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Editorial

A response to the editorial of March 2026 Bridging the Research–Practice Gap: A Crisis of Values in Rehabilitation" by Zelalem Dessalegn Demeke

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EDITORIAL

The editorial in the last issue of this journal entitled "Bridging the Research–Practice Gap: A Crisis of Values in Rehabilitation" (Zelalem Dessalegn Demeke, March 2026) was and is of great importance and touching some important failures in terms of providing appropriate and effective rehabilitation of the child with neurodevelopmental disabilities. The author used Ethiopia, the country where he lives and works, as an example of an ongoing and troubling paradox. While there is ample evidence about effective rehabilitation interventions for the group of children with neurodevelopmental disabilities everyday practice in Ethiopia and in many, perhaps most, low- and middle-income countries (LMICs) remains largely unchanged. Rehabilitation approaches are often still impairment-focused and based on outdated philosophies and principles.

Among the interventions that continue to dominate practice are passive stretching, Neurodevelopmental Therapy (NDT/Bobath) – popular in the US and the UK, and Vojta therapy – popular in Germany and Russia. These approaches are familiar to me personally, as I was trained as a physiotherapist in the late 1970s and early 1980s. During that time, I was enthusiastic about the rigor and structure of NDT training, which I received in Johannesburg in the early 1980s. However, there is evidence that despite NDT being the most widely used approach for neurodevelopmental rehabilitation, it is not superior to other treatment approaches. In fact, Novak et al. (2020) state in their article that there is no evidence for the efficacy of NDT.

Having travelled extensively in different LMICs, I continue to observe therapists are still being trained in old school therapy. As a result, mothers and caregivers are also taught to implement interventions often limited to passive stretching and massage, to prevent contractures. The burden it places on both the child and the mother is enormous. For the child, it is often a matter of undergoing painful sessions. For mothers, devoting significant energy and time to offer ineffective interventions adds yet another burden to already demanding daily responsibilities…

Yet, just as families were searching for better answers in the 1980s, parents today continue to seek more meaningful and effective support for their children with neurodevelopmental disability. In the years that I worked in South Africa, mothers travelled as far as 500 km to reach the Reakgona Parent Guidance centre are Gelukspan Hospital where we initiated an intensive training programme for mothers to be a better caregiver for their child with neurodevelopmental disability. It was certainly not perfect when we started but now – 40 years later – it continues to serve hundreds of families under the leadership of Undine Rauter (Rauter, 2016).

Today, similar approaches can increasingly be seen across multiple countries. Initiatives such as the Ubuntu Hub – formerly Getting to know Cerebral Palsy, initiated in 2015 and now hosted by the London School of Hygiene & Tropical Medicine (LSHTM) – represent powerful developments in countries including Colombia, Brazil, Ghana, Rwanda, Uganda and Bangladesh (Ubuntu-hub, accessed May 2026). Likewise, international organisations such as Liliane Fonds have in recent years placed greater emphasis on effective rehabilitation interventions for children with neurodevelopmental disabilities. Similarly, the Enablement Foundation (established 2 years ago through the merger of Enablement BV with the foundation Cerebral Palsy Africa) actively promotes an approach based on the work done by CanChild (CanChild, accesses May 2026). This places a strong focus on improved functionality and quality of life of the entire family of the child with Cerebral Palsy and is currently being implemented in 4 African countries (Enablement Foundation accessed May 2026).

As Demeke argues, the persistent focus on impairment rather than function and well-being raises critical questions about the relevance of professional training curricula used in LMICs, the quality of clinical supervision, and the capacity of health systems to support contemporary, evidence-informed practice (Zelalem Dessalegn Demeke, March 2026). In my view, it also reflects a serious underestimation of the role and importance of continuing professional education.

We can and should ask ourselves the question if universities feel responsible for such shortcomings or is the importance of continuing education just a matter of individual responsibility? Do professionals and their professional boards sufficiently realise that they have a strong obligation towards the society to ensure that the services that they deliver are based on evidence? Meanwhile, that responsibility should equally be a concern of the universities offering professional training of therapists. In the case of the child with neurodevelopmental disability, the child – and family – are being denied interventions that are proven effective. One wonders why, despite the growing body of readily available evidence, many professionals continue using the old failing approaches. Are rehabilitation professionals in LMICs sufficiently engage with contemporary professional literature? Is undergraduate training perceived as adequate preparation for an entire carrier? Even when access to academic journals is limited by costs and language barriers, high-quality and accessible information is increasingly available online. Much of it is written in simple English and not per se written for professionals but also for CBR fieldworkers, lay people and mothers of children with neurodevelopmental disabilities.

The evidence that we can and should do better than we often do is there and is not confined to academic journals. The challenge now is not simply generating more evidence, but ensuring that evidence is translated into practice. Rehabilitation professionals should embrace this responsibility and transform their services to produce meaningful outcomes. Not only for children with disability, but also of the wellbeing and resilience of their families and households.

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Original Research Article

Enhancing Rehabilitation Access: A Program Evaluation of Embrace a Child Program for Children with Disabilities

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ABSTRACT

Aim: This study evaluates the potential of the *Embrace A Child Program*, an initiative of the Open Arms Organization delivering telehealth-based occupational therapy, as a model for inclusive development and service delivery in the Philippines. The program responds to gaps in access to rehabilitation services for children with disabilities (CWD) in developing countries, where high costs, geographic isolation, and social exclusion remain persistent barriers.

Method: Using a concurrent mixed-methods design guided by the PACE Framework (Population and Health Outcomes, Access, Cost-Effectiveness, and Stakeholder Experiences), the study purposively sampled twenty-five caregivers and five volunteers for surveys and semi-structured interviews. Data were analyzed through descriptive statistics and thematic analysis, with triangulation employed to enhance rigor and trustworthiness.

Results: Findings indicate that the program contributed to notable improvements in children's functional participation, communication, and emotional and behavioral regulation. Telehealth delivery effectively extended services to underserved and geographically isolated communities while significantly reducing the financial burden on families. Stakeholders reported high satisfaction, citing strong therapeutic relationships and sustained caregiver engagement

Conclusions: The study demonstrates how Embrace A Child Program expands access to rehabilitation services through a cost-effective, stakeholder-endorsed, and community-based approach, albeit limited by a small sample size and the inherent risk of unconscious bias. The findings hold significant implications for the future practice of occupational therapists and related professionals, who may benefit from incorporating telehealth into community-based rehabilitation (CBR) models to enhance service delivery and inclusivity in underserved settings. Stakeholders are urged to explore telehealth-driven CBR models as viable approaches.

Keywords: Program assessment, Community-based rehabilitation, telehealth, Philippines

INTRODUCTION

Children with disabilities (CWD), particularly those in remote communities of developing countries, face significant challenges in reaching basic services, including rehabilitation (Dew et al., 2013). In the Philippines, high cost, geographical inaccessibility, and cultural disability aggravate the situation, many of people being deprived of proper care (Mwangi et al., 2022). Financial constraints feature centrally in challenges that face households with CWD. Having a disability normally has the effect of incurring additional costs for a family, with this having a probable impact on the household budget. Research shows that CWD need around 40% to 80% additional expenditure to reach the same standards of living as children without disabilities, and poverty rates are higher in households with CWD (United Nations Children's Fund [UNICEF] Philippines, 2022). This financial cost is even higher in far-flung areas, where there are fewer work prospects and the expenditure of acquiring goods and services is higher due to remoteness (Dew et al., 2019; Liao et al., 2022). Disability and poverty have been extensively documented, with poor children being more prone to disabilities due to malnutrition and low access to healthcare (Rahman, 2024). Besides economic difficulties, social exclusion continues to be a pressing concern for CWD in such contexts. The children are often discriminated against and stigmatized, leading to social isolation from communities and peers (Asuman et al., 2020; Sarkar & Parween, 2021). Exclusion is especially acute in rural communities, where cultural values surrounding disability might not be as progressive, and there might be a shortage of inclusive programs (Frączek, 2022). Their marginalization is also compounded by the lack of community-based rehabilitation (CBR) services, which are essential in promoting participation and integration into society (Olaogun et al., 2009). Even though CBR is being done in over 90 countries as an effective strategy for rehabilitation, poverty alleviation, and social inclusion of persons with disabilities, there is only a few people with disabilities, approximately 2%, have access to basic health and rehabilitation services (World Health Organization [WHO], 2010; World Physiotherapy, 2023), demonstrating the need to scale up evidenced-based and community-focused strategies. While existing studies provide insights on these barriers extensively, it tends to show them in isolation rather than exploring how intersecting forces, including but not limited to poverty, geography, digital inequity and stigma, compound one another to systematically exclude CWD from rehabilitation. This gap in analytical framing hinders the development of integrated and context-related interventions and solutions.

The introduction of telehealth has been suggested by many as a solution for addressing such gaps, but how it can work in the context of low- and middle-income countries (LMICs) has not received adequate attention. Telerehabilitation was widely adopted in LMICs following the onset of the pandemic, leading to an increase in telehealth-based initiatives whose efficacy and feasibility have not yet been fully explored (Bonnechère et al., 2023). As for the Philippine context, there is a dearth of information regarding the role of telerehabilitation in LMICs, where problems such as slow internet speed, legality, and skepticism are prevalent among practitioners (Leochico & Valera, 2020). Such issues are reminiscent of those linked to the digital divide, a structural problem that threatens the equal utilization of telehealth: factors such as poverty, low literacy rates, lack of motivation for using technology, and lack of technology are among the reasons that the digital divide constitutes a global issue (Zhang et al., 2025). These concerns apply in the case of CWD in developing nations. Despite this, few studies have rigorously evaluated how community-based telehealth programs serving CWD navigate the digital divide while sustaining therapeutic effectiveness, cost effectiveness, and stakeholder engagement simultaneously.

The disparity is particularly noticeable in the Philippines, where telehealth policies have matured over time, with telemedicine being considered as far back as 2012 as a possible approach to serve the needs of around 600 municipalities that have difficulty accessing health care services (Padmanaban & Udayasankaran, 2021), but there is an absence of reviews about the effectiveness of telerehabilitation for CWD. In the current literature, studies on telerehabilitation in the Philippines mostly involve assessments of the implementation and uptake of technology among adults or healthcare professionals, while the holistic outcomes of pediatric rehabilitation interventions supported by telemedicine within communities are rarely explored (Leochico & Valera, 2020; Dulawan et al., 2022). Furthermore, the integration of telehealth approaches with the CBR paradigm, which highlights the involvement of the community, caregivers' agency, and cross-sectoral cooperation, has received little attention both in the context of the Philippines and other comparable LMICs. This is a notable gap in the literature, as CBR supported by telehealth could be a promising model of disability services provision in LMICs.

Embrace A Child Program

The "Embrace A Child" program is an outreach program of the Open Arms Organization in the Philippines that seeks to empower families through accessible social support and rehabilitation services (Open Arms Organization, 2024). Open Arms Organization offers occupational therapy, among other holistic rehabilitation services, to CWD under this program. Besides therapy, the program also offers social support to families to enable them to overcome challenges and access resources they need (Embrace-A-Child Online Community, 2025). Potential and actual clients have access to the organization via the Facebook page, where they are scheduled and matched with interns or staff for therapy. The program also offers webinars and a private Facebook group community to further support them. With a focus on rehabilitation and support, the Embrace A Child program is integral to the promotion of the welfare of CWD and their families in the Philippines. This initiative, launched in 2019 (Open Arms Organization, 2025), has been successfully providing accessible services (Roja, 2023), but its impact evaluation has not yet been pursued extensively and sustainably. As it aims to address the identified key challenges that include prohibitive costs, inaccessibility of services, and systemic discrimination based on cultural and ethnic diversity (Carraro et al., 2023), the lack of assessment inhibits the scope of understanding of the program's effectiveness and the establishment of its areas for improvement. With the increasing scale and reputation of the program, a formal assessment is necessary to assess its reach, impact, and sustainability, and ensure responsiveness to the evolving needs of CWD in the Philippines.

Aims and Research Questions

This study aims to comprehensively evaluate the Embrace A Child program by looking at the program’s effectiveness, accessibility, cost implications, and its stakeholder experiences. Specifically, the study seeks to: (1) assess health outcomes and functional improvements among CWD enrolled in the program; (2) examine how telehealth delivery extends or constrains access to rehabilitation services across geographic and socioeconomic contexts; (3) analyze the program's cost-related impact on families; and (4) document the experiences of caregivers and program volunteers as key stakeholders. In essence, the research tries to bridge two major gaps in the existing literature that are interrelated, which include the need for more empirical studies evaluating the effectiveness of telehealth-based occupational therapy programs for CWDs in the Philippines and the limited information regarding the structure of digital CBR models necessary to ensure inclusivity, affordability, and sustainability in LMICs. The findings are intended to contribute to evidence-based policy and practice discussions on scaling inclusive rehabilitation for marginalized children and families in LMICs.

Moreover, to organize this study, the PACE Framework was utilized. It was developed by Little and his associates in 2021 to help understand and assess telehealth programs. The PACE Framework comprises four domains: (1) Population and Health Outcomes, (2) Access for All Clients, (3) Costs and Cost Effectiveness, and (4) Client and Practitioner Experiences. Each domain includes specific outcomes and operational definitions according to the American Occupational Therapy Association's [AOTA] Occupational Therapy Practice Framework – 4th Edition (2020) and/or WHO (2001), as applicable. It was specifically designed for evaluating evidence-based telehealth interventions with an emphasis on outcome and process. Instead of acting as a strict list of criteria to follow, the PACE Framework acts more as an evaluation tool that is adaptable enough to be used in evaluating a program such as Embrace A Child, where outcomes span functional, relational, financial, and systemic domains. A concurrent mixed-methods design, combining quantitative surveys and qualitative interviews, was selected to ensure that both measurable outcomes and lived stakeholder experiences are captured with appropriate depth and rigor.

METHODS

Research Design

Mixed methods research is currently a standard methodology in contemporary research, providing a more effective examination of research questions (Damyonov, 2023). Concurrent mixed-method design has been employed in this research to fulfill its research objectives. A concurrent mixed-method design involves the simultaneous collection of quantitative and qualitative data (Castro et al., 2010). In this study, priority is placed on evaluating the probable worth and usefulness of the Embrace A Child program across the various dimensions outlined in the PACE Framework. A concurrent mixed-methods approach is the best choice for evaluating the Embrace A Child Program because it allows for a comprehensive analysis of the program's effectiveness, accessibility, and stakeholder experiences.

Participants Recruitment

The study applied a purposive sampling approach study (Palinkas et al., 2015) since the perspectives of participants who were engaged in the Embrace A Child program is critical to the process of further improving its implementation. This sampling method was intentionally chosen to capture the experiences of those most directly affected by the program. However, the authors acknowledge that this approach may limit the generalizability of findings, as participants were drawn exclusively from within the program's existing stakeholder pool. For the qualitative part, which included in-depth interviews, participants were primary caregivers or family members of children in the Embrace A Child program who are at least 18 years old, have provided extensive care to the child, have direct experience of the child's participation in the program, and are able to read and communicate in conversational English and/or Tagalog. See Table 1.1 for the demographic data of the carers' included in the study. Moreover, volunteers or interns who have been part of the program and have directly cared for at least one child were recruited, provided they are aged 18 and above, have prior or ongoing experience with the program, possess conversational knowledge of English and/or Tagalog, and reside in the Philippines. See Table 1.2 for the details.

Table 1.1 Demographic Details of Interviewees

Code	Gender	Age
Carer 1	Female	46 years old
Carer 2	Female	39 years old
Carer 3	Female	34 years old

Carer 4	Female	42 years old
Carer 5	Female	43 years old

Table 1.2 Demographic Details of Volunteers

Code	Gender	Age
Volunteer 1	Male	24 years old
Volunteer 2	Male	23 years old
Volunteer 3	Female	23 years old
Volunteer 4	Female	21 years old
Volunteer 5	Female	36 years old

For the quantitative phase, old and/or current caregivers or family members of the enrolled children were reached through various platforms to send them the validated survey questionnaire. To ensure accessibility, study participants selected must be able to use one or more functional gadgets (e.g., smartphone, tablet, or computer) to complete the survey, be at least 18 years old, and know basic Tagalog to be able to answer appropriately. See Table 2 for the demographic details of the survey participants for the quantitative part of the study.

Table 2 Demographic of Survey Respondents

Cetegory	Total Number (n=20)	Percentage
Relation to Child		
Mother	20	100%
Father	0	0
Others	0	0
Age		
30–34	6	30%
35–39	3	15%
40–44	6	30%
45–49	5	25%
Location		
NCR	11	55%
Region IV-A (CALABARZON)	6	30%
Region III (Central Luzon)	2	10%
Region XII (SOCCSKSARGEN)	1	5%

By employing this participant recruitment method, the study got a whole picture of key stakeholders, having varied views that will help further develop and refine the *Embrace A Child* program.

Data Collection

The study commenced upon approval of a panel. Data collection for both qualitative and quantitative components was carried out simultaneously. A semi-structured interview guide for the major stakeholders, including clients (children's caregivers and families), occupational therapy practitioners, interns, and volunteers, was developed. The semi-structured guide questions were organized around the domains of the PACE Framework to ensure alignment between the data collected and the program evaluation objectives. Moreover, the semi-structured guide questions were reviewed by an external expert. Participants were chosen through a purposive sampling method, and informed consent were obtained prior to conducting in-depth interviews to gather their opinions and experiences regarding the program. It took at least 45 minutes to a maximum of 60 minutes via an online platform to finish the interview. Each was recorded. The two (2) research assistants, who were trained by the primary author, facilitated the interview to mitigate biases and influence during the interactions. Research assistants were briefed on

standardized interview protocols and instructed to avoid leading questions, probe neutrally, and refrain from sharing personal opinions during sessions. The research assistants were interns with a background in occupational therapy and has experience in doing research. A sample of at least four (4) was targeted, since Tanovic (2024) cited that this is the minimum number of participants necessary to make an in-depth interview work. At the end, there were five (5) interviewed caregivers or parents and five (5) volunteers in the sample gathered.

For the quantitative component, a formal survey was designed for program clients and partners to establish accessibility, satisfaction, and health outcomes. The survey tool underwent content validation by at least three external experts, each holding a master's degree and with experience in research and program evaluation. Experts were asked to rate each item for relevance, clarity, and appropriateness, and revisions were made based on their consolidated feedback prior to administration. If the participant needed help to fill out the survey, the research assistants provided time to guide him/her. Like the qualitative process, participant recruitment was conducted according to inclusion criteria, and informed consent was sought before data collection. At least 10% (Fox, 2024) of the beneficiaries within the year 2025, as of writing, were targeted, which is at least 5 participants. The study was able to get at least 20 respondents.

Data Analysis

The analysis of data from both parts was directed in accordance with domains identified in the PACE Framework. The interviews were transcribed electronically and thematically analyzed with codes and themes developed to supply stakeholder experience, program success, and areas of improvement. It followed Braun and Clarke's steps (2006) in thematic analysis. Specifically, the process involved familiarization with the data, generation of initial codes, searching for and reviewing themes, and defining and naming themes. Initial coding was conducted independently by the authors, after which codes were compared and discrepancies resolved through discussion to strengthen inter-rater reliability. For the quantitative data, responses from the online survey were treated using descriptive statistical analysis (Kanade, 2023) to gauge critical program measures such as accessibility, perceived effectiveness, and levels of satisfaction. For ensuring comprehensive evaluation, data and methodological triangulation were employed in the study and included findings of thematic analysis and descriptive statistics. This process allowed integration of different sources of data to establish stronger validity in the findings.

Rigor and Trustworthiness

Ensuring rigor and authenticity is mandatory while constructing the reliability and credibility of research findings (Ahmed, 2024). To ensure the quality of this research, some significant standards were utilized. Credibility was ascertained by extended participation, persistent observation, and triangulation of data and collection methods. Transferability was ensured through the description in detail and depth of the context of research, thus allowing follow-up studies to evaluate the fitness for purpose of results in corresponding settings. Dependability was ensured through tight documentation of the research process itself, including an audit trail of ensuring consistency and traceability. Confirmability was enhanced through peer debriefing and member checking, so that the findings are grounded in participants' experiences rather than researcher bias. As the primary author is an active participant in the Embrace A Child program, additional measures were taken to ensure objectivity. This included the involvement of research assistants and a research adviser. The research adviser served as a check, overseeing the research process to ensure impartiality. Furthermore, participant validation (Hadi & Closs, 2016) occurred to verify that the results accurately mirror stakeholders' perceptions and contribute meaningfully

to program development. These research precautions corroborate the validity and integrity of the study, which ensure the rigor and impact of the evaluation of the Embrace A Child program.

Positionality

The primary author of this study is a Filipino occupational therapist with professional experience in clinical practice, academia, and community-based rehabilitation. He is also the current Executive Director of the Open Arms Organization, the program that is the subject of this evaluation. The author acknowledges that his position as a key internal stakeholder necessitates a transparent and rigorous approach to research. To critically address this potential conflict of interest, the primary author deliberately excluded himself from direct data collection, delegating all interviews and survey administration to trained research assistants. All preliminary findings were reviewed and validated by the research adviser prior to interpretation, providing an additional layer of independent oversight. Therefore, this study is framed from the perspective of an "engaged researcher." This paradigm advocates for inclusivity and participatory methods such as action research, co-production, and co-creation to move beyond the limiting frames of conventional approaches. This reflects the core philosophy that research should be conducted "with" society, not "for" it. Notwithstanding the author's personal connection to the program, he is deeply committed to the trustworthiness of the research findings, which were assessed and validated through each stage of the study's methodology. The second author is the research adviser who has an extensive background in research and community-based programs.

Ethical Considerations

This study follows the research ethical rules specified in the World Medical Association's Declaration of Helsinki (2024). The research protocol was reviewed and approved by the institutional panel of the School of Governance, Public Service, and Corporate Leadership of De La Salle University – Dasmariñas, in accordance with the capstone project requirements of the postgraduate program in which the primary author was enrolled. As this study involved minimal interaction with participants, posed no foreseeable physical or psychological risk, and utilized a small, purposively selected sample drawn from an existing community program, it was classified as exempt from full ethical review under the institution's guidelines for low-risk capstone research. All participants received an informed consent form (ICF) prepared in plain and readable language. The participants' rights and voluntariness of participation were emphasized. Confidentiality and anonymity were maintained strictly during the research. Data collected was stored securely by the principal researcher and passed on to the adviser as needed on a need-to-know basis only. The right to withdraw from participation at any time was also emphasized.

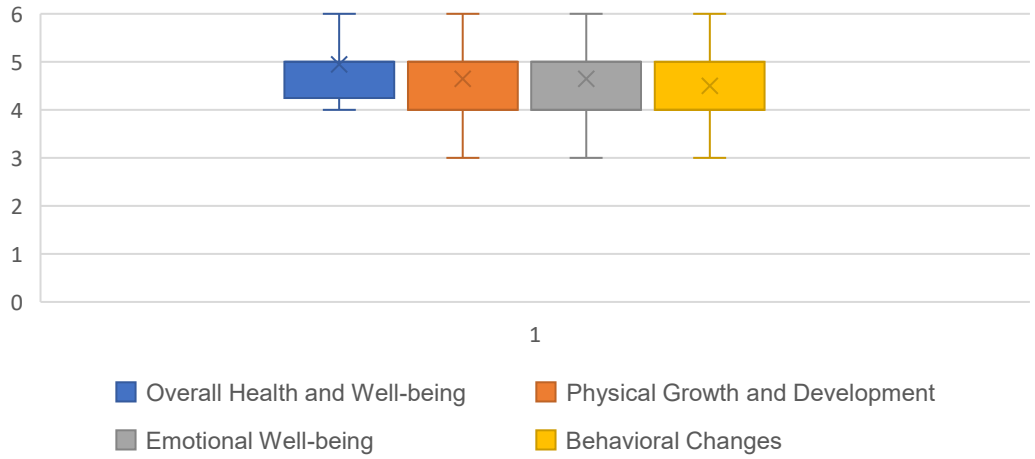
RESULTS

The study explored the perspectives of both volunteers and beneficiaries through one-on-one semi-structured interviews, generating rich narratives that were analyzed along with the quantitative ratings to enable a comprehensive evaluation of the Embrace A Child program. From these interviews, four (4) themes emerged that address the effectiveness of the program based on the PACE framework. The themes included (1) enhancing functional participation and health outcomes through telehealth-based occupational therapy, (2) expanding access to rehabilitation in underserved areas via telehealth, with persistent digital divide challenges, (3) reducing financial burdens through free and home-based services, yet hidden costs remain, and (4) building positive engagement and satisfaction among stakeholders, with opportunities for system strengthening. In a critical lens, these themes are distinct but not isolated, wherein they intersect and reinforce one

another. These are also a product of the analysis of both quantitative scores and qualitative stories, which can be read below.

Enhancing Functional Participation and Health Outcomes through Telehealth

The PACE framework's foundational component is its focus on the population-level health outcomes, which highlights whether the program enables measurable improvements in the functional and developmental domains of its recipients. The Embrace A Child program was perceived by volunteers and carers in general as effective in enhancing the health status and functional participation of CWD. Carers reported notable improvement in their children's communication, emotional regulation, frustration tolerance, and fine motor skills, which were expressed in greater responsiveness during therapy and improved behavior at home and school. As one volunteer attested, "*The caregivers are very satisfied*." Another said, "*They observed improvements at home—fewer tantrums, and their child is now more cooperative.*" Emotional acceptance of the child's condition was also brought about by the program among the families, enabling positive mental health outcomes. For the volunteers, they observed that "[children] *became more well-behaved and more responsive to instructions*," which signifies observable change in functional behaviors. These qualitative remarks are corroborated by the quantitative data.



Note: 6 – Significantly Improved, 1 – Not Significantly Improved; X-axis: Health Outcome Domains; Y-Axis: Health Outcome Ratings

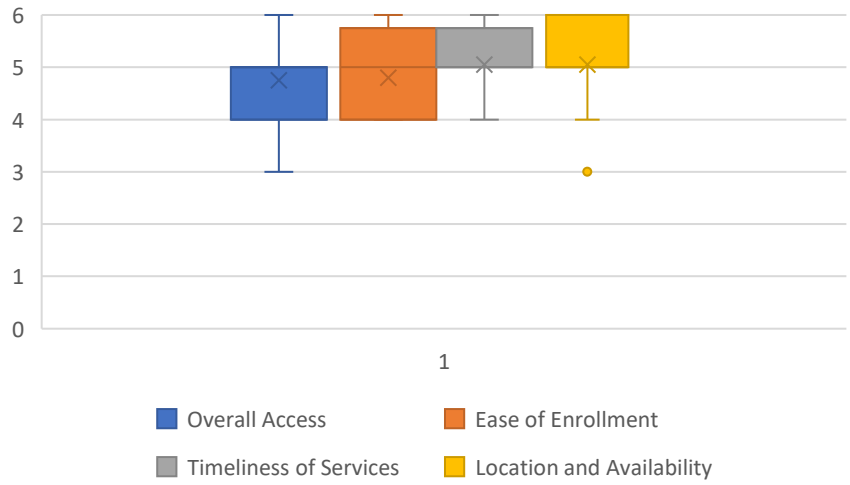
Figure 1. Population and Health Outcomes (P)

When asked whether they had seen changes in their child's physical and mental and/or emotional wellbeing since being in the program, all the participants said "*yes*" although one participant suggested a lack of confidence in physical development. This single reservation is analytically significant as it suggests that while emotional and behavioral gains are more readily perceptible to the caregivers, physical development may require longer timeframes or a more specific tool to be observable. Figure 1 illustrates perceived changes among children receiving the Embrace a Child program rated on a scale of 1 to 6, with 6 being a much improvement and 1 being no improvement at all. Rather than confirming positive ratings, the distribution of scores reveals meaningful variation that warrants interpretation. All the domains have a median score of 5, indicating that caregivers widely saw positive change in these domains. Of the four, Overall Health and Well-being is most consistent, with scores bunched over a narrow range from 4 to 6, reflecting strong consensus among caregivers that the child's overall health improved significantly. This consistency is notable given the diversity of the children within the program and suggests

that the program's holistic approach enables reliable gains even when individual circumstances vary. On the other hand, Physical Growth and Development, Emotional Well-being, and Changes in Behavior, while also positively rated, are more variable among ratings of 3 to 6. This is not a simple noise rather it reflects genuine heterogeneity in children's baseline conditions, the nature of children's disabilities and the duration of engagement with the program. As all four domains reached a maximum score of 6 indicates that some caregivers felt and seen transformative improvements, while the lower-end scores among a minority convey that program impact is moderated by individual factors that a one-size-fits-all telehealth model may not full address. These results collectively shed light to the program's effectiveness while pointing to an unmet need for differentiated treatment pathways and longitudinal follow-up. The volunteers of the program themselves acknowledged that short placement durations limited their ability to witness long-term outcomes, which is a structural gap that warrants attention.

Expanding access to Rehabilitation in Underserved Areas via Telehealth, with Persistent Digital Divide Challenges

Equitable access is essential to the PACE framework's evaluation criteria, which highlights whether the program is serving marginalized populations properly. The program was crucial in enhancing the accessibility of occupational therapy services, especially to disadvantaged and rural populations. Carers and volunteers alike highlighted how telehealth assisted geographically isolated and economically disadvantaged children in accessing therapy at no cost of transport or pricey services. According to one volunteer, "*Not everyone can afford therapy at a center because it can be quite expensive. That's why this program is very helpful.*" Another added, "*…even though they were at a distance, they were still reached*." The caregiver-mediated model, where caregivers or parents were greatly involved, further enhanced access by equipping parents with the ability to offer therapy activities at home, thus making the program available in low-resource environments. These accounts of broad access must, however, be read alongside the structural constraints that simultaneously limit them. The digital divide emerged as a significant systemic challenge. Some of the carers described inconsistent internet connectivity, a lack of digital devices, and conflicting timetables. A carer commented, "*Access to the internet is really the biggest problem…especially in areas where the signal is weak, making it difficult to join the session*." This is not a simple inconvenience, but rather presents a structural inequity in which the very community the program is designed to serve are paradoxically the least equipped to access its services in digital space. Volunteers made suggestions such as providing tutorials, leaflets, and personal mentoring to enhance digital competence, and designing hybrid or offline delivery mechanisms to address connectivity problems. These findings highlight the importance of targeted infrastructure investments for bridging digital divides and upgrading more inclusive access to rehab services.



Note: 6 – Very Accessible, 1 – Not Very Accessible; X-axis: Accesibility Domains; Y-Axis: Accesibility Ratings

Figure 2. Access for All Clients (A)

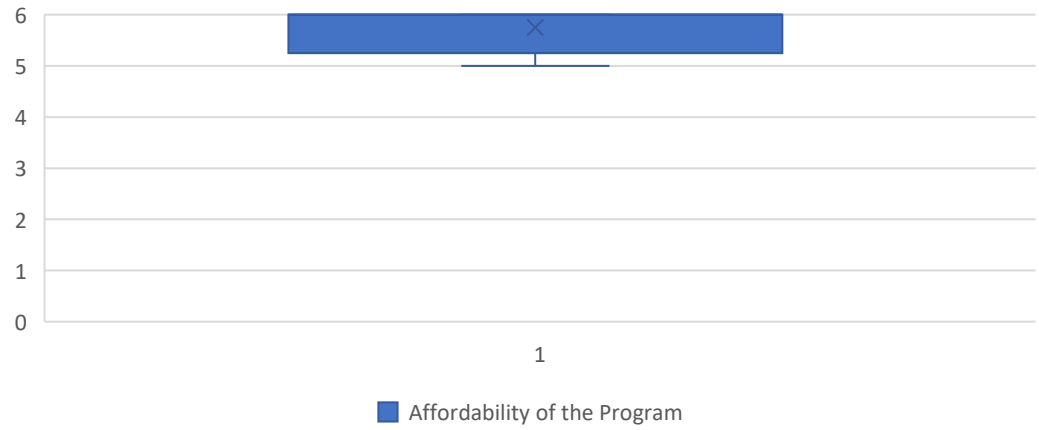
The quantitative data both confirm and complicate this picture. Most of the participants (80%) indicated that they were highly aware of the services of the Embrace A Child program. All the participants indicated that they were encouraged by their child's individual needs. Furthermore, all indicated that the program is comprehensive and caters to all the needs of their children with diverse backgrounds. Based on Figure 2, client satisfaction with program availability is generally good in all aspects being measured since all median scores are 4.5 or higher on a 6-point scale, with 6 indicating very satisfied. The differential pattern across these sub-dimensions is analytically instructive. Clients were most satisfied with Location and Availability and Timeliness of Services, indicating strong, consistent satisfaction. Ease of Enrollment was also held in the highest regard, with an extremely high median score of 5. These three dimensions are connected primarily to the program's design and administrative functioning, which are within the control of the program, and consistency of high scores suggest that the program's structural set-up is well-positioned for its population. In contrast, Overall Access had the most diversified feedback. Although still positive at a median of 4.5, it was most spread in a range of scores (3 to 6), highlighting to an experience that is positive in average but with significant uneven practice. One outlier in the Location and Availability dimension further explains that for some clients, even logistical arrangements that most find adequate remain problematic. Now, taken all together, both quantitative and qualitative data converge on a common conclusion: the program's administrative structures and design facilitate access effectively, but the digital infrastructure on which it depends introduces inequities that are external to the program itself to the program itself and therefore need targeted, system-level proposals, including partnerships with local government units, organizations or telecommunication providers rather than program-level adjustments alone.

Reducing Financial Burdens through Free and Home-based services, yet Hidden Costs Remain

The next essential aspect of the PACE Framework is cost effectiveness, which is significant in the context of the program as it tries to address the economically disadvantaged population. The no-cost structure of the program and telehealth provision largely reduced the economic burden to families, which was always cited as one of the strongest points.

The carers appreciated not spending money on sessions that would otherwise cost them ₱1,000 to ₱1,500 (17 USD to 25 USD) per session in private clinics. Furthermore, the elimination of transport and other logistics expenses made the service more accessible. A volunteer corroborated, "…*they don't have to spend on transportation, and the therapy is already completed even though it's done at home.*" Despite these positive notes, other remarks reveal a pattern of hidden costs that threaten to undermine the program's financial accessibility. Some families continued spending small money for printing worksheets or buying simple materials, while others faced problems, most critically, in paying for reliable internet or computing devices. A carer commented, "*The* [only] *challenge sometimes is that Wi-Fi or data is still needed…not everyone has a device they can use*." These costs are individually modest but collectively significant. They pose as regressive burdens, falling disproportionally on the families with the least resources and potentially deterring sustain participation and engagement. This dynamic echo a broader phenomenon in telehealth literature, wherein the programs designed to lower costs inadvertently shift certain expenditures to service users rather than eliminating them.

Figure 3. *Costs and Cost Effectiveness (C)*



Note: 6 – Very Cost-Effective, 1 – Not Very Cost-Effective; X-axis: Cost Domain; Y-Axis: Cost Ratings

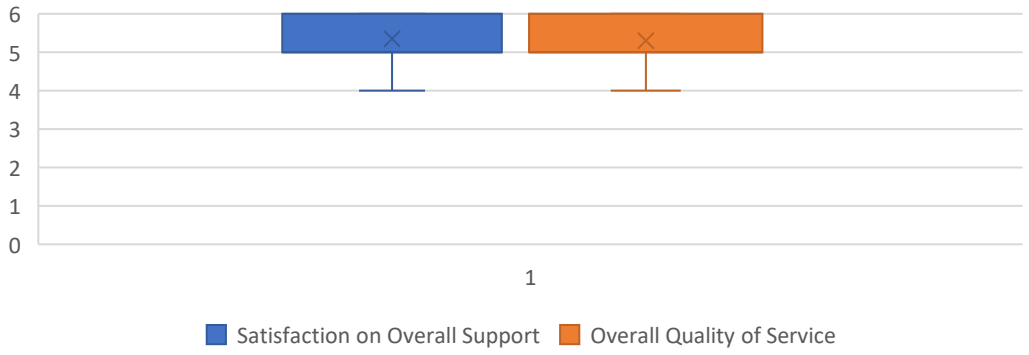
Figure 3. Cost and Cost Effectiveness (C)

The quantitative data on cost perceptions are really striking in their consistency. The majority (70%) of the interviewees marked on a 1-6 scale (where 6 would mean very worthwhile the cost and 1 not worth the cost) that the program is a 6, while 30% marked it as a 5. This means that no participant rated the program below the midpoint, a significant result finding given that even no-cost programs can be perceived as burdensome when hidden costs and time demands are factored in. As indicated by Figure 3, the perceived affordability of the program is very high, with all client comment tightly grouped in the range 5 through 6 on a scale of 6, where 6 is "very affordable." The compression of the scores towards the upper end of the scale, with at least 25% of clients awarding the maximum score, is analytically meaningful. This indicates that the program's cost structure is not merely acceptable but genuinely exceptional relative to what families would otherwise face. Furthermore, 20% of the clients reported obstacles to access despite these positive affordability ratings, sending signals that financial barriers do not account for all access difficulties. This disjuncture between affordability perceptions and access outcomes directs evaluation towards non-monetary barriers, which includes the demands of

caregiving, the inconsistency of the internet access, and the dynamics of single parenthood and other related constraints. Addressing these challenges would need targeted and non-financial support such as flexibility in scheduling, provision of offline and practical materials and community-based support.

Building Positive Engagement and Satisfaction among Stakeholders, with Opportunities for System Strengthening

Finally, the last part of the PACE Framework concerns the quality of stakeholder experience. This encompasses therapeutic relationships, caregiver engagement, and overall satisfaction with program delivery. Stakeholder experiences of the Embrace A Child program were overwhelmingly positive, with therapeutic relationships that were strong, caregiver engagement that was high, and satisfaction with the child-led, play-based focus of the therapy being reported. Carers felt respected, involved in goal setting, and heard by the therapists and volunteers. One volunteer said, "*Even small improvements, like the child being more open to communicate, are a big deal for us and the parents*." These small successes were precious for families. Volunteers emphasized how caregiver attendance at sessions significantly impacted outcomes, and the need for family-centered practice was emphasized. Yet, several issues with implementation were noted that temper an otherwise positive picture. Volunteers noted last-minute session links, inconsistencies with therapist assignment, and child distraction during online sessions, wherein 75% of children were at times disengaged. Volunteers suggested stronger caregiver preparation, monthly workshops, and a school or government partnership to enable hybrid delivery. Carers also recommended including progress reports and follow-up procedures. These are not peripheral concerns since they directly affect the therapeutic gains reported under the first theme, and their recurrence across multiple informants suggests they are systemic rather than incidental.



Note: 6 – Very Satisfactory, 1 – Not Very Satisfactory: X-axis: Experience Domains; Y-Axis: Experience Ratings

Figure 4. Experience of Clients and Other Stakeholders (E)

The quantitative satisfaction data are consistent with this nuanced landscape of the program. Figure 4 shows caregiver ratings of Overall Quality of Service and Satisfaction with Overall Support, both on a 6-point scale. The Overall Quality of Service achieved the highest median value of 5.5, with Satisfaction with Overall Support at 5.0, and in both cases, at least 75% of clients rated the program at 5.0 or above. These are strong scores that indicate that the program has established genuine trust and relational quality with its clients. This is a foundation that is difficult to build and important to protect. The lowest score across both dimensions was 4, reported by 10% of respondents in the context of staff

interactions. Instead of dismissing this as marginal, it should be critically seen as a signal that even at high overall satisfaction levels, a meaningful minority encountered friction in staff communication, and this experience warrants staff training check-ins and feedback integration mechanisms.

All participants shared they would recommend the program to others. Moreover, their feedback was predominantly constructive and future oriented. This is itself a significant insight. Community-based programs are associated with strong social trust and perceived legitimacy, which are necessary preconditions for program sustainability and community-level uptake. Many suggest expansion of service scope, which includes speech and language therapy, increased staffing or interns, the possibility of physical offices and hybrid delivery options, and practical improvements like simplified registration procedures and more structured scheduling communication. Overall, this feedback does not point to dissatisfaction rather an opportunity. Stakeholders who are sufficiently engaged with the program to envision its evolution and advocate for its improvement are an additional win.

To sum it up, four intersecting themes that were revealed show a program whose core design is well-aligned with its population's needs, but whose implementation and delivery are challenged by infrastructural and systemic factors that lie partly beyond its direct control. The qualitative accounts and quantitative scores converge on a consistent finding. The Embrace A Child program delivers meaningful outcomes, high accessibility within its structural constraints, exceptional cost value, and strong stakeholder relationships. However, at the same time, the digital divide, hidden costs, inconsistent service delivery, and absence of longitudinal monitoring systems represent gaps that, if unaddressed, risk limiting the program's impact and equity over time.

This multi-layered understanding, through the lens of the PACE framework, affirms the value of narrative inquiry as an evaluative method. Quantitative data confirmed the program's reach and satisfaction levels, but it is the qualitative accounts of technological frustration, caregiver empowerment, and the meaning of small gains that reveal the mechanisms through which outcomes are produced and the conditions under which they are constrained. As Clandinin and Connelly (2000) argue, narratives and qualitative data are the primary mode through which human experience is rendered meaningful, and it produces situated, contextual knowledge that aggregate scores cannot capture. By integrating both data types within the PACE Framework, this evaluation moves beyond a simple verdict of success or failure toward the generation of actionable, specific insights for program improvement, which Patton (2015) identifies as the central purpose of developmental evaluation.

DISCUSSION

The Embrace A Child program has a salient beneficial effect on the health outcomes and functional participation of its clients, a conclusion well-supported by all sources of evidence. Qualitative interviewing of volunteers and carers provides rich testimony to improved children's communication, emotional regulation, and functional behavior, directly complemented by quantitative survey evidence of a high median score of 5 out of 6 across developmental areas. Furthermore, on the domains of physical growth, emotional well-being, and behavioral change, which scored with greater variability, correspond precisely to the qualitative narratives of individual differences in children's starting point and caregiver engagement levels, conveying that quantitative variance in these areas is not a sign of program inconsistency but rather a reflection of the heterogeneous nature of disability itself (WHO, 2021). This focus on the outcome is further grounded in the principles of CBR, which puts the family and members of the local community as active agents

in the rehabilitation process rather than passive recipients of interventions (ILO, UNESCO, & WHO, 2004). The Embrace A Child program's caregiver-mediated approach aligns closely with this framework, which effectively extends therapeutic reach into the home environment and reinforces capacities of the family.

Such an emphasis on enablement aligns with growing evidence for the efficacy of telehealth for childhood rehabilitation. For instance, a telehealth-based study by Bagner and peers (2023) of developmentally delayed children also registered similar gains in functional skills and caregiver empowerment. The primary problem against the effectiveness of the program, the limited duration of volunteer assignments precluding long-term measurement, is a recognized issue even in the general domain of telerehabilitation. In accordance with a systematic review by Seron and peers (2021), while telehealth interventions consistently demonstrate high short-term effectiveness and patient satisfaction, proving long-term sustainability of the outcome is a methodological issue requiring longitudinal research designs.

The program greatly improves access to rehabilitation services by utilizing a telehealth model, particularly for rural and underserved families, even though the digital divide is one of the main barriers to equal access. The praise for the model in eliminating geographical and travel burdens is a well-known benefit of telehealth. Yet, users still face barriers due to unstable internet, lack of devices, and low digital literacy that reveals a fundamental paradox. This "digital paradox," wherein a technology intended to increase equity may inadvertently reinforce existing inequalities, is a central theme of contemporary telehealth research (Petretto et al., 2024). These barriers are now understood not as mere inconveniences but as powerful "digital determinants of health" that effectively decide who can, and cannot, take advantage of modern healthcare innovations (WHO, 2024). This challenge is especially acute in LMIC contexts, where infrastructure barriers remain significant and telehealth adoption has outpaced the development of enabling conditions (Mahmoud et al., 2022). The results of this research thus confirm that for telehealth to be equitably effective, programmatic support will have to extend beyond clinical care to address these fundamental infrastructural and educational inequities.

Financially, the program is highly successful in lowering costs to families, although certain "hidden costs" associated with the telehealth model still are a problem. The great relief provided to carers from the otherwise prohibitive costs of private therapy costs and travel costs is one of the key drivers of the value proposition of telehealth. These advantages have been monetarily measured by research, with telehealth proven to save families hundreds of dollars per visit in travel avoided and wages not lost (Jungbauer et al., 2023). However, this study's acknowledgment of "hidden costs"—e.g., for internet data, printing papers, or a suitable digital device—resonates with concerns raised by Ramsetty and Adams (2020), who found that patient-side costs in resource-poor settings can present new, if smaller, financial barriers. From the lens of CBR, this underscores the importance of embedding programs within current community support structures and utilizing local resources to offset indirect costs, rather than relying solely on families to absorb them (Iemmi et al., 2017). This means that for programs aimed at economically disadvantaged populations, true cost-effectiveness requires a strategy for limiting these indirect costs, for instance, through providing data subsidies or non-digital material packet.

Stakeholders' experiences with the program are overwhelmingly positive, with high satisfaction and good therapeutic alliances, yet several challenges in implementation suggest clear opportunities for system-level improvement. These levels of satisfaction are a recurring motif within the telehealth literature and are frequently attributable to convenience and the focused, one-on-one nature of virtual visits (Seron et al., 2021). Qualitative comments regarding the "kind and accommodating" staff highlight the critical role of the

therapeutic alliance that Fairweather and associates (2021) found was just as vital in virtual as in in-person relationships. However, the issues observed, such as child distraction during virtual sessions and administrative inconsistencies, are likewise common. The difficulty in maintaining ongoing attentiveness of pediatric clients while in the home environment is an extensively cited issue for clinicians (Fairweather, 2021). Recent research further suggests that structured caregiver preparation protocols and session-readiness checklists can reduce disengagement among clients in telehealth settings, offering a practical and low-cost mechanism for improvement (Quon et al., 2026). In line with this, therefore, the stakeholders in this study's unanimous recommendation of hybrid models blending telehealth with face-to-face elements reflects an emerging consensus in the literature. Most now recommend that hybrid care is not a temporary solution but the perfect going forward because it leverages telehealth's access while preserving the high-touch benefit of in-person contact (Thomas, 2022).

CONCLUSION

This comprehensive evaluation answered the key objectives from the PACE perspective in a systematic manner and concluded that Embrace A Child is a highly valued, effective program. The evidence shows that the program has a categorically positive impact, with clear gains in children's communication, control of emotions, and function behavior as reported by stakeholders, which are upheld by high quantitative indicators for health and well-being.

Telehealth has been instrumental in growing services to economically and geographically disadvantaged populations, though fair access is hampered by a widespread digital divide. Moreover, the program is amazingly effective at lowering costs, but minor hidden technology and material-related expenses continue to be a problem. Finally, participants universally reported good interactions and high satisfaction, while still identifying scheduling and communication inconsistencies that offer clear potential for system-wide improvement. The Embrace A Child program is a successful and valuable service whose sustainability and impact in the long term can be significantly enhanced by strategically addressing the challenges identified in each section of the PACE framework.

From a policy standpoint, the results carry direct implications for local and even national rehabilitation systems in the Philippines and similar LMIC. Integrating volunteer-driven telehealth models into existing CBR frameworks could extend the reach of services without proportional increases in government expenditure (Mwangi et al., 2022; Carraro et al., 2023). The replication of the program model is feasible under conditions of adequate digital infrastructure, trained volunteer pools, and institutional partnerships with local government units or schools: priority areas that policymakers should investigate when designing inclusive rehabilitation initiatives.

The multi-domain strategy was critical in integrating the mixed-methods data so that quantitative measures (e.g., high satisfaction ratings) could be grounded and enriched by qualitative depths (e.g., stories about the digital divide). The PACE framework really came to be the analytical backbone of the study, crystallizing disparate data points into one cohesive and integrated assessment of the Embrace A Child program. As the program evolves, it continues to lead in the empowerment of children and families, a beacon of what is possible through compassion, imagination, and uncompromising dedication to public service. Future studies with larger, more diverse samples are needed to test whether these patterns hold beyond the current setting.

Limitations

It must be pointed out that this research has its own limits to provide an accurate reflection of its results. To start with, the study was restricted by a small sample of respondents analyzed. Hence, this research was not designed as an exhaustive, summative

review of the Embrace a Child program. Instead, it gives an exploratory image of the existing situation of the program to inform existing development and leave room for potential replication. Second, the application of the PACE framework is based on its broad conceptual areas rather than an exhaustive detailing of all delicate items. This degree of analysis helped provide an overview but could have overlooked some finer nuances. Also, being an insider researcher invested in the program, the author's positionality is an aspect that needs to be considered. Even with cautious procedures followed to determine trustworthiness and counteract bias, the scope for unconscious bias in interpreting data cannot be eliminated entirely. Lastly, the research was conducted under the large time constraints characteristic of a project, which restricted the overall scope and depth of the investigation. These constraints define the boundaries of this current study and identify lucrative directions for subsequent, more in-depth studies.

Ways Forward

It is possible for future studies to contemplate a longitudinal design that would allow them to monitor the same group of people for several years. This design would reveal the long-term effects of telehealth practices on children's development, independence, and social acceptance. Using comparative studies, resource distribution may be directed and service delivery optimized in areas with little resources by examining models based on telehealth only, a combination of telehealth and face-to-face, and face-to-face only. The integration of programs like Embrace A Child into public health and education systems may be hindered by certain factors or supported by others, thus indicating, through some case studies of LGU and school partnership, what the best way is for scaling inclusive rehabilitation services. Using the PACE framework in such studies may facilitate the methodical evaluation of outcomes, accessibility, cost-effectiveness, and stakeholders' experiences, which will, in turn, provide actionable insights for program refinement and sustainability.

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Data Availability Statement: The data that support the findings of this study are not publicly available due to confidentiality obligations and the privacy of participants. Interview transcripts and survey responses contain personally identifiable information and were collected under informed consent agreements that restrict public disclosure. The data may be made available to qualified researchers upon reasonable request to the corresponding author, subject to ethical review and approval.

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Original Research Article

Physical Activity, Sedentary Behaviour and Physical Fitness among Male Adolescents with and without Intellectual Disability in Kinshasa, Democratic Republic of Congo

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ABSTRACT

Background: Physical activity, sedentary behaviour, and physical fitness are key health indicators, yet they remain under-documented in the Democratic Republic of Congo, particularly among adolescents with intellectual disability (ID).

Objective This study aimed to (i) compare levels of physical activity, sedentary behavior, body composition, and physical fitness between adolescents with and without intellectual disability, and (ii) examine the associations between body composition and physical fitness variables.

Method: A cross-sectional analytical study was conducted over a three-month period (November 2022 to February 2023) among 322 male adolescents aged 12-17 years attending school in Kinshasa, Democratic Republic of Congo. A stratified convenience sampling strategy was used, whereby schools were first stratified by type (specialized vs. mainstream), and participants were then recruited based on availability within each stratum. The sample included 180 adolescents with clinically diagnosed moderate intellectual disability and 142 without ID. Physical fitness (balance, flexibility, and upper limb strength) was assessed using standardized EUROFIT tests. Body composition (waist circumference, fat mass, and muscle mass) was measured using anthropometry and bioelectrical impedance. Physical activity and sedentary behavior were assessed using the validated CAPAS-Q questionnaire. Group comparisons were conducted using Student's t-test or Mann–Whitney U test, and χ^2 tests for categorical variables. Effect sizes (Cohen's d, Cramér's V) and regression analyses were computed.

Results: Adolescents with ID showed higher waist circumference (66.2±1.5 vs 65.6±1.3, d = -0.42, $p < 0.001$) and body fat percentage (21.0±1.9 vs 20.6±1.6, d = -0.26, $p = 0.017$), and lower muscle mass (20.9±2.6 vs 25.5±2.9, d = 0.69, $p < 0.001$) compared to peers without ID. They also demonstrated lower flexibility (8.3±2.1 vs 12.8±1.8, d = 2.26, $p < 0.001$) and balance (6.8±3.4 vs 10.0±2.2, d = 1.09, $p < 0.001$). Sedentary behavior was significantly higher (Cramér's V = 0.73–0.88, $p < 0.001$), while physical activity levels were lower (Cramér's V = 0.50–0.84, $p < 0.001$). Regression analyses indicated that muscle mass positively

predicted flexibility ($\beta = 0.57$, $p < 0.001$) and balance ($\beta = 0.81$, $p < 0.001$), whereas waist circumference negatively predicted both outcomes.

Conclusion: Adolescents with intellectual disability exhibit lower physical activity, higher sedentary behavior, poorer body composition, and reduced physical fitness compared to their peers. Body composition, particularly muscle mass and abdominal adiposity, is strongly associated with physical fitness outcomes. These findings highlight the need for targeted, inclusive physical activity interventions in the Congolese context.

Keywords: Physical activity; Adolescents; Intellectual disability; Physical fitness; Sedentary behaviour.

INTRODUCTION

Adolescents with intellectual disability (ID) represent a particularly vulnerable group in terms of physical health. Research consistently shows that these youths exhibit significantly lower levels of physical activity and higher levels of sedentary behaviour compared with their peers without ID (Elmahgoub, 2025; McGarty et al., 2021; Choi et al., 2020; Xu et al., 2020; Holloway et al., 2018). These generally unfavourable lifestyle patterns are often associated with reduced overall physical fitness, particularly with respect to balance, flexibility, and muscular strength, especially in the upper limbs (Lee et al., 2016; Pace & Bricout, 2015; Jaakkola et al., 2021; Herwegen et al., 2018; Sansi et al., 2019).

In the Democratic Republic of the Congo (DRC), approximately 13 million people live with a disability, representing nearly 18% of the population, including individuals with ID (Langwana & Bitumba, 2016). This high prevalence may be explained by several factors, including armed conflicts, domestic accidents, disabling diseases, and limited access to preventive and curative healthcare services (Omadjela & Angalawe, 2022; World Health Organization, 2022).

Adolescents with ID in the DRC face multiple forms of marginalization. They are often stigmatized and sometimes kept at home due to sociocultural beliefs associating disability with family shame (Aldersey et al., 2014; Kuper et al., 2020). Even when enrolled in special schools, these adolescents have very limited access to adapted physical activity (APA) programs. This situation may be explained by a lack of sports infrastructure, insufficient teacher training in APA, and limited support from families and the educational community. As a result, these adolescents are at increased risk of low physical activity levels, deteriorating physical fitness, and higher sedentary behaviour. Furthermore, in the sociocultural context of the DRC where masculinity is often associated with physical performance and strength, poor physical fitness among boys with ID may exacerbate stigma and further limit their social participation and autonomy.

Despite these challenges, no empirical study has yet been conducted in the DRC to systematically examine physical activity levels, sedentary behaviour, and physical fitness among male adolescents with ID. This lack of contextual data represents a major barrier to the development of appropriate, inclusive, and culturally relevant interventions (Mactaggart et al., 2018; Bright et al., 2019).

The present study is guided by the following research question: What are the levels of physical activity, the extent of sedentary behaviour, and the state of physical fitness among adolescents with intellectual disability in the Congolese context, and how do these variables interact with one another?

The objectives of this study are: (1) to assess physical activity levels, sedentary behaviour, and physical fitness among adolescents with ID enrolled in schools in Kinshasa,

and to compare them with their peers without ID; (2) to analyse the relationships between physical activity, sedentary behaviour, and physical fitness; and (3) to examine the association between these variables and body composition indicators.

We hypothesize that adolescents with ID have lower levels of physical activity, higher levels of sedentary behaviour, and poorer physical fitness compared with their peers without ID. It is also assumed that physical activity is positively associated with physical fitness, whereas sedentary behaviour is negatively associated with it. Finally, body composition indicators, particularly body mass index and fat mass, are expected to be significantly associated with physical fitness and to influence the relationships between physical activity, sedentary behaviour, and physical performance (Carbone et al., 2020; Hills et al., 2021).

METHODS

Study Design and Setting

This study was a cross-sectional analytical observational study conducted in accordance with the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines (Von et al., 2007). The study was carried out in Kinshasa, Democratic Republic of Congo, across seven secondary-level schools, including five specialized institutions for adolescents with intellectual disabilities (Bondeko Twendeleye Village, Sembola, Mawete, Kikesa Centre, and Bon Départ School) and two mainstream schools (Complexe Scolaire Les Chérubins and École Frère Emmanuel Stablum). These institutions were purposively selected based on their accessibility, their enrollment of adolescents with and without intellectual disabilities, and their capacity to support standardized physical fitness assessments.

Study Population

The target population consisted of male adolescents aged 12 to 17 years who were enrolled in either specialized or mainstream schools in Kinshasa. The study population included all eligible adolescents attending the selected schools during the study period. Participants were categorized into two groups: adolescents with intellectual disability (ID group) and adolescents without intellectual disability (control group).

Identification and Classification of Intellectual Disability

Adolescents with intellectual disability were identified through a two-step verification process:

1. **Clinical diagnosis:** Participants in the ID group had a prior diagnosis of moderate intellectual disability established by qualified neuropsychiatrists or clinical psychologists, based on standardized diagnostic criteria consistent with international classifications (DSM or ICD frameworks as applied in the institutions).
2. **Institutional verification:** The diagnosis was confirmed through review of school medical and administrative records. These records included clinical assessments and educational placement documentation indicating enrollment in specialized education programs for intellectual disability.

No additional diagnostic screening was conducted by the research team; only previously established and documented diagnoses were used to ensure reliability and ethical compliance.

Adolescents in the control group were recruited from mainstream schools and had no history or record of intellectual disability, as confirmed by school records and teacher reports.

Sampling Procedure

A multi-stage stratified convenience sampling strategy was employed.

Stage 1: Stratification of schools

Schools were first stratified into two categories:

- Specialized schools (for adolescents with intellectual disabilities)
- Mainstream schools (for adolescents without intellectual disabilities)

Stage 2: Selection of schools

Within each stratum, schools were selected purposively based on accessibility, willingness to participate, and suitability for conducting physical assessments.

Stage 3: Participant recruitment

Within each selected school, eligible participants were recruited using a convenience sampling approach. All adolescents meeting the inclusion criteria and present during the data collection period were invited to participate. This approach allowed the inclusion of participants from different institutional contexts while accounting for logistical and ethical constraints.

Sample Size and Distribution

The final sample consisted of 322 male adolescents, including 180 adolescents with intellectual disability and 142 adolescents without intellectual disability. Participants were recruited from seven schools, namely Bondeko Twendeleye Village (n = 48), Sembola (n = 40), Mawete (n = 30), Kikesa Centre (n = 32), Bon Départ School (n = 30), Complexe Scolaire Les Chérubins (n = 80), and École Frère Emmanuel Stablum (n = 62).

Inclusion Criteria

Participants in the intellectual disability (ID) group were male adolescents aged 12–17 years who were enrolled in specialized schools. All participants in this group had a confirmed diagnosis of moderate intellectual disability made by a qualified professional, with diagnoses verified through school records. In addition, all adolescents were medically cleared for participation in physical activity and provided assent, alongside informed consent from their parents or legal guardians.

The control group consisted of male adolescents aged 12–17 years enrolled in mainstream schools. Participants in this group had no diagnosis of intellectual disability, were medically cleared for physical activity, and similarly provided assent with parental or guardian consent prior to participation.

Data Collection

A structured data collection form was developed to record sociodemographic information (age), body composition variables (waist circumference, body fat percentage, and muscle mass percentage), and physical fitness components (balance, flexibility, and upper limb strength). This form was supplemented by the *Children and Adolescents Physical Activity and Sedentary Questionnaire (CAPAS-Q, 8–18 years)* to assess physical activity levels and sedentary behaviours in the school context.

Questionnaire

The Children and Adolescents Physical Activity and Sedentary Questionnaire (CAPAS-Q; 8-18 years) was used to assess physical activity levels and sedentary behaviours across different contexts. For this study, only school-related dimensions were considered. Although this instrument has been previously used in adolescent populations, its validation should be explicitly supported by appropriate references, and key information regarding its development and psychometric properties needs to be clearly documented. Moreover, it should be noted that the CAPAS-Q has not yet been formally validated in the Congolese context.

Rather than detailing individual items, the questionnaire was operationalized by grouping variables into two domains: physical activity (e.g., indicators related to intensity

and daily movement within the school setting) and sedentary behaviour (e.g., time spent sitting and screen-related activities during school hours). Internal consistency of the selected items was assessed using Cronbach's alpha, with reference to prior methodological work (e.g., Fillon et al., 2022), although further clarification of this analytical approach is warranted.

The questionnaire was administered under standardized conditions and supervised by the principal investigator. To ensure comprehension among adolescents with intellectual disabilities, questions were read aloud and, when necessary, simplified or reformulated while attempting to limit interviewer-induced bias. Additional details regarding the mode of administration, scoring procedures, and measurement protocols should be provided to strengthen methodological transparency and reproducibility.

Physical Fitness Tests

Based on previous studies involving individuals with intellectual disabilities, three tests from the EUROFIT battery were used: balance, flexibility, and flexed-arm hang tests. These were complemented by body composition measurements (waist circumference, body fat percentage, and muscle mass percentage).

Body Composition Measurements

Body composition measurements were conducted in accordance with the standards of the International Society for the Advancement of Kinanthropometry (ISAK, 2019). For adolescents with intellectual disabilities, adaptations such as simplified instructions and assistance were provided.

Waist Circumference

Waist circumference was measured using a SECA 201 tape measure (SECA GmbH, Hamburg, Germany; precision ±1 mm). Participants stood upright with feet shoulder-width apart and arms relaxed at their sides. The tape was placed horizontally at the upper border of the iliac crest, parallel to the ground. Measurements were taken after normal expiration without abdominal contraction. Two measurements were recorded and the mean value was used.

Body Mass Index (BMI)

BMI was calculated using the formula: weight (kg) / height (m^2). Weight was measured using a Seca 760 scale (Hamburg, Germany; precision 0.1 kg), and height was measured with a Seca stadiometer (range 0–200 cm; precision 0.1 cm).

Body Fat and Muscle Mass

Body composition (fat mass and muscle mass) was assessed using a bioelectrical impedance analyser (OMRON BF511, Omron Healthcare, Kyoto, Japan; accuracy ±1% for fat mass and ±0.1 kg for muscle mass). Participants stood barefoot on the device electrodes, holding the handles with their arms relaxed at their sides. Metallic or electronic objects were removed before measurement. Assessments were performed after at least two hours post-exercise or fasting conditions to standardize hydration status. Two measurements were taken and averaged.

Physical Fitness Tests

Participants wore standardized sports clothing. Evaluators were trained, and familiarization sessions were conducted. Close supervision was ensured in accordance with recommendations for functional assessment in this population (Léger et al., 1988). All tests followed EUROFIT protocols, with prior demonstrations to ensure understanding and safety. Teachers from each class assisted in the process.

Flamingo Balance Test

Static balance was assessed using the Flamingo Balance Test. Participants maintained one-leg stance on a narrow beam for 60 seconds. Each participant had three attempts, and the best score was recorded.

Sit-and-Reach Test

Flexibility was assessed using the Sit-and-Reach test. Participants were asked to bend forward from a seated position with legs extended. Two trials were performed, and the best score (cm) was recorded.

Flexed-Arm Hang Test

Upper limb strength was assessed using the flexed-arm hang test, in which participants hung from a bar with the chin above the bar for as long as possible. The score corresponded to the duration (seconds).

Data Analysis

Data were entered using Microsoft Excel 2013, checked for quality control, and analysed using Jamovi software version 2.6.44. Minimum sample size was estimated using G*Power version 3.1, indicating at least 53 participants per group to detect statistically significant differences. Quantitative variables were expressed as means ± standard deviations, while categorical variables were presented as frequencies and percentages. Normality was assessed using the Shapiro-Wilk test and Q–Q plots.Group comparisons were performed using the independent Student's t-test for normally distributed data and the Mann–Whitney U test for non-normal distributions. The Chi-square test was used for categorical variables, and Fisher's exact test was applied when expected frequencies were below 5. Multiple linear regression analyses were conducted to examine associations between body composition (independent variables) and physical fitness outcomes (dependent variables). Each fitness outcome was analysed in a separate model, adjusting for age where appropriate. Standardized β coefficients, p-values, and 95% confidence intervals were reported. Model assumptions were verified (linearity, independence of residuals, normality, homoscedasticity, and multicollinearity with VIF < 5). Only models meeting these assumptions were retained. Pearson correlation coefficients were used for normally distributed variables, and Spearman's rank correlation for non-normal distributions. Effect sizes were calculated using Cohen's d (small = 0.2, moderate = 0.5, large ≥ 0.8) and Cramer's V for categorical variables. Statistical significance was set at $p < 0.05$ (two-tailed). Overall, the methodological and ethical choices of this study were guided by the aim of producing rigorous, respectful, and useful findings for professionals, families, and stakeholders involved in the inclusion of adolescents with intellectual disabilities.

Ethical Considerations

The study protocol was reviewed and approved by the National Ethics Committee of the Ministry of Public Health of the Democratic Republic of the Congo (Approval No. 404/CNES/BN/PMMF/2022, dated 30 October 2022). The study was conducted in accordance with international ethical principles governing research involving human participants. Written informed consent was obtained from parents or legal guardians, and assent was obtained from all participating adolescents. Data were anonymized prior to statistical analysis. Participants had the right to withdraw from the study at any time without any consequences.

RESULTS

Table 1 indicates that adolescents with intellectual disability (ID) had significantly higher waist circumference and body fat percentage compared to their peers without ID ($d = -0.42$ to -0.26, $p \leq 0.017$). In contrast, muscle mass percentage was significantly lower in the ID group ($d = 0.69$, $p < 0.001$). Regarding physical fitness, adolescents with ID demonstrated markedly poorer performance in flexibility ($d = 2.26$, $p < 0.001$) and balance ($d = 1.90$, $p < 0.001$). However, no significant difference was observed in upper limb strength between the two groups ($d = 0.03$, $p = 0.777$). Age did not differ significantly between groups ($d = 0.21$, $p = 0.062$), indicating comparability in this characteristic.

Table 1. Comparison of mean sociodemographic, body composition, and physical fitness of adolescents with and without intellectual disabilities.

	Boys with DI (n=180)	Boys without DI (n=142)		
Variables	Mean±SD	Mean±SD	P	Size effect Cohen's [CI 95%]
Age (year)	13.2±0.8	13.0±0.7	0.062	0.21 [0.04, 0.49]
BMI (kg/m2)	21.6±2.4	21.1±2.5	0.131	0.21[-0.44,0.02]
Waist circumference (cm)	66.2±1.5	65.6±1.3	<.001	-0.42 [-0.63,-0.19]
Total fat (%)	21.0±1.9	20.6±1.6	0.017	-0.26 [-0.48,-0.05]
Muscle (%)	20.9±2.6	25.5±2.9	<.001	0.69 [0.46, 0.92]
Flexibility(cm)	8.3±2.1	12.8±1.8	<.001	2.26 [1.98, 2.54]
Balance (seconds)	6.8±3.4	10.0±2.2	<.001	1.09 [0.85, 1.33]
Arm strength (seconds)	2.6±1.0	2.7±1.1	0.777	0.03 [-0.18, 0.25]

ID : Intellectual disability, BMI : body mass index, SD : standard deviation, CI : confidence interval

Table 2. Comparison of School-Based Physical Activity Levels between male Adolescents with and without Intellectual Disability

Variables/categories	Boys with ID (n=180) N(%)	Boys without ID (n=142) N(%)	p (Chi²)	Effect size (Cramér's V)
Number of PA hours at school (Q1)			<.001	0.70
Less than 2 hours	117 (65.0%)	-		
2 to 4 hours	47 (26.1%)	134 (94.4%)		
4 to 6 hours	16 (8.9%)	8 (5.6%)		
More than 6 hours	-	-		
Occurence of sweating during the PA (Q2)			<.001	0.84
No way	152 (84.4%)	5 (3.5%)		
A little	21 (11.7%)	60 (42.3%)		
Moderately	7 (3.8%)	40 (28.2%)		
A lot	-	37 (26.1%)		
Daily time spent walking or running (Q3)			<.001	0.57
Less than 15 minutes	154 (85.6%)	56 (39.4%)		
15 to 30 minutes	26 (14.4%)	63 (44.4%)		
30 minutes to 1 hour	-	16 (11.3%)		
More than 1 hour	-	7 (4.9%)		
Occurrence of Breathlessness walking (Q4)			<.001	0.50

No way	160 (88.8%)	42 (33.8%)		
A little	14 (7.7%)	52 (41.9%)		
Moderately	6 (3.3%)	19 (15.3%)		
A lot	-	11 (8.8%)		
Number of flights of stairs climbing per day (Q5)			<.001	0.73
Less than 2	48 (26.6%)	43 (30.3%)		
3 to 5	5 (2.7%)	41 (28.9%)		
6 to 10	-	22 (15.5%)		
More than 10	-	36 (25.4%)		

N=180 boys with ID, n=142 boys without ID. Cramer's V=0.1 : low , 0.3=medium, 0.5=high, PA: physical activity

Adolescents with intellectual disability (ID) demonstrated significantly lower levels of daily physical activity compared with their peers without ID ($p < 0.001$), with very strong effect sizes (Cramer's V = 0.50–0.84). The majority of adolescents with ID reported engaging in less than 2 hours of physical activity at school (65% vs. 0%), and the absence of sweating during physical activity was far more frequent in this group (84.4% vs. 3.5%). Similarly, most adolescents with ID reported walking or running for less than 15 minutes per day (85.6% vs. 39.4%) and rarely experienced breathlessness or sweating during activity (88.8% vs. 33.8%). In addition, adolescents with ID more frequently reported climbing fewer than two flights of stairs per day (26.6% vs. 30.3%) compared with their peers without ID, who generally exhibited higher overall activity levels (Table 2).

Table 3. Comparsion of School-Based Sedentarity Behaviour between male adolescents with and without Intellectual Disabilities

Variables/categories	Boys with ID (n=180) N(%)	Boys without ID (n=142) N(%)	p (Chi²)	Effect size (Cramér's V)
Time spent sitting/day in class			p<.001	0.73
Less than 2 hours	-	45 (31.7%)		
2 to 4 hours	6 (3.3%)	19 (13.4%)		
4 to 6 hours	22 (12.2%)	26 (18.3%)		
6 to 8 hours	145 (80.5%)	25 (17.6%)		
8 to 10 hours	7 (3.8%)	15 (10.6%)		
More than 10 hours	-	12 (8.5%)		
Time spent in front of the screen			p<.001	0.88
Less than 30 minutes	-	61 (43.0%)		
30 minutes to 1 hour	-	37 (26.1%)		
1 to 1.5 hours	6 (3.3%)	12 (8.5%)		
1.5 to 2 hours	139 (77.2%)	8 (5.6%)		
2 to 2.5 hours	30 (16.7%)	5 (3.5%)		
More than 2 hours and 30 minutes	5 (2.7%)	19 (13.4%)		
How many times have I spent sitting for more than 1 hour and 30 minutes without moving?			p<.001	0.76
0 times	-	25 (17.6%)		

1 time	-	26 (18.3%)
Twice	8 (4.4%)	22 (15.5%)
3 times	51(28.3)	19 (13.4%)
4 times	90 (50.0%)	16 (11.3%)
more than 4 times	31 (17.3%)	34 (23.9%)

N=180 adolescents with ID, n=142 adolescents without ID. Cramer's V=0.1: low, 0.3=medium, 0.5=high

Table 3 shows that adolescents with intellectual disability (ID) exhibited significantly higher levels of sedentary behaviour compared with their peers without ID. In the classroom setting, a large proportion of adolescents with ID reported prolonged sitting time of 6–8 hours per day (80.5% vs. 17.6%, $p < 0.001$; Cramer's V = 0.73). Similarly, screen-based sedentary time was substantially higher in the ID group, with 77.2% reporting 1.5–2 hours of screen exposure compared to 5.6% in the non-ID group ($p < 0.001$; Cramer's V = 0.88). In addition, adolescents with ID more frequently reported prolonged uninterrupted sitting episodes (>1.5 hours), with 50% indicating being seated at least four times per day compared to 11.3% of their peers without ID ($p < 0.001$; Cramer's V = 0.76).

Table 4. Linear regression analysis between flexibility and body composition variables

Predictor	B	Standard error	t	P	95% confidence interval		VIF
					Terminal inf	Superior	
Originally ordered	31.3203	6.3206	4.955	<.001	18,885	43.7559	
Waist circumference	-0.4184	0.1033	-4.048	<.001	-0.622	-0.2150	1.24
Total Fat	-0.2977	0.0952	-3.128	0.002	-0.485	-0.1105	1.61
Muscle	0.5701	0.0448	12,721	<.001	0.482	0.6583	1.55

N=180

Table 4 presents the results of the linear regression analysis examining the association between body composition and flexibility. Flexibility was significantly associated with body composition variables. A positive relationship was observed between muscle mass percentage and flexibility ($\beta = 0.57$, $p < 0.001$), indicating that higher muscle mass is associated with better flexibility performance. In contrast, waist circumference ($\beta = -0.42$, $p < 0.001$) and total body fat percentage ($\beta = -0.30$, $p < 0.002$) were significant negative predictors of flexibility. Assessment of multicollinearity using variance inflation factors (VIF < 1.61) indicated no evidence of problematic collinearity among the independent variables (Table 4).

Table 5. Linear regression analysis between equilibrium and body composition variables

Predictor	B	Standard error	T	P	95% confidence interval		VIF
					Terminal inf	Superior	

Originally ordered	0.1100	4.2395	0.0260	0.979	-8.2311	8.4511	
Waist circumference	-0.1705	0.0693	-2.4591	0.014	-0.3068	-0.0341	1.24
Total Fat	0.0546	0.0638	0.8548	0.393	-0.0710	0.1801	1.61
Muscle	0.8088	0.0301	26.9046	<.001	0.7496	0.8679	1.55

N=180

This regression analysis table indicates that balance is significantly influenced by body composition. Muscle mass was identified as a major positive predictor ($\beta = 0.81$, $p < 0.001$), whereas waist circumference showed a moderate negative but non-significant effect ($\beta = 0.05$, $p = 0.393$). The variance inflation factors (VIF < 1.61) indicate the absence of problematic multicollinearity (Table 5).

Table 6. Correlation between age, body composition parameters and motor skills in adolescents with intellectual disabilities

Variables		Age	Waist circumference	Total Fat	Muscle	BMI	Flexibility	Balance	FBMG
Age	Pearson's r	—	r=0.141**	r=0.132**	r=0.316***	r=-0.024	0.275***	0.335***	0.001
	p-value	—	p=0.006	p=0.009	p<.001	p=0.678	<.001	<.001	p=0.490
Waist circumference	Pearson's r	0.141**	—	0.365***	0.363***	0.291***	-0.020	0.250***	0.112*
Total Fat	Pearson's r	0.132**	0.365***	—	0.568***	0.362***	0.139**	0.496***	0.197***
Muscle	Pearson's r	r=0.316***	0.363***	0.568***	—	0.300***	0.528***	0.875***	0.183***
Flexibility	Pearson's r	0.275***	-0.020	0.139**	0.528***	0.050	—		0.095*
Balance	Pearson's r	0.335***	0.250***	0.496***	0.875***	0.212***	0.665***	—	0.169
FBMG	Pearson's r	0.001	0.112*	0.197***	0.183***	0.088	0.095*	0.169**	—

N=180 boys. r=Pearson correlation. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$, two-tailed test

Pearson correlation analyses (Table 6) revealed significant associations between age, body composition, and motor skills among adolescents (n = 180). Age was positively correlated with muscle mass ($r = 0.316$, $p < 0.001$), flexibility ($r = 0.275$, $p < 0.001$), and balance ($r = 0.335$, $p < 0.001$). However, no significant association was observed between age and upper limb strength (Table 6).

DISCUSSION

This cross-sectional analytical study involving 322 adolescents (180 with intellectual disability [ID] and 142 without ID) aimed to compare physical activity levels, sedentary behaviour, and physical fitness between the two groups, and to examine associations between body composition and motor performance. The findings indicate that boys with ID have significantly lower physical activity levels, higher sedentary behaviour, and reduced motor performance compared with their peers without ID. These differences are accompanied by an unfavourable body composition profile, characterised by lower muscle mass and higher adiposity. In particular, reduced muscle mass and increased waist circumference were associated with poorer balance and flexibility, whereas upper limb strength appeared relatively preserved.

These findings are consistent with previous literature reporting that adolescents with ID often have higher fat mass and poorer physical fitness, particularly in balance and flexibility (Farías et al., 2022; Totsika et al., 2022). They also confirm that body composition is an important determinant of motor performance in this population. The association analyses further show that muscle mass is positively related to balance and flexibility, highlighting its role in postural control and functional stability. Conversely, waist circumference is negatively associated with these motor abilities, suggesting that central adiposity may impair coordination and reduce movement range. Total body fat was not consistently associated with motor outcomes, indicating that fat distribution particularly abdominal fat may be more relevant than overall adiposity in explaining functional limitations (Ferrero et al., 2023; Wang et al., 2022).

High sedentary behaviour combined with low physical activity levels in adolescents with ID may contribute to worsening body composition and reduced motor performance, as previously reported (Yilmaz & Mirze, 2024; Delfa et al., 2025). These findings support the existence of a negative cycle linking sedentariness, increased adiposity, and reduced functional capacity (Gutiérrez-Cruz et al., 2025; Li & Hu, 2025).

Regression analyses confirmed that muscle mass is a positive predictor of balance, while waist circumference exerts a significant negative effect. Overall, motor performance in adolescents with ID appears to depend more on body composition quality, particularly muscle mass and central adiposity, than on total body fat (Zwack et al., 2023). Enhancing muscle mass and reducing abdominal adiposity should therefore be considered key targets for improving functional autonomy in this population (Beck et al., 2022; Yuan, 2021).

This study highlights significant inequalities in physical health among male adolescents with intellectual disability. Compared with their peers without ID, they exhibit higher levels of sedentary behaviour and adiposity, as well as lower levels of physical activity and physical fitness, particularly in balance and flexibility. The findings also underline the key role of muscle mass in physical performance and the strong association between body composition and physical fitness. These results emphasise the need for concrete action at both practice and policy levels. The development and implementation of inclusive, accessible adapted physical activity (APA) programmes tailored for adolescents with ID in school and community settings are essential. Strengthening the capacity of teachers, educators, and health professionals in APA is also a key priority.

Furthermore, the integration of inclusive public policies ensuring equitable access to environments that promote physical activity is crucial, particularly in low-resource settings such as the Democratic Republic of Congo. Multisectoral strategies involving families, schools, and communities may help reduce sedentary behaviour, improve physical fitness, and ultimately decrease the risk of non-communicable diseases in this vulnerable population.

Limitations and Future Research Directions

Several limitations should be acknowledged. The cross-sectional design limits causal inference. Although the sample size (n=322) was adequate, it may not allow full generalisation of the findings. The physical activity questionnaire was not validated in the Congolese context. Additionally, potential confounding factors such as nutrition and socioeconomic status were not controlled. Another limitation of this study is the reduction of physical activity and sedentary behaviour variables to nominal/ordinal scales, rather than retaining interval/ratio-level data. This resulted in a loss of information and restricted the statistical analyses to chi-square tests instead of more powerful approaches such as ANOVA or regression models suited to continuous data. Consequently, the full variability of the original data may not have been adequately captured, potentially limiting the sensitivity and depth of the findings. Future research should include longitudinal or intervention-based designs focusing on adapted physical activity programmes, incorporate

additional physical fitness indicators, control for confounding variables, and validate assessment tools in the Congolese context.

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Authors' Contributions

Conceptualisation: TB, BM, PB, GB, AB, CN, MK, VF
Data collection: TB, EK
Statistical analysis: TB, MK, EK
Manuscript writing: TB, BM, PB
Manuscript revision: All authors

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Original Research Article

Return-To-Work Status And Quality Of Life Of Persons With Lower Limb Amputation In South India

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ABSTRACT

Aim: The constraints brought forth by amputation cause immense impairments in the realms of physical, social, and psychological functioning of individuals. The exact estimates of the number of persons with amputation in India are unknown. Past studies report that the incidence of amputation is 0.62/1000 individuals in India, which is nearly 1 million of its population. Lower limb amputation impacts Return-to-Work status. Prosthetic training offered to individuals with lower limb amputation could empower them to get back to work, thus refining their Quality of Life. The aim of this study is to determine the Return-to-Work status and Quality of Life of persons with lower limb amputation after prosthetic training.

Method: This cross-sectional observational study recruited eighty-four participants who underwent prosthetic training after lower limb amputation from a tertiary care hospital in South India. Demographic and clinical characteristics were obtained using a self-designed data form through a telephone survey. Quality of Life was measured using WHOQOL-BREF. Data analysis was done using chi square tests and t-tests.

Results: In our study, we found that 60.7% of our participants returned to work. Prosthetic use (p value = 0.016) and independence with transfers (p value = 0.007) are significant factors that facilitated positive Return-to-Work. Psychosocial characteristics such as self-motivation (p value = 0.001), social support (p value= 0.001) and family support (p value = 0.017) have enabled individuals to get back to work. Quality of Life among individuals who returned to work was found to be significantly higher than the persons who have not returned to work in all domains (p value < 0.01).

Conclusion : Prosthetic training has enabled persons with lower limb amputation to get back to their work. Daily use of prosthesis coupled with socket comfort, has facilitated positive Return-to-Work, thereby improving their Quality of Life.

Keywords: Lower limb amputation, Prosthetic Training, Return-to-Work, Quality of Life

INTRODUCTION

Lower limb amputation stands as one of the most profound physical and psychological challenges, leading to significant disfigurement, reduced mobility, and heightened vulnerability to losing one's independence (Sinha et al., 2011). In 2017, it was estimated that 57.7 million people worldwide had undergone amputation due to trauma (McDonald

et al., 2021). In low and middle-income countries, road traffic accidents are the main cause of the same, and the most affected persons are men who belong to the working-class population (McDonald et al., 2021 ; Sinha et al., 2011; Shankar et al., 2020). Deterrents yielded by the consequences of lower limb amputation influence physical, social, and psychological functioning of the individuals (Schoppen, Boonstra, Groothoff, de Vries, et al., 2001). This might cause absenteeism in workplaces and sometimes leading to discontinuation of jobs (Burger & Marinček, 2007). The threat of loss of capacity to work and the potential to earn a livelihood subsequent to such trauma is of paramount concern to both the survivors as well as to the society (Asano et al., 2008). Studies conducted in the UK and Ontario report that 66% to 74% of people returned to work after lower limb amputation (Magnusson et al., 2019; Gerhards et al., 1984). Studies indicate that a significant number of persons have returned to work but the types of job in which they have occupied themselves are physically less demanding and require modifications (Schoppen, Boonstra, Groothoff, de Vries, et al., 2001).The combination of comfortable prosthetic usage, high-quality vocational services and comprehensive in-patient rehabilitation services facilitate individuals' Return-to-Work _(Schoppen, Boonstra, Groothoff, de Vries, et al., 2001; Hebert & Ashworth, 2006; Schoppen, Boonstra, Groothoff, Sonderen, et al., 2001).Personal and social factors regarding the place of work of a person play an important role in determining the status of Return-to-Work (Bruins et al., 2003). Acclimating to new challenges following amputation is indeed a barrier that would hinder the participation of most of the survivors (Batten et al., 2020). Discrimination and exclusion from society tend to restrict individuals within the confines of their insecurities. Challenges stemming from environmental factors such as architectural barriers, uneven terrains, climate, crowded spaces etc., are the hurdles that impose substantial restrictions on persons with lower limb amputation (Batten et al., 2020). The lack of modifications at homes and workplaces reduced the functional use of prostheses (Stuckey et al., 2020). A shortage of multidisciplinary teams and lack of accessibility to rehabilitation services have prevented individuals in South Africa from re-integrating into society (Naidoo & Ennion, 2019). Efficient prosthetic use coupled with requisite fitness promotes optimum performance (Batten et al., 2020). Walking is a meaningful function that enables individuals to actively participate in family and social situations by evoking an appreciable sense of independence (Batten et al., 2020).

Determining the Quality of Life of individuals suffering from physical disabilities would enable us to understand the challenges posed by them and also to analyse the outcomes of rehabilitative services being offered to them (Magnusson et al., 2019). The Quality of Life in persons with amputation has been studied less compared to other conditions (Matos et al., 2020). The existing studies have focused more on physical aspects rather than biopsychosocial well-being (Matos et al., 2020). In developed countries, the prevalence of people with lower limb amputation is above 65 years and is mostly due to vascular complications (Sinha et al., 2011). Since they belong to the retired population, the relevance of Return-to-Work status in determining the Quality of Life has not been reported much (Sinha et al., 2011). In contrast, in developing countries, one of the leading causes of lower limb amputation is trauma, and people who are subjected to it are men who belong to the working population with a mean age of 37 years (Sinha et al., 2011). For a country like India where men are the primary breadwinners of families, their status of unemployment will negatively affect the living standards and self-worth as well (Shankar et al., 2020). The ability to walk independently serves as a milestone to the liberty to live independently (Matos et al., 2020). There have not been many studies identified that assess the significance of Return-to-Work status in influencing the Quality of Life in persons after lower limb amputation in India (Schoppen, Boonstra, Groothoff, de Vries, et al., 2001; Sinha et al., 2011). Also, there are fewer studies relating to psychosocial status

and Quality of Life in these persons at tertiary health care services (Matos et al., 2020). Timely access to rehabilitation can curtail the effects of disability and worker-role hardships accompanied by it. Prosthetic training offered by the multidisciplinary services of our institution offers functional training and helps persons with lower limb amputation to be self-reliant in the matter of mobility. Despite the possible restoration of independence with mobility and transfers, persons with lower limb amputation tend to be either inhibited or prevented from returning to work (Bruins et al., 2003). Identifying the Return-to-Work status would help us in determining the extent to which individuals have made use of the rehabilitative services so that further interventions can be brought forward in the future for the betterment and upliftment of these individuals (Davie-Smith et al., 2017; Magnusson et al., 2019). Therefore, this study aims to identify both the return -to -work status and Quality of Life of persons with lower limb amputation who have undergone prosthetic training. Furthermore, it compares the differences in Quality of Life among individuals who have returned to work to that of people who have not returned to work.

METHODS

This study employed a cross-sectional observational survey design and was conducted in the outpatient unit of the Department of Occupational Therapy. The study setting provided access to participants receiving outpatient occupational therapy services during the study period.

Ethical Considerations

This study was approved by the Institutional Research and Ethics Committee (IRB MIN No. 14463 dated 09.02.2022).

Sample Size

The sample size required to find the Return-to-Work status of people with lower limb amputation is 82, with a 95% Confidence interval and at 10% precision. The sample size calculation is given below:

$$n = \frac{Z^2_{1-\alpha/2}\, p(1-p)}{d^2}$$

Where,

p : Expected proportion

d : Absolute precision

1- α/2 : Desired Confidence level

Data Collection Procedures

This cross-sectional observational survey recruited eighty-four participants through purposive sampling. The contact information of the individuals who underwent lower limb amputation and completed prosthetic training, residing within a 100km radius of our centre from the years 2017 to 2021 was obtained by the principal investigator from the database of our tertiary care hospital. Individuals aged between 18 and 60 years who underwent lower limb amputation due to diabetes or traumatic causes (excluding malignancies) and who have completed prosthetic training at our hospital were contacted by the

principal investigator, through a telephone survey. Participant Information Sheet and Informed Consent form was read aloud. The Principal Investigator documented the verbal consent, along with recording the subject's name, the representative's name, and the date on which verbal consent was obtained.

Return-to-work status was evaluated using a self-designed data collection form developed based on prior literature, from a study conducted at our centre (Blessyolive et al., 2021). The form comprised thirty-nine questions across eight domains: demographic data, amputation characteristics, prosthetic use, work characteristics, environmental factors, transport and mobility, psychosocial aspects, and financial status. We required a culturally specific and contextually relevant data collection form that aligned with our service delivery. As no such forms were readily available for our context, the above-mentioned data form was developed. The items in the form were reviewed and subsequently modified by experts in our institution before administration. The WHOQOL-BREF questionnaire was used to identify the Quality of Life. It contains a total of 26 questions, and has been found to have good psychometric properties of reliability, validity and internal consistency. (Cronbach's $\alpha > 0.7$). The World Health Organization Quality of Life -Bref (WHOQOL-Bref) questionnaire is an abbreviated version of the WHOQOL-100 addressed to adults. It consists of two general questions (one covering overall QOL and one addressing the person's general health situation) and 24 specific questions covering four domains of QOL: physical health (seven items), psychological (six items), social relationships (three items), and environment (eight items). Each item is answered on a scale of 1 to 5, with 5 signifying the highest QOL. WHOQOL-BREF demonstrates good discriminant validity, content validity, internal consistency and test-retest reliability. This is of great help in a brief assessment of Quality of Life. The overall duration of the telephone survey was 45 to 60 minutes.

Data Management And Analysis

Data analysis was done using SPSS Version 21.0 The data were presented using descriptive statistics (mean and standard deviation) and frequency/percentage. The statistical significance between the categorical variables was tested using independent samples t-test and chi square test. A P value <0.05 was considered statistically significant.

RESULTS

Prior to their amputation, a vast majority of the subjects were active members of the workforce. Following the procedure, there was a notable decline in employment rates, with only a portion of the original group successfully maintaining or obtaining a job. Among those who did return to work, the most common outcome was returning to the same position they held previously, while a significant number of others transitioned into entirely different roles. A small minority of the group entered the workforce for the first time post-amputation.

Conversely, for the substantial group that remained unemployed, several key barriers to re-entry were identified. The most prominent obstacles included physical discomfort associated with using prosthetic devices and various logistical hurdles, such as a lack of resources, limited transportation options, and personal anxieties regarding their new circumstances. A large segment of the unemployed population also cited a variety of other unspecified reasons for their inability to return to the workforce(Figure 1).

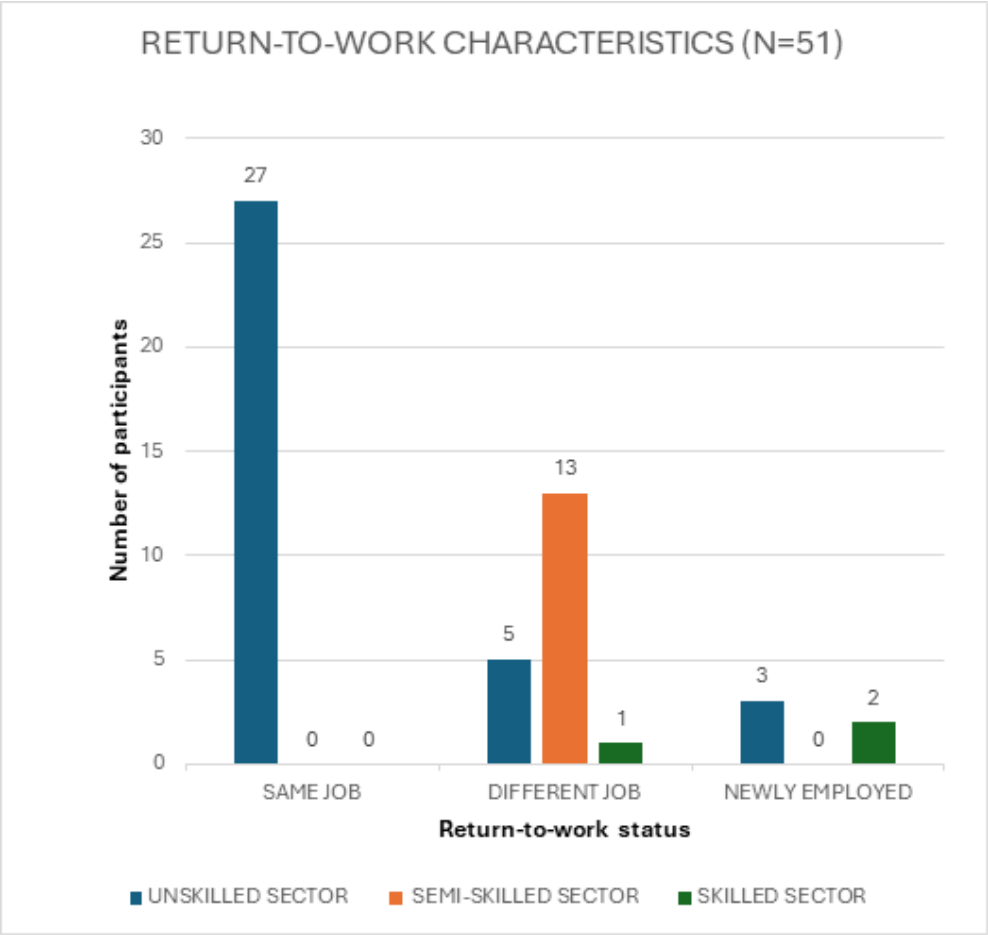

Figure 1: Return-Work-Characteristics

The survey population was predominantly comprised of males, with a much smaller representation of females and a single transgender participant. This gender disparity carried over into the employment outcomes, as the vast majority of those who successfully returned to work were men, while only a small handful of women were able to do the same. Conversely, among those who remained unemployed following their amputation, males still made up the largest group, though women and the transgender participant also accounted for a portion of this population. Statistical analysis confirmed that men were significantly more likely to return to the workforce than women, marking gender as a primary factor in post-amputation employment success. In contrast, other personal factors such as educational background and marital status did not appear to have a meaningful impact on whether or not an individual returned to work (Table 1a, Table 1b).

Table 1a: Demographic Details Of Participants

Demographic Details		Number (N=84)	Employed (N=51)	Unemployed (N=33)	P- Value
Gender	Male	70(83.3%)	47(92.1 %)	23(69.6%)	0.022*
	Female	13(15.4%)	4(7.8%)	9(27.2%)	
	Transgender	1(1.1%)	0	1(3%)	
Education	0-5th Standard	14(16.6%)	6(11.7%)	8 (24.2%)	0.554
	6-10th Standard	40(47.6%)	24(47%)	16(48.4%)	
	11-12th Standard	9(10.7%)	7(13.7%)	2(6%)	
	Diploma/	13(15.6%)	8(15.6%)	5(15.1%)	

	Graduation				
	Post Graduation	7(8.33%)	5(9.8%)	2(6.06%)	
Marital Status	Married	70(83.3%)	44(86.2%)	26(78.7%)	0.369
	Unmarried	14(16.6%)	7(13.7%)	7(21.2%)	

** Denotes Statistical Significance(P<0.05)

Table 1b – Employment Status Based On Gender And Education

Gender	Education	Employed	Not Employed	Total no. of individuals
Males	0-5th grade	5	6	11
	6-10th grade	24	11	35
	11-12th grade	6	1	7
	Diploma/Graduate	8	4	12
	PG	4	1	5
	Sum			70
Females	0-5th grade	1	2	3
	6-10th grade	1	5	6
	11-12th grade	1	0	1
	Diploma/Graduate	0	1	1
	PG	1	1	2
	Sum			13
Transgender	0-5th grade	0	0	0
	6-10th grade	0	0	0
	11-12th grade	0	1	1
	Diploma/Graduate	0	0	0
	PG	0	0	0
	Sum			1

The data regarding amputation and prosthetic characteristics highlights that the primary drivers for lower limb amputation were road traffic accidents, diabetes, and trauma. Among these, road traffic accidents emerged as the most frequent cause of lower limb amputations, though the specific cause did not significantly influence whether an individual successfully returned to work. For those utilizing prostheses, a vast majority incorporated them into their daily lives, with most expressing overall satisfaction with their devices. In terms of mobility, participants relied on various forms of transportation, including two-wheelers, buses, and auto-rickshaws. Crucially, nearly all individuals who re-entered the workforce reported a high level of functional autonomy, noting they were able to manage physical transfers independently to access transportation and reach their necessary destinations (Table 2).

Table 2: Amputation, Prosthetic, And Mobility Characteristics

Factors Associated With Return-To- Work		Return To- Work Status		P- Value
Amputation Characteristics		Employed	Unemployed	
Cause	Road Traffic Accidents	43(84.31%)	24(72.7%)	0.43
	Diabetes	7(13.7%)	8(24.2%)	

	Traumati C	1 (1.96%)	1(3.03%)	
Side	Left	16(31.3%)	18(54.5%)	0.013*
	Right	35(68.6%)	13(39.3%)	
	Bilateral	0(0%)	2(6.06%)	
Level	Hip Disarticu Lation	0(0%)	1(3.03%)	0.662
	Transfemoral	16(31.3%)	12(36.3%)	
	Knee Disarticulation	5(9.8%)	4(12.1%)	
	Transtibial	28(54.9%)	16(48.4%)	
	Symes	1(1.96%)	0(0%)	
	Others	1(1.96%)	0(0%)	
Prosthetic Use Daily Use	Yes	47(92.1%)	24 (28.5%)	0.016*
	No	4(7.84%)	9(10.7%)	
Satisfaction	Yes	41(80.3%)	21(25 %)	0.008*
	No	10(11.9%)	12(14.2%)	
Mobility Independence In Transfers	Yes	47(92.1%)	23(69.6%)	0.007*
	No	4(7.84%)	10(30.30%)	
Accessibility To Places	Yes	47(92.1%)	26(78.7%)	0.076
	No	4(7.84%)	7(21.2%)	

*Denotes statistical significance($p<0.05$)

The psychosocial and financial landscape for those returning to work was characterized by a sense of internal drive, with almost all employed individuals citing self-motivation as a primary factor in their transition. Beyond personal determination, the vast majority benefited from the support of their families, which served as a crucial pillar of support during the recovery process. While family ties were a dominant influence, a smaller segment of the population also noted the importance of broader social support systems in facilitating their successful return to the workforce (Table 3).

Table 3: Psychosocial And Financial Characteristics

Psychosocial Characteristics		Employed (N=51)	Unemployed (N=33)	P Value
Self-Motivation	Yes	50(98.0%)	11(33.3%)	<0.001 *
	No	1(1.96%)	22(66.6%)	
Family Support	Yes	45(88.2%)	11(33%)	<0.001 *
	No	6(11.7%)	22(67%)	
Social Support	Yes	8 (15.6%)	0 (0%)	0.017*
	No	43(84.3%)	33(100%)	
Financial Characteristics				

Adequate Income	Yes	7(13.7%)	1(3.03%)	0.103
	No	44(86.2%)	32(96.9%)	
Disability Pension	Yes	33(64.7%)	25(75.7%)	0.285
	No	18(35.2 %)	8(24.2%)	
Earning Members (Number)	0	0(0%)	6(18.1%)	0.015*
	1	34(66.6 %)	19(57.5%)	
	2	16(31.3%)	8(24.2%)	
	3	1 (1.96 %)	0 (0%)	

*Denotes statistical significance (p<0.05)

Table 4 shows a comparison of the Quality of Life among employed and unemployed people. People who have returned to work had reported a better Quality of Life compared to the people who have not been employed, in all four domains of the WHOQOL-BREF Scores (p value<0.01).

Tabl 4: Comparison Of Quality Of Life Of Employed And Unemployed People

Quality of Life Domains	Employed (n = 51)		Unemployed (n = 33)		
	Mean	Standard De-viation	Mean	Standard De-viation	P-value
Physical Qol	78.78	14.14	55.18	26.89	<0.01*
Psychological Qol	65.64	13.67	48.78	15.95	<0.01*
Social Qol	59.29	15.023	40.76	18.10	<0.01*
Environmental Qol	68.35	13.37	52.18	15.95	<0.01*

*Denotes statistical significance (p<0.05)

DISCUSSION

From our study, it was found that 60.7% of the subjects have returned to work following amputation, which is consistent with the Return-to-Work rate in previous studies, ranging from 57% to 77% (Hebert & Ashworth, 2006; Journeay et al., 2018; Millstein et al., 1985; Schoppen, Boonstra, Groothoff, de Vries, et al., 2001). **[Figure 1]** Married males accounted for 92.15% of the individuals who returned to work, with 64.2% of respondents reporting that they were the only earning members in their families.**[Table 1A]**

The necessity of supporting their family as the sole breadwinner has compelled them to return to work. Our findings are also analogous to previous studies that report that males who are primary breadwinners have better Return-to-Work outcomes (Gerhards et al., 1984; Shankar et al., 2020; Whyte & Carroll, 2002).

Among the people who returned to work, 52.9% retained their jobs, 37.2% had a change of job, and 9.8% were employed in a new job. **[Figure 1]** A majority of our participants with transtibial amputations (54.9%) had returned to work. **[Table 2]**

All individuals who returned to the same job belonged to the unskilled work sector, which included self-employment and was predominantly agricultural activities. The largest group (27 individuals) resumed the same unskilled job, indicating strong job retention but limited diversification. **[Figure 1]**

Returning to the same job in the unskilled sector may reflect economic necessity rather than choice, as individuals may lack opportunities to upgrade their skills or shift to other sectors. In contrast, the semi-skilled sector absorbed the highest number of

individuals who had a change of job. The skilled sector remained marginal, with only 3 individuals represented, highlighting barriers to entry such as higher qualifications, training requirements, or reduced accessibility following rehabilitation.

A study by Millstein reports that the provision of vocational training and counselling services have facilitated Return-to-work (Millstein et al., 1985). Only one person out of the 51 employed benefitted from vocational training services in our study. The reason for this could be the lack of vocational training centres within the vicinity of our hospital.

The type of jobs in which people have employed themselves following amputation differ according to studies and is dependent on the previous occupation and level of amputation (Burger & Marinček, 2007). In studying the levels of amputation, we did not find any statistically significant association between levels of amputation and Return-to-Work. This is contrary to findings stated in the literature which reports that different levels of amputation have shown variations in employment status and the lower the level of amputation, the better the return-to-work status (Burger & Marinček, 2007; Gerhards et al., 1984; Millstein et al., 1985). Our sample had an uneven representation of people with different levels of amputation; since the numbers varied for each level, this would not have contributed to statistical significance.

Daily prosthesis use was reported by 92.1% of the people who returned to work, with 80.3% of them expressing satisfaction with their prosthesis**.[Table 2]** In our hospital, following the completion of the prosthetic training program, patients are asked to report to the amputee follow-up clinic. They are instructed to visit the clinic if there are any issues with prosthetic fit or any other problems with the stump that make prosthetic use difficult. We believe that a systematic prosthetic training program and follow-up would have strengthened prosthetic use. Research shows that frequent and continuous prosthetic use influence positive Return-to-Work (Gerhards et al., 1984). All the participants who used prosthesis daily were independent with transfers and had accessibility to their places of need. Prosthetic training begins with orientation - which involves familiarizing the individual with the prosthesis, including its parts, functioning, wearing schedule, and maintenance, followed by an initial check-out by a multidisciplinary team to assess alignment, comfort, fitting, and overall functioning. During this phase, patients are taught the techniques of donning and doffing the prosthesis and are guided in performing transfers with the aid of mobility devices. Once orientation is complete, functional training focuses on progressive skill development, starting with weight-bearing on the prosthesis and transfers from a plinth or chair using various supports such as a quadripod or cane, eventually advancing to transfers without external assistance. Training also emphasizes standing balance activities, obstacle crossing with different levels of support, pivot transfers, and floor transfers, gradually preparing the individual for community ambulation. This includes negotiating ramps and stairs, walking on uneven terrain, moving through crowded environments, and learning transfer strategies for public transport, thereby enabling safe and independent participation in daily and social activities. Our protocols also include educating patients to modify their environment and remove architectural barriers to maximize participation and function.

Among those who were employed, 98.03% reported that they had self-motivation, and 88.2% had adequate family support and 15.08% subjects had social support to get back to work. Most of the unemployed individuals had a low level of self-motivation and family support and no one received social support that could enable them to return to work**.[Table 3]**

In developed countries, the relevance of Return-to-Work status in determining Quality of Life has not been predominantly reported much (Sinha et al., 2011). We identified that people who returned to work have a better Quality of Life compared to individuals

who have not. Among the individuals who returned to work, the mean Quality of Life score was highest in the physical domain (mean 78.78, SD=14.14), followed by environmental domain (Mean= 68.35, SD= 13.37), psychological domain (Mean= 65.64, SD= 13.67) and social domain (Mean= 59.29, SD= 15.02). This contradicts the study conducted in Pune at a tertiary prosthetic rehabilitation center, where the mean Quality of Life score was highest in the social domain and lowest in the physical domain (Shankar et al., 2020).Their study recruited individuals who had a recent amputation and who were not aided with prostheses. In our findings, the highest score in the physical domain shows that prosthetic training has helped them to be independent in their daily activities and has enabled them to access their needs. This is supported by a study conducted in Mumbai, which states that use of prosthesis influences the domain of physical health positively among individuals with lower limb amputation (Sinha et al., 2011). The satisfaction with prosthetic use, as reported by 80.39% of the subjects who have returned to work would also have helped them adapt functionally with the level of amputation. A study conducted in Brazil stated that functional satisfaction with prosthesis improves the Quality of Life among persons with lower limb amputation (Matos et al., 2020). From our study, better adaptability and satisfaction with the prostheses would have enabled individuals to relearn transfer techniques and regain functional abilities. This also helped in maximizing independence to access transport and other areas of their needs, which improved the Quality of Life in the environmental domain. Our study found that people who had self-motivation, family support and social support returned to work. This could be a determining factor for improved psychological health among employed individuals.

In studying the Return-to-Work status in rehabilitated persons with lower limb amputation, factors such as male gender, daily prosthetic use, good satisfaction with the prosthesis, independence in transfers, accessibility to places, self-employment, good self-motivation, family support and social support were influencing factors for returning to work. People who have returned to work had a better Quality of Life compared to those who did not return to work.

Limitations

The mode of administration of the interview was through a telephonic survey, as this was convenient due to COVID-19 pandemic situation. Hence, the accuracy of the information could be challenged. Since this is a cross-sectional survey, the results obtained cannot be generalized for a larger population. The objective of our study was to identify the Return-to-Work status of individuals following lower limb amputation; hence, the reasons for successful and unsuccessful job reintegration were not studied in depth. Since the participants were not met in person, their functional status could not be assessed.

CONCLUSION

Most of the participants in our study population have returned to work after prosthetic training (60.7%). Self-motivation, family support, social support, self-employment effective prosthetic use and satisfaction have enabled people with lower limb amputation to return to work. People with a positive Return-to-Work status have experienced a better Quality of Life compared to those who have not returned to work.

Implications

The role of prosthetic training extends beyond functional mobility; it serves as a critical enabler of workforce reintegration. This underscores the need for structured, accessible, and context-specific prosthetic training as a core component of rehabilitation services with multidisciplinary team integration. Gainful employment not only contributes to financial independence but also enhances psychological well-being, social participation, and overall life satisfaction. These findings suggest that rehabilitation programs should adopt a holistic approach that integrates vocational goals alongside physical

recovery. A lack of vocational training programs has been identified. Additionally, workplace accommodations and employer awareness programs may further facilitate successful reintegration. Future research should explore the long-term sustainability of employment outcomes and identify factors that influence a successful return to work, such as the demands of occupation, level of training, and social support systems. The reasons behind the lack of Return-to-Work need to be examined along with the effectiveness of social support systems.

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Declaration of interest: the authors report no conflict of interest

Data availability and statement: to ensure the confidentiality of the study participants, the details of the study were stored in encrypted, password-protected files with restricted access limited to the principal investigator and authorized research team members. Participants were informed in advance about how their inputs would be used, who would have access to them, and the measures in place to protect their privacy and confidentiality. Informed consent was obtained, and the participants were assured of their rights to confidentiality throughout the study. These measures align with ethical guidelines and best practices for protecting participant privacy and maintaining research integrity.

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Original research article

Parenting Paradox: Exploring the Lived Experiences of Raising Young Adult and Twins with Down Syndrome in Mauritius

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ABSTRACT

Aim: There is a paradox of challenges and development in raising a child with Down syndrome (DS). This research explores the lived experiences of Mauritian parents raising identical twins with Down syndrome and other young people with this condition. The study aims to examine positive and negative affect, resilience, cultural dynamics, and the interactions between child, parent, family, and community..

Method: The study employed a qualitative interpretive design guided by Family Systems Theory, examining relationships and structures within family dynamics and how the family environment supported coping efforts. Sixteen parents of young adults with Down syndrome, recruited from U-Link and Down Syndrome Mauritius, participated in semi-structured interviews through purposeful sampling. Thematic analysis was used to examine positive and negative parental experiences from different layers of relationships.

Results: Initially, parents described shock, confusion, stigma, and grief at diagnosis, but gradually developed resilience through community support, peer social networks, spiritual beliefs, and adaptive parenting strategies. While raising twins with Down syndrome, parents reported increased caregiving demands, experiencing a resilient paradox of grief and growth, but eventually their presence brought profound joy despite financial strain, limited access to inclusive services, and other challenges. In summary, families raising young adults with Down syndrome in Mauritius exemplify vulnerability, instability, and positive resistance.

Conclusion: Parents reported increased family cohesion, stronger social networks, and a growing sense of purpose, despite ongoing challenges related to stigma, access to services, and emotional fatigue. These findings call for sustained, multidimensional support systems and inclusive policies that recognize both the burdens and the transformative potential of parenting young adults with DS in resource-constrained and culturally diverse settings like Mauritius .

Keywords: Parenting paradox, Down Syndrome and Twins, Coping strategies, Resilience, Lived experiences, Mauritius.

INTRODUCTION

Parenting a child with Down syndrome is a profoundly complex experience, often characterised by a paradox of emotional distress and growth. Historically, research has

predominantly framed disability within deficit-based narratives, portraying families – especially parents – as overwhelmed by grief, isolation, and chronic stress (Grech, S. 2016; Raap, E., Weille, K.L., & Dedding, C. 2024; Mishra, S. 2025). While this perception is grounded in real challenges, it has overshadowed a growing body of literature that emphasises resilience, empowerment, and positive adaptation in families raising a member with disabilities (Van Riper, M. 2007; Nelson Goff, B.S., Monk, J.K., Malone, J., Staats, N., Tanner, A., & Springer, N.P. 2016; Desimpelaere, E.N., De Clercq, L.E., Soenens, B., Prinzie, P., & De Pauw, S.S.W. 2023). This study explores the lived experiences of Mauritian parents, examining how they construct meaning in raising twins and other young adults with Down syndrome, and delves into both the positive and negative dimensions of their parenting, encompassing emotional paradoxes, challenges, resilience, and growth trajectories.

Down syndrome, caused by the presence of an extra chromosome 21, remains the most recognised chromosomal disorder worldwide (Centers for Disease Control and Prevention, 2019). Individuals with Down syndrome often experience developmental delays, health complications, and unique learning profiles, which place additional caregiving demands and burdens on families (Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025; Hendrix, J.A., Amon, A., Abbeduto, L., Agiovlasitis, S., Alsaied, T., Anderson, H.A., Bain, L.J., Baumer, N., Bhattacharyya, A., Bogunovic, D., Botteron, K.N., Capone, G., Chandan, P., Chase, I., Chicoine, B., Cieuta-Walti, C., DeRuisseau, L.R., Durand, S., Esbensen, A., Fortea, J., Giménez, S., Granholm, A.C., Hahn, L.J., Head, E., Hillerstrom, H., Jacola, L.M., Janicki, M.P., Jasien, J.M., Kamer, A.R., Kent, R.D., Khor, B., Lawrence, J.B., Lemonnier, C., Lewanda, A.F., Mobley, W., Moore, P.E., Nelson, L.P., Oreskovic, N.M., Osorio, R.S., Patterson, D., Rasmussen, S.A., Reeves, R.H., Roizen, N., Santoro, S., Sherman, S.L., Talib, N., Tapia, I.E., Walsh, K.M., Warren, S.F., White, A.N., Wong, G.W., & Yi, J.S. 2021). In some African societies, including Mauritius, disability is often perceived as a form of divine punishment, karmic debt, or personal failure, fostering exclusion and shame within families and communities (Chitando, E., Ohajunwa, C. & Dube, K. 2025; Ndlovu, H.L. 2016). Over the past two decades, both academic and policy discourses have shifted from viewing families with a member who has a disability as victims of circumstance to recognising their capacity for resilience, personal growth, strengthened bonds, adoption of new life priorities, and positive transformation (Galán-Vera, I.Z., Robles-Bello, M.A., Sarhani-Robles, A., & Valencia-Naranjo, N. 2025; Barklı, A., & Doğan, A. 2025; Rakap, S., & Vural-Batik, M. 2024; Farkas, L., Cless, J.D., Cless, A.W., Nelson Goff, B.S., Bodine, E., & Edelman, A. 2019). This paradigm shift aligns with broader movements in disability advocacy that emphasise empowerment, inclusion, and dignity over charity and pity (Alshdaifat, S. 2025).

Mauritius, with its multicultural and diverse population, presents a distinctive context with varying philosophies and interpretations regarding how parents cope with raising their young adults with Down Syndrome, across different layers of social relationships and cultural environments. Approximately 59,870 people live with disabilities, including Down Syndrome, with 28,923 receiving basic pensions from the State due to invalidity (Statistics Mauritius, 2015 and April 2026). The country reflects both the challenges and opportunities of a transitioning disability landscape. Many report positive changes following the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and families often rely on informal networks and NGOs. However, sociocultural taboos and infrastructural limitations still impede full inclusion (Lecomte, U., De Los Ríos Berjillos, A., Lethielleux, L., Deroy, X., & Thenot, M. 2024). The growing network of NGOs, such as U-Link and Down Syndrome Mauritius, is reshaping the narrative by fostering peer support and advocacy. In the local context, the impact of disability on caregivers of young adults, especially identical twins with Down Syndrome, is rarely

discussed. In Mauritius, little is known about (i) the lived experiences of parents with a family member who has Down syndrome (DS); (ii) the factors or enablers that empower them with effective coping strategies; and (iii) the related disablers or challenges they encounter throughout their parental journey. Given that the island does not have an established genuine data on individual with DS and their parents' lived experiences in place, it is critical to understand and unveil these experiences from different angles i.e. child, parents, family and community approaches in order to improve their needs and support for a more inclusive society in a developing country. Similarly, many previous studies examined how characteristic parenting styles were adopted by parents who raised a child with DS in relation to their level of coping with their children's adverse behaviours and constantly sought professional help (Celik, P., & Kara Uzun, A. 2023; Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025). But in this study, it focuses on the holistic approach of parenting dyad, emphasizing more on parent-child link and the entire interactive system across different levels: Child, Parents, Family & Community. Despite the ratification of the Convention on the Rights of the Children (CRC) and the mobilisation for the adoption of the CRPD in developing countries, people with DS and their families continue to face daily challenges. It is even more challenging in getting support to raise young adult with DS of families in Mauritius, thus leading to anxiety, societal stigma, a complex mix of acceptance, denial and this insufficient information and lack of advocacy for their inclusion, remain a continuous barrier till you end up with self-child understanding and thus parents requiring for the need of better communication, 'understanding the healthcare situation' and coping strategies (Gothwal, V.K., Bharani, S. & Reddy, S.P., 2015; Bottcher, L., & Dammeyer, J. 2025). Existing research has historically emphasized the negative outcomes of raising children with developmental and intellectual disabilities, including psychological strain, stigma, and social isolation. However, these perspectives often overlook the resilience, adaptive strategies, and positive affect that the parents develop over time. There is a gap in literature that captures the unique experiences of raising twins with DS, a statistically rare and emotionally nuanced circumstance. In Mauritius, where cultural beliefs, limited access to inclusive services, and emerging disability advocacy intersect, the lived realities of such families remain underexplored. There is a critical need to understand how these parents navigate the emotional, social, and structural challenges and how they draw meaning, support, and strength from their experiences to inform inclusive policy, family-centered intervention, and community support systems. Despite the increasing prevalence of individuals with special needs, there remains a dearth of localized, in-depth qualitative research that captures the unique socio-cultural, emotional, and practical challenges within the Mauritian context. This study is a novelty research based on parenting experiences while raising twins and young adults with DS in the country, leading to the acquisition of new and unfamiliar experiences, knowledge, practical and scientific progress in the context of disability. Academically, this study enriches the general discourse on disability, parenting, and family dynamics by incorporating perspectives from a developing island nation, which are often underrepresented in literature. Past research on families of children with DS reflected a pathological model such that families were naturally assumed to suffer as a consequence of a child with a specific disability. By adopting the Family System Theory (FST) in an event of disability of a family member, derive different meanings towards a positive contribution with the available resources including health, finance, social networks, support systems and belief systems. The study provides a valuable contribution in understanding family dynamics and how parents raising a young adult with DS, perceive his development as challenging and responding to the related stress with available coping resources. Findings highlight the need for policy improvements, enhanced support networks and financial assistance programs tailored to families of adult with DS in Mauritius. By exploring the lived

experiences of these parents, the study contributes to filling this gap in knowledge, offering critical insights into the paradoxical nature of parenting where profound joy coexists with intense stress, hope intersects with uncertainty, and resilience emerges alongside vulnerability.

Despite limited research focused solely on Mauritius, regional studies from the Indian Ocean and African contexts offer valuable parallels. A recent study by Soll, B.A., Oxenham, V., Kowlessur, S., Kassam, F., Bhoosun, O., and Reebye, R. (2025) examined disability perceptions in Mauritius, revealing limited medical care, isolation, cultural stigma, and inadequate community support for families, especially during the Covid-19 pandemic. These socio-cultural barriers increase parental stress and isolation, reflecting findings from similar island nations (Nimusiima, C., Kawesa, E. S., Seeley, J., and Mbazzi, F. B. 2024). Stigma, and the intersection of cultural beliefs and disability, remains a critical factor shaping parental experiences. Luetke Lanfer, H., Anderson, E., Bah, F., Krawiec, S., Rossmann, C., and Vines, A. (2025) documented that in many African and island societies, spiritual and traditional interpretations of disability influence both family coping strategies and societal acceptance, affecting access to resources and emotional support. This underscores the need for Mauritius-specific qualitative research to contextualise parenting paradoxes within its unique multicultural framework. The review synthesises studies to highlight paradoxical parental experiences, coping mechanisms, cultural influences, and the specific challenges of raising twins with DS. This study aims to synthesise theoretical and empirical literature on various types and levels of family influences in Mauritius, and to describe their perceived interrelationships through positive and negative dimensions across Child, Parents, Family, and Community. The discussions in this study focus on 'Experiencing Growth, Coping and Resilience' and 'Grappling with Stress, Stigma, and Structural Barriers'.

Family Systems Theory (FST) is widely adopted in psychology, therapy, and family studies, as it demonstrates how individual issues often reflect broader family dynamics rather than isolated problems. Grounded in Family Systems Theory (Turnbull, A. P., & Turnbull, H. R. 1990; 2001), this study examines how Mauritian parents understand, cope with, and ultimately grow through the experience of raising young adults and twins with Down syndrome. The research investigates coping mechanisms, resilience, social interactions, cultural interpretations, and structural barriers, providing a holistic and human-centred account of parenting in a multicultural context. In the scoping review (2017–2022), studies reported using a family framework, including strength, resilience, stress, coping, negatives, and challenges (Van Riper M, Cosgrove B, Fleming L. 2023). Recent studies continue to apply transactional and family systems models to explain how parents adapt to the dual demands of caregiving stress and emotional reward (Cunningham, C. 1996; Rutter, T.L., Hastings, R.P., Murray, C.A., Enoch, N., Johnson, S., & Stinton, C. 2024). Çaksen, H. (2025) highlighted the critical role of meaning-making and positive reframing in parents' psychological adaptation, showing that social support networks and culturally embedded coping strategies significantly influence well-being. Mishra, S. (2025) further demonstrated that parents benefit from tailored interventions that enhance resilience and reduce parenting stress, particularly when these interventions consider cultural and familial dynamics. These insights underline the importance of culturally sensitive psychosocial support to mitigate the paradoxical pressures faced by parents.

Grounded in FST, this study provides a comprehensive lens to understand the dynamic interactions and challenges within families raising twins and young adults with DS and posits that families function as emotional units where individual behaviors and experiences cannot be fully inferred in isolation but must be seen as part of the larger family context. This theory illuminates how the birth of a child and twins with DS impacts family roles, relationships, communication patterns, and overall functioning, highlighting the

interconnectedness of each family member's coping strategies. In line with Bornstein, M.H. (2019) and Wallis, A., James, K., & Rhodes, P. (2024), which underscore the importance of family systems approach about understanding 'the effect of relationships on relationships' and managing emotions and address the complexities of parents require dialogical reflective processes in the form of systemic therapeutic relationship of family, especially for those looking after young adult with DS. It recognizes that parenting a child with a special needs is not static but evolves through continuous transactions involving family dynamics, social support, cultural expectations, and external stressors. It also aids in unpacking how families negotiate challenges, adapt to stress, and construct meaning amidst the paradoxical realities of parenting young adult with DS. Guided by FST, the study focusses on how the members connect to form a family with a member with DS and reveals the way the family organize and interact among themselves. It is assumed that familial, community and social relationships are reciprocal and this theory guides the analysis in a systematic way while framing the family as an internonnected unit. The researcher highlights relational dynamics, boundaries, interdepending behaviours and tracking interactions with specific groups inside the family that are close to the young adult with DS, i.e parent-child dyad or sibling relationship. With this model, it enlightens the study to examine the positive and negative patterns and roles within a family having a member with DS to better address social, relational, emotinal and behavioral challenges. In this study, the parent, as a prime caretaker of a young adult with DS, is responsible for managing the emotional and practical needs of the latter and as well as other family members. While the parent's role seek to maintain family stability, foster trust and act as a mediator in conflicts and provide support during crises but they often neglect their own needs, thus leading to burnout and difficulty in asserting boundaries to run the household smoothly. Therefore, it is vital to explore the holistic exploration of parenting paradox, capturing both micro-level family interactions and macro-level societal influences that shape the lived realities of these parents.

Paradoxical Parenting Experiences

The jargon of 'parental paradox' in raising an individual with DS is highlighted into two-folds of phenomena, that is, parents' experiencing coexistence and contradictory emotions of stress, grief, tearful and joyful, well-being, uplifting and challenging. Parents from various studies (Skotko, B.G. Levine, S.P & Goldstein, R. 2011; Sheldon, J.P, Oliver, M. & Yashar, B.M., 2021; Vilaseca, R. Rivero, M, Ferrer, F. & Bersabé, R.M. 2020) demonstrated immense love, pride, strength, rewarding, personal growth and unique relationship with their child with DS and other disabilities whereas other studies (Chaudhry, N., Sattar, R., Kiran, T., Wan, M.W., Husain, M., Hidayatullah, S., Ali, B., Shafique, N., Suhag, Z., Saeed, Q., Maqbool, S. & Husain, N. 2023; Zhang, X.N, Zhang, S. Lui. C.Y., Ni, Z.H., & Lv, H.T. 2025; Rusu, P.P. Candel, O.S, Bogdan, I. Iicius, C, Ursu, A. & Podina, I.R. 2025) showed several parenting challenges like psychological distress, social issues, increased demands and tension in the family environment and caregiving difficulties. Therefore, parents see themselves in a situation of a "paradox of the heart" where they simultaneously feel opposing emotions and desires such as grief and joy, hope and fear, social isolation, acceptance and desire to eliminate the disability (Ipsen, C. & Repke, M. 2022; Raap, et al 2024). From another school of thought, parents are able to maintain optimism and a sense of control in the maternal work and look like "embracing of paradox". According to research (Mishra, T.A, Pandey, K., Bhujel, B. & Adhikari, S. 2022; Alsamiri, Y.A. Alaghdaf, A.A. Alsawalem, I.M. Allouash, B.A. & Alfaidi, S.D. 2024), this paradox is manifested differently by both parents, at times, mothers reporting more unhappiness in the initial caregiving years due to a greater burden of care on them whereas from other studies, fathers feel more confident in their parental role than in their professional roles. (Davies, A., Rix, J. & Robb, M., 2024; Langley, E. 2025). Mothers reported that their

extended families often misunderstood the child's condition, which diminished their likelihood of seeking support from them (Yee, E.G.X, Folashade, A.T. & Perveen, A. 2025). From past studies, (Safe, A., Joosten, A., & Molineux, M. 2012; Woodgate, R.L, Ateah, C. & Secco L. 2008; Sharpley, C. F., Bitsika, V., Efremidis, B. 1997) there were also a strong paradox of sentiments where parents highlighted 'frustration of finding the right support', 'mother as therapist', 'supporting their wider family and partner', 'father mental health', 'flexible employment', 'grief associated with the ambiguous loss of normalcy', 'to live a valuable life' and 'normal life'. Caregivers reported 'knowledge deficit' and being routinely met with a lack of understanding about the types of disabilities, indifferences and their respective characteristics regarding the diagnosis, insensitivity and meeting their child's distinct needs, and, at times, rejection or stigma (Safe, A. & et al. 2012; Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025). Recent literature validates the persistence of parenting paradox while extending understanding of specific factors impacting parents of twins with DS and those in culturally complex environments. The current study aims to address this gap by providing an in-depth exploration of these parents' lived realities, thereby enriching the global discourse with localized, culturally sensitive insights. This will inform targeted interventions and policies tailored to the needs of families in Mauritius and those in the similar settings.

The complexity of parenting twins with Down syndrome has received increased attention in recent years, although empirical studies remain limited. Medical professionals note that the likelihood of both twins being born with Down syndrome is exceedingly rare. This study is notable for including a rare case of identical twins with Down syndrome, a condition estimated to occur in approximately one in 1 to 5 million pregnancies (Brown, G. 2022). The experiences of these parents, who navigate not only the demands of caregiving but also societal curiosity, twin-specific challenges, and spiritual reframing, offer valuable insight into the dualities of pain and pride, limitation and love, that define the parenting paradox (Yee, E.G.X., Folashade, A.T., & Perveen, A. 2025). According to Niedbalski, J. (2025), individuals with twin siblings who have profound intellectual and multiple disabilities tend to be more family-oriented and mutually supportive. Niedbalski identified financial strain, time management difficulties, and emotional exhaustion as primary challenges in one of the few recent comprehensive analyses. Research indicates that parents of twins require specialised support programmes to address the compounded demands distinct from those faced by parents of a single adult with Down syndrome. Additionally, various studies highlight the importance of including sibling dynamics and family-wide coping processes to better understand how raising twins with Down syndrome affects overall family functioning. According to Steed, L. C., and Langlais, M. (2025) state that in the context of FST, if there is a lack of support for individuals with a sibling with a disability, that individual may experience disruptions to their psychological well-being due to disequilibrium in one or more dyads within the system. These studies highlight the multiplicative effect of raising multiple children with disabilities, underscoring the need for targeted psychosocial resources.

METHODS

Mauritius, a small island nation in the Indian Ocean with a population of approximately 1.3 million, has an estimated 59,870 persons living with disabilities, equating to nearly 1 in 22 people (Statistics Mauritius, 2015). Due to limited data on parents raising a member with Down syndrome in Mauritius, purposful sampling was used to select sixteen (16) Mauritian parents (aged 40-66) deemed information-rich for this qualitative study, representing the primary caregiver of young adults with Down syndrome, including twins. Participants are married with multiple children, except one widow, and their young adults with Down Syndrome (9 boys, 5 girls, including one set of twins) ranged from 13 to 40 years old. According to literature, the minimum sample size to achieve

saturation in qualitative data analysis is at least 12 respondents (Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper, H. L., & Shelton, R. C. 2019: Braun, V., & Clarke, V. 2019) and this research caters for 16 respondents. Recruitment was effected through one NGO 'U-Link and Down Syndrome Mauritius', serving individuals with Down syndrome in Mauritius. Using an interpretive phenomenological approach guided by Van Manen's (2016) methodology, the study explored parents' lived experiences and strengths despite the emotional challenges they face. One of the research objectives is to see how the Mauritian parents construct meaning in raising twins and young adult with DS and rely on rich, contextually grounded interpretations of narrative experiences, uncovering layers of meaning with essential characteristics of strengths and challenges within broader societal and cultural significances (Lim, W.M. 2024).

Data Collection and Interview Process

Given the lack of accurate statistics on the number of people with DS in Mauritius, a purposeful sampling approach was employed. Parents are chosen as the primary respondents for this study because of the closeness and personal contact with their young adult's needs, challenges and strengths. Semi-structured interviews were conducted during two periods: October–December 2020 and October–November 2024. Parents were asked to describe their experiences, feelings, thoughts and coping mechanisms related to being parent of a young adult with Down syndrome. In period one, parents from social contacts were selected at the first wave for interview. During this phase, it was observed that there was a lack of openess from parents' on their experiences and the researcher could only gather basic, uncover simple themes, behaviours and little valuable information that correspond to the depth of this study. According to study of Lim, W.M (2024), exploring complex phenomena within human-centrered contexts, it is important to delves into the contextual relevance, in-depth insights, holistic perspective literature and actively seeks out the lived experiences and perspectives of parental coping styles in different phases. It felt that more meetings with the same participants became necessary to develop this research with rich, precise, contextually relevant themes and capture critical insights and then decided to retake the study after some time. In the light of this, the second wave was organised and it became more interesting and comprehensive to see how the experiences have changed over time and over their lifecourse. When comparing the second wave to the first wave, a pertinent point was noticed about the parental behaviours and genuine connection of diluting the complexities into a more exposed and well-told experiences and was likely winning their hearts for more clarity about the paradoxical parenting and feelings. In the second wave, parents highlighted having frequent meetings with NGOs and socialise with other parents in the same condition and this further enlightened my study and strengthened the course of actions towards parental resilience. In a disguised way, these two-phase techniques acted as a natural stepping stones that has allowed to enhance the research process, foster a holistic understanding of the complex phenomena of paradoxical parenting, leading to richer insights and more nuanced conclusions. Gathering face-to-face interviews were conducted mostly at participants' homes, lasting approximately two hours each, with follow-up phone interviews in period two for clarification. Interviews were audio-recorded and transcribed verbatim. Contextual notes were made after each interview to enrich data interpretation. The interview process followed an interview guide with the lists of questions to be asked and this help to maximise consistency of data collection in both periods. The interview guide included open-ended questions about parenting roles, family dynamics, child development, coping mechanisms, social support, and parental well-being. Participants were encouraged to freely share their stories, providing control over the meaning-making process, rather than focusing narrowly on stress or grief. The conduct of interviews reached thematic saturation in the second phase. All participants provided informed consent after receiving explanations about the

study's purpose, confidentiality, and voluntary participation. The NGOs provided formal consent to carry out this study. Anonymous code was applied to streamline the thematic analysis of each participant as shown in the table below of 'participant characteristics'. For illiterate participants, consent was obtained from legally authorized representatives. The research followed ethical protocols allowing participants to withdraw at any time.

Data Analysis

Data analysis followed by Clarke, V., & Braun's. V. (2013) thematic analysis framework, supported by Atlas.ti software. The researcher familiarized herself with the transcripts by repeated reading and note-taking to identify patterns. A systematic coding process was employed in an inductive approach as displayed in tables below. Codes were grouped into themes and subthemes from both waves, reflecting parental experiences and coping strategies. Themes were refined through collaborative review with independent experts to enhance rigor and minimize bias. Saturation was reached when no new codes or themes emerged. The collection of data run over two phases was effective as it allowed to go back and examined other themes, drew out patterns and followed transitions across the four-tiered perspectives: Child, Parents, Family and Community. This was highly effective and useful when exploring and evaluating new and under-researched phenomenon in the local context on in-depth parental experiences and derive their unique life contexts.

FINDINGS AND DISCUSSION

Participants ranged the age from 40 to 66 years old, with various educational backgrounds from primary to master's degrees and represent matured parenting with clearer perspective to raising children of older age with Down syndrome. Most mothers were housewives, while fathers were employed in public or private sectors. The young adults with Down syndrome ranged from 13 to 40 years old, including a set of twins (see Table 1).

Table 1: Participant Characteristics

S/N	Parent	Age	Profession	Marital Status	Education	No. of children	DS Age	Gender	Code
1.	Mother	66	Retired	Widow	Primary	4	Twins 30	F	001
2	Mother	51	Housewife	Married	Secondary	2	17	F	002
3.	Mother	40	Housewife	Married	Primary	2	16	M	003
4.	Mother	63	Retired	Married	Primary	1	39	M	004
5.	Father	62	Private employee	Married	Master degree	2	30	M	005
6	Mother	57	Housewife	Married	Secondary	2	27	F	006
7	Mother	55	Housewife	Married	Secondary	3	30	F	007
8	Mother	54	Housewife	Married	Secondary	2	22	M	008
9	Mother	58	Public employee	Married	Bachelor degree	2	25	M	009
10	Father	56	Public employee	Married	Primary	5	15	M	010
11	Mother	53	Housewife	Married	Primary	3	19	F	011
12	Father	58	Self-employed	Married	Secondary	2	23	M	012
13	Mother	42	Private employee	Married	Secondary	2	13	F	013
14	Father	55	Public employee	Married	Secondary	2	18	M	014

15	Mother	56	Unemployed	Married	Primary	2	32	M	015
16	Mother	51	Unemployed	Married	Secondary	2	17	M	016

This study's thematic analysis revealed rich, nuanced insights into the paradoxical experiences of parents raising young adult and twins with Down syndrome in Mauritius. The findings (in the tables below) crystallize into two overarching dimensions positive and negative each interacting across child, parent, family, and community levels, consistent with Family Systems Theory (Turnbull, A. P., & Turnbull, H. R. 1990). (see table 2)

Table 2: Generic Emerging Thoughts on Negative and Positive dimensions

Negative dimensions	Positive dimensions
Chronic stress, stressful experiences	Happy, good quality of life
Daily care demands	Strong positive feelings
Emotional distress, emotional stress	Parents lives have increased meaning
Maternal depression	Enrichment as a result of their experience
Interpersonal difficulties	Claims of personal growth
Parental discord	Positive views about relative with a disability
Financial problems, extra financial burdens	Positive perceptions
Adverse social consequences	Adapt in a manner that restores faith in the goodness and inherent value of self and of live
Social isolation	Growth and development of the self and the family unit
Marital conflicts, marital dissatisfaction, higher risks of marital discord	Mother's personality
Fatigue, burnout, anxiety, stigma, strain	Religious support
Loss of leisure time due to care-taking responsibilities	Optimism
Negative reactions from others	Positive attitude
Every day management of disruptive behaviours	Social support from family, parents, friends and community
Heavy caregiving responsibilities	Spirituality, Faith in God
Concerns about the future of the child – Parents are no longer able to care for him/her	Positive outlook on the part of supporting parents
Deleterious effects, traumatic event	More compassionate
Feelings of pessimism, hostility and shame, embarrassment	Less self-focused
Denial, projection of blame, guilt, constant grief, withdrawal, rejection	Developing endurance
Helplessness, feelings of inadequacy, anger, shock and guilt	Greater personal strength
Disbelief, depression and self-blame	Facing life with new boldness

Tragedy, better dead than disabled	Cultivate a sense of humor
Negative and unrealistic	Increase the 'happy times' in life
Fatalistic attitudes	Positive outlook
External dependence in families	Hope, growth
Could not do anything and just needed help and sympathy	Commitment and patience
Low motivation	Tolerance & resilience
A punishment for past karmas, a curse, sins committed	Gratitude
Harmful psychological effects	Strong Relationship
Negative health outcomes	Accepting responsibility
Unstable emotionality,	Venting emotions
Psychological ill health, unsatisfactory social health	Acceptance
Low self-efficacy	Household income
Significant demands	Parenting efficacy

The above emerging themes were further refined into four layers: Child, Parents, Family and Community and are displayed below in this study. This research showcases the interactions between these different levels and there is ample evidence to suggest that some parents raising young adult with DS reported lower self-efficacy while others reported the fear of the future while dealing with their young's adult challenging behaviours but described their faith in God as a source of hope and strength to cope with their difficulties. (see table 3)

Table 3: Positive Dimensions: Experiencing Joy, Growth, Coping and Resilience

Main Themes Category	Common Themes	Coping Strategies	Main Themes Category	Common Themes	Coping Strategies
Child Level	Child diagnosis with Down syndrome; Child characteristics; Autonomy; Child relative self-support; Child activity level; Routine	Creating a warm relationship with the child; warm welcome; accepting the situation and others; God's will; involving with the "Down Community"; developing autonomy and self-sufficiency; providing autonomy support; attention-seeking; social network and professional counsel	**Parent Level**	Parents' reaction; Parents as model; Partner relationship; Parents' resilience and autonomy; Physical/material support; Parent characteristics; Parents' participation; Happy parents; Caring parents; Importance to child's health and conditions; Flexible work conditions; Positive feelings & assistance; DS advantages; Source of hope, aspiration,	Avoiding or resolving negative feelings; Expressing feelings and affection; Spiritual growth & support; Family physical activity; Independence; A moment for parent; Familiarizing with child's supportive needs; Acceptance and inclusion; Being more involved in religious activities; Increasing faith or seeking help from God

				gratitude, joy & love; Parental expectations; Parental burnout; Mother's & father's role	
Family Level	Family members support & relationship; Family functioning & stability; Supportive information gathering to cater for child's needs; Developing familial support; Siblings as motivators; Social interaction development; Family routine & behaviour; Culture, spirituality & beliefs; Happiness and togetherness; Communication, comprehension and collaboration	Increasing adaptability; Increasing togetherness & cohesion; Developing parents' information support sources (doctors and other professionals); Accompanying the child in social interactions; Family religious beliefs; Belief in divine providence; Worship to obtain peace; Increased religious involvement; Increasing faith or seeking help from God; Respect and empowerment with moral values	**Community Level**	Family reactions; Clustering with NGOs; Network with DS community; Caring family; Access to other institutions; Regular social networking (online or offline); Presence of social support systems; Peer support; Communication; Proximity of resources; Access to services; State and local community support and services; Access to inclusive facilities; Access to early intervention, medical specialists & related professionals; Law protection	Keeping active in activities/hobbies; Social inclusion; Seeking assistance and support from others; Teaching/advising other individuals how to interact with the child in public areas; Freedom of thought, movement, decision-making, and self-care

Child Level:

From the accounts, parents celebrated their children's distinct personalities and milestones, emphasizing moments of joy and increasing autonomy. Parents narrated that their children's autonomy help them to grow and it corroborates the findings of Ijezie, O.A., Healy, J., Davies, P., Balaguer-Ballester, E., & Heaslip, V. (2023), by showing the value and importance of becoming independent, participating in the communities, knowing their human rights and the key role parents play in raising them. These sentiments echo findings of Skotko, B. G., Levine, S. P., & Goldstein, R. (2016) and Barklı, A., & Doğan, A. (2025), that emphasize the role of positive affectivity and benefit-finding in parental well-being. From the findings, the families experienced a transformative process from which they learn to tolerate, accept and finally celebrate the birth of their own child. The parents'

narratives show alignment with the "Down Syndrome advantage" hypothesis, which suggests lower parental stress and higher familial support and cohesion compared to other disabilities, linked to adaptive child behaviors and supportive family dynamics (Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. 2024; Sheldon, J.P, Oliver, M. & Yashar, B.M. 2021; Mitchell, D.B., Hauser-Cram, P., & Crossman, M.K. 2015). The 'DS advantage' indicates that parents having a child with DS, enjoy greater parenting rewards compared to parents raising other types of developing disabilities because of behavioural phenotype, less severe problem behaviours, easy-going temperament, cheerful, outgoing and apparently positive personality traits and characterictics of children themselves (Channell, M.M., McDuffie, A.S., Bullard, L.M., Abbeduto, L. 2015; Adamson, L.B., Deckner, D.F., Bakeman, R. 2010; Fidler, D.J, Most, D.E, Booth-LaForce C., & Kelly, J.F. 2008) . From the findings, parents confer an advantage with more social support thus making their parenting experience less stressful but with more positive interactions.

One mother reflected:

"They are gifts from God. Watching the girls learn to communicate and engage with others fills my heart every day. Their smiles light up the family." (Code 001)

Another parent highlighted how her child's progress inspired hope:

"He surprised me when he started going to the community center. He is not just my son with Down syndrome; he is growing into a young man who wants to be independent." (Code 003)

Parent Level:

From the accounts, faith and spiritual coping were key strategies in managing emotional distress, resilience and gradually rebuilding hope amidst emotional hardship and other challenges. Parents find strength during difficult experiences and thus turn to prayer, acceptance and trust in God's plan to face fear, guilt and hopelessness stemming from social support (Lakhani, A., Ali, T.S., Kramer-Roy, D., & Ashraf, D. 2024; Findling, Y., Barnoy, S. & Itzhaki, M. 2023). This "can-do" mindset was a recurrent theme, reflecting positive reappraisal and meaning-making strategies central to coping models. The frequent invocation of faith and spirituality resonates with the cultural context of Mauritius and the documented role of religion and informal social support (Lakhani, A., Ali, T.S., Ashraf, D., & Roy, D.K. 2025; Çaksen, H. 2025) in buffering stress among parents of young people with disabilities. Parents described an evolving identity characterized by resilience, advocacy, and spiritual growth. As one father stated:

"Initially, I was overwhelmed. But over time, I learned to be an advocate for my son. Our faith in God gave me strength to face daily challenges." (Code 005)

Family Level:

From the encounters, supportive family interactions and sibling encouragement were pivotal and reshaped the entire family dynamic and enhanced cohesion with the theory of Family Systems Theory. From the studies of (Alon, R. 2026; Skotko, B.G. & Levine, S.P. 2006), the support of siblings build optimism, acceptance and nurture sibling relationships and future caregiving. Sibling involvement not only benefits the child with special needs but also fosters empathy and social learning within the family unit (Steed, L. C., & Langlais, M. 2025).

One mother shared:

"Our other children love and protect their siblings with Down syndrome. The family has grown closer; we communicate more and support each other." (Code 007)

Community Level:

Parents valued connections with Down Syndrome organization as their own community and involved in inclusive community activities. The holistic support systems for individuals with DS in Saudi Arabia and engagement in peer support group play a crucial role in enhancing their quality of life (Praveen, S. Ahmad, A. and Reshi, A.A. 2024) and offer emotional sustenance in line with the theory of FST. The respondents claimed that community-based programs and other activities in NGOs are essential to help families understand DS and to empower the kids with DS into the community with adequate resources, promoting inclusion, sense of belonging and social interaction. The mauritian families will be better equipped to provide the best possible care and advocacy for their loved ones and surroundings as depicted in theory. But, the extent of community inclusion varied, often limited by infrastructural and societal barriers. Nevertheless, active advocacy efforts demonstrate parental agency, consistent with research emphasizing empowerment in disability contexts (Farkas, L. et al 2019). One the participants stated that his child cannot keep up with schooling but is grateful for the NGO that allow him to experience inclusion and provide endlessly support in this learning growth in a different way but look further for respite care.

One participant noted:

"Joining the Down Syndrome Association changed everything. I no longer feel alone. We share stories, strategies, and hope." (Code 002)

The Twin Experience

Parents of twins with Down syndrome emphasized both the amplified caregiving demands and deep blessings. From studies of Lambert, F. (2003) and Niedbalski, J. (2025), a parent of twins with intellectual disabilities is extremely challenging, caregiving intensifies stress and requires extra work but it is noticed that the positive side of 'twin-thing' is that they are at the same level, mutually supportive and this strengthens adaptive family coping.The rarity of identical twins with DS compounded public curiosity and emotional intensity, but also reinforced family bonds and collective purpose. Under the Family Systems Theory, a family is perceived as an interconnected emotional unit. As such, the diagnosis, health needs, and developmental milestones of twins with DS cause a domino effect throughout the entire family system. A mother poignantly accounted that this was a phenomenal shock but acknowledged of doing everything in her power in an extremely organised way to help the identical girl twins to get all those things that one wants from one's children. She added:

"Caring for the girls means double the work but double the love. They are miracles; their smiles erase the fatigue" (Code 001). (see table 4)

Table 4: Negative Dimensions: Grappling with Stress, Stigma, and Structural Barriers

Main Themes Category	Common Themes	Coping Strategies	Main Themes Category	Common Themes	Coping Strategies
Child Level	Diagnosis with DS – unpreparedness to the child's condition & impact of disability; DS diagnosis; Dependence; Physical needs; Need for company; Assistive devices; Severe health	Adaptive behaviour; Socialization; Connecting	Parent Level	Unreadiness to child's condition; Shock; Denial; Guilt; Negative feelings; Rejection; Lack of knowledge & skills to care for a	Knowledge and skills for parents; Adjustment & adaptation; Marital support/status

	condition; Isolation; Peer reaction; Physical demands and child's needs; Insufficient development; Limitations in self-care; Communication & language problems; High temperament; Disruptive behaviour; Stigmatization/social stigma; Problematic behaviours			child with disability; Parental stress; Emotional exhaustion; Marital conflicts; Burnout; Work responsibilities; Parental burden; Marital tensions; Grief; Fear of the unknown; Future expectancy; Limited time; Looking after other children; Frustration; Financial burden; Stigmatization and attitudes of others; Blurred future; Over-parenting	
Family Level	Family instability; Insufficient funds for treatment, extra care, and other needs; Lack of harmony and support; Misunderstanding; Lack of communication; Loaded responsibilities; Lack of support from family members	Greater participation of family members; Increased family involvement in caring for the child with DS; Maintaining routines	Community Level	Absence of social support; Restricted mobility; Limited access to facilities and services; Impact on social life; Limited access to education and other facilities; Structural and process barriers; Limited access to public areas and transport; Seeking more information; Socio-cultural implications; Rights for DS and legal protection	More support; Removal of barriers; Fostering an inclusive mindset; Mobility access policies in different areas; Strengthening legal protection for people with disabilities; Policy improvements

Child-Level Challenges:

The initial diagnosis was overwhelmingly distressing, triggering shock, denial and grief. Parents struggled with behavioral challenges, communication difficulties, and medical complications. Isolation, both social and emotional, was frequently reported.

The narrated statements are:

"When the doctor said 'your son has Down Syndrome,' my world collapsed. I felt lost, afraid of what the future holds." (Code 012)

"People avoid us; they don't understand. My child is treated differently at school and in the community." (Code 008)

These experiences resonate with the studies of (Er-rida S, Oubibi M, Mafhoum M, Alami M, Alaoui A. 2025; Runcheva, J., Perić Prkosovački, B., & Stojanovska, S. 2025), documentation of parental grief, lack of adaptive educational strategies and social exclusion, exacerbated by cultural misconceptions and where disability is sometimes seen as a spiritual failing (Chitando, & Ohajunwa & Dube, K., 2025; Ndlovu, H.L. 2016).

Parental-Level Struggles:

Participants expressed emotional exhaustion, guilt, frustration, and marital tensions. Balancing caregiving with employment and care of other children often led to burnout. Parents manifested on the financial strain and uncertainty about their children's long-term care were persistent stressors. The statements from parents confessed:

"Sometimes I feel overwhelmed. I want to do everything perfectly but end up exhausted and guilty." (Code 006)
"Who will care for him when we are gone? The future is scary." (Code 014)

These concerns of uncertainty mirrorerd the findings of Bujnowska, A.M., Rodríguez, C., García, T., Areces, D., & Marsh, N.V. (2019) and Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. (2025) on the spillover effects of caregiving stress on family wellbeing and the fear about the lack of kindness and empathy in the world that may affect their children and show future anxiety about who will be there to protect them in the absence of parents.

Family-Level Instability:

Cultivating a robus support system from family members is pivotal as highlighted in FST theory and this encompasses support from spouses, children, extended family members, relatives and other stakeholders in the community surroundings. The demands of caring for a member with DS impact the family relationships and according to Bhandari, C., Douglas, S.N., Jensen, E.J. & West, P. (2025) impact siblings and marriage relationships and put on huge strain on their relationship and the entire family system. Strained communication, uneven caregiving roles, and lack of extended family support challenged family harmony. One participant noted:

"My in-laws don't understand. I carry most of the burden, and it is lonely." (Code 002)

This underscores the fragility of social and family support in some families and the risk to family cohesion documented in previous studies (Darla, S., & Bhat, D. 2021).

Community-Level Barriers:

Parents described limited access to inclusive education, inadequate resources, healthcare, and assistive technologies. This was consistent with Boot, F.H., MacLachlan, M., & Dinsmore, J. (2020) on factors influencing access and continued use of assistive products for people with intellectual disabilities living in group homes. Painted from literature, raising a child with a disability as an unmitigated tragedy for the entire family but these narratives have shifted into growing open-mindedness with the help of disability rights and legal support. Legal protections, cultural adaptation and disability awareness were noted as insufficient, echoing regional research on infrastructural gaps and resource-related barriers (Nimusiima et al., 2024; Parveen, S. Ahmad, A. and Reshi, A.A. 2024; Abebe, S. M., Batorowicz, B., Xu, X., Okoroafor, N. A. E., Mekonnen, F., Melak, M. F., & Aldersey, H. M. 2023). Social stigma manifested in public spaces and schools, increasing isolation. A focus on social construction of disability could help to address parental caretaking hardships without stigmatizing people with disabilities.

"There are no ramps, no special schools nearby. Society doesn't accommodate my child." (Code 006)

Synthesis: The Parenting Paradox in Context

The duality of joy and hardship reflects the parenting paradox, where love and pride cohabit with stress and uncertainty. Parents' narratives demonstrate dynamic coping shaped by cultural context, spiritual beliefs, family interactions, and community support. These findings support the transactional view of family adaptation (Kerig, P. K. 2019; Yakren, S. 2018) highlighting reciprocal influences between individuals and their environments. It looks like the paradoxical feelings appear as a profound failure for parents to accept and love their children fully because of disabilty, but in fact, serve as an important coping mechanism and driving force behind difficult caretaking work.

Parents who accessed community resources and nurtured supportive family environments exhibited greater resilience, confirming the buffering role of social capital (Albedeiwi, M.S., Alshammari, S.N. & Aluzeib, A.A., 2022; Souza, M.S., Romano, M.C.C., Oliveira, P.P., Duarte, E.D., & Braga, P.P. 2024). The inclusion of twins with Down Syndrome adds depth to the literature, revealing how multiplicity intensifies caregiving demands but also fosters solidarity and meaning.

CONCLUSION

This study illuminates the complex and multifaceted lived experiences of Mauritian parents raising adult and twins with Down syndrome, revealing a profound parenting paradox characterized by simultaneous joy and struggle, resilience and vulnerability. Anchored in Family Systems Theory, the research highlights how emotional responses evolve from initial shock and grief to acceptance, spiritual reframing, and advocacy. Parents' narratives underscore the vital roles of family cohesion, community support, and cultural beliefs in shaping adaptive coping and resilience. Parents experiences not only grief and despair, but also love and joy, even in the most extreme circumstances, such as, when their child is unreponsive due to multiple severe health conditions and disabilities. The inclusion of a rare case of identical twins with Down syndrome adds a unique perspective, demonstrating intensified caregiving demands balanced by enhanced familial solidarity and meaning-making. Despite positive dimensions such as strengthened bonds and personal growth, parents continue to face significant challenges, including stigma, limited access to inclusive services, financial strain, and emotional fatigue.

These findings contribute to a more balanced understanding of parenting adult with Down syndrome, moving beyond deficit-focused models to recognize both the transformative potential and persistent systemic barriers in resource-constrained, culturally diverse settings like Mauritius. This study underscores the need for culturally sensitive, multidimensional support systems that acknowledge the parenting paradox, promote inclusion, empowerment, and sustainable family well-being.

It is recommended that stakeholders have to contribute towards family-centered psychosocial counselling, peer support programs and promote collaboration across the state, healthcare, education and community sectors to coordinate effective and comprehensive family support. Other bodies such as the Ministry of Social Security, National Empowerment Foundation and other religious bodies, leaders and media organization may launch culturally sensitive awareness campaigns to reduce stigma. Advocacies to implement inclusive education policies with appropriate resources with the relevant ministries will help the young individual with Down syndrome. Healthcare service is a vital support that need to be strengthened by the Ministry of Health and Wellness, public hospitals, pediatric specialists, therapists (speech, occupational) and other professionals through multidisciplinary teams focused on early intervention and ongoing support.

Limitations and Future Research

There are few caveats presented in this study. With inadequate data on the number of individuals with Down syndrome in Mauritius, the findings arise from a small sample size. Although it is sufficient to achieve saturation in the analysis, it is relatively small. Studying old parents with older children with DS, excluding single parents, are highlighted and therefore, conclusions cannot be generalised on a broader analytical categories. Another caveat is that this research was conducted in Mauritius. Given the qualitative nature of this research and the specificity of Mauritian's social-cultural context, the outcomes of this study cannot be extrapolated. Further exploration of themes and the selection of interviewees to include other young age categories of parents are call for future research. Although this study was guided by the principles of Family Systems Thoery, the exploration of multiples and indepth themes, encompassing the four levels (child, Parents, Family and Community), warrant solid grounds for generating broader arguments to contribute to the emergence of a model or theoretical concept as future research. Further research should incorporate multiple stakeholders to develop a more comprehensive understanding of support mechanisms and policy implementation for families navigating special needs caregiving.

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Consent to Participate: Informed consent was obtained from all individual participants included in the study.Participants were advised that they were free to withdraw at any time, should they wish to do so. The NGO provided consent to conduct this study with its members.

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Review Article

Pattern of Sedentary Activity among Persons with Neuro-developmental Disabilities: A Scoping Review

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ABSTRACT

Aim: The global prevalence of Neuro-developmental Disorders (NDDs) is alarming, with approximately 316.8 million cases identified. Individuals with NDDs are reportedly less physically active compared to their peers. However, reviews are limited, focusing on sedentary patterns of individuals with NDDs alongside disorder-specific data. This study aims to identify disorder-specific patterns and factors influencing sedentary lifestyles in this population.

Method: The review followed PRISMA-ScR guidelines and Arksey and O'Malley's framework, with study selection guided by the JBI Population–Concept–Context (PCC) approach. Searches were conducted in PubMed, Scopus, Web of Science, and Google Scholar using keywords such as "sedentary activity," "screen time," "sitting time," "neurodevelopmental disorders," "ASD," "ADHD," and "intellectual disability," combined with Boolean operators "AND" and "OR." Eligible studies were peer-reviewed articles examining sedentary patterns in individuals with NDDs. Review articles, studies on typically developing populations, and studies addressing only physical activity were excluded.

Results: A total of 19 articles were entitled for this study, involving 27,180 samples. Screen media usage was the most common form of sedentary activity among individuals with NDDs. Other sedentary activities were reading, imaginative play, playing with toys, crafting, indoor games, and playing musical instruments. Screen time was higher among individuals with Autism Spectrum Disorder (ASD) (2 to 7 hours/day) and Intellectual Disability (2 to 10 hours/day) compared to other groups. Moreover, sedentary time was higher on weekends compared to weekdays.

Conclusion: The findings indicate that individuals across all age groups with NDDs exceed the ideal screen time limits. Disorder traits, physical and socio-economic barriers, and quality of life influence sedentary behaviors. The limited exploration of disorders, aside from a few observational studies in this context, highlights the need for broader, more comprehensive research.

Keywords: Neurodevelopmental disorders; Sedentary activity; Screen time; Influencing factors.

INTRODUCTION

Neurodevelopment involves a complex interaction among genetic, neural, cognitive, emotional, and behavioural processes throughout development. Disruptions to this process, whether due to genetic or environmental risk factors, are strongly associated with neurodevelopmental disorders and impairments (Arora et al., 2018). Neurodevelopmental disorders (NDDs) are a diverse group of conditions that differ from one another (Damianidou et al., 2022). Autism Spectrum Disorder (ASD), Attention Deficit/Hyperactivity Disorder (ADHD), Cerebral Palsy (CP), and Intellectual Disability (ID) are common types of NDD that often exhibit early-onset impairments in physical, cognitive, social, and occupational domains, significantly affecting daily functioning and persisting across the lifespan (Koly et al., 2021; Yang et al., 2022; Naik et al., 2023). A range of factors, such as genetic influences, premature birth, metabolic or viral infections, nutritional deficiencies, physical injuries, and environmental exposures, can contribute to neurodevelopmental disorders (Tang et al., 1992).

The prevalence of NDDs in children and adolescents varies considerably across regions. Rates are higher in high-income countries compared to low- and middle-income countries (Lau et al., 2022). Globally, an estimated 316.8 million individuals are affected by developmental disorders, with boys showing greater rates than girls (Rahman et al., 2024). In some European regions, NDD prevalence rates range between 4.70% in Scotland and 55.5% in Norway. According to 2015 data from the National Centre for Health Statistics (NCHS), approximately 15% of children aged 3 to 17 years in the United States are affected by NDDs. Notably, the rate has approached 90% in Japan (Frances et al., 2023). The estimated prevalence rates of the most common NDDs are as follows: ADHD ranges from 7.9% to 9.5%; ASD from 0.7% to 2.2%; and motor coordination disorder from 1.4% to 19% (Frances et al., 2022).

The prevalence of NDDs in children and adolescents in low- and middle-income countries (LMICs) is substantial, yet under-evaluated, according to mounting data (Kipkemoi et al., 2025). Although it is challenging to pinpoint the precise incidence because of methodological differences and a lack of data, research indicates that NDDs such as ADHD, autism spectrum disorder, and intellectual disability are common. The prevalence of stigma, substantial care barriers, and increased exposure to risk factors are just a few of the complex issues that children in LMICs face in comparison to their counterparts in high-income nations (Kipkemoi et al., 2025; Olusanya et al., 2023; Namazzi et al., 2019).

Worldwide, changes in economic, educational, cultural, and technological developments have contributed to lifestyle changes, leading to a rise in sedentary behavior (Abonie & Ackah, 2024). Sedentary behavior (SB) refers to waking activities or minimal physical activities characterized by low energy expenditure (≤1.5 METs), typically performed while sitting or lying down (Meneses-Echavez et al., 2025). Examples of SB include using electronic devices (e.g., tablets, mobile phones, TVs, or computers), reading, sketching, and painting, completing homework, or sitting at school (Krol et al., 2024). These habits are associated with approximately 6–10% of non-communicable diseases and contribute to 9% of premature deaths. The World Health Organization (WHO) recommends at least 60 minutes of moderate-to-vigorous physical activity (MVPA) each day for children and adolescents aged 5 to 17 years and 75 to 300 minutes of MVPA in a week for adults, with sedentary behavior (SB) limited to less than 2 hours (Yuan et al., 2022). According to the reports, children and adolescents are found highly inactive in recent years (Abonie & Ackah, 2024; McCoy et al., 2020; Hossain et al., 2022).

Children with NDDs are consistently less physically active and more sedentary compared to their typically developing peers. Studies indicate that they not only engage in fewer physical activities but also spend significantly more time being inactive, which may increase the risk of cardiometabolic complications and obesity (Sit et al., 2016; Lynch et

al., 2025). For example, parents of children with specific learning disabilities report that their children engage in minimal physical activity and spend approximately nine hours per day engaged in sedentary pursuits (Ariapooran et al., 2022). A study conducted in Thailand revealed that children with ASD watched television more than twice as much as their typically developing peers. Similarly, a study in the United States found that children with ASD watched an average of 3.8 hours of television per day (Must et al., 2014). Furthermore, even physically independent children with cerebral palsy (CP) in Ireland were found to spend a substantial portion of their day being idle rather than engaging in physical activity (Alamoudi et al., 2024). In contrast, reports indicate that less than 10% of adults with intellectual disabilities meet the physical activity guidelines by WHO (Safi et al., 2024).

Sedentary lifestyles are increasingly recognized as a critical public health concern, particularly for individuals with NDDs who face unique cognitive, behavioral, and environmental challenges to physical activity. Recent studies have underscored the lack of disorder-specific evidence in these populations (Nakhostin-Ansari et al., 2023), emphasizing the need for comprehensive reviews to better understand and address sedentary lifestyles among individuals with NDDs (Peng et al., 2022; Liu et al., 2024). Existing studies suggest a common pattern of being inactive across all age groups of individuals with NDDs; however, most of them focused on individuals with physical disabilities or on specific neurodevelopmental disorders and primarily examined screen time, leaving a gap in synthesized evidence on SB among individuals with NDDs (Ophir et al., 2023; Ganz et al., 2021).To address these gaps, the present study adopts a scoping review approach to systematically map the existing empirical literature on sedentary activities among individuals with NDDs. This study aims to identify disorder-specific patterns and influencing factors related to sedentary lifestyles in the NDD population. Such reviews seek to inform future research and support the development of targeted interventions and public health strategies that can be integrated into disability-inclusive policies in low- and middle-income countries (LMICs), where formal disability support services are often limited.

METHODS

This scoping review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018). and the five-stage methodological framework established by Arksey and O'Malley (Arksey et al., 2005). This framework encompasses (1) research question identification, (2) relevant study identification, (3) study selection, (4) data charting, and (5) data collation, summarization, and reporting.

Research Questions:

This scoping review was guided by the following research questions:

1. What are the patterns of sedentary activity among individuals with neurodevelopmental disorders (NDDs)?
2. Do sedentary patterns differ across various types of NDDs?
3. What factors are associated with influencing sedentary behavior in individuals with NDDs?

Identifying Relevant Studies

A comprehensive and systematic search strategy has been designed to identify literature examining patterns of sedentary activity among individuals with neurodevelopmental disorders. In this study, "patterns of sedentary activity" refers to the specific types of SB in which individuals frequently engage in (e.g., screen time, reading, playing sedentarily, sitting). For each type of sedentary activity, we primarily extracted information on frequency (number of sessions per day or week) and, where reported, duration of engagement to characterize habitual participation. The search was conducted across

multiple electronic databases, including PubMed, Scopus, Google Scholar, and Web of Science. The search strategy was based on two main concepts: sedentary activity and neurodevelopmental disorders. For sedentary activity, the search terms included "sedentary activity," "sedentary behavior," "screen time," and "sitting time." For neurodevelopmental disorders, the search terms included "autism spectrum disorder," "attention-deficit/hyperactivity disorder," and "intellectual disability." Within each concept, terms were combined using **OR**, and the two concepts were linked using **AND**. For example: *("sedentary activity" OR "screen time" OR "sitting time") AND ("autism spectrum disorder" OR "attention-deficit/hyperactivity disorder" OR "intellectual disability")*. Full search strings for each database are provided in Annex 1 (A1).

The review included articles if they met the following criteria: peer-reviewed articles published in English; published between 2000 and 2024; focused on sedentary activities among individuals with neurodevelopmental disorders; and primary empirical research using either quantitative or qualitative study designs. The language was restricted to English because the research team did not have sufficient proficiency in other languages and lacked access to reliable translation resources. The study did not provide many restrictions on the publication year; however, it did take into account the rise of neurodevelopmental issues and the influence of digital media on reducing physical activity in the 21st century.

Studies were excluded if they were review articles, including systematic reviews, narrative reviews, or meta-analyses; did not present primary empirical data; had undefined sources; focused on typically developing individuals rather than persons with neurodevelopmental disorders; or were studies that addressed only physical activity without discussing sedentary pattern. While qualitative reviews can be informative for identifying factors influencing SB, this was not the primary aim of the present review. Our objective was to summarize empirical evidence on patterns of sedentary activity among individuals with neurodevelopmental disorders. Moreover, secondary sources from review articles could have led to duplication of data and biased interpretations.

Selection of Studies

This study selection was guided by the JBI-recommended Population–Concept–Context (PCC) framework, which informed the development of the eligibility criteria. The population included individuals diagnosed with NDDs, such as ASD, ADHD, intellectual disability, CP, developmental delay, cognitive developmental delay, specific learning disorder (SLD), or others with developmental, behavioral, and emotional issues. The concept focused on sedentary activity patterns (e.g., screen time, sitting time, sedentary or imaginary play). The context was kept broad, with no restrictions on geographic location or study setting, consistent with JBI scoping review methodology. Both the population and context were maintained broadly due to the limited research on SB among individuals with NDDs, ensuring that all relevant evidence could be captured. Moreover, this review did not have a pre-registered protocol on a public registry such as the Open Science Framework (OSF).

The literature search was conducted between February 2025 and May 2025 across all selected databases. Two reviewers independently screened all titles and abstracts, followed by independent full-text screening for studies that met the initial criteria. Disagreements were resolved through group discussion, and consensus was reached on the final inclusion of 19 eligible studies. "EndNote" was used for the screening and data management process.

Charting the Data

By using a standardized charting form, data were systematically extracted from the selected studies. This form recorded important facts about:

- Study characteristics: author(s), year, country, and study design.
- Participant characteristics: sample size, age, gender, and type of neurodevelopmental disorder.
- Methods: tools used to assess sedentary behavior and types of sedentary activities measured.
- Outcomes: patterns of sedentary behavior, associated factors, or determinants
- Key findings and conclusions
- Notes on limitations and recommendations

Two reviewers independently charted the data to ensure accuracy, with any disagreements resolved through discussion. After that, the data were arranged to facilitate the synthesis of evidence in a descriptive and thematic manner.

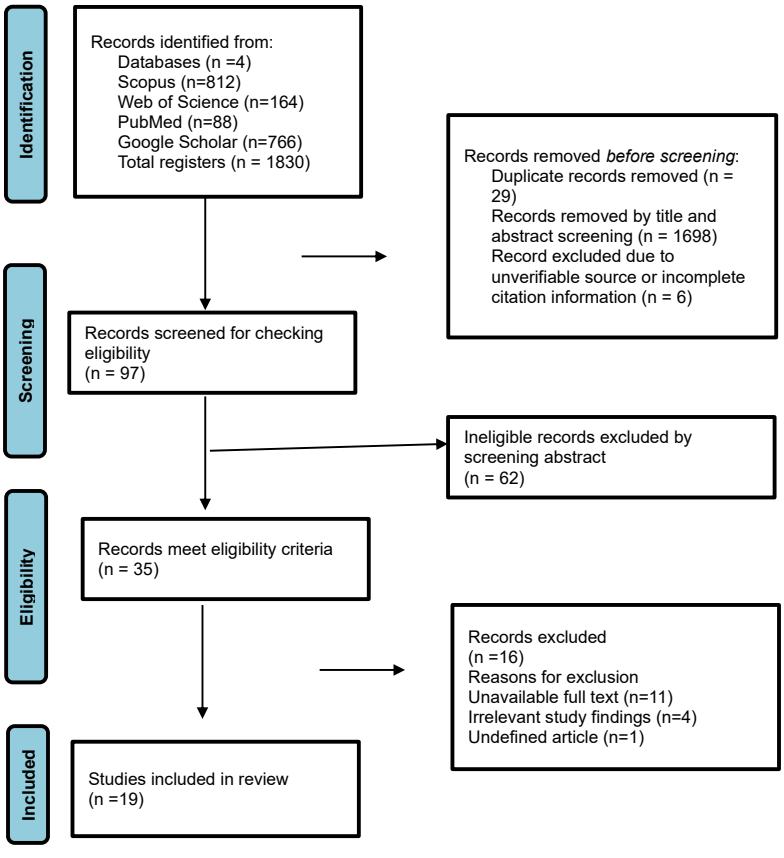
Collating, Summarizing, and Reporting the Results

In this stage, the review provided a comprehensive quantitative summary of the included studies. Specifically, it outlined the total number of studies, participant details, study designs, publication years, measurement tools, and geographic locations. The analysis also included key characteristics of the study populations, including age groups and types of neurodevelopmental disorders. Furthermore, the types of inactivity examined and associated factors identified were systematically summarized. This structured synthesis facilitated the identification of research trends, gaps in the literature, and areas for future investigation.

Ethical Approval:

Ethical approval and informed consent were not required for this study. This scoping review was conducted using data derived solely from previously published studies. No new data were collected, and there was no direct involvement of human participants or use of identifiable personal information.

Figure 1: PRISMA Flow Diagram of Study



RESULTS

The database search identified 1,830 records across four databases. After the removal of 1,733 records during title and abstract screening, 97 full-text articles were assessed for eligibility. Only 35 articles met the inclusion criteria. In total, 19 studies were included for data charting and synthesis (Figure 1).

The review consists of 17 descriptive studies, 1 cohort study, and 1 case-control study. These studies collectively involved 27,180 participants. Among them, individuals with cognitive disorders (approximately 11,000) and ASD (14,400) formed the largest groups. Additionally, 1,039 participants had ID, 418 had CP, and 231 were identified with Specific Learning Disorders (SLD). The fewest participants were reported in studies involving Attention-Deficit/Hyperactivity Disorders (ADHD), developmental delay, and behavioral dysregulation. Participants ranged in age from 1 to 55 years. Most studies focused on children (n = 11), followed by adolescents (n = 6) and adults (n = 2).

Most of the studies were conducted in the USA (n = 5), with others from China, Australia, and Iran (n = 2 each). Single studies were conducted in Japan, Germany, Taiwan, Poland, Singapore, India, and Canada. One multinational study included participants from seven countries: the USA, Brazil, Finland, Hong Kong, China, Singapore, and South Korea. A detailed overview of the reviewed literature has been provided in Supplementary 1.

To assess sedentary activity patterns, most studies relied on subjective measurement approaches. Seven studies used parent-reported questionnaires, and one study employed an adapted questionnaire. Several studies used objective measures, including ActiGraph accelerometers (models WGT3X+BT and GT1M). A variety of validated instruments were also applied to capture sedentary activities, such as the Children's Leisure Activities Study Survey (CLASS), the Screen Viewing Time (SVT) Questionnaire, the Youth Screen Time Survey, the Modified Sedentary Behavior Questionnaire, the Child Weekly Screen Time Scale, and self-reported time logs. Qualitative and developmental assessment tools, including semi-structured pro forma, the Critical Incident Technique, and the Gesell Developmental Schedule, were used in a smaller number of studies. One study combined objective accelerometer data with self-reported logs to quantify both total sedentary time and specific activities, including television viewing, computer use, and reading. Table 1 presents a summary of the charted data, including study characteristics, participant characteristics, measurement instruments, and key findings related to sedentary behavior patterns.

Sedentary Activities in Individuals with ASD

This scoping review identified consistent patterns of SB among children, adolescents, and adults with ASD, based on findings from 13 studies. Screen media usage was the most common form of sedentary activity across all age groups, ranging from approximately 2 to 7 hours per day. Watching TV emerged as the most frequently reported screen activity, followed by playing video games and using computers, tablets, or smartphones. Mean screen time for children and adolescents ranged from 2 to 5 hours per day, while adults with ASD spent an estimated 6 to 7 hours daily on screen-based activities (Kushima et al., 2022; Must et al., 2015; Stiller et al., 2019; Must et al., 2014; Dong et al., 2021; Thomas et al., 2020; Haegele et al., 2024; Nakhostin-Ansari et al., 2023; Pan et al., 2021; Dong et al., 2023; Kiing et al., 2024; Must Aviva et al., 2023; and Lee et al., 2024).

Along with screen use, other sedentary activities included imaginative or quiet play, playing with toys, doing homework or reading, playing indoor games, crafting, and listening to or playing music. These activities typically accounted for approximately 1 ± 0.5 hours per day (Must et al., 2014; Thomas et al., 2020; Nakhostin-Ansari et al., 2023; Pan et al., 2021). Five studies compared SB between weekdays and weekends, showing that individuals with ASD tended to spend 1 to 1.5 hours more on sedentary activities on

weekends than on weekdays (Must et al., 2015; Must et al., 2014; Pan et al., 2021; Kiing et al., 2024; Lee et al., 2024).

Sedentary Activities in Individuals with Intellectual Disability

Three studies specifically assessed the sedentary activity patterns among individuals with intellectual disabilities, highlighting that screen media is the most prevalent SB across all age groups, with usage ranging from 2 to 10 hours per day. Children and adolescents spent more time on screens on weekends (3.85 hours/day) compared to weekdays (3.38 hours/day). Adults reported the highest screen usage (5–10 hours/day), while children and adolescents reported usage ranging from 2 to 3.6 hours/day (Wyszyńska et al., 2017; Nakhostin-Ansari et al., 2023; Safi Sana et al., 2024).

Other slothful habits among children and adolescents included homework, reading, indoor play, listening to music, and imaginative play, with each activity averaging around 0.5 hours/day (Nakhostin-Ansari et al., 2023; Safi Sana et al., 2024). In contrast, adults spent more time on similar activities such as reading, arts and crafts, knitting, and listening to music, ranging from 0.5 to 4.5 hours/day (Safi Sana et al., 2024).

Sedentary Activities in Individuals with Cerebral Palsy (CP)

SB among individuals with CP was primarily reported in two of the included studies**.** One study found that children and adolescents with cerebral palsy spent an average of 2.2 hours per day on screen media, while another study reported that adolescents engaged in recreational screen-based activities for an average of 4.07 hours per day (Nakhostin-Ansari et al., 2023). The same study further reported that screen time was higher on weekends (5.97 hours per day) compared to weekdays (3.46 hours per day) (Carol et al., 2007).

In addition to screen media, one study highlighted other forms of idleness among children and adolescents with CP, including homework, reading, and art-related activities (approximately 2 hours/day); sitting activities (1.2 hours/day); and a range of low-frequency sedentary pursuits such as playing with toys or board games, listening to music or playing musical instruments, and engaging in imaginative play, which ranged from 0.2 to 0.53 hours per day.

Sedentary Activity Patterns in Other Neurodevelopmental Disorders

Three studies separately identified patterns of sedentary activity among individuals with cognitive developmental disorders, ADHD, and SLD, all consistently highlighting screen media as the most prevalent form of inactivity. Among individuals with cognitive developmental disorders, the average daily screen time was 3.8 ± 3.07 hours. Youth spent significantly more time on screen media during weekends (4.64 ± 3.61 hours/day) compared to weekdays (3.47 ± 3.1 hours/day) (Yang Anyi et al., 2022).

In contrast, the study on the ADHD population revealed that the average daily screen time was 2.83 ± 2.13 hours per day. Television (98.2%) was the most commonly used screen-based activity, followed by mobile phones (87.3%), tablets (17.9%), and laptops (10.7%) (Vaidyanathan et al., 2021).

The estimated screen time among children with specific learning disorders was 4.39 hours per day. However, screen time on weekdays (4.42 hours per day) and weekends (4.3 hours per day) among the participants was quite similar. TV watching (2.43 hours/day) was the most common motionless activity, followed by playing with handheld devices (0.67 hours/day) and playing mobile games without internet (0.65 hours/day). Other screen-based activities, such as watching DVDs, playing video games, and using computers with or without internet, ranged from 0.18 to 1.58 hours/day (Ariapooran et al., 2022).

Factors Associated with Sedentary Activity

Among the 19 studies, 6 highlighted factors contributing to sedentary activities. Identified key factors were disorder trait (Must et al., 2023; Vaidyanathan et al., 2021), physical and socio-economic barriers (Must et al., 2015), parenting style (Ariapooran et al., 2022), and quality of life (Lee et al., 2024 & Safi et al., 2024)

DISCUSSION

Pattern of Sedentary Activity

This scoping review mapped evidence from 19 studies and demonstrated that screen-based SB was the most prevalent form of sedentary activity across neurodevelopmental disorders, with particularly high levels observed among individuals with ASD and intellectual disabilities, and greater sedentary time was reported on weekends compared with weekdays. Screen media use, including television viewing, smartphone use, video gaming, and other digital activities, was consistently identified as the most frequently reported SB, especially among children with ASD. These findings are consistent with previous reviews indicating substantially higher screen time among children with ASD, reaching up to 430 minutes per day (Jones et al., 2017). In contrast, participation in non-screen-based sedentary activities, such as reading, imaginative play, playing with toys, crafting, indoor games, and playing musical instruments, was limited. Evidence suggests that limited parental education and guidance may be associated with higher screen use and an increased risk of digital device dependence among children with ASD (Dong et al., 2021). Additionally, higher levels of SB among individuals with intellectual disabilities have been linked to greater disorder severity (Oppewal et al., 2008).

Although screen media use is commonly reported across childhood, adolescence, and adulthood, adults with ASD and individuals with ID exhibit higher screen time. However, existing evidence does not consistently demonstrate a consistent increase in screen use with age, suggesting that elevated screen usage may not be associated with age (Oppewal et al., 2008).

A clear weekday–weekend difference was observed. Each group, including children, adolescents, and adults across most NDD categories, engages in more sedentary time on weekends than on weekdays. However, children with SLD demonstrate similar durations of inactivity across weekdays and weekends, suggesting minimal variation in inactivity patterns. However, This scoping review indicates that individuals with neurodevelopmental disorders across all age groups exceed these recommended limits, which are as follows: no screen time (except video chatting) for children under 2 years, 0.5 to 1 hour per day for children aged 3–7 years, 1 hour for ages 7–12, 1.5 hours for adolescents aged 12–15, and 2 hours per day for those aged 16 years and above (Muppalla et al., 2023). These findings highlight the need for parent- and caregiver-focused educational strategies to improve understanding of age-specific screen-time guidelines. Healthcare professionals and educators can play a key role in supporting families by integrating screen-time counselling into regular clinical follow-up visits.

Among screen-based sedentary activities, television viewing emerged as the most common form of SB among children and adolescents with NDDs, particularly those with ASD, ADHD, and SLD. Mobile phone use was the second most common screen activity. Previous studies have indicated that children with neurodevelopmental disorders are exposed to television viewing before 2 years of age, while prolonged screen exposure, specifically watching television, may increase disorder severity (Pons et al., 2022; Melchior et al., 2022). In contrast, other sedentary activities, such as doing homework, reading, arts and crafts, sitting activities, or less frequently reported leisure activities (e.g., playing with toys or board games, listening to music, or engaging in imaginative play) accounted for considerably less time. These activities were typically reported as lasting less than one hour per day, showing that screen use dominates sedentary patterns in these groups.

However, insufficient evidence exists regarding non-screen-based habits to support detailed reporting.

Additionally, this scoping review included four studies comparing screen time between typically developing children and children with ASD. These studies revealed that screen time is higher among children with ASD than their typically developing peers, and that may be negatively affecting their behavioral outcomes, socialization, sleep, and brain development (Dong, H. Y., Wang, B. et al., 2021; Dong, H. et al., 2023).

By mapping a broad spectrum of sedentary activities and accounting for disorder-specific differences across multiple neurodevelopmental disorders, this review advances existing literature that has largely focused on total sedentary time or individual disorder groups (Melville et al., 2017; Oppewal et al., 2008; Jones et al., 2017). This comprehensive perspective may inform the development of tailored interventions and guide disorder-specific recommendations. Furthermore, the findings may assist policymakers in developing inclusive home- and school-based play environments, such as accessible and engaging playgrounds and adaptive play areas, which may help reduce SB and promote physical activity.

Influencing Factors Associated with Sedentary Behavior

Traits related to poor self-regulation, associated with ASD and ADHD, are key contributing factors. For example, children with ASD often present repetitive behaviors, such as repeatedly playing the same games or watching the same videos, which may contribute to prolonged screen time. In contrast, children with ADHD may find structured, task-oriented play more challenging than engaging with screen-based media, reflecting difficulties with sustained attention (Must et al., 2023; Vaidyanathan et al., 2021).

Furthermore, barriers such as motor difficulties, low self-confidence, limited access to facilities, and high program costs often prevent individuals with ASD from engaging in physical activity, making screen use a more accessible alternative (Must et al., 2015). In children with SLD, screen use is influenced by the appeal of and easy access to digital devices, and shaped by parenting style (Ariapooran et al., 2022). For adults with intellectual disabilities and ASD, SB is influenced by financial hardship, discrimination, safety concerns, and limited social support (Lee et al., 2024; Safi et al., 2024). In this context, Community-Based Rehabilitation (CBR) programs, which emphasize health, inclusion, functional independence, and equitable access to participation, may serve as an important strategy to improve physical activity opportunities, enhance community engagement, and address systemic barriers faced by individuals with disabilities (Lankester et al., 2019).

Existing Research Gaps and Future Directions

A large proportion of studies included in the review relied on self-reported questionnaires to assess SB, which introduces the potential for recall bias or data misinterpretation (Kushima et al., 2022; Must et al., 2015; Must et al., 2014; Pan et al., 2021; Must et al., 2023; Ariapooran et al., 2022). The use of observational methods, such as camera monitoring, may provide more reliable data in future studies.

Disorders except ASD are often underrepresented in existing literature, highlighting a notable gap in fully understanding the sedentary patterns in those groups. Notably, no study identified that explored sedentary behavior among individuals with Down syndrome, despite its relatively high prevalence (1 in every 336 babies), according to the NCARDRS Congenital Anomaly Official Statistics Report-2021. Additionally, there is limited evidence on the adult population with NDD, including gender-specific analysis and exploration of the relationship between socio-demographic data and SB (Dong et al., 2021).

Future research may explore the impact of screen time on psychological well-being, the effectiveness of interventions aimed at reducing screen use before bedtime, and the types of screen-media content, targeting the population with NDD (Stiller et al., 2019; Haegele et al., 2024; Dong et al., 2023).

CONCLUSION

The scoping review provided a comprehensive overview of sedentary activity patterns among individuals with NDD. The review highlighted screen time as the predominant form of sedentary activity across all groups, with reading, imaginative play, playing with toys, and crafting as the least frequently reported activities. Furthermore, sedentary time was higher on weekends compared to weekdays.

The review also examined factors associated with SB. NDD traits, such as repetitive behavior in young people with ASD and poor concentration in individuals with ADHD, were some of the key factors associated with higher sedentary screen time. In contrast, excessive screen usage in adults with NDD was often linked to poor quality of life.

This review underscores the need for organizations involved in Community-Based Rehabilitation (CBR) to prioritize individuals with NDDs. Strengthening CBR initiatives to include inclusive physical activity programs, environmental modifications, and community participation opportunities could help address the unique barriers faced by this population and support more active and engaging daily routines.

Limitations

A key limitation of this review is the absence of a preregistered protocol, which may reduce methodological transparency and increase the potential for bias. Additionally, there were limited studies focusing specifically on individuals with ADHD, SLD, cerebral palsy, Down syndrome, cognitive impairments, and other neurodevelopmental conditions. Moreover, most included studies emphasized screen time, with limited attention given to other forms of SB. Future reviews should address these limitations by including a broader range of databases to increase study coverage and enhance the comprehensiveness and transparency of the evidence base.

Data Availability: This scoping review did not generate or collect primary data. All data were extracted from studies published in peer-reviewed journals and other publicly available sources.

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Annex

A1.Table 1: Databases and Search Strategies

Database	Search Strategy
PubMed	(Autism Spectrum Disorder OR ASD OR Attention Deficit Disorder with Hyperactivity OR ADHD OR Neurodevelopmental Disorders OR Cerebral Palsy OR Speech and Language Disorder OR Developmental Disabilities) AND (Sedentary behavior OR sedentary activity OR screen time)
Scopus	(Autism OR Attention Deficit Disorder with Hyperactivity OR Neurodevelopmental Disorders OR Cerebral Palsy OR Developmental Disabilities OR Intellectual Disabilities) AND (Sitting activity OR sedentary activity OR screen time)
Web of Science	(Neurodevelopmental disorders OR Developmental delay OR Autism Spectrum Disorder OR Attention Deficit Hyperactivity Disorder OR Cerebral Palsy OR Intellectual disabilities) AND (Sedentary play OR sedentary activity OR screen Time OR sitting time)
Google Scholar	Neurodevelopmental disorder OR sedentary activity

Note: In the case of Google Scholar, screening was limited to 100 pages. Google Scholar orders results by relevance rather than date; studies beyond 100 pages appear to be duplicates or low in relevance. Screening restriction is consistent with methodological guidance for scoping reviews and maintains feasibility without compromising comprehensiveness.

Review Article

Playing for wellbeing: A scoping review of students with disabilities and tertiary sport

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ABSTRACT

Aim: Students with disabilities at tertiary institutions do not have guaranteed opportunities for recreational sport and physical activity (RS&PA). This scoping review synthesized evidence on the contribution of RS&PA towards improving the social inclusion and wellbeing of these students to inform implementation of policy into practice.

Methods: EBSCOhost, PubMed, Scopus, Web of Science and ProQuest were searched before two reviewers screened studies based on the following inclusion criteria: social inclusion and/or wellbeing; recreational sport and physical activity; students with disabilities; tertiary institutions. Studies published in English from between 1995 and 2025 were included.

Results: From 349 studies from the search, 10 were included. An additional 10 studies were included from screening the reference lists of the selected studies. Most studies were qualitative and from the Global North. Evidence supports RS&PA facilitating students with disabilities' social inclusion and wellbeing through enabling health outcomes, physical accomplishment, academic persistence, empowerment and a sense of belonging.

Conclusions: More evidence from the Global South is needed. Equitable policies that facilitate implementation of inclusive sport and physical activity practices can be achieved through engaged research about students' experiences.

Implications: Addressing the gap in research from the Global South will provide evidence to influence disability inclusion on policy and practice. Institutional leadership needs to be intentional about increasing the participation of students with disabilities in RS&PA.

Keywords: Disability; Recreation; Sport; Physical activity; Higher education institutions; Social inclusion; Wellbeing .

INTRODUCTION

Tertiary education institutions, including universities, colleges, technical training institutes, and vocational schools (World Bank, 2025), facilitate learning, work, and play for

a range of students. They can provide access to infrastructure persons with disabilities need to participate in recreational sport and physical activity (RS&PA). RS&PA are extramural activities that students can participate in on an individual or collective level for social or intra-institutional interactions (Abdeahad & Mock, 2023). These activities are essential to student life for all tertiary students (Oakes et al., 2021). The United Nations Educational, Scientific and Cultural Organisation's (UNESCO) (2015) International Charter of Physical Education, Physical Activity and Sport states that full participation in society involves opportunities to engage in RS&PA.

Persons with disabilities include those with physical, mental, sensory or intellectual impairments who face environmental barriers that stifle their full and equal participation in society (United Nations, 2017). Critical Disability Theory acknowledges that disability is a social construct. It is the oppressive perceptions and actions of the social, cultural, and political structures that create systemic barriers, which curtail meaningful participation for people with impairments (Carmel et al., 2025; Devlin & Pothier, 2006; Tremain, 2005). Participation in RS&PA has been shown to benefit individuals' physical, psychological and social wellbeing, especially for persons with disabilities (Carretti et al., 2022). Wellbeing is a positive state which "encompasses quality of life, as well as the ability of people and societies to contribute to the world in accordance with a sense of meaning and purpose" (WHO, 2021, p. 10). Social inclusion is improving how disadvantaged individuals and groups participate in society by championing ability, opportunity, and dignity (World Bank, 2026). RS&PA's benefits align closely with the PERMA theory of wellbeing (Positive Psychology Centre, 2026). PERMA comprises five core elements, namely, Positive emotion, Engagement, Relationships, Meaning, and Accomplishment (see Table 1).

Table 1: Core elements of PERMA (Ntovoli et al., 2025)

Core element	Description
Positive emotion	feelings of happiness, enjoyment, and fun
Engagement	deep involvement in and connection with an activity
Relationships	extent to which individuals are socially integrated, accepted, and respected within a community
Meaning	experiencing a sense of purpose and contributing to one's community
Accomplishment	attainment of personal goals and a sense of achievement

Problem statement

Chiwandire (2021) claims that while policies exist championing opportunities for participation in RS&PA, students without disabilities have guaranteed opportunities while students with disabilities do not. This inequity stems from support, services and accommodations for RS&PA not matching the promotion of academic support at institutions (Braga et al., 2015). Students with disabilities have shown interest in being included in sports, but their voices in research about their participation experiences at South African and American tertiary institutions are underrepresented (Abrahams, 2024; Stokowski & O'Donnell, 2022). Even where there is an emphasis on student wellbeing, students with disabilities have been ignored in policies, particularly those with invisible disabilities (Stokowski & O'Donnell, 2022).

There is no cohesive picture of how RS&PA facilitates the social inclusion and wellbeing of students with disabilities at tertiary institutions. A preliminary search of Google Scholar, and JBI Evidence Synthesis was conducted and identified no past or current

systematic or scoping reviews on this topic. This scoping review synthesises evidence on the influence of RS&PA towards improving the social inclusion and wellbeing of students with disabilities at tertiary institutions, and identifying the gaps to be addressed in future studies.

Review question

How does participation in recreational sports and physical activities facilitate the social inclusion and wellbeing of students with disabilities at tertiary institutions?

METHODS

The protocol for this review was registered on the Open Science Framework on 29 January 2026. Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al., 2018), and JBI scoping review methodology (Peters et al., 2024) were used for this review

Types of Sources

This scoping review considered the following sources provided they met the inclusion criteria: published primary research, secondary research in the form of scoping and systematic reviews, and grey literature in the form of unpublished dissertations. Qualitative, quantitative and mixed methods study designs studies were considered. All included research had to be in English and meet the participants, concept and context inclusion criteria

Participants

Studies involving undergraduate and postgraduate students with disabilities at tertiary institutions were included. Studies involving students in primary or secondary school were excluded.

Concept

Studies involving social inclusion and/or wellbeing through recreational sports and physical activity were included. Studies were excluded where the form of recreation did not involve physical activity.

Context

Studies involving tertiary institutions, including universities, colleges, technical training institutes, and vocational schools, were included. Studies were excluded where the institution was not tertiary.

Search strategy

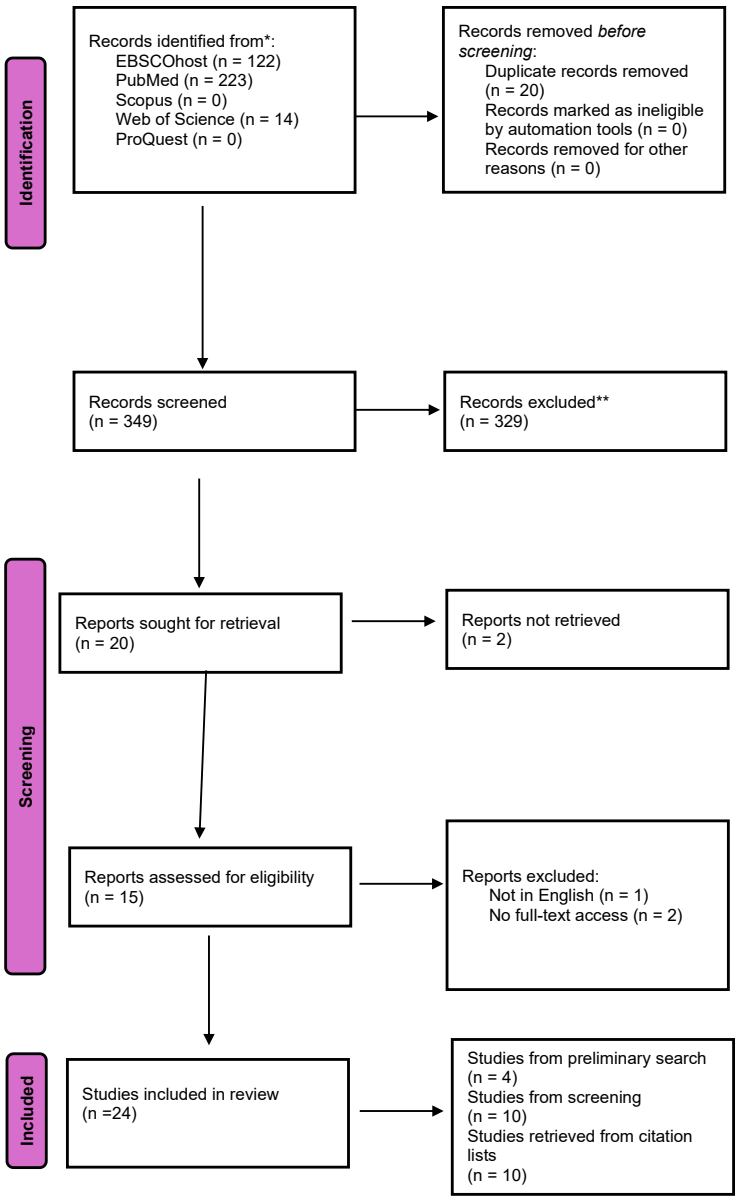
An initial limited search of EBSCOhost and Google Scholar was used to identify studies on the topic. The search terms were refined in consultation with a university librarian before the full search strategy was implemented on EBSCOhost, PubMed, Scopus, and Web of Science on 18 November 2025. Subject headings and Boolean operators were used. Unpublished studies and grey literature were searched using ProQuest. Reference lists of published journal articles were also searched for additional studies. Only studies published in English were included. Publication dates were limited to 1995 to 2025 to balance having a comprehensive review, while also engaging with literature based on ideas around disability inclusion and sport from the last 30 years.

Source of Evidence selection

All identified citations were collated and uploaded into Rayyan (Ouzzani et al., 2016), and duplicates were removed. Titles and abstracts of collected research were screened by two reviewers (Koloko and Mukasa) against the review's inclusion criteria. Potentially relevant sources that we agreed on were then retrieved for full article screening. The results of the search and screening process are presented in a Preferred Reporting

Items for Systematic Reviews and Meta-analyses extension for scoping review (PRISMA-ScR) flow diagram (Tricco et al., 2018) (see Figure 1).

Figure 1: PRISMA Flow Diagram



Extraction

We used Rayyan to extract data from papers identified in the scoping review through comparisons of the data to the inclusion criteria (Ouzzani et al., 2016). The extracted data included specific details about the participants, concept, context, study methods and key findings relevant to the review question.

Data Analysis and Presentation

A total of 349 results were found through the three searches and 20 duplicates were removed. The reviewers screened the remaining 329 results by title and abstract, leaving 20 results for full-text screening. A total of 24 results were included in the final synthesis: four from the preliminary search, 10 from the full-text screening and 10 from scanning the citations of screened results. The results were analysed using both inductive and deductive approaches.

RESULTS

This section presents the study characteristics, and two themes, namely, 1. Reciprocity of personal and collective accomplishments through RS&PA, and 2. Spotlighting institutional responsibilities.

Study Characteristics

All included studies (n=24) were peer-reviewed journal articles, as no grey literature was found. Six studies were done prior to 2016. See Table 2 for details indicating the increased academic interest in sport and recreational participation of tertiary students with disabilities. Most studies were across impairments, with only eight studies focusing on a specific impairment, i.e., physical, visual, or hearing impairment (see Table 3). This result supports the human rights approach to focusing on equity of opportunities for participation rather than individual's impairment. The research designs were mostly qualitative in nature, focusing on the experiences of students. The Global North dominates this field of research, with only three papers from South Africa. Two of the South African papers focus on physical and attitudinal barriers compared to Global North studies that reflected both barriers and facilitators. This disparity highlights the inequality between the Global North and Global South in the provision of resources and opportunities for RS&PA. The role of the Global North academics in spearheading disability research could also be responsible for the dominance of the Global North literature compared to their counterparts from the Global South.

Table 2: Study Characteristics

Authors	Year	Country	No. of Participants	Study Design	Study Aim
Abrahamson, et al.	2025	USA	Three campus recreation facilities through staff interviews (n = nine)	Mixed method: Collective case study (thematic): Surveys then interviews	Evaluated the accessibility of campus recreation facilities at southeastern U.S. public universities using the AIMFREE assessment and interviews with campus recreation directors and staff.
Blinde, & Taub	1999	USA	28 male college students with physical or sensory disabilities	Qualitative: Individual interviews	Examined the empowerment capability of participation in sport and physical activity by students with disabilities
Brown, et al.	2024		39 studies involving 17,771 participants	Systematic review	Identified barriers and facilitators to university students' participation in physical activity
Dalbudak, & Yigit	2019	Türkiye	136 students (46 in university) with hearing impairments	Quantitative: Cross-sectional: Survey with analysis of variance	Determined the attitudes and opinions of hearing impaired students who are athletes and non-athletes about physical education and sports lessons, to determine if there are differences in attitudes across demographic characteristics
Dalbudak, et al.	2016	Türkiye	100 students (62 in university) with visual impairments	Quantitative: Cross-sectional: Survey with analysis of variance	Determined students with visual impairments' attitudes and views about physical education and sport

Devine	2016	USA	16 students with disabilities from five different universities	Qualitative: Grounded Theory: Individual interviews	Understanding the experiences of college students with disabilities and their leisure-time physical activity, focusing on factors that facilitate or form barriers to engagement
Devine	2013	USA	16 students with disabilities	Qualitative: Grounded Theory: Individual interviews	Explore the perceptions of college students with disabilities on their access to and engagement in leisure time physical activities on their campus
Dysterheft, et al.	2016	USA	13 undergraduate students	Mixed methods: Explanatory: Surveys then interviews	Examine the undergraduate students with disabilities' perspectives regarding physical activity in the context of their university environment
Fines, & Block	2021	USA	13 leaders followed by three foundational leaders	Qualitative: Case Study: Individual interviews	Examine programme development of collegiate adapted sports, specifically Goalball
Fultz, et al.	2024	USA	n = 358 NCAA Division-1 Universities; n = 73 Universities with adaptive sport	Document analysis	Assess the availability of adaptive sport opportunities for students at National Collegiate Athletic Association (NCAA) Division-1 Universities to better understand university-affiliated adaptive sport opportunity for students.
Gillies, & Pedlar	2003	Canada	Four students with disabilities transitioning from high school to university	Qualitative: Inductive analysis: Individual interviews	Examine how a small group of first-year students with disabilities integrated into a large Canadian university
Lundberg, et al.	2008	USA	126 students	Quantitative: Quasi-experimental pre-post design: Surveys	Examine the effects of a campus-wide intramural wheelchair sports programme on attitudes toward people with disabilities
Martin, & Griffiths	2016	Ireland	Four students with disabilities; five staff members	Qualitative: Focus groups	Examine factors influencing students with physical disabilities' participation in leisure activities at an Irish university
Mokwena, et al	2024	South Africa	18 African studies	Scoping review	Review the barriers African tertiary students with disabilities face in sports participation

Mokwena, et al.	2025	South Africa	16 undergraduate students with disabilities; ten universities' disability units' staff; & three sport and recreation staff	Qualitative: Exploratory: Individual interviews	Explore the personal and architectural barriers to students with disabilities' sports participation at rural universities in Limpopo province.
Moola	2020	Canada	Seven students with disabilities; seven volunteers	Qualitative: Individual interviews	Explore physical activity experiences and phenomena of students with disabilities and volunteers in a physical activity programme at a Canadian university
Moritz, et al.	2022	Canada	Nine	Qualitative: Individual interviews	Investigate the experiences, access and inclusion of students with mobility-related physical disabilities at a Canadian tertiary institution
Mululuma, et al.	2025	South Africa	17	Qualitative: Individual interviews	Explore the promotion of recreational opportunities and experiences of students with disabilities at a university in Limpopo
Rich, et al.	2024	USA	Six Deaf or hard of hearing students	Qualitative: Interpretive phenomenology: Individual interviews	Explore the lived sport experiences, including benefits, challenges, and interpersonal relationships, of D/H Deaf or hard of hearing collegiate athletes
Rosselli, et al.	2023	USA	255 university students involved in a wheelchair basketball tournament	Quantitative: Cross-sectional: Survey with t-tests	Examine current attitudes of college students toward persons and athletes with disabilities, and if said attitudes are impacted by participating in or watching an adapted sporting event
Sullivan	2016	USA	Eight students (three male; five female)	Mixed method (interpretivist): two questionnaires and focus groups	Explore how participation in an exercise and recreation programme impacted the empowerment and attitudes of students with disabilities when they participated in the programme with an assigned university "buddy".
Taub, et al.	1999	USA	24 male students	Qualitative: Exploratory: Individual interviews	Explore how involvement in sport and physical activity may be a strategy to counter stigma of bodies with disabilities
Townsend, et al.	2024	USA	457 university students without disabilities from one university	Quantitative: Cross-sectional: Survey and factor analysis	Explore college students' attitudes toward persons with disabilities and examining the various factors influencing said attitudes

Yoh, et al.	1998	USA	122 students with disabilities	Quantitative: Survey	Investigate satisfaction with campus recreation facilities among college students with physical disabilities

Table 3: Summary of study characteristics

	Total	24 (100%)
Year of publication	2016-2025	19 (79%)
	Pre-2016	5 (21%)
Disability type	All	16 (67%)
	Physical	5 (21%)
	Visual	1 (4%)
	Hearing	2 (8%)
Study design	Qualitative	12 (50%)
	Quantitative	6 (25%)
	Mixed	3 (12.5%)
	Systematic review	1 (4%)
	Scoping review	1 (4%)
	Document analysis	1 (4%)
Country	USA	15 (63%)
	Canada	3 (12.5%)
	South Africa	3 (12.5%)
	Türkiye	2 (8%)
	Ireland	1 (4%)

Theme 1: Reciprocity of personal and collective accomplishments

Both students with and without disabilities benefit individually and collectively from participation. Participation facilitates social inclusion and wellbeing by embedding physical and psychological health, academic fortitude, and belonging. Equalising participation allows students without disabilities to grow through their interactions with students with disabilities. They also gain the full campus experience and grow social capital.

Promoting physical and psychological health

Physical and psychological outcomes were highlighted in qualitative and quantitative data from 46% (n = 11) of the studies included. Only one study was from the Global South. Students with disabilities confirmed physical and psychological benefits of participating in recreational sport and physical activity, such as improved cardiovascular fitness and self-esteem (Mululuma et al., 2025; Dysterheft et al., 2016). Participation facilitates wellbeing by providing students with opportunities to relax and feel renewed (Gillies & Pedlar, 2003). Stress relief was also identified as a facilitator (Dysterheft et al., 2016).

Students with disabilities in two American studies noted feeling accomplished, independent and aware of their potential through physical activity (Dysterheft et al., 2016; Blinde & Taub, 1999). Rich and colleagues' (2024) Deaf or hard-of-hearing participants from an American university reported escaping barriers through recreational sport and physical activity, providing "an environment in which their hearing level did not act as limitation, as it would in other parts of university life" (Rich et al., 2024, p. 71). Sullivan's (2016) American participants who partnered with a university peer buddy who promoted social opportunities, community service and an exercise regime as part of a transitional programme gained empowerment over the course of the programme and felt more confident to ask for help when they needed it.

Participation also motivates continued engagement in physical activity among students (Sullivan, 2016). Taub and colleagues (1999) presented outcomes related to physical competence and enhanced body image. Similarly, participants in Moola's (2020) study in a Canadian university peer-to-peer physical activity programme facilitated enhanced body image (Moola, 2020).

Physical activity enhances wellbeing outcomes in persons with disabilities (Rich et al., 2024). Being able to engage in their preferred campus recreational activities promotes wellbeing in students (Martin & Griffiths, 2016; Gillies & Pedlar, 2003). However, despite all students being able to benefit from participation, students with disabilities are not afforded equitable participation opportunities. Inequalities in recreational opportunities hamper their health and wellbeing (Mululuma et al., 2025). This inequality, mentioned in the only Global South study featured above, shows that despite physical activity enhancing wellbeing outcomes in tertiary students and persisting after graduation, such activities are not prioritised.

Forging academic fortitude

RS&PA also have educational benefits, such as encouraging academic persistence till graduation. Educational benefits were presented in six (25%) studies included. Data from Canada, the USA and Ireland show that participation breeds academic fortitude in students with disabilities (Townsend et al., 2024; Martin & Griffiths, 2016; Moola, 2015; Gillies & Pedlar, 2003). This fortitude assists with academic perseverance and achievement - a challenge for some students with disabilities.

All students benefit from participation, but equitable access remains scarce for students with disabilities. Despite attending institutions alongside students without disabilities, they are excluded from the community because they do not have access to activities. Having limited opportunities and inaccessible facilities is detrimental to students with disabilities' psychological and academic health (Mululuma et al., 2025). This inequality also hampers students without disabilities' development as they do not have opportunities to interact with persons with disabilities.

Embedding belonging

Recreational sport's facilitation of social inclusion for students with disabilities was presented in 79% (n = 19) of the studies included. Social support networks and social interaction skills are gained from leisure participation (Gillies & Pedlar, 2003; Blinde & Taub, 1999). Joining clubs and societies aids in making friends outside of one's existing social network, getting involved in university life and feeling successful in transitioning to tertiary life (Gillies & Pedlar, 2003). Participation facilitates social inclusion by providing students with disabilities opportunities to build social capital and interact as equals with students without disabilities.

Working with like-minded peers assists the social inclusion of sports participation (Rich et al., 2024). Mokwena and colleagues (2025) commented that students with disabilities' social health is improved: "You can communicate with others and make friends. The more you network with others who are not disabled, [the more] you become free yourself" (p. 377). A sense of belonging is encouraged as participation in sport and leisure-time physical activity provides spaces for students with disabilities to connect with their peers (Mululuma et al., 2025; Rich et al., 2024; Martin & Griffiths, 2016; Devine, 2016; Blinde & Taub, 1999). Participation also helps students feel part of the university community (Martin & Griffiths, 2016; Devine, 2013).

The Goalball Club at Fines and Block's (2021) American study site provided inclusive learning opportunities for students with and without disabilities to interact and connect. It positively changed the university culture as more students with disabilities were recruited. Such a result confirms the positive transformative power of participation and how

the transformation is not exclusive to the students with disabilities. There is a reciprocity of accomplishment through the interactions that support positive relationships wherein power imbalances between students with and without disabilities are countered.

For some, the social engagement is more important than the physical activity itself (Devine, 2013). Martin and Griffiths (2016) noted that establishing relationships can be one motivation students have for engaging in physical activities. Relationships can help students build social capital, which is useful for advocating for equitable inclusion. Continued interactions between students with and without disabilities can equalise power relationships between students by providing students without disabilities a better understanding of disability. Some of the activities can be accessed by all students and require minor adaptation for students with disabilities (Mululuma et al., 2025). These interactions can make all students feel welcome, accepted and free when opportunities to participate are available and taken.

Theme 2: Spotlighting institutional responsibilities

Apart from personal and collective accomplishments, social inclusion and wellbeing are facilitated by, firstly, changing discriminatory perceptions about disability related to physical activity. Secondly, the duality of self-advocacy reveals the shared responsibility of disability inclusion. These facilitators spotlight the responsibilities tertiary institutions have for students.

Changing discriminatory perceptions

The ableist gaze may be a larger barrier than the physical environment (Moola, 2020). Tertiary institutions should be providing safe and welcoming environments for their students. Data from Global South and North suggest that discriminatory perceptions about students with disabilities' participation are prevalent. Mokwena and colleagues' (2024) scoping review on the barriers experienced by tertiary students with disabilities in Africa face in recreational sport and physical activity revealed perceived dependency on others, stigma, segregation, and cultural stereotypes as hampering participation. These findings were supported by Brown and colleagues' (2024) systematic review highlighting stigma as a significant barrier to participation as students with disabilities aren't seen to fit into public perceptions of normalcy. South African research has uncovered that students without disabilities tend to have negative attitudes towards students with disabilities participating in sport (Mokwena et al., 2025). American and Canadian studies show that stereotypes pose disability as separate from physical activity (Brown et al., 2024; Moola, 2020; Devine, 2016). Facing such stereotypes can leave students feeling unaccepted and fragile, which discourages self-advocacy (Devine, 2016).

The demonstration of physical skill and physical fitness countered the stereotypes that persons with physical disabilities not being able to participate in physical activities at a Canadian university (Moola, 2020). This emphasises how participation in recreational sport and physical activity can further institutional transformation goals by providing environments where people are able to recognise the humanity in others. Removing the presumption that sport and disability are contradictory is paramount to transformation (Moola, 2020). Tertiary institutions are responsible for such inclusive development.

Turkish students with visual impairments (Dalbudak et al., 2016) and hearing impairments (Dalbudak & Yigit, 2019) were found to have positive attitudes towards physical education and sport. Students without disabilities were found to have positive attitudes towards students with disabilities while participating in or spectating a wheelchair basketball tournament on their American campus (Rosselli et al., 2023). Their positive attitudes were not affected by participating, spectating or not taking part in the tournament (Rosselli et al., 2023). Changes in negative attitudes may be possible through such integrated participation and spectating. Rosselli and colleagues (2023) suggest that more

information and contact with players with disabilities may influence a change in attitudes. Tertiary institutions need to ensure that students with disabilities are well integrated into university life so that students can participate as players and/or spectators, and feel included in campus life.

American data showed students have mostly positive attitudes, which suggests that interaction leads to better attitudes towards students with disabilities (Townsend et al., 2024). They revealed that one's past and current experiences, knowledge about disabilities, and type and frequency of contact with persons with disabilities influence current attitudes. Students without disabilities overcame high baseline levels of discomfort through participating in an American intramural wheelchair sport programme championed by students with disabilities (Lundberg et al., 2008). Frequent, high-quality interactions between students with and without disabilities are needed.

The duality of self-advocacy

Self-advocacy and awareness raising allow for RS&PA to contribute to the social inclusion and wellbeing of students with disabilities by providing students with disabilities a voice and a sense of purpose. The Goalball programme at Fines and Block's (2021) study site opened pathways for disability advocacy at that American university. Such self-advocacy by students with disabilities is presented as a way of addressing knowledge gaps around disability while also allowing the students to grow in confidence as they become better able to articulate their needs (Brown et al., 2024; Rich et al., 2024). Rich et al., (2024) also recognised that self-advocacy may be emotionally draining for students with disabilities. The development of self-advocacy through participation emphasises the need for RS&PA to be recognised as essential to the campus experience. While it places the burden of institutional and cultural change on students with disabilities rather than on the institutions and their leaders, articulation is essential for the appropriate changes to be made at institutions.

DISCUSSION

Appreciating how recreational sport and physical activity (RS&PA) facilitates social inclusion and wellbeing is central in different facets. First, it demonstrates the opportunity cost for persons with disabilities and the community at large of not availing resources and opportunities for participation in RS&PA. Second, it awakens the duty bearers to create inclusive and enabling environments for participation in RS&PA as a catalyst for disability inclusive development. Our scoping review shows that participation in RS&PA facilitates the social inclusion and wellbeing of students through reciprocity of personal and collective accomplishment and by spotlighting institutional responsibilities.

Addressing the inequalities in recreational opportunities that Mululuma et al., (2025) found hampered students' health and wellbeing is crucial as it will enhance their wellbeing outcomes beyond graduation. While more females with disabilities were included in recent studies, there is overrepresentation of white students and well-resourced institutions in the literature. Students with invisible disabilities are also not well represented. These patterns indicate that access to, and visibility within, RS&PA is shaped by intersecting axes of race, gender, type of impairment, and institutional resourcing, rather than disability alone, underscoring the need for explicitly adopting intersectionality lens in the analysis of participation outcomes on social inclusion and wellbeing.

Continued interactions between students with and without disabilities can equalise power relationships between students by providing students without disabilities a better understanding of disability. Some of the activities can be accessed by all students and require minor adaptations for students with disabilities (Mululuma et al., 2025). Students with invisible disabilities might not need equipment adaptations or even specific

programmes/clubs. Some already take part in various clubs, and their stories need to be explored for more ways of being inclusive.

Interactions between students with and without disabilities can make all students feel welcome, accepted and free, thereby growing stronger campus communities. Stronger communities could assist in further advocacy for inclusion and access because advocacy would be beneficiary-led while acknowledging that everyone benefits from inclusive development. Continued interaction facilitated by RS&PA can demolish the systemic barriers created by oppressive social, cultural and political systems that cause disability (Tremain, 2005; Devlin & Pothier, 2006).

A deductive analysis of the findings using PERMA as a theoretical lens illustrates how students with disabilities' participation in RS&PA influenced their well-being. The feeling of relaxation (Gillies & Pedlar, 2003) and stress relief (Dysterheft et al., 2016) rhyme with the element of positive emotions (Ntovoli et al., 2025). Accomplishment was experienced through gaining independence (Dysterheft et al., 2016; Blinde & Taub, 1999), empowerment (Brown et al., 2024; Rich et al., 2024; Sullivan, 2016) and academic fortitude (Townsend et al., 2024; Martin & Griffiths, 2016; Moola, 2015; Gillies & Pedlar, 2003). Accomplishment is a fundamental motivator for students with disabilities to try other opportunities beyond their participation in RS&PA even in the face of societal barriers. While white females with disabilities have been featured in studies on the empowerment potential of RS&PA participation, African females with disabilities need more attention. Patriarchy, poverty, and exclusion may be exacerbated by disability in females, which warrants further research. Students experienced engagement through participation in RS&PA (Devine, 2013). Relationships and meaning generated a sense of belonging (Mokwena et al., 2025; Rich, et al., 2024; Martin & Griffiths, 2016) and the capacity to self-advocate (Brown et al., 2024; Rich et al., 2024; Fines & Block, 2021). Contrasting experiences in well-resourced and resource-constrained institutions also highlight how disability intersects with geography and socio-economic context to structure which students can benefit from RS&PA-related belonging and social capital.

The review also finds that building social capital is a major benefit of participating in RS&PA. The power of social capital is a major livelihood asset as it fosters reciprocal benefits fundamental for poverty alleviation and the achievement of sustainable livelihoods (Mulubiran, 2021; Chambers & Conway, 1992). Students cannot build this social capital if they are isolated in campus environments. Similarly, their opportunities to build social capital are limited when they have unequal access and have to fight for all facets of a campus experience. If sustained, social networks and connections and their value could transcend campus life to impacting livelihoods through employment connections and continuous reciprocal support.

Critical Disability Theory (CDT) views disability as being created through the same ableist gaze. Participation in RS&PA highlights institutional responsibilities to address barriers to the participation of students with disabilities in campus life. Brown and colleagues (2024) agree with Moola (2020) that ableist perceptions and stigma are significant barriers to participation in RS&PA. Ableist perceptions are more disabling than the physical environment (Moola, 2020). Environmental barriers are created by institutions that nurture exclusionary perceptions of normalcy and do not appreciate impairment as part of human diversity (Davis, 2025).

Participation in RS&PA counteracts ableist perceptions and reminds tertiary institutions, as well as other relevant government institutions, of their responsibility to avail resources and provide facilities and opportunities that are disability inclusive. CDT seeks to identify actors who can change what is wrong in the societal landscape (Sztobryn-Giercuszkiewicz, 2017). The leadership of tertiary institutions are the actors who have the responsibility to provide all their students with an inclusive campus life, not just for

academic success, but to foster their well-being and set them up for career transitions to ensure socio-economic inclusion. The duality of self-advocacy reveals the imbalance of responsibility that students with disabilities carry to influence change. So far, they have been at the forefront while the institutions remain reactive. Crucially, participation in RS&PA provides a platform for self- advocacy. The confidence gained through participation in RS&PA places students with disabilities in a better position to demand their rights. Students must repeatedly demand, more so in environments where their academic needs are not met. They are stuck between their studies and being change agents, but then also have to decide which changes to fight for. Institutions prioritise academic accommodations but tend to neglect the students' wellbeing. Students with disabilities, who are poor, and otherwise outliers (in terms of race and gender) bear the heaviest self-advocacy burden, yet they are currently the least studied.

Self-advocacy becomes more difficult when there is an array of disabilities on campuses as students might feel they are competing with students with different disabilities for equity. Institutions are more reactive than proactive in their inclusive practices and often do not implement the changes students advocate for. Being reactive leaves institutions serving the loudest category of students with disabilities rather than all students.

Institutions are meant to provide all students with the full campus life experience. Therefore, the onus falls on the institutions to ensure equitable access to recreational participation for their students with disabilities. An intersectional lens enables an audit of inequities of power relations can guide transformation in RS&PA to avoid reproducing existing campus hierarchies. Research amplifying student voices could clarify needs related to their contexts to find solutions collectively with leadership. Tertiary institutions are melting pots and recreational participation provides opportunities for meaningful interactions. It is important to note that institutions from the Global South are usually constrained by limited resources unlike their better-resourced counterparts in the Global North. RS&PA needs to be prioritised as part of transformation agendas in tertiary institutions, particularly in the Global South. Our findings highlight the outcomes related to social inclusion and wellbeing that are achieved through participation in RS&PA. Inclusive development happens when facilities are accessible to all and equitable opportunities for participation exist.

Gaps in Literature

Gaps exist in the scope and context of the available research. There is limited overall research on RS&PA for students with disabilities, even in the Global North. Studies on tertiary students with disabilities in general are minimal (Gillies & Pedlar, 2003), more so studies on their leisure-time physical activity experiences and access to campus-based recreation are even scarcer (Moola, 2020; Devine, 2016). Additionally, there is a pronounced Global South gap; there is little evidence on RS&PA participation and experiences in low- and middle-income or tertiary institutions in Africa (Mokwena et al., 2024). Data is urgently needed, given that 80% of approximately 1.5 billion persons with disabilities globally live in such contexts (Mokwena et al., 2024).

The interaction between RS&PA and educational outcomes remains understudied. Similarly, more certainty is needed on why participation is low and how to address it in sustainable ways. For example, campus interventions that generate social capital between students with and without disabilities need attention, as do participation patterns of both groups in such interventions.

Methodological gaps in the literature also exist. Most studies are qualitative (see Tables 2 and 3). While these studies help provide students with disabilities a voice, varying the research techniques could aid in providing students with more facts for evidence-based advocacy and making a sound business case to the leadership. Incorporating

quantitative data through mixed methods studies could add to the breadth of findings that inform the implementation of institutional policies in a sustainable manner.

Limitations

While the scoping review ensured rigour by using multiple databases, trying to incorporate grey literature and engaging with a librarian when refining the search terms, it still had limitations. Excluding studies from before 1995 might have limited historical perspectives. The grey literature search did not yield any useable results. Three articles were excluded because they were not available in English or behind paywalls.

Implications

Institutions stand to benefit from students with disabilities participating in RS&PA because students will feel more connected to the institution, build academic fortitude, and the model of inclusivity could be replicated. Institutions are called upon to be proactive in fostering accessibility for inclusion so that the burden of advocacy is not on the students with disabilities. Such inclusive leadership allows students with disabilities to reap the benefits of participation instead of having to fight to participate and be included.

In Global South contexts, economic constraints intersect with existing institutional challenges, underscoring the need for inclusion strategies that are designed to be financially sustainable as well as disability inclusive. Policies alone are insufficient; implementation plans and accountability mechanisms are required to prevent inclusion from remaining symbolic or inconsistently applied.

Further studies into the livelihood potential and skills development of RS&PA for students with disabilities would facilitate their economic inclusion. Investigating institutional and individual investment in recreational sport and physical activity at tertiary institutions could provide opportunities for students with disabilities to transition to employment in this field.

CONCLUSION

While understudied, the scoping review has provided evidence that the participation of students with disabilities in recreational sport and physical activity facilitates social inclusion and wellbeing. Students with disabilities become part of the university community while demystifying disability for students without disabilities. Social inclusion is further facilitated by enabling students to spotlight how institutional leadership needs to develop inclusive campuses. The gap in Global South research must be addressed through more studies conducted by locally based researchers. Documenting students with disabilities' experiences should lead to more sustainable, inclusive policies. Resourcing inclusive facilities, coaching, and accessibility matters to facilitate equitable participation opportunities for students is possible with political will.

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Review Article

Parent-Child Play And Playfulness Among Children With Disabilities: A Systematic Review

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ABSTRACT

Aim: This systematic review examines the role of parent–child play and playfulness among children with disabilities, and their impact on child development and parent–child relationships.

Method: A comprehensive literature search was conducted across multiple electronic databases, supplemented by reference list screening and hand-searching of relevant journals. Studies examining parent–child play and playfulness in children with disabilities were included based on predefined inclusion criteria. A total of 16 studies were identified and analysed.

Results: Findings indicate that symptoms associated with medical, developmental, or psychological conditions may negatively influence playfulness in children. However, active parental involvement and responsive interaction were consistently associated with increased playfulness. Parent–child play was also linked to improved parental self-efficacy, stronger parent–child relationships, enhanced emotional regulation, and positive developmental outcomes in children.

Conclusion: Parent–child play plays a significant role in supporting the emotional, social, and developmental wellbeing of children with disabilities, while also strengthening parental confidence and relationships.

Keywords: parent–child play, playfulness, children with disabilities, parental involvement, child development, systematic review

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INTRODUCTION

The time parents spend engaging in play with their children is increasingly constrained in today's fast-paced world. The American Academy of Paediatrics (2016) emphasises the importance of daily, high-quality interaction, highlighting play as a key medium through which parents understand their child's experiences, emotions, and individuality. Parent–child play fosters emotional bonding, enhances parental sensitivity, and supports children's social, emotional, and cognitive development.

Parenting a child with a disability presents additional emotional, social, and practical challenges. Following diagnosis, parents often experience stress, anxiety, and uncertainty,

which may have long-term implications for psychological wellbeing (Northouse et al., 2012). Financial strain, caregiving demands, and societal stigma further contribute to parental burden (Baker & Heller, 1996). Research consistently shows that parents of children with disabilities report higher levels of stress and poorer psychological wellbeing than parents of typically developing children (Ha et al., 2008; Seltzer et al., 2004), particularly in the context of autism spectrum disorder (ASD) (Bouma & Schweitzer, 1990; Koegel & Schreibman, 1992).

While much of the literature focuses on deficits and challenges, there is increasing interest in strength-based approaches that emphasise positive interactions and developmental opportunities. Parent–child play and playfulness represent one such domain. Playfulness is conceptualised as a relational construct involving creativity, flexibility, intrinsic motivation, and emotional engagement (Schaefer & Drewes, 2009; Landreth, 1983). Parental playfulness—defined as the ability to engage in responsive, flexible, and emotionally attuned interactions—has been associated with improved wellbeing and stronger parent–child relationships (Shorer, 2019; Yue et al., 2016).

Theoretical perspectives, including Winnicott's (1971) concept of transitional space, highlight the role of play in facilitating emotional development and bridging internal and external experiences. However, engaging in play may be more complex for parents of children with developmental conditions such as ASD, where social communication differences can affect interaction quality. Parent-mediated interventions have demonstrated effectiveness in improving both parental competence and child developmental outcomes (Kasari et al., 2010; Keen et al., 2010).

In low- and middle-income countries (LMICs), research on play among children with disabilities remains limited. Cultural beliefs, stigma, and restricted access to resources may constrain opportunities for play and participation. Although some studies have demonstrated the benefits of play-based interventions, the evidence base remains fragmented and lacks a comprehensive synthesis.

Despite growing recognition of the importance of play, there remains a limited understanding of how parent–child play and playfulness influence developmental and psychosocial outcomes.

Research question:

What is the role of parent–child play in influencing playfulness and developmental outcomes among children with disabilities?

METHODS

Study design Protocol and Registration

This review was not registered in PROSPERO. However, the methodology was defined a priori and conducted in accordance with established systematic review guidelines.

Study Design

This systematic review examined the role of parent–child play and playfulness among children with disabilities and their associated outcomes for children, parents, and families. The review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA 2020) guidelines to ensure transparency, completeness, and methodological rigour. A PRISMA flow diagram (Figure 1) illustrates the study selection process.

Search Strategy

A comprehensive systematic literature search was conducted across multiple electronic databases, including JSTOR, EBSCOhost, PubMed, ProQuest, PsycINFO, and Google Scholar.

Studies published between 1997 and 2019 were included. This extended timeframe was selected due to the limited availability of empirical research specifically focusing on parent–child play and playfulness among children with disabilities. Earlier foundational studies were therefore included to ensure a comprehensive synthesis of the evidence base and to capture the development of concepts in this field.

Search terms were organised across four key domains:

1. Children (e.g., "child*", "children with disabilities")
2. Parents/caregivers (e.g., "parent*", "caregiver*")
3. Play (e.g., "play", "parent–child play")
4. Playfulness (e.g., "playfulness", "interaction")

Boolean operators (AND, OR), truncation, and wildcard variations were used to maximise search sensitivity. Search strategies were adapted for each database. A sample PsycINFO search string was:

("child*" OR "children with disability*") AND ("parent*" OR "caregiver*") AND ("play" OR "parent-child play") AND ("playfulness" OR "interaction").

Reference lists of included studies and relevant reviews were also hand-searched to identify additional eligible studies.

Inclusion and Exclusion Criteria

Inclusion Criteria

Studies were included if they were empirical in nature, including quantitative, qualitative, or mixed-methods designs, and examined parent–child play and/or playfulness. Eligible studies also needed to include children with a diagnosed disability or developmental condition and report outcomes related to children, parents, or overall family functioning. In addition, only studies published in peer-reviewed journals and written in English were considered for inclusion.

Exclusion Criteria

Studies were excluded if they focused exclusively on adolescents or adults. Review articles, commentaries, editorials, and grey literature were also excluded from the analysis. In addition, studies were not included if they did not examine parent–child play or playfulness as a primary variable of interest.

Study Selection Process

All identified records were imported into a reference management system, and duplicates were removed. Study selection followed a two-stage screening process in line with PRISMA guidelines:

1. Title and abstract screening
2. Full-text review for eligibility

A total of 35 studies were initially identified. After removal of duplicates and screening, 16 studies met the inclusion criteria and were included in the final review. Reasons for exclusion at the full-text stage are reported in the PRISMA flow diagram (Figure 1).

Data Extraction and Synthesis

Data were extracted using a structured data extraction form developed in Microsoft Excel (2013). Extracted information included author(s), year of publication, sample characteristics, study design, and key findings. These data were tabulated and presented in Annex Table 1. A narrative synthesis approach was adopted due to heterogeneity in study designs, populations, and outcome measures. Findings were organised thematically to identify patterns related to parent–child play, playfulness, and associated developmental and psychosocial outcomes.

Quality Appraisal and Risk of Bias

The methodological quality and risk of bias of included studies were assessed using the Joanna Briggs Institute (JBI) critical appraisal tools, with checklists selected according to study design (e.g., qualitative, cross-sectional, quasi-experimental).

Each study was assessed using predefined criteria, including the clarity of research questions, appropriateness of the study design, sampling strategy, validity of measures, and clarity of reporting. Each criterion was rated as "Yes," "No," "Unclear," or "Not applicable." Based on the total proportion of criteria met, studies were categorized as having a low risk of bias (≥70%), moderate risk of bias (50–69%), or high risk of bias (<50%). Screening and quality appraisal were independently conducted by two reviewers, with any disagreements resolved through discussion. The findings were summarized in Annex Table 1 and interpreted in relation to methodological quality to ensure a balanced and rigorous synthesis of the evidence.

Ethical Considerations

The authors declare that no ethical issues were involved in the preparation of this review article. All cited literature is properly credited, and no original research on humans or animals was conducted.

RESULTS

Study Selection

A total of 35 records were initially identified through database searching and additional sources. After removal of duplicates and screening of titles and abstracts, full-text articles were assessed for eligibility. Sixteen studies met the inclusion criteria and were included in the final synthesis. Reasons for exclusion at the full-text stage are presented in the PRISMA flow diagram (Figure 1).

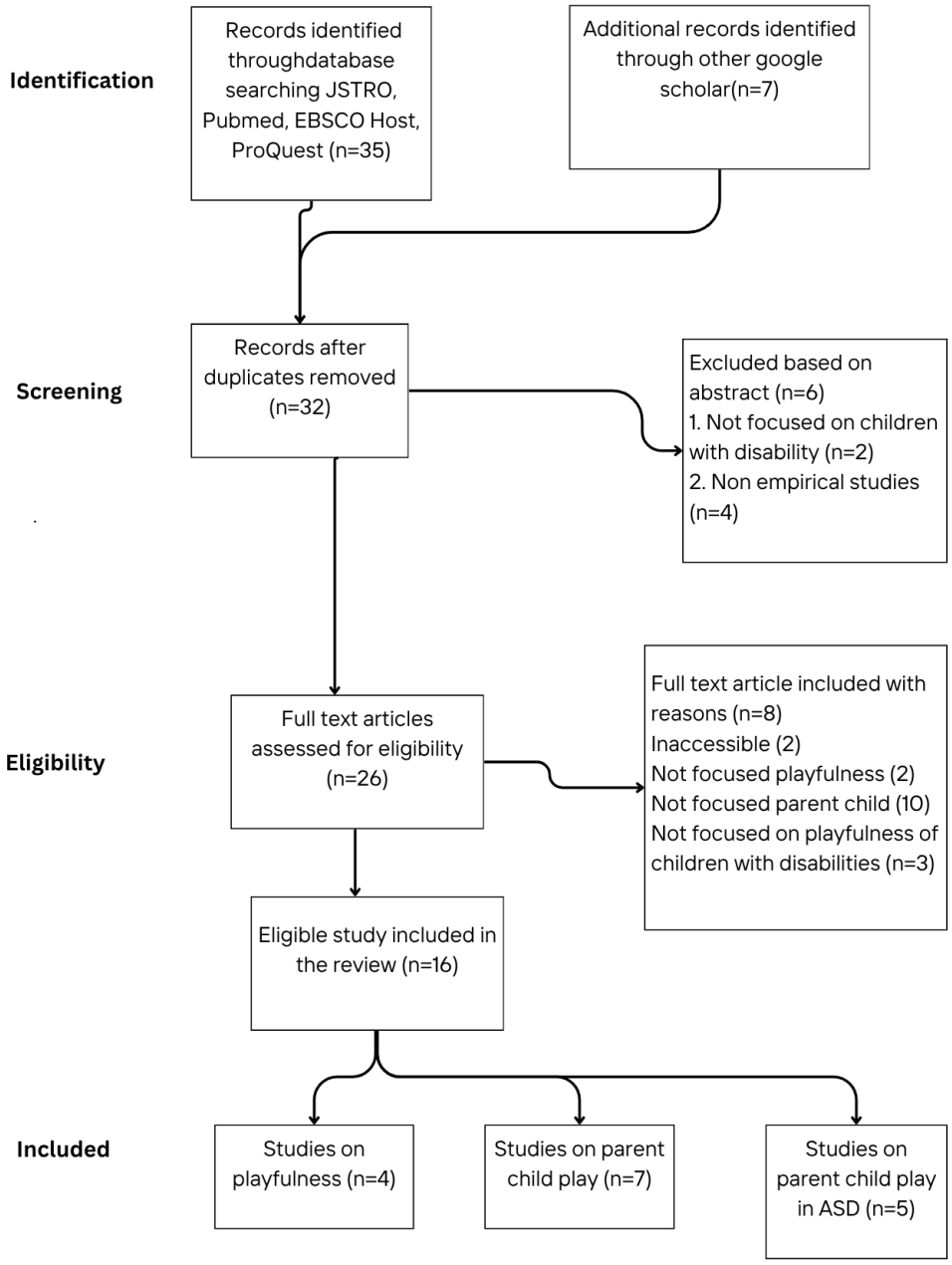

Figure 1. Presents the flow chart on the number of identified abstracts, reasons for exclusion, and articles that were further considered.

Study Characteristics

The characteristics of the included studies are summarised in Annex Table 1, including author, year of publication, sample characteristics, study design, and key findings. The included studies were published between 1997 and 2019 and varied in methodological design, including qualitative, quantitative, and intervention-based approaches.

Thematic Synthesis of Findings

Findings from the included studies were synthesised narratively and organised into three overarching themes: (1) playfulness in parents, (2) playfulness in children, and (3) parent–child play interactions.

Theme 1: Playfulness in Parents

1.1 Parental Playfulness and Self-Efficacy

Evidence examining parental playfulness in the context of disability was limited but suggests a meaningful association with parental self-efficacy. Quantitative findings indicated that higher levels of adult playfulness were associated with greater emotional parental self-efficacy during play interactions. In addition, child-related factors, particularly sensory processing characteristics, were identified as significant predictors of parental self-efficacy, highlighting the influence of child presentation on parental confidence. Qualitative findings further suggested variation in parental self-efficacy across caregivers, with fathers reporting higher confidence in play interactions than mothers, potentially reflecting differences in motivational orientation and engagement styles during play.

1.2 Parental Beliefs, Engagement, and Facilitation of Play

Beyond self-efficacy, parental attitudes and engagement in play emerged as important factors. Parents were found to value play as a meaningful context for interaction and actively supported their child's engagement, often adapting their involvement to the child's developmental level. Intervention-based and observational studies also indicated that structured and activity-based play contexts, such as music-based interactions, were associated with increased child engagement and social interaction. These findings suggest that parental facilitation and the nature of play activities contribute to the quality of play experiences.

Theme 2: Playfulness in Children

2.1 Impact of Disability on Child Playfulness

Across studies, children with disabilities were generally reported to demonstrate lower levels of playfulness compared to typically developing peers. This pattern was observed across a range of conditions, including autism spectrum disorder (ASD), cerebral palsy, and developmental delays. However, findings also indicated variability in play profiles depending on the type of play assessed. For example, children with ASD were observed to demonstrate higher levels of exploratory play, with no significant differences in symbolic play when compared to typically developing peers. These findings suggest that playfulness in children with disabilities may be uneven across different play domains rather than uniformly reduced.

2.2 Influence of Context and Parent–Child Interaction

Child playfulness was consistently influenced by both environmental and relational factors. Contextual elements, such as structured versus unstructured play settings, were found to affect observed play behaviours. Parental responsiveness, interaction style, and emotional availability were identified as key contributors to variations in child playfulness. Evidence suggests that playfulness is not solely determined by developmental factors but is shaped through ongoing interaction between the child and their environment, particularly within parent–child relationships.

Theme 3: Parent–Child Play Interactions

3.1 Collaborative and Interactive Play

Collaborative play between parents and children was consistently associated with increased engagement and more complex play behaviours. Children demonstrated higher levels of exploratory and symbolic play during interactive play with caregivers compared to solitary contexts. Parental behaviours such as responsiveness, guidance, and emotional engagement were linked to improved child participation. Additionally, interactional qualities such as mutual initiation and compliance within play were associated with better social competence outcomes, highlighting the importance of reciprocal engagement in play interactions.

3.2 Parent Play Strategies in ASD

Distinct patterns of parental behaviour were observed in families of children with ASD. Parents of children with ASD were more likely to initiate play interactions and adopt structured or directive strategies compared to parents of typically developing children. These adaptations may reflect attempts to support engagement and compensate for reduced child-initiated interaction. Evidence from intervention studies further indicated that parent-implemented strategies, including structured play routines and script-fading techniques, were associated with improvements in children's communicative and social engagement during play.

3.3 Parent–Child Interaction Interventions

Intervention-based studies suggested that approaches targeting parent–child interaction during play may support improvements in child engagement and playfulness. Interactive and relationship-focused play interventions were associated with more positive outcomes compared to approaches focused solely on child-directed developmental skills. However, the evidence base remains limited, and findings should be interpreted as preliminary, indicating potential benefits rather than definitive conclusions.

DISCUSSION

This review aimed to examine the effects of parent–child play and playfulness among children with disabilities. Overall, the findings highlight the importance of both parental playfulness and structured parent–child play, while also revealing significant gaps and inconsistencies in the literature.

Playfulness in Parents

The review identified a limited number of studies examining parental playfulness in the context of disability, indicating a significant research gap. Available evidence suggests that parental playfulness is positively associated with parental self-efficacy. Quantitative findings indicate that adult playfulness predicts emotional parental self-efficacy, while child-related factors, particularly sensory processing characteristics, also influence parental confidence during play interactions.

Qualitative evidence further suggests variability across caregivers, with fathers reporting higher self-efficacy and emotional engagement during play compared to mothers, who tend to adopt a more outcome-oriented approach focused on developmental goals. In addition, observational findings indicate that parents value play and actively support their child's engagement, adapting their involvement based on the child's developmental level. Structured play contexts, including activity-based approaches such as music-based interactions, were also associated with increased child engagement and social interaction.

Critical Analysis: While these findings highlight the potential role of parental playfulness and engagement, the evidence base remains limited and is largely concentrated within ASD populations. Existing studies primarily rely on self-report or small qualitative samples, with few observational or longitudinal designs. Furthermore, parental playfulness has not been examined as a multidimensional construct (e.g., emotional, cognitive, or behavioural domains), and little is known about how it varies across different disability types or cultural contexts. Future research should adopt more rigorous and diverse methodologies to better understand how parental playfulness influences both parent and child outcomes over time.

Playfulness in Children

Children with disabilities, including ASD, cerebral palsy, and developmental delays, were generally reported to demonstrate lower levels of playfulness compared to typically developing peers. However, findings suggest that playfulness is not uniformly reduced across all domains. For example, children with ASD were observed to demonstrate higher levels of exploratory play, with no significant differences in symbolic play compared to

typically developing children. This indicates that playfulness profiles may vary depending on the type of play assessed.

Environmental and relational factors also play a critical role. Structured or adult-facilitated contexts were associated with increased play engagement, suggesting that environmental support can enhance play behaviours. Additionally, parental responsiveness, emotional availability, and interaction style were consistently linked to variations in child playfulness, highlighting the importance of relational context in shaping play outcomes.

Critical Analysis: Although many studies report reduced playfulness in children with disabilities, methodological variability—such as differences in assessment tools (e.g., observational coding vs. standardised measures), age ranges, and play contexts—limits direct comparison across studies. Furthermore, few studies examine how the developmental stage interacts with playfulness or how specific disability characteristics influence different types of play (e.g., exploratory vs. symbolic). There is also limited integration of measurement validation studies, despite evidence supporting the reliability of commonly used play assessment tools. These gaps highlight the need for more standardised and developmentally sensitive approaches to studying playfulness.

Parent–Child Play, Down Syndrome and Mixed Disabilities

Collaborative parent–child play consistently emerged as beneficial across studies. Children demonstrated higher levels of exploratory and symbolic play during interactive play with caregivers compared to solitary contexts. Emotional engagement from parents, including both mothers and fathers, was associated with more complex play behaviours.

Parental behaviours such as responsiveness, direction, and support were found to facilitate child engagement. Mothers were often observed to adopt more directive and supportive roles, while children's play behaviours reflected their developmental level, indicating that parental scaffolding plays a key role in supporting engagement and learning. Additionally, interactional qualities such as mutual initiation and compliance were linked to improved social competence, underscoring the importance of reciprocal engagement during play.

Critical Analysis: Despite consistent evidence supporting the benefits of collaborative play, most studies focus on small samples and specific caregiver roles, particularly mothers. Father–child interactions and broader family dynamics remain underexplored. In addition, limited research compares the effectiveness of different play strategies across disability types, restricting the generalisability of findings.

Autism Spectrum Disorder

Distinct interaction patterns were observed in families of children with ASD. Parents were more likely to initiate play interactions and use directive or structured strategies compared to parents of typically developing children. These behaviours appear to function as compensatory mechanisms to support engagement in children who may demonstrate reduced spontaneous initiation.

Intervention-based studies further suggest that parent-mediated strategies, such as structured play routines, script-fading techniques, and activity-based interventions, can improve children's communicative and social engagement during play. However, findings also indicate that children's engagement may vary across interaction partners and contexts, with some evidence suggesting greater responsiveness in interactions with siblings or other adults.

Critical Analysis: Although intervention studies demonstrate promising short-term outcomes, they are often limited by small sample sizes, short durations, and a lack of longitudinal follow-up. Most studies focus on immediate behavioural changes, with limited exploration of broader developmental outcomes such as emotional regulation,

relationship quality, or long-term social competence. Additionally, cultural and contextual influences on parent–child play in ASD populations remain largely unexamined.

Implications for Future Research

To advance the field, future studies should:

- Examine both global and domain-specific parental playfulness across different disabilities and cultural contexts.
- Incorporate longitudinal designs to assess sustained effects of parent–child play and playfulness.
- Explore father–child, sibling–child, and broader family dynamics in play interactions.
- Investigate how environmental structure, sensory characteristics, and relational factors interact to influence playfulness.
- Develop and utilise standardised, validated tools for assessing play and parent–child interaction across diverse populations.

Implications of the Study

This review highlights the critical role of parental playfulness and parent–child play in promoting wellbeing among children with disabilities and their caregivers, with important implications for low- and middle-income country (LMIC) contexts.

Parental Wellbeing

Parents of children with disabilities often experience increased stress, reduced self-efficacy, and social isolation. The findings suggest that engaging in playful interactions may enhance parental emotional regulation, confidence, and perceived competence. In LMICs, where access to specialised services may be limited, promoting play-based parent training can serve as a cost-effective and accessible intervention.

Child Development

Playful parent–child interactions support children's social, emotional, and communication development. When parents are actively engaged and responsive, children demonstrate increased participation and improved developmental outcomes. In resource-limited settings, empowering parents as facilitators of play may help address gaps in early intervention services**.**

Professionals and Service Delivery

The findings provide guidance for professionals working with children with disabilities. Integrating play-based, family-centred approaches into community programs, schools, and early intervention services may enhance accessibility and effectiveness. Training for practitioners should include strategies to support parent–child play and address cultural and contextual barriers.

Limitations

Several limitations must be considered:

1. Small and uneven evidence base: Only a limited number of studies addressed parental playfulness, and many used small or convenience samples.
2. Methodological variability: Differences in study design, measurement tools, and play contexts limit comparability across studies.
3. Short-term focus: Many studies examined immediate outcomes, with limited longitudinal evidence.
4. Lack of contextual diversity: Most studies were conducted in high-income countries, with minimal representation from LMIC settings.
5. Database coverage limitations: Although major databases were included, the exclusion of Scopus and Web of Science due to access constraints may have limited the comprehensiveness of the literature search.

These limitations highlight the need for more rigorous, context-sensitive research that captures the complexity of parent–child play across diverse populations.

CONCLUSION

This review demonstrates that **parental playfulness and parent-child play are key factors in enhancing child development and parental well-being**, particularly for children with disabilities. The evidence suggests that structured, playful interactions can improve emotional regulation, communication, and social engagement, but gaps remain, especially in LMIC contexts.

Policy Recommendations

- Integrate parent-child play and playful interaction training into **national early intervention and disability support programs**.
- Promote awareness campaigns to **reduce stigma surrounding disability**, emphasizing the importance of play in child development.
- Ensure **equitable access to resources and services**, including community-based and school-based play interventions in resource-limited settings.
- **Practice Recommendations**
- Train parents and caregivers in **playful interaction strategies**, including low-cost, culturally appropriate activities.
- Encourage **family-centered approaches** where fathers, siblings, and extended family members are involved in play interventions.
- Adapt interventions to **resource-constrained environments**, leveraging community centers, schools, or digital platforms where possible.

Research Recommendations

- Conduct **longitudinal, LMIC-focused studies** to explore the impact of parental playfulness and parent-child play in diverse cultural and socioeconomic settings.
- Investigate **interventions targeting both parents and children**, including script-fading, music-play, and structured collaborative play.
- Examine **father-child interactions, sibling involvement, and community-level factors** to understand broader influences on playfulness.
- Develop **standardized, culturally validated tools** to assess playfulness and parent-child interaction outcomes across settings.

In conclusion, promoting **playfulness in parents and parent-child play** offers a low-cost, scalable strategy to enhance the well-being of both children with disabilities and their families, especially in LMICs where access to specialized services is limited. Future research and policy must address existing gaps to support the holistic development of children with disabilities and empower their caregivers in real-world, resource-constrained contexts.

Data Availability Statement: All data used in this review are from published studies and are available from the respective sources.

Competing Interests: The authors declare no competing interests.

Declaration of interest statement: The authors declare that they have no known competing financial, professional, or personal interests that could have influenced the work reported in this manuscript.

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Annex

Table 1: Summary of the characteristics of the eligible studies and their key findings.

Playfulness among parents and children with disabilities

Authors, year of publication	Sample description	Design	Measures / Method	Summary of Results
Roman, Reynolds, Feliciano, Cabrera, & Vega (2017)	136 parents of children diagnosed with ASD aged 3–7 years	Quantitative study	Short Sensory Profile; Playfulness Scale for Adults; Parenting Self-Efficacy Tool	Child sensory profile was a key predictor of parental self-efficacy. Findings suggest evaluating interventions based on parental playfulness and self-efficacy.
Rosa, Veronica, Yoliannie, Jorg, Keyshla, Samariz, & Luis (2018)	8 parents of children aged 3–7 years with ASD	Qualitative study	Semi-structured interviews	Parents linked self-efficacy to play experiences and emotional engagement. Fathers reported higher self-efficacy than mothers due to differences in motivation.
Buchanan (2009)	3 toddlers with disabilities and their mothers	Qualitative study	Home-based observation of play	Children's play reflected developmental level. Mothers supported play engagement and valued play highly.
Grace, Emily, & Ian (2018)	9 mother–child dyads	Qualitative study	Content analysis of weekly play sessions	Music-based play increased perceived child engagement and social interaction.

Parent–child play among children with Down syndrome and other disabilities

Authors, year of publication	Sample description	Design	Measures / Method	Summary of Results
Okimoto, Bundy, & Hanzlik (2000)	38 children (CP, developmental delays, TD) playing with mothers	Quantitative study	Test of Playfulness (ToP)	Children with disabilities showed lower playfulness than TD peers; parent–child interaction supports play expression.
Hamm (2006)	20 children with disabilities and 20 TD children (6–38 months)	Quantitative study	ToP; TOES	ToP and TOES were reliable/valid; children with disabilities were less playful.
Chiarello, Huntington, & Huntington (2006)	20 children and their parents	Qualitative study	Home video-recorded play sessions	Similar play behaviours with both mothers and fathers; importance of both parent roles in play.
Paola, Simona, Zeno, & Marc (2008)	28 children with Down syndrome and mothers	Qualitative study	Observational coding	Children showed more exploratory play during mother–child interaction than solitary play.
Falco, Esposito, Venuti, & Bornstein (2008)	19 children with Down syndrome and fathers	Quantitative study	Play coding; Emotional Availability Scales	Father–child emotional engagement was linked to increased symbolic play.
Roach, Barratt, Miller, & Leavitt (1998)	28 mothers and children with Down syndrome	Qualitative study	Observational analysis	Mothers were more directive and supportive compared to TD groups.

Authors, year of publication	Sample description	Design	Measures / Method	Summary of Results
Eric, Jacquelyn, & Gregory (1997)	35 preschoolers and parents	Quantitative study	Video coding and interviews	Higher mutual initiation and compliance linked to better social competence.

Parent–child play among children with Autism Spectrum Disorders

Authors, year of publication	Sample description	Design	Measures / Method	Summary of Results
Stephanny & Connie (2013)	16 ASD dyads and 16 TD dyads	Quantitative study	Structured play observation	Parents of children with ASD initiated more play acts and used more directive strategies.
Nabil & Raymond (1999)	9 families with a child with autism	Qualitative study	Dyadic play observation	Parents initiated more interactions; siblings received more child-initiated play.
Kara & Thomas (2009)	3 mothers of children with autism	Qualitative study	Script-fading intervention	Increased scripted and spontaneous vocal initiations during play.
Pinchover, Shulman, & Bundy (2016)	29 children with ASD and 32 TD children (3–6 years)	Quantitative study	Observational play assessment	Playfulness differed by context; environment influences play behaviour.
Bentenuto, Simona, & Paola (2016)	75 mothers and children with ASD	Quantitative study	Coding of exploratory and symbolic play	Children with ASD showed higher exploratory play; no differences in symbolic play.

Note. Summary of empirical studies on parent–child play and parental playfulness among children with disabilities. The number of studies reviewed on parental playfulness is 8 and on parent–child play is 10.

Review article

The Role of Interdisciplinary Teams in Preventing ICU-Acquired Weakness: A Systematic Review

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ABSTRACT

Background: ICU-Acquired Weakness (ICUAW) is a frequent complication among critically ill patients and is associated with prolonged mechanical ventilation, extended hospitalization, functional decline, reduced quality of life, and long-term disability. Various nursing and rehabilitation interventions have been implemented to prevent ICUAW; however, evidence regarding their effectiveness remains variable.

Objectives: To synthesize current evidence on nursing and interdisciplinary interventions for preventing ICU-Acquired Weakness in critically ill adult patients and to identify interventions associated with improved functional outcomes.

Method: A systematic review was conducted using PubMed, ProQuest, MEDLINE, ScienceDirect, and Google Scholar. Studies published between January 2014 and May 2024 were screened according to predefined inclusion and exclusion criteria. Eligible studies included adult ICU patients receiving nursing or interdisciplinary interventions aimed at preventing ICUAW. Study quality was assessed using the Joanna Briggs Institute Critical Appraisal Checklist.

Results: Of 693 records identified, seven studies met the inclusion criteria. The findings indicated that early mobilization consistently improved muscle strength, mobility, and functional recovery while reducing the incidence of ICUAW. Nutritional optimization, range-of-motion exercises, massage therapy, neuromuscular electrical stimulation, blood flow restriction-assisted mobilization, and structured rehabilitation programs demonstrated beneficial effects on muscle preservation and recovery. Multidisciplinary collaboration involving nurses, physiotherapists, nutritionists, rehabilitation specialists, and psychologists was associated with improved rehabilitation outcomes and functional independence.

Conclusion: Nursing and interdisciplinary interventions, particularly early mobilization and comprehensive rehabilitation strategies, may effectively reduce the risk of ICUAW and improve recovery among critically ill adults. Nurses play a central role in coordinating rehabilitation, monitoring patient safety, providing education, and facilitating patient engagement throughout the recovery process.

Keywords: Critical illness; Early mobilization; Functional recovery; Rehabilitation nursing; Muscle preservation; Intensive care rehabilitation.

BACKGROUND

ICU-Acquired Weakness (ICUAW) is a common and serious complication among people experiencing critical illness, characterized by generalized muscle weakness that develops during intensive care treatment [1]. ICUAW contributes to prolonged mechanical ventilation, extended hospitalization, functional decline, reduced quality of life, and increased long-term disability among survivors of critical illness [2]. Beyond the acute care setting, ICUAW may negatively affect individuals' ability to return to work, participate in family and social roles, and reintegrate into their communities.

The development of ICUAW is multifactorial and commonly associated with prolonged immobilization, systemic inflammation, malnutrition, deep sedation, and neuromuscular blocking agents [1,2]. These factors contribute to muscle wasting, impaired mobility, and delayed recovery [1,2]. Consequently, preventing ICUAW has become an important priority in critical care practice.

Several interventions have been proposed to prevent or reduce ICUAW, including early mobilization, nutritional optimization, structured rehabilitation programs, range of motion exercises, electrical stimulation, and multidisciplinary rehabilitation strategies [3]. Nurses play a central role in implementing many of these interventions because they are continuously involved in patient monitoring, rehabilitation coordination, patient education, nutritional management, and communication with patients and families [4].

Although previous studies have reported promising outcomes, the effectiveness of specific interventions remains inconsistent. Some studies demonstrate significant improvements in muscle strength and functional outcomes, while others report limited or variable benefits. Furthermore, previous reviews have often focused on isolated rehabilitation strategies without adequately examining the collaborative role of nurses within interdisciplinary care teams.

Therefore, this systematic review aimed to synthesize current evidence regarding nursing and interdisciplinary interventions for preventing ICUAW among critically ill adult patients. The review also aimed to identify interventions with the strongest evidence and discuss their implications for long-term rehabilitation, functional independence, and quality of life.

METHODS

Literature Search Strategies and Databases

A systematic review was conducted to identify studies evaluating nursing and interdisciplinary interventions to prevent ICU-Acquired Weakness (ICUAW) in critically ill adult patients. Literature searches were performed in ProQuest, PubMed, ScienceDirect, MEDLINE, and Google Scholar for studies published between January 2014 and May 2024.

The primary search terms included "ICU-Acquired Weakness," "Nursing Interventions," "Critical Care," "Early Mobilization," "Rehabilitation," and "Muscle Weakness in ICU." Boolean operators (AND/OR) were used to combine keywords. Example search strategies included "ICU-Acquired Weakness AND Nursing Interventions" and "Early Mobilization OR Physical Therapy AND Critical Care." Handsearching and grey literature searches were not conducted, and this has been acknowledged as a limitation of the review..This strategies comes from the PICO format (table 1):

Table 1. PICO Format

Population	Adult ICU patients
Intervention	Nursing and interdisciplinary interventions
Comparation	Usual care
Outcomes	Prevention or reduction of ICU-Acquired Weakness

Eligibility Criteria

Inclusion Criteria

Studies were included if they:

- Were peer-reviewed original research articles;
- Were published in English between January 2014 and May 2024;
- Included adult ICU patients;
- Evaluated nursing or interdisciplinary interventions aimed at preventing ICUAW;
- Used randomized controlled trial, intervention, cohort, or observational study designs.

Exclusion Criteria

Studies were excluded if they:

- Focused on pediatric populations;
- Included animal or laboratory studies;
- Were review articles, editorials, commentaries, conference abstracts, or protocols without original data.

Quality Appraisal of Studies

The quality of included studies was assessed using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Randomized Controlled Trials. Some items were classified as "Not Applicable" because several included studies used observational or non-randomized designs in which blinding or randomization procedures were not feasible [5]. The possible score range was 0 to 13 (Table 2).

Table 2. Results of Critical Appraisal

Critical Appraisal Tool for RCTs	6	7	8	9	10	11
Was true randomization used for assignment of participants to treatment groups?	NA	Y	Y	NA	NA	NA
Was allocation to treatment groups concealed?	Y	Y	Y	Y	Y	Y
Were treatment groups similar at the baseline?	Y	Y	Y	Y	Y	Y
Were participants blind to treatment assignment?	NA	Y	Y	NA	NA	NA
Were those delivering treatment blind to treatment assignment?	NA	N	N	NA	NA	NA
Were outcomes assessors blind to treatment assignment?	NA	N	N	NA	NA	NA
Were treatment groups treated identically other than the intervention of interest?	Y	Y	Y	Y	Y	Y
Was true randomization used for assignment of participants to treatment groups?	NA	Y	Y	NA	NA	NA

Were participants blind to treatment assignment?	NA	Y	Y	NA	NA	NA
Were those delivering treatment blind to treatment assignment?	NA	N	N	NA	NA	NA
Were outcomes assessors blind to treatment assignment?	NA	N	N	NA	NA	NA
Were treatment groups treated identically other than the intervention of interest?	Y	Y	Y	Y	Y	Y
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Y	Y	Y	Y	Y	Y
Were participants analyzed in the groups to which they were randomized?	NA	Y	Y	NA	NA	NA
Were outcomes measured in the same way for treatment groups?	Y	Y	Y	Y	Y	Y
Were outcomes measured zin a reliable way?	Y	Y	Y	Y	Y	Y
Were treatment groups treated identically other than the intervention of interest?	Y	Y	Y	Y	Y	Y
Was the trial design appropriate, and any deviations from the standard RCT accounted for in the conduct and analysis of the trial?	NA	U	U	NA	NA	NA
Total Score	7	10	10	7	7	7

Note :Y: Yes; N: No; U: Unclear; NA: Not Applicable

Study Selection

A total of 693 records were identified. After removing duplicates and screening titles and abstracts, 35 studies were reviewed in full text. Seven studies met the inclusion criteria and were included in the final analysis.

Data Extraction and Synthesis

Data extracted from the included studies included study characteristics, intervention type, outcome measures, and major findings. Because of substantial heterogeneity across interventions, study designs, and outcome measures, a quantitative meta-analysis was not feasible. Therefore, findings were synthesized narratively using descriptive comparison.

Ethical Considerations

As this study was a systematic review using previously published literature, ethical approval and informed consent were not required.

Data Availability Statement

The data supporting the findings of this review are available within the article and through the cited references included in the review.

Risk of Bias

We utilized the free software RevMan (version 5.4.1) to evaluate the risk of bias. High risk was associated with blinding of participants and personnel (performance bias). Nevertheless, the risk of bias in our review was generally similar and low in most of the studies. The results of the bias assessment are shown in Figures 1 and 2.

Figure 1. Risk of bias graph: review authors' decisions about each risk of bias item used RevMan 5.4.1

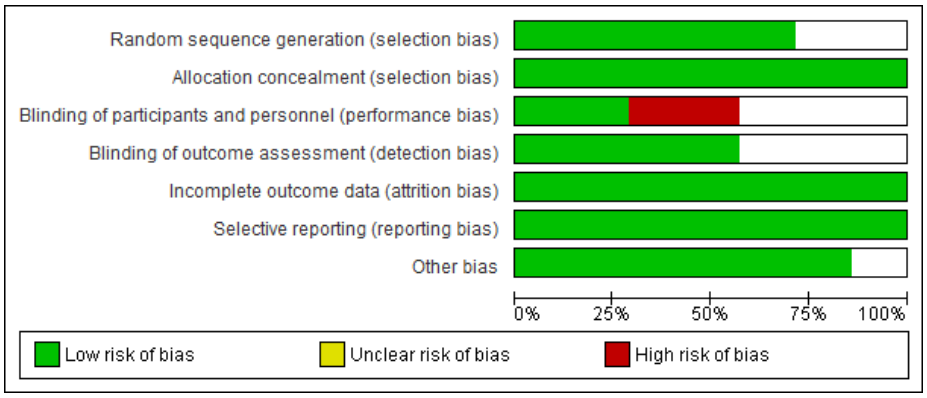
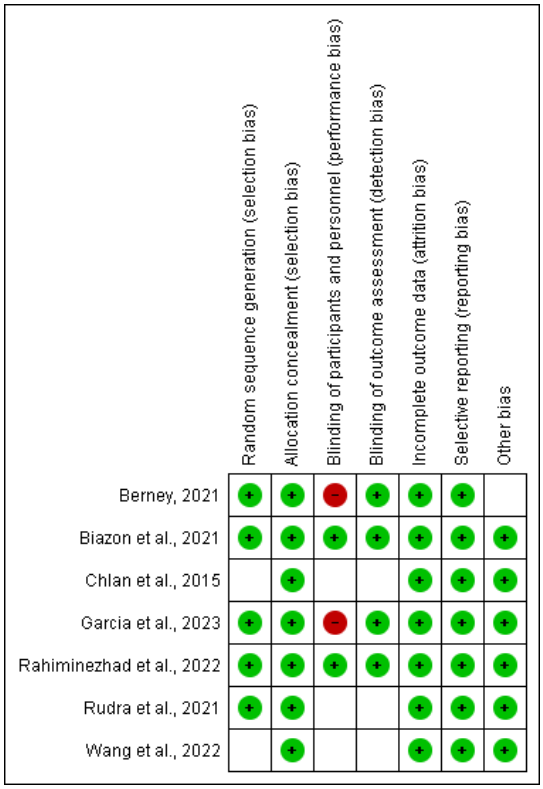


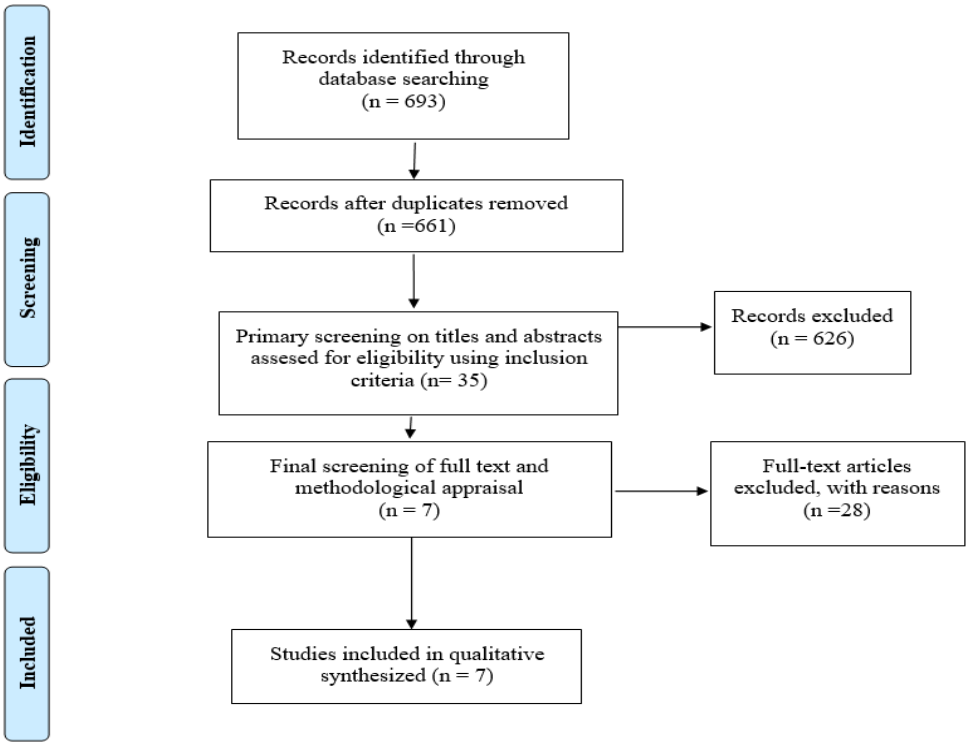
Figure 2. Risk of bias summary used RevMan 5.4.1



RESULTS

Using the search strategies, 693 articles were initially identified. After removing 32 duplicates, 661 articles remained. Following a review of their titles and abstracts, 35 articles were chosen for further consideration. Ultimately, seven studies met the inclusion criteria and were included in the analysis, while 28 were excluded. The excluded articles were not intervention studies, focused on pediatric populations, were long-term programs, or were study protocols (Figure 3).

Figure 3. PRISMA Flow Diagram



The seven included studies demonstrated that both nurse-led and interdisciplinary interventions may reduce the incidence and severity of ICUAW and improve functional outcomes among critically ill patients.

Early mobilization was consistently associated with improved muscle strength, mobility, and reduced ICUAW incidence across multiple studies. Nutritional interventions focusing on adequate caloric and protein intake were also associated with improved muscle preservation and recovery. Range of motion exercises and massage therapy demonstrated beneficial effects on muscle strength and circulation among critically ill individuals.

More advanced rehabilitation strategies, including passive mobilization combined with blood flow restriction and neuromuscular electrical stimulation, as well as functional electrical stimulation cycling, demonstrated promising effects on muscle mass and muscle quality. However, these interventions were evaluated in smaller studies and require further validation through larger randomized controlled trials.

Interdisciplinary collaboration involving nurses, physiotherapists, nutritionists, rehabilitation therapists, and psychologists demonstrated positive effects on functional independence, mobility, rehabilitation progress, and patient recovery. Importantly, these collaborative interventions highlighted the role of nurses as coordinators of rehabilitation, patient educators, and facilitators of patient and family engagement.

Despite positive findings, heterogeneity among study designs, intervention protocols, and outcome measures limited direct comparison across studies and prevented quantitative meta-analysis.The research presented in the table encompasses diverse investigations into interventions aimed at mitigating muscle weakness in critically ill patients across different regions and methodologies. Studies conducted in various countries, including Spain, Iran, Brazil, the United States, and China, explored interventions ranging from enteral nutrition management to passive mobilization combined with blood flow restriction and electrical stimulation. These interventions were assessed through randomized controlled trials, retrospective cohort studies, and prospective nationwide multicenter cohort studies. Key findings suggest that early mobilization, specific nutritional targets, range of motion exercises, massage, and passive mobilization combined with

innovative techniques such as blood flow restriction and neuromuscular electrical stimulation significantly contribute to improving muscle strength and quality among ICU patients. Additionally, rehabilitation programs, multidisciplinary collaboration, and alternatives to sedative medications emerge as effective strategies for promoting functional independence and enhancing peripheral muscle strength in critically ill individuals undergoing mechanical ventilation.

A study conducted by Zaragoza-García et al. (2023) in Madrid, Spain, explored enteral nutrition management in critically ill adult patients and its impact on intensive care unit-acquired muscle weakness (ICUAW). This prospective, nationwide, multicentre cohort study involved 316 patients from a network of 80 ICUs. Using the Medical Research Council Scale (MRC-Sum score), the study emphasized early mobilization and specific nutritional targets, recommending an energy intake of 25–30 kcal/kg/day and protein intake of 1.2–2 g/kg/day. For patients with a BMI over 30 kg/m², the energy target was 11–14 kcal/kg/day and protein 2 g/kg ideal body weight/day. The results showed that early mobilization and nutrition management significantly reduced the incidence of ICUAW. Similarly, Rahiminezhad et al. (2022) conducted a single-blinded randomized controlled trial in Kerman, Iran, involving 90 ICU patients. This study assessed the effects of range of motion (ROM) exercises and massage on muscle strength, finding that both interventions significantly enhanced muscle strength in critically ill patients.

In São Carlos, Brazil, de Campos Biazon et al. (2021) performed a double-blind randomized controlled trial to evaluate the impact of passive mobilization, blood flow restriction (BFR), and neuromuscular electrical stimulation (BFRpE) on muscle mass and quality in ICU patients. Thirty-nine patients were randomly assigned to different intervention groups, and muscle measurements were obtained using ultrasound. The study concluded that BFRpE notably improved muscle mass and quality. Rudra et al. (2022) in Hershey, Pennsylvania, conducted a retrospective cohort study on 270 adult patients to investigate rehabilitation outcomes in those with ICUAW. The study found that patients with ICUAW showed significant improvements in functional independence measures (FIM) and had a higher home discharge rate following inpatient rehabilitation. Additionally, Chlan et al. (2015) in Minnesota, US, demonstrated that mobility programs and alternatives to sedative medications significantly enhanced peripheral muscle strength in mechanically ventilated patients, highlighting the benefits of such interventions in ICU settings.

The collective results underscore the importance of early intervention and a comprehensive approach to managing muscle weakness in the intensive care unit. These findings offer valuable insights into the potential efficacy of various interventions, providing clinicians with evidence-based strategies to optimize patient outcomes and reduce the incidence of ICU-acquired weakness. Moreover, the diversity in study designs and geographical locations highlights the global relevance and applicability of these interventions, emphasizing the need for tailored approaches based on patient demographics, clinical context, and available resources. Overall, these studies contribute to advancing our understanding of muscle weakness in critical illness and inform the development of targeted interventions to enhance rehabilitation outcomes and improve the quality of life for ICU patients.

DISCUSSION

This systematic review identified several nursing and interdisciplinary interventions that may contribute to preventing ICU-Acquired Weakness among critically ill patients. The findings demonstrate that early mobilization, nutritional management, rehabilitation strategies, electrical stimulation therapies, and multidisciplinary collaboration may improve muscle strength, mobility, and functional independence.

Among the included interventions, early mobilization demonstrated the most consistent evidence for reducing ICUAW and improving functional outcomes. Early mobilization helps counteract muscle wasting associated with prolonged immobilization and mechanical ventilation while also improving circulation, respiratory function, and psychological well-being. Nurses play a critical role in assessing patient readiness, monitoring safety during mobilization, and coordinating rehabilitation activities with physiotherapists and physicians.

The intervention was categorized as early mobilization, enteral nutrition management, range of motion exercises, massage, collaboration with physiotherapists to conduct passive mobilization with blood flow restriction and neuromuscular electrical stimulation (BFRpE), functional electrical stimulation, inpatient rehabilitation, and early multidisciplinary collaborative team. The incorporation of early mobilization into nursing interventions for preventing ICU-Acquired Weakness (ICUAW) is supported by its potential to counteract muscle wasting and weakness associated with prolonged bed rest. By initiating early mobilization protocols, nurses facilitate the restoration of muscle function and prevent the onset of ICUAW 13. Furthermore, early mobilization improves physical outcomes and enhances patient comfort and psychological well-being, thereby promoting overall recovery 14. Nurses are pivotal in implementing and overseeing early mobilization programs, ensuring patient safety and adherence to prescribed protocols.

Adequate nutrition is essential for maintaining muscle integrity and preventing ICUAW 6. Nurses oversee enteral nutrition management, ensuring patients receive appropriate caloric and protein intake to support muscle function and prevent catabolism. By closely monitoring nutritional status and collaborating with dietitians and healthcare teams, nurses optimize nutritional support tailored to individual patient needs, thereby mitigating the risk of muscle weakness and promoting recovery 15.

Range of motion exercises and massage therapy are valuable adjuncts to nursing interventions for preventing ICUAW 7,9. These interventions help maintain joint flexibility, improve circulation, and alleviate muscle stiffness and discomfort associated with prolonged immobility. In collaboration with physiotherapists, nurses can guide patients through appropriate range of motion exercises and administer massage therapy, promoting muscle relaxation and preventing contractures. Additionally, massage therapy contributes to patient comfort and relaxation, enhancing the overall effectiveness of rehabilitation efforts 16.

Passive mobilization combined with blood flow restriction and neuromuscular electrical stimulation (BFRpE) represents an innovative approach to preventing ICUAW 8. This intervention aims to stimulate muscle contraction and improve muscle mass and strength in critically ill patients. Nurses collaborate closely with physiotherapists to administer BFRpE safely and effectively, ensuring proper technique and patient monitoring. By integrating BFRpE into multidisciplinary care plans, nurses contribute to optimizing patient outcomes and reducing the incidence of ICUAW 8.

Functional electrical stimulation and inpatient rehabilitation are integral to nursing interventions for preventing ICUAW. These interventions promote muscle activation, enhance motor function, and facilitate recovery of physical independence 12. Nurses are crucial in coordinating and facilitating functional electrical stimulation sessions and inpatient rehabilitation programs, ensuring patient safety and adherence to prescribed protocols. Through their expertise and collaborative efforts with other healthcare professionals, nurses contribute significantly to maximizing the effectiveness of these interventions in preventing ICUAW and promoting overall patient recovery 12.

The integration of early multidisciplinary collaboration represents a comprehensive approach to preventing ICUAW and promoting patient recovery 11,17. Nurses play a central role in this collaborative effort, utilizing their communication skills to engage patients

in understanding the importance of rehabilitation training 11. By patiently explaining the necessity of exercise and rehabilitation, nurses empower patients to actively participate in their recovery process. Moreover, nurses closely monitor patients' vital signs and overall condition, promptly addressing any signs of distress or maladjustment to ensure optimal safety and comfort during rehabilitation sessions.

Compared with previous systematic reviews, this review specifically highlights the central role of nurses within multidisciplinary rehabilitation efforts. Nurses not only implement rehabilitation strategies but also facilitate communication, empower patients through education, monitor safety, and support patient-centered recovery.

Study limitation

Several limitations should be acknowledged in this systematic review. First, substantial heterogeneity existed across study designs, interventions, rehabilitation protocols, and outcome measures, limiting direct comparison among studies and preventing quantitative meta-analysis. Consequently, the findings should be interpreted cautiously when developing standardized clinical guidelines.

Second, the quality of evidence varied among included studies, with some studies using small sample sizes or non-randomized designs. Third, the review included only English-language studies, which may have introduced language bias.

Fourth, hand-searching and grey literature searches were not conducted, potentially limiting the identification of additional relevant studies. Additionally, although this review focused on nursing and interdisciplinary interventions, the specific contributions of individual healthcare professionals were not consistently differentiated across studies.

Finally, most included studies lacked long-term follow-up data. Therefore, the long-term impact of these interventions on quality of life, return to work, community participation, social reintegration, and caregiver burden remains unclear. Future research should include standardized outcome measures, larger randomized controlled trials, and long-term follow-up assessing functional independence and quality of life among ICU survivors.

CONCLUSION

This systematic review demonstrates that early mobilization, nutritional management, rehabilitation exercises, electrical stimulation therapies, and interdisciplinary rehabilitation programs may contribute to preventing ICU-Acquired Weakness among critically ill adult patients. The findings highlight that prevention of ICUAW requires comprehensive interdisciplinary collaboration involving nurses, physiotherapists, nutritionists, rehabilitation therapists, psychologists, patients, and families. Nurses play a central role as coordinators of care, patient educators, rehabilitation facilitators, and patient safety advocates.

Beyond improving short-term muscle strength and mobility, these interventions may support long-term functional independence, quality of life, and successful reintegration into family and community life among ICU survivors. Healthcare institutions should prioritize early rehabilitation programs, standardized mobilization protocols, nutritional optimization, and collaborative multidisciplinary care models to reduce ICUAW incidence and improve patient outcomes.

Future research should focus on larger high-quality randomized controlled trials, standardized outcome measurements, and long-term evaluation of rehabilitation outcomes, including quality of life, social participation, and return-to-work outcomes.

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Conflicts of Interest: The authors declare that they have no conflicts of interest related to this work.

Ethics Approval: Ethical approval was not required for this study because it is a systematic review based exclusively on previously published literature and does not involve human participants, animals, or identifiable personal data.

Consent to Participate: Not applicable.

Consent for Publication: Not applicable.

Availability of Data and Material: All data generated or analyzed during this study are included in this published article and its referenced sources. Additional information is available from the corresponding author upon reasonable request.

Code Availability: Not applicable. No custom code or software was developed or used for data analysis in this systematic review.

Authors' Contributions

Amelia Ganefianty: Conceptualization, study design, literature review, data extraction, data interpretation, manuscript drafting, and critical revision of the manuscript.
Ardi Zulfariansyah: Literature screening, quality appraisal, data analysis, interpretation of findings, and manuscript revision.
Titin Mulyati: Methodological supervision, critical review of the manuscript, interpretation of results, and final approval of the manuscript.
All authors read and approved the final manuscript.

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