demographic table of participants.

Pseudonym	**Gender**	**Age**	**Highest Level of Education**	**Disability**
Abi	Woman	26	Completed secondary school	Mobility Disability
Amy	Woman	40	Completed secondary school	Pain-related Disability, Mobility Disability
Nelly	Woman	25	Completed secondary school	Mobility Disability
Lucille	Woman	44	Bachelor's Degree	Mobility Disability
Christian	Man	31	Completed secondary school	Developmental Disability, Mobility Disability

Table 1: Participant characteristics

Findings

The narratives shared by participants reveal the complex realities of disabled people navigating rehabilitation services in Guyana. Four core themes emerged from the data: (1) Structural and Material Barriers to Access, (2) Emotional and Epistemic Dismissal, (3) Acts of Agency, Adaptation, and Mutual Support and (4) The Transformative Potential of Rehabilitation when Care is Collaborative. These themes are interconnected and reflect how exclusion, survival, and resistance co-exist in participants' daily lives. In presenting these findings, participants' voices are foregrounded to preserve the depth and integrity of their lived experiences.

Structural and Material Barriers to Access

Across all interviews, participants described persistent and overlapping physical and financial barriers to accessing rehabilitation services. These included inaccessible infrastructure, long travel distances, limited availability of services, and high transportation costs. Such conditions shaped how participants experienced rehabilitation, often determining whether they could access it at all.

Amy, 40, who uses a wheelchair, shared how getting to rehabilitation at Georgetown Hospital was physically painful and logistically burdensome:

> Because of the upstairs house, I had to be carried down… walking was difficult, standing… so I resorted to using a wheelchair… then to get in the car, and to get the therapy. And then I would use a wheelchair.

Here, the challenge was not only the distance to services, but the fact that her home, like many in Guyana, was built without accessibility in mind. Rehabilitation access was therefore dependent on the physical labour of others, often family members, to move her through environments that had never been designed for disabled bodies.

Despite these difficulties, she noted that no one asked about her access challenges:

> I don't believe, you know, there was an interest about if it was easy or not, or if there were any challenges or obstacles you had to get to come. It was just a matter of being able to get there.

This absence of inquiry reflects an institutional expectation that people should arrive for rehabilitation, regardless of what it takes to get there, with little attention to the cumulative impact of these journeys on their health and wellbeing.

Christian, 31, emphasized how transportation was the single biggest challenge he faced:

> The biggest issue would definitely be transportation…especially in the [rehabilitation centre], I would roll in and… a lot of the entrance areas… either weren’t wide enough or had cracks and crevasse… It’s not always safe.

He also highlighted how the built environment itself felt hostile to mobility:

> There was a primary school I attended… the first really big issue I had with infrastructure in Guyana… stairs, stairs, stairs everywhere. It wasn’t built for someone like me.

For Christian, these memories illustrate how exclusion is built into everyday spaces, beginning in childhood and continuing into adulthood. The built environment, from schools to clinics, signals who belongs and who does not, reinforcing social marginalization long before rehabilitation is even an option.

Although some participants had the financial support of family to pay for private transport or in-home services, others noted this was not the case for most disabled people in Guyana. Even those who could pay described exclusion as a default in public systems. Amy explained:

> I had to call around… most places said they only offer services to children… otherwise, you go to the [Rehabilitation Clinic]…it's not easy for me to get there.

This reflects a pattern where rehabilitation services, when available, are narrowly targeted and urban-centred. Adults are deprioritized, and there is little structural support to bridge the gap between medical eligibility and physical access.

This theme reveals how rehabilitation is often experienced as an obstacle course, where the work of showing up is exhausting, resource-intensive, and shaped by historical neglect of accessibility. Public buildings remain physically inaccessible; transportation is inconsistent or unaffordable; and the burden of navigation falls mostly on disabled people and their families. These structural exclusions reflect deep legacies of underinvestment in accessible infrastructure and the colonial-era centralization of health systems in Georgetown. All participants in this study were based in Regions 3, 4, and 5, which include some of Guyana's most urbanized and economically active areas. Region 4 (Demerara-Mahaica) contains Georgetown, the capital and main port; Region 3 (Essequibo Islands–West Demerara) has seen significant economic growth, particularly along the coast; and Region 5 (Mahaica-Berbice) includes both agricultural and urban areas. Yet even within these relatively connected regions, participants described rehabilitation as fragmented, difficult to navigate, and shaped by social and economic inequalities that limited consistent access to services.

For Christian, his relative ease in accessing services at one point was unusual-made possible only because of personal support. As he reflected:

> I didn't have any major hindrances accessing disability service…if you're talking about, you know, physical accessibility. But that's because I had support. If I didn't? I don't know.

His statement underscores that access in Guyana is not determined by need, but by the presence or absence of personal networks, financial means, and determination.

Navigating Disrespect, Dismissal, and Power Imbalances

Participants frequently described feeling dismissed, infantilized, or disrespected by rehabilitation providers. These encounters were part of a wider system where professional authority often overrides the voices and expertise of disabled people.

Amy shared that during one therapy session, a provider refused to let her try a suggested exercise modification:

> She said, 'No, that's not the way we do it here.

In this interaction, professional expertise was framed as fixed and non-negotiable, leaving no space for Amy's own knowledge of her body. This reflects the legacy of biomedical authority in Guyana's health system, where provider training is often shaped by Global North standards that value compliance over collaboration.
Christian described a similar dynamic when he asked a therapist about adjusting his schedule to fit his transportation availability:

> They looked at me like I was asking for a favour instead of a reasonable accommodation.

This reaction reframed a basic access need as an imposition, revealing how, in the absence of enforceable disability rights, such requests are treated as discretionary rather than fundamental Several participants spoke of being treated as if they were less intelligent or less capable of making decisions about their own rehabilitation care needs. Sofia, 28, recalled:

> They talk to you like you don't understand… like you're a child.

This paternalism strips disabled people of agency and reinforces the idea that their role is to be passive recipients of care, not active decision-makers.

The experience of disrespect was not only interpersonal but also structural. Rehabilitation settings were described as physically arranged to privilege providers' authority-for example, open wards where conversations could be overheard, no private space for sensitive discussions, and rigid session protocols that left little time for patient-led dialogue.

Some participants linked this to broader socio-political hierarchies in Guyana, where medical professionals hold significant status and where challenging them can risk perceived retaliation or denial of service. Amy noted:

> You can't push too much or you might not get your next appointment.

This dynamic reflects the imbalance of power in resource-limited systems, where scarcity can be used to discipline patients into compliance. The lack of alternative service providers means that speaking out often comes at the cost of losing access entirely.

Participants developed strategies to navigate this imbalance. Some withheld their opinions to avoid conflict, while others sought out sympathetic providers through informal networks. Christian explained:

> You find out who will listen to you from other patients… it's not official, but you know who to ask for.

This reliance on word-of-mouth highlights how trust and respect are often sought outside of formal systems, reinforcing the importance of social networks as survival tools in navigating rehabilitation.

These conditions mean that navigating rehabilitation in Guyana often requires managing both the interpersonal risks of challenging authority and the structural barriers that limit alternatives.

As a result, disabled people's ability to advocate for themselves depends not only on their confidence or knowledge, but also on the social networks, provider relationships, and resources they can draw upon in a system without guaranteed protections.

Acts of Agency, Adaptation, and Mutual Support

Despite navigating systems that were physically inaccessible, under-resourced, and at times dismissive, participants described persistent and creative ways they asserted control over their rehabilitation journeys. These acts of agency disrupt the dominant narrative that positions disabled people in Guyana as passive recipients of charity or medical intervention. Instead, they reveal forms of resistance that are deeply rooted in lived experience and collective survival strategies.

Christian, who has been involved in accessibility audits of public spaces, explained:

> When you live it, you know what to look for… I'd go to these places and show them-no, this step is too high. No, this isn't wide enough. And sometimes they listen, sometimes not. But at least I show them.

Here, advocacy is framed as both a technical and political act- challenging physical barriers while also confronting the underlying assumption that buildings are designed for all bodies. This form of expertise, grounded in lived experience, is rarely recognized in formal policy but plays a critical role in shaping more inclusive spaces.

Others described acts of agency that were more personal but equally transformative. Nelly recounted how she chose to stop seeing a therapist who dismissed her pain:

> I told my family I ain't going back to she. It hurting me. So we look for another place. You can't just take what they give you, you have to speak up.

Refusing care in a context where options are scarce is a significant act of self-protection, especially when doing so risks losing access altogether. This decision underscores the agency involved in setting personal boundaries, even when the system offers few alternatives.

Several participants also described stepping into informal leadership roles to help others navigate the same barriers they had faced. They saw mutual aid and peer-to-peer encouragement as essential in a system where official supports were often slow, limited, or absent. Abi explained:

> I try to tell people, if I can do it, you can too. It's not easy, but we have to help each other. If you wait on them [the system], you might wait forever.

In practice, this support often took the form of sharing information about accessible providers, pooling resources to cover transport costs, or accompanying peers to appointments to ensure they were taken seriously by staff. Abi's reflection highlights how disabled people in Guyana often create their own informal networks of guidance and motivation, recognizing that waiting for the formal system can mean indefinite delays in accessing rehabilitation.

Amy adapted to transportation and infrastructure barriers by reorganizing her appointments to align with moments when she could access family assistance or afford private transport:

> You have to plan ahead, you have to know who you can call. Sometimes it's not ideal, but you work with what you have. You learn how to move through.

This logistical work is a form of disability labour that is rarely acknowledged in health systems research. It reflects the reality that, in Guyana, accessing rehabilitation often requires parallel planning to secure transportation, coordinate with informal networks, and negotiate physical barriers — all before the clinical session even begins.

These acts of agency cannot be separated from the structural inequities that shape rehabilitation in Guyana. They emerge in the context of historically centralized services, limited rural investment, and policies that often overlook disabled people's expertise. Taken together, these accounts reveal how acts of agency are embedded in daily life and shaped by the broader political economy of rehabilitation in Guyana. Agency here is about collective action in the face of systemic neglect rooted in colonialism. These strategies challenge the boundaries of what counts as 'rehabilitation' by recognizing that disabled people are themselves key architects of accessible futures.

The Transformative Potential of Rehabilitation

Participants' accounts revealed that, despite prolonged struggles to access rehabilitation, moments of timely, respectful, and collaborative care could bring tangible physical, emotional, and social benefits. These experiences illustrate what rehabilitation can achieve when disabled people are recognized as active partners rather than passive recipients.

For some, the absence of early rehabilitation had lasting consequences. Lucille learned about rehabilitation only by chance while searching online for exercises:

> I was on YouTube looking at exercises I can do at home, and then I saw people going to rehab. Why am I not at rehab? And I posed the question at my next visit… [The doctor said,] 'Yeah, if you want to.' It wasn't, 'You have to go to rehab'.

Such delays highlight a systemic gap: rehabilitation is not routinely embedded in care pathways, leaving individuals to self-identify its relevance. Postcolonial health literature links these gaps to fragmented services and weak referral mechanisms, particularly in settings where rehabilitation is underdeveloped.

Christian similarly traced his long-term mobility decline to missed rehabilitation at a critical stage:

> Prior surgery I had overseas… led me to a wheelchair because I didn't have the therapy needed to build back the strength. So, it eventually led me to a wheelchair.

These absences caused not only physical harm but also epistemic harm- excluding people from timely knowledge needed for informed recovery decisions.

Once accessed, rehabilitation could have immediate benefits. Lucille recalled:

> Before I left therapy that day, the pain was better. It wasn't gone, but it was better.

Amy described physiotherapy as central to her healing:

> It has become a number one priority… one step of positivity that will help my body.

Positive experiences were defined as much by the relational quality of care as by technical expertise- therapists who listened, explained, and adapted to participants' realities. Disability rights scholarship underscores that such relational trust is as critical to rehabilitation outcomes as clinical intervention.

Participants noted that these experiences were rare. In Guyana, where services are concentrated in urban centres and shaped by colonial-era biomedical models, realizing rehabilitation's potential requires both structural reform and cultural change in practice. When disabled people are engaged in setting goals, shaping treatment plans, and negotiating access, rehabilitation can shift from a sporadic intervention to a sustained source of empowerment.

These accounts point toward clear priorities: integrate rehabilitation earlier in care, expand community-based delivery, and embed collaborative decision-making as standard practice. Such changes could establish a consistent, rights-based rehabilitation system that advances both individual recovery and broader social inclusion

Discussion and Analysis

Our analysis highlights how people with disabilities interpret and respond to the layered challenges of accessing rehabilitation services in Guyana. Participants described both structural barriers such as transportation costs, limited services availability, and inaccessible environments and relational barriers, including inconsistent communication and lack of follow-up with providers. Rather than positioning them as passive recipients of care, the narratives foreground them as active decision-makers who weigh trade-offs, mobilize social networks, and adapt strategies to secure the support they need. By situating these experiences within the broader socio-political and geographic context of Guyana, the study extends existing literature on rehabilitation access in low- and middle-income countries, demonstrating how local realities shape what services are available, how they are understood, valued, and acted upon by those who use them.

Structural Exclusion: Access as Work

Participants' accounts show that the work required to use rehabilitation services in Guyana extends well beyond the clinical encounter. The effort to arrange transport, navigate stairs, and narrow entrances, coordinate assistance, and secure information about where and when to attend therapy, is built into how rehabilitation is currently delivered. This labour is not an unfortunate side effect of a scarce system; it is a patterned outcome of design choices that have historically centered able-bodied users and centralized services (Erevelles, 2000; Grech, 2009, 2012). The result is that rehabilitation becomes conditional on a person's ability to have money, time, and social support rather than a right supported through public infrastructure and reliable referral and follow-up.

These patterns are consistent with postcolonial analyses of health governance in the Caribbean, where colonial administrative logics normalized urban centralization and left accessibility concerns to be solved privately by families and communities (Persaud, 2022). What is notable in this study is that the burden of access remains high even for participants based in Regions 3, 4, and 5, which include some of the most urbanized parts of the country. In other words, proximity to Georgetown or coastal corridors does not guarantee usable rehabilitation. The everyday realities participants described indicate that key enabling conditions remain weak: transportation support is unreliable or unaffordable, buildings are not consistently accessible, and referral pathways and follow-up are inconsistent. Availability of a clinic or a therapist therefore cannot be equated with access.

The data complicates policy assumptions that coordination alone will secure equitable rehabilitation. National policy commitments and regional guidance have emphasized integration of rehabilitation within health systems and universal health coverage (WHO, 2017), yet participants' narratives in this study point to implementation gaps at points that matter most to them: getting to appointments, entering facilities, being scheduled at feasible times, and receiving timely information about options and next steps. When these elements are absent, people construct "workarounds" through family labour, private transport, or discontinuing therapy altogether. The costs of making rehabilitation usable are shifted onto disabled people and their networks, while the system fails to recognize those costs as part of service delivery.

Situating these findings within Southern disability scholarship also clarifies what is being resisted. Dominant rehabilitation models prioritize individual functional gains and assume the clinic as the primary site of intervention. Participants' accounts locate critical parts of the process in the *journey* to and from the clinic and in the coordination that precedes it. This reframes the question from "Is there a physiotherapist available?" to "What concrete supports exist to enable a disabled person to reach, participate in, and continue physiotherapy?" That shift is substantive. It directs attention to transport subsidies, scheduling practices, physical accessibility standards, and clear referral and follow-up communication as core parts of rehabilitation delivery rather than peripheral concerns (Chataika, 2012; Ghai, 2002).

Reading participants' stories as situated knowledge, this analysis centers the places where policy often does not look: the staircase at home, the minibus step, the clinic doorway, the unanswered question about where to go next. In line with Grech's argument for grounded Global South disability knowledge, these are not anecdotes at the margins; they are the mechanisms through which exclusion is reproduced or dismantled. The implication is practical and actionable. Strengthening rehabilitation for users like those in this study requires investment in transport access, accessible facilities, predictable referral and follow-up, and provider practices that proactively ask about and address these conditions, alongside continued expansion of clinical capacity (Grech, 2009, 2012; WHO, 2017; Persaud, 2022).

Emotional and Epistemic Dismissal: Being Ignored, Not Heard

The accounts of participants in this study reveal a consistent pattern of having their insights, experiences, and needs disregarded within clinical encounters. This was not limited to moments of overt disrespect but was embedded in routine interactions that signaled whose voices were considered authoritative. Drawing on Fricker's (2007) framework, these encounters can be read as forms of epistemic injustice, where credibility is discounted because of who the speaker is rather than the substance of their contribution. In the rehabilitation context, this took the form of privileging biomedical authority and professional expertise over the situated knowledge of disabled people themselves (Carel & Kidd, 2014).

In Guyana, where rehabilitation services are scarce, dismissal takes on heightened significance. With few alternative providers and limited safety nets, being disbelieved, ignored, or coerced into unsuitable treatment plans is not simply a poor interpersonal exchange; it can mean a permanent break in access to care. The participants' accounts demonstrate that this dismissal operated both emotionally through minimization of distress, pain, or frustration and epistemically through reframing lived expertise as anecdotal or overly subjective. The result was a hierarchy of credibility in which professional perspectives were consistently positioned above those of participants, even when their accounts were specific, evidence-informed, and grounded in the realities of daily life with disability.

The cumulative impact of this dynamic was profound. Several participants described withdrawing from therapy altogether after repeated invalidation, not because their need for rehabilitation had diminished, but because their presence in the system no longer felt viable. This form of disengagement mirrors patterns identified in broader Southern disability scholarship, which documents how dismissal and disbelief silence marginalized voices and actively restructure participation by narrowing who remains in the system (Chataika, 2012; Ghai, 2002). In these narratives, dismissal functioned as a gatekeeping mechanism, regulating tone, content, and perceived legitimacy of contributions, and in doing so, curtailing opportunities for co-production of care.

Seen in this light, participants' accounts call for a reconceptualization of care in rehabilitation. It cannot be reduced to the delivery of technical interventions such as exercises or mobility aids; it must also include practices that actively listen, solicit, and integrate users' perspectives at every stage of service delivery. When rehabilitation systems fail to recognize disabled people as credible knowers, they not only perpetuate interpersonal inequities but also reinforce structural exclusion. Addressing epistemic injustice in this context means reshaping provider-user relationships, embedding participatory decision-making into service models, and ensuring that the lived realities of rehabilitation users are treated as central to both clinical reasoning and policy design.

What participants are naming in these stories is the need for healthcare systems that listen, that respond, and that treat disabled people as credible sources of knowledge. This requires a shift in orientation from assuming expertise resides only in professionals to recognizing that it also lives in the people seeking care. Epistemic injustice isn't just about being unheard. It's about being denied the chance to shape what care looks like. And in the context of Guyana, where systems are already stretched thin, that denial can mean disappearing from healthcare altogether.

Acts of Agency and Mutual Support: Navigating a System That Doesn't Fit

The accounts of participants reveal that exclusion and dismissal did not fully determine their relationship with rehabilitation. Within the constraints of structural barriers and epistemic injustice, participants identified and acted upon opportunities to alter their own care pathways and those of others. These were not isolated acts of individual resilience but situated strategies that both responded to and subtly reshaped the conditions of rehabilitation delivery in Guyana. Participants described changing providers when treatment felt ineffective or dismissive, actively seeking alternative referral routes, and sharing experiential knowledge with peers navigating similar challenges. These acts can be read as micro-level interventions that contest the hierarchies and access conditions described in the earlier sections. By drawing on personal and collective resources, participants created forms of mutual support that filled gaps left by inaccessible facilities, unreliable scheduling, or inadequate communication.

Such strategies complicate narratives that position rehabilitation users solely as recipients of care. They instead illustrate how disabled people engage in a form of co-production, shaping the meanings, practices, and reach of rehabilitation beyond what is formally sanctioned. This aligns with Southern disability scholarship's emphasis on relational and community-driven responses to systemic inadequacies, where knowledge exchange and collective action become integral to sustaining participation in care (Chataika, 2012; Grech, 2015).

The data also suggest that agency was not only about individual persistence but about creating pathways for others. Encouraging a discouraged peer to return to therapy or advocating for building modifications were not framed by participants as extraordinary acts, but as necessary contributions to shared survival within an unaccommodating system. These practices challenge the assumption that responsibility for access lies solely with individuals.

Placing these findings alongside the earlier analysis of structural exclusion and epistemic dismissal makes visible the dialectic between constraint and possibility. The same infrastructural gaps and credibility hierarchies that limit formal access also create the conditions in which informal, user-led solutions emerge. While these forms of agency can mitigate immediate barriers, they do not erase the need for systemic change. Instead, they point to the importance of policy and service design that removes barriers and recognizes and supports the knowledge, networks, and strategies that rehabilitation users are already employing to make the system work.

When Care Works: Relational Practice and the Transformative Power of Rehabilitation

The accounts of when rehabilitation "worked" offer important analytical counterpoints to the exclusion and dismissal described earlier. These moments show what becomes possible when structural and relational conditions align to support users. They underscore that access is not merely a question of physical arrival at a clinic, but of the quality of the interaction, the respect for participant's knowledge, and the responsiveness of services to individual circumstances.

Participants' narratives indicate that the success of rehabilitation is closely linked to the presence of relational care, where trust, mutual recognition, and collaboration shape the therapeutic process. These practices disrupted the hierarchies of credibility identified in the discussion of epistemic injustice by positioning users as co-constructors of their care. Where earlier sections documented the cost of being unheard, here participants described the benefits of being listened to and taken seriously. This relational orientation did not erase the logistical challenges described under structural exclusion, but it altered how those challenges were experienced, making the work of accessing services feel purposeful rather than futile.

The accounts of Amy and Nelly, for example, highlight how relational care enabled them to sustain participation despite significant barriers in getting to sessions. The clinicians who listened, explained, and adjusted their approaches created conditions in which users could engage physically and emotionally reinforcing Southern disability scholarship that tells us that meaningful rehabilitation requires localised, user-centred practice that values situated knowledge alongside professional expertise.

Importantly, these narratives also make visible the consequences of its absence. Christian's account of not receiving post-operative rehabilitation demonstrates that without timely and relational care, the potential benefits of surgical intervention are undermined. This gap reflects the same systemic fragmentation identified earlier, where policy commitments to continuity of care are not translated into practice. It also illustrates that the absence of relational care is an active determinant of long-term outcomes.

By reading these positive experiences alongside the accounts of exclusion and dismissal, it becomes clear that the same system contains both the mechanisms that harm and the possibilities that heal. Relational care operates as a form of resistance to the structural and epistemic barriers described earlier, offering a template for what rehabilitation might look like in Guyana. It shifts the focus from compliance with prescribed treatment to collaboration around user-defined goals, and from passive receipt of services to active co-production of care.

Rehabilitation is often imagined as a technical process, restoring function, reducing pain, but participants showed that it is also relational. It requires time, trust, and collaboration. Participants describe what Dossa (2009) calls relational care: care that is shaped through mutual recognition and respect, rather than hierarchical expertise. These stories also reflect a broader argument in Southern disability studies: that care becomes meaningful when it responds to local realities, centers lived knowledge and treats people as full participants in their healing.

These moments in the data show that transformation requires concrete practices that honour disabled people as experts in their own lives. They demonstrate that early, consistent, and relationally grounded rehabilitation has the capacity to build trust, restore agency, and enable participation on terms defined by users themselves. In doing so, they provide an empirical foundation for reimagining rehabilitation as a social and political process that can either reproduce exclusion or actively dismantle it. Their stories are blueprints for reimagining care that is collaborative, inclusive, and led by those who need it most.

Conclusion

This study offers one of the first in-depth, narrative-based accounts of how disabled people in Guyana experience rehabilitation services. While most global research on rehabilitation remains focused on clinical outcomes or service efficiency, the stories shared here offer a grounded account of how disabled people navigate, endure, and reimagine care in a system shaped by colonial legacies and fragmented infrastructure. Participants' experiences disrupt the notion that rehabilitation is merely a technical fix. Instead, they reveal it as a deeply relational and political process that raises critical questions about who is heard, who is included, and whose knowledge guide healthcare needs.

Each participant offered insight into what rehabilitation is and what it could be if systems were designed to support, rather than strain, those who use them. Participants showed how rehabilitation care often begins long before a therapy session, in the logistical work of finding transport, coordinating with family, and physically moving through inaccessible spaces. They also described how care breaks down when trust is eroded, when pain is ignored, and when they are treated as incapable of understanding or directing their own treatment. They shared what it felt like when care worked, when therapists listened, when treatment was adapted to their needs, and when relationships were built on respect rather than compliance.

This study is limited in scale, with five participants primarily living in or near Georgetown. Their stories do not represent the full range of experiences across Guyana, especially in rural, or interior communities where access to rehabilitation services may be even more constrained. Future research should explore rehabilitation access across regions, disabilities, and identities, and examine how rehabilitation care is shaped by geography, gender, class, and race. There is also value in exploring longitudinal methods, participatory action research, and co-design approaches that deepen the collaborative ethos already evident here. Research should attend to the specific experiences of people who have disengaged from rehabilitation services altogether, and to the ways rehabilitation is negotiated over time and across life stages.

Still, the narratives in this study provide compelling evidence of epistemic injustice in healthcare encounters, revealing how disabled people are structurally prevented from shaping the very systems intended to serve them. These accounts do more than document exclusion; they demonstrate the existence of a situated disability knowledge in the Caribbean that is grounded in lived experience, political awareness, and collective strategies of survival. By centering this knowledge, the study challenges dominant framings that position disabled people as passive recipients of care and offers a framework for how research can be accountable to disabled people's leadership and priorities. In this way, the work contributes to a growing body of critical disability studies that insists on linking empirical evidence to structural critique and on embedding scholarship within the communities whose struggles and insights make such research possible.

Notes

[1] Harry's (2020) work on childhood disability, advocacy, and inclusion in Trinidad and Tobago, alongside Stephenson and Persadie's (2023a) examination of workplace discrimination and access across Caribbean states, extends a regional body of scholarship that situates disability within histories of colonialism, inequality, and resistance. Together, these studies underscore the importance of locally grounded analysis that centers lived experience, social structures, and the continuing struggle for equity and participation among disabled people in the Caribbean.

References

Carel, H. & Kidd, I. J. (2014). Epistemic injustice in healthcare: A philosophical analysis. *Medicine, Health Care and Philosophy,* 17(4), 529–540.

Chataika, T. (2018). Deconstructing disability in development: A southern critical approach. In K. Soldatic & K. Johnson (eds.), *Disability and the Global South: The Critical Handbook* (pp. 47–61). London: Routledge.

Cieza, A., Causey, K. et al. (2020). Global estimates of the need for rehabilitation based on the Global Burden of Disease Study 2019: A systematic analysis. *The Lancet,* 396*(*10267), 2006–2017.

Dossa, P. (2009). *Politics and care: A case study of home care workers in Canada*. Toronto: University of Toronto Press.

El-Lahib, Y. (2016). Disability and colonialism: Accessing the narratives of exclusion. *Canadian Journal of Disability Studies, 5*(1), 143–169.

Erevelles, N. (2000). Educating unruly bodies: Critical pedagogy, disability studies, and the politics of schooling. *Educational Theory,* 50(1), 25–47.

Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press.

Gayle-Geddes, A. N. (2016). A Situational Analysis of Persons with Disabilities in Jamaica and Trinidad and Tobago: Education and Employment Policy Imperatives. In: P. Block, D. Kasnitz et al. (eds.) *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. Dordrecht: Springer.

Ghai, A. (2002). Disability in the Indian context: Post-colonial perspectives. In M. Corker & T. Shakespeare (eds.), *Disability/postmodernity: Embodying disability theory* (pp. 88–100). London: Continuum.

Grech, S. (2009). Disability, poverty and development: Critical reflections on the Global South debate. *Disability & Society,* 24(6), 771–784.

Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global South. *International Journal of Inclusive Education,* 15(1), 87–100.

Grech, S. (2015). Decolonising Eurocentric Disability Studies: Why Colonialism Matters in the Disability and Global South Debate. *Social Identities*, 21(1), 6–21.

Harry, B. (2020). Childhood disability, advocacy, and inclusion in the Caribbean: A Trinidad and Tobago case study. Cham, Switzerland: Palgrave Macmillan. https://doi.org/10.1007/978-3-030-23858-2

Office of the United Nations High Commissioner for Human Rights. (2023, January 4). Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic (A/HRC/52/52). United Nations. Available at: https://www.ohchr.org/en/documents/thematic-reports/ahrc5252-support-systems-ensure-community-inclusion-persons-disabilities

O'Toole, B. (2003). Disability in Guyana: A study of the situation of persons with disabilities in Guyana in the context of the UN Convention. Guyana Association for the Blind/Handicap International.

Pan American Health Organization (2017) Rehabilitation in health systems. Washington, DC: PAHO. Available at: https://www.paho.org/en/documents/rehabilitation-health-systems

Persadie, N., Stephenson, M. A. et al. (2020). *Disability in the workplace: A Caribbean perspective*. US: Springer.

Persaud, S. (2022). No sovereign remedy: Distress, madness, and mental health care in Guyana. Doctoral dissertation, York University, Canada.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. London: Sage Publications, Inc.

Stephenson, J. H., & Persadie, N. (2023a). Disability in the workplace: A Caribbean perspective. Cham, Switzerland: Springer Nature. https://doi.org/10.1007/978-3-031-19340-8

Stephenson, M. A., & Persadie, N. (2023b). Institutional inclusion of persons with disabilities in the Caribbean. In S. Grech & K. Soldatic (eds.), *Disability in the Global South* (2nd ed.). US: Springer.

Tonge, K. (2023). Spinal cord injury and disability in the Eastern Caribbean: A narrative study. Masters thesis, Unicaf University, Zambia. Available at: https://cdn.unicaf.org/websites/unicaf/wp-content/uploads/2024/06/Kwasi-Tonge-FINAL-thesis.pdf

World Health Organization (WHO). (2017). Rehabilitation in health systems. WHO. Available at: https://www.who.int/publications/i/item/9789241549974

World Health Organization (WHO), & United Nations Children's Fund (UNICEF). (2023). Global report on children with developmental disabilities: From the margins to the mainstream. United Nations. Available at: https://digitallibrary.un.org/record/4020810
