DISABILITY, CBR AND INCLUSIVE DEVELOPMENT

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BOOK REVIEWS

Editorial

Stigma in Disability, Rock-hard Beliefs and Religion

In my consultancy work over the past 5 years in a number of African countries, it increasingly became clear to me that organisations of persons with disabilities, local and international non-governmental organisations are expecting that laws and policies will have an important role in curtailing or preventing stigma due to disability. While acknowledging the importance of legislation which is of course needed, we need to be honest about the fact that the impact of legislation on the mindsets of people is limited.

Changing mindsets and subsequent behaviour will prove a useless exercise until we examine the roots of stigma and understand its very nature. Only then will we be able to build structures to support the understandings and mechanisms that reduce stigma.

The core questions we need to ask - in whatever society one lives in and whatever stigmatising condition one has – are: what causes people to behave in a stigmatising manner? What causes people not to challenge or change stigmatising behaviour, even when they have the right knowledge about the disabling condition? Why are people treating their loved ones, employees, friends, as well as religious brothers and sisters in such inhumane ways? Why is stigma so widespread, regardless of social, educational, or economic strata?

The answer is simple, at least conceptually: at the core of any behaviour you will find a (or a series of) belief(s) – usually rock-hard and difficult to change – that cause individuals or groups to behave in a specific manner. We need to strip those beliefs to their core before we can effectively counteract stigma. It appears that there are reasons why people might fear people with certain types of disabilities. Is it the fear that the condition is contagious? Is it the fear of dealing with someone who looks or behaves different from what we see, and think is 'normal'? Is it the wrong doctrine that is being preached in religions where some religious leaders may be using selective scriptures from Holy Books to show that it is God who is punishing individuals with a disability? Is it witchcraft that raises intense fear because it destroys human life and results in serious violations of human rights including, beatings, banishment, cutting of body parts, and amputation of limbs, torture and murder?

As long as we don’t have the courage to challenge people’s core beliefs, stigma will not disappear. Confronting society as well as traditional and religious leadership, with the devastating causes of stigma is not a comfortable – nor a popular – process. All too often, we have all sorts of excuses because we are afraid to offend tradition and culture even though we know that there are harmful elements in that culture. Let us, however, be bold and start challenging these – wrong – beliefs albeit in respectful ways. If we do not do this, we will have failed in doing what needs to be done to serve those who are stigmatised and scorned.

What has intrigued me in the past years is if and how we can confront and involve religious leadership about their (likely unconscious) role in stigmatising their followers. In most religions, one notices forms of charity directed at those considered to be weak. Charity in itself is not wrong but at the moment that it becomes disempowering to those who are cared for, we must ring the alarm bell. However, in our work in a number of African countries we hoped to show that in working with religious leadership we could a spread a message of solidarity, justice and righteousness for those with stigmatising conditions such as leprosy, cerebral palsy, and albinism.

Working increasingly in the field of cerebral palsy, I observe that in many cultures – not only African ones – there is a widespread belief that: *If you get a child with Cerebral Palsy, it must have been a long-ago sin so loathsome that the parents believe it as the cause for giving birth to such a child. That belief may be even compounded by superstition or witchcraft*.

What does it mean in practice for the mother and her child with cerebral palsy? It often means that fathers are running away from their families or that mothers abandon their child with a disability. At worst, they leave the child to die in the forest and, at best, they find a grandmother willing to take care of the child. The child is seen as worthless and a burden; fathers put the blame on mothers for conceiving a child with a disability; and mothers are either able to stay strong, love and care for their child, or they run away fearing the opinions and looks of the community in which they live.

In my most recent assignment in Congo I met a 14-year-old girl with Albinism. She told me that she didn’t feel safe at school where fellow students mocked her. Her home was the place where she felt safest and her faith in God helped her to be strong. When we departed, she asked me if I could not take her with me to Europe…

What is relevant is that the above reality in many cultures illustrates behaviour based upon a belief that is quite fundamental and widespread. Such beliefs are expressed in different ways by a wide range of people, including parents of children with a disability, religious people, politicians, and the public at large. This belief is based upon what has been told from generation to generation, that it must be the result of divine intervention, superstition or witchcraft.

How to counter this?

In my view, we should educate the right people; the ones who are listened to; the ones who influence or can influence beliefs because they have legitimate power to do so. Legitimate power is perhaps the most prevalent and ubiquitous form of power in society. It refers to the formal authority given to a person as a result of their position in a hierarchical system. Such systems include governments. However, increasingly, I became aware that it is in actual fact by far more the traditional- and religious leaders who can be key in changing mindsets in a massive way...

We started in various countries to engage with religious leaders and involve them in training programmes about disability inclusion. We also developed specific training trajectories whereby we raise awareness; have in-depth discussions and work together in the development of local training manuals. We will test this year a new toolkit for clergy in two countries. We use in the training participatory methods and offer direction on the exegesis of difficult and controversial scriptures. It is interesting to see the usual positive response of clergy - especially among those who lack a robust theological training. I realise that we are not the only ones who are targeting religious leaders in becoming agents of change first in their own congregation. However, we believe that an inclusive congregation becomes also a witness of acceptance, participation and belonging of all members and as such may contribute to similar developments in society. I personally strongly believe that this approach is by far more effective than the impact of conventional community awareness raising efforts.

Huib Cornielje
(Assistant Editor-in-Chief)

ORIGINAL RESEARCH ARTICLES

Features of Telerehabilitation and Considerations for Resource-Limited Settings: A Scoping Review

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ABSTRACT

***Aim**: The global need for rehabilitation is extensive yet remains significantly unmet. Health systems, especially in low- and middle-income countries (LMICs), lack structures and resources to address the rapidly growing need for rehabilitation services. Telerehabilitation offers an innovative approach to narrow health systems gaps and facilitate rehabilitation services. Few studies have investigated features and functionalities used in telerehabilitation, especially regarding implications for resource-limited settings and LMICs. This scoping review aims to identify technological features and functionalities used to deliver telerehabilitation, map them onto clinical care processes, and outline gaps and directions for future research, especially regarding considerations for resource-limited settings.*

***Methods**: This study utilized the PRISMA- checklist. Six databases were searched (PubMed, Embase, Scopus, CINAHL, Compendex, NARIC) to identify articles that described the remote delivery of rehabilitation services. Three reviewers screened and selected relevant publications. Descriptive statistics and qualitative content analysis were used to analyze full-text articles. **Results**: 135 articles were included in the full-text review. The publication year ranged from 1997 to 2021. The most frequently identified telerehabilitation feature was*

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"data collection," followed by "videoconferencing," and "messaging." Features mapped onto six clinical categories, with "implementation" accounting for 41% of all features, Only 18% of articles focused on LMICs. Few papers included a comprehensive platform of features, discussed integration into health systems, or included financial analyses.

***Conclusions**: Diverse technological tools exist for the remote delivery of rehabilitation services, but few cohesive platforms offer features across multiple clinical categories. Additionally, high income countries are overwhelmingly represented in the literature. Future directions for research include expanded focus on resource-limited settings and LMICS, discussion about financial considerations, and attention to health systems integration. **Limitations**: The generalizability of our findings are limited given the rapid growth of literature on telerehabilitation and continued development of apps and platforms since the time of review.*

***Keywords:** Rehabilitation, low-and middle-income countries (LMICs), telehealth, disability, health systems integration*

INTRODUCTION

As the world's population ages and prevalence of chronic health conditions grows, there has been a rapid increase in the number of people experiencing disability or functional changes who need rehabilitation services. Extending beyond curative care, rehabilitation encompasses interventions to optimize functioning and reduce the experience of disability in individuals with health conditions in their interactions with their environment (World Health Organization [WHO], 2023). Rehabilitation is broad in its scope and presents as a uniquely relevant service for diverse health conditions, impairments, and ages across the lifespan (Cieza, 2019). Though identified as a global public health goal (Heinemann et al., 2020), the need for rehabilitation greatly surpasses its availability, with global estimates of 2.4 billion people who would benefit from rehabilitation services (Institute for Health Metrics and Evaluation, n.d.).

Health systems lack structures and resources to address this growing need, particularly in resource-limited settings and low- and middle-income countries (LMICs). Populations in LMICs are disproportionately affected by unmet rehabilitation needs. Seventy-seven percent of global physical rehabilitation needs are in LMICs (Jesus et al., 2019) but only 3% of people in LMICs receive needed rehabilitation services (Khan et al., 2018). Clinical leaders, health planners, and patients in LMICs have been found to have a poor understanding of the nature of rehabilitation (Khan et al., 2018). With limited awareness of its potential for far-reaching health, social, and economic benefits to both individuals and systems, service planning for rehabilitation delivery is undervalued and often deprioritized by governments (Bernhardt et al., 2020). Where rehabilitation does exist, services are often delayed, fragmented, poor in quality, insufficiently covered, and separated from mainstream healthcare delivery (Naicker et al., 2019). Moreover, a lack of trained rehabilitation providers across care levels (e.g., primary and community) renders rehabilitation inaccessible to many individuals who would otherwise benefit from services (Iemmi et al., 2015) .

Telerehabilitation has been defined as "the provision of rehabilitation services at a distance using telecommunications technology as the delivery medium" (Russell, 2007). The number of publications referencing telerehabilitation has increased exponentially in recent years (Zheng et al., 2022), corresponding with advances in telecommunications technology. As a field, telerehabilitation is still emerging, having been broadly introduced in 1997 within a set of proposed priorities for new Rehabilitation Engineering Research Centers outlined by the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education (1998). The funding priority for telerehabilitation was driven in part by shorter hospital stays and a subsequent need for innovative ways to continue rehabilitative care outside of acute care facilities, especially for those living in rural or remote settings. Winters (2002) outlined a conceptual framework for telerehabilitation service delivery that was extended by Parmanto and Saptono (2009) and which includes four models of teleconsultation, telemonitoring, telehomecare, and teletherapy that can be mapped along four quadrants defined by axes of service delivery intensity (i.e., volume of information exchanged) and duration. Consideration for intensity of information exchange and duration of clinical care can inform selection of optimal technological approaches for telerehabilitation service delivery. Recent technological advances and the COVID-19 pandemic have led to an upsurge in telerehabilitation adoption and innovation (Matsumoto et al., 2021), representing an unprecedented opportunity for growth within the field.

Telerehabilitation offers an innovative approach to narrow health systems gaps by relying on information and communications technologies to provide rehabilitation services across the care continuum. Telerehabilitation has the potential to enhance access to rehabilitation services and increase the quality of care by reducing geographic and mobility barriers, decreasing the cost of care via increased time efficiencies and centralization of client data, and customizing services via intervention in the client's home environment. Effective integration of telerehabilitation requires an understanding of technological requirements and user needs and preferences. As remote and technology-based delivery of health services has become more common (Giacalone et al., 2022; Uscher-Pines et al., 2020), there have been corresponding increases in research on implementation and outcomes. Relatively few studies, however, have investigated emerging information and communication technologies in the specific context of telerehabilitation. Moreover, to the best of our knowledge, no studies have synthesized evidence on this topic with respect to implications for resource-limited settings and LMICs.

Objective

The purpose of this scoping review is to systematically document telerehabilitation features and functionalities (e.g., software design architecture, user interface, delivery modalities) that have been tested or used to deliver rehabilitation through some form of technology, with particular attention to features that are appropriate for implementation in resource-limited settings and LMICs. We also aim to summarize key telerehabilitation features, categorize them in relation to clinical care processes, and describe gaps and deficiencies in existing features.

METHODS

A scoping review of the literature on telerehabilitation features and functionalities was conducted using the methodological framework outlined by Arksey and O'Malley (2005) and in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018). The breadth of our purpose and aims are suitable for analysis via a scoping review.

Stage 1: Identify the Research Question

The primary research question of interest was: *what features and functionalities have been developed and/or tested for the delivery of telerehabilitation services?* Within the context of this review, we use the phrase "features and functionalities" (hereafter referred to simply as "features") to refer to the range of tasks and services enabled via the use of information and communications technologies. The results of the scoping review will additionally inform the creation of a telerehabilitation application specifically designed for use within LMICs, which is currently in development. Given our overarching focus of this research, we were interested in the following sub-questions:

1. What features have been tested and implemented in LMICs?
2. How do the existing telerehabilitation features integrate with and map onto healthcare delivery processes and services?
3. What is known about the economic costs of implementation and long-term sustainability of telerehabilitation service delivery technologies?

Stage 2: Identify the Relevant Studies

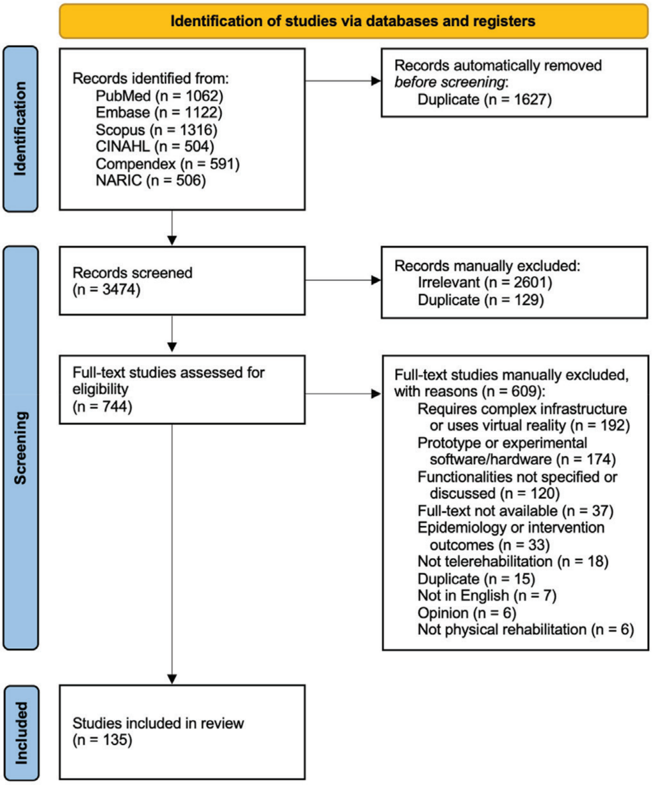
Our review included full-text articles in peer-reviewed and gray literature published any time up until the literature search was concluded in October of 2021. We included articles that described the provision of rehabilitation through telehealth or telemedicine services, as part of an overall telehealth or standalone telerehabilitation service. All types of rehabilitation services (physical, sensory, mental health) were included across all conditions, age groups, and genders. To capture the full breadth of features, any study design was included without any geographic restrictions. Articles were excluded if there was no full-text available in English, if the focus was on intervention outcomes without description of features, or if the service provision was exclusively in-person. With the assistance of a librarian, we searched for articles in the PubMed, Embase, Scopus, CINAHL, Compendex, and NARIC databases. For example, search terms used to search the PubMed database were: (“Telerehabilitation”[Mesh] OR telerehabilitat*[tiab] OR tele-rehabilitat*[tiab] OR “e-rehabilitat*”[tiab] OR “remote rehabilitat*”[tiab] OR “virtual rehabilitat*”[tiab]) AND (“Technology”[Mesh] OR “Software”[Mesh] OR technolog*[tiab] OR application*[tiab] OR platform*[tiab] OR feature*[tiab] OR functionalit*[tiab] OR “virtual reality”[tiab] OR software*[tiab]).

Stage 3: Literature Selection

With the assistance of a librarian, all publications were imported into Covidence, a web-based collaboration software platform that streamlines the production of systematic and other literature reviews. Initial screening for exact duplicates excluded 129 articles. The remaining abstracts were independently reviewed by three of the authors (EK, JT, and HH). These three authors met regularly with another author (NZ) during the screening process to ensure standardization of approach; group discussion and consensus were used when it was unclear if a publication met inclusion or exclusion criteria. At the full-text review phase, a consensus decision was made to exclude articles that exclusively described features requiring difficult to access (e.g., limited production of proprietary movement sensors) or virtual reality technologies; articles were included if they incorporated additional features. This decision was made to better manage the full-text review process, while minimizing data loss. Review of abstracts excluded 2,601 publications that did not meet inclusion criteria. Full-text review was completed by the same three authors, after which an additional 609 studies were excluded, leaving 135 publications that met criteria for data extraction. Figure 1 depicts the PRISMA flow diagram for this review.

Figure 1

PRISMA Flow Diagram



Stage 4: Charting the Data

A literature extraction tool was created using Microsoft Excel. Extracted data included title, author(s), publication/journal, year of publication, study design, research objective, hardware and software requirements, features, condition (i.e., rehabilitation treatment target), age (i.e., age for intervention target), geographic location (grouped into WHO regions), and income level of geographic context. Reviewers also provided a subjective relevance rating to identify publications that included rich details about multiple features, especially those that included more than simply audio- or videoconferencing capabilities, or which described comprehensive telerehabilitation platforms. One reviewer (EK) read 10-15 articles and created a preliminary list of features. All reviewers then met to review the list and agree on common terminology. The features list was iteratively refined throughout the full-text review and all reviewers met regularly to ensure common understanding of feature definitions. Since one of our aims was to map features onto healthcare delivery processes and services, the features were grouped into categories (listed in Table 1) by steps of the nursing process (American Nurses Association, 2021) and one extra "administrative" category. This categorization system was selected based on its succinct grouping of healthcare delivery processes, which were deemed broad enough to apply across the various healthcare disciplines involved in telerehabilitation.

Stage 5: Collating, Summarizing, and Reporting the Results

Following review of all full-text articles, the collected data was summarized by frequency of occurrence. One article could describe multiple features, which were coded separately, therefore one article could contribute to frequencies across multiple features. Frequencies were analyzed to identify emerging trends and overall themes.

Table 1

Telerehabilitation Features Organized by Case Management Category

Category	%	Feature	Includes	All		LMICs	
				n	%	*n*	%
Assessment	25	Data collection	Remote collection and storage of electronically collected patient information (ROM, pulse rate, time and date of intervention, etc.), electronic storage and transmission of patient progress on treatment (captured via technology)	72	11	9	7
		Motion tracking	Gesture recognition, wearable sensors, gait/limb tracking	20	3	4	3

		ePRO or ePROM (electronic patient reported outcomes/measures)	Self-reported patient data (e.g., completion of exercises, subjective rating of pain/fatigue/ strength) without clinical interpretation	38	6	8	7
		Environment Modeling*	3D modeling of home environment for adaptation assessment; home assessments via videoconferencing (e.g., for safety evaluations)	4	1	1	1
		Video recording	Patient recording exercise performance	9	1	1	1
		Video transmission	Electronic transmission of recorded videos (e.g., store and forward)	22	3	4	3
Diagnosis	8	Report/statistics generation	Treatment algorithms based on patient data, automatic reports of patient progress	26	4	4	3
		Rehab database	Library of preset therapeutic regimens for specified conditions, evidence-based treatment guidelines	17	3	6	5
		Video review*	Provider review of patient-uploaded videos	5	1	0	0
Plan	18	Plan of care management	Provider orders, rehabilitation care plan, treatment planning, patient demographic data	53	8	9	7
		Patient instructions	Specific treatment, exercise, or rehabilitation instructions (written/ video recorded)	41	6	7	6
		Decision Support	Software algorithms offering insight to providers based on evidence and/or client data; consultation with other providers for treatment decisions (e.g., specialty providers)	9	1	2	2
		Scheduling	Appointment, meeting, or task scheduling	21	3	5	4
Implement	40	Audioconferencing	Analog telephone/mobile phone calls	27	4	7	6
		Videoconferencing	Synchronous video calling with audio (e.g., Skype, Facetime, Facebook calling)	63	9	9	7
		Patient education	General health education, written/video resources, synchronous classes/sessions	41	6	4	3
		Synchronous TR (telerehabilitation)	Real-time videoconferencing with provider and patient doing rehab exercises/therapy	36	5	7	6
		Support group(s)		14	2	2	2
		Referral mechanisms*	Provider-to-provider referrals	1	0	0	0
		Serious games	Therapeutic exercises in a gaming framework	22	3	4	3
		Remote operation	Remote operation of assistive technologies	3	0	0	0
		Self-management	Software or hardware specifically designed to assist patients with unsupervised self-management, or tracking tools that can be used to share information with providers	11	2	0	0
		Messaging	a/synchronous chatting, emails, provider-patient, provider-provider	58	9	13	11
Evaluation	3	Note recording	Provider documentation	6	1	2	2
		Real-time (RT) feedback	Real-time feedback to the patient regarding technique or progress during exercise or activity (via automated visual, auditory, or haptic modalities)	11	2	1	1
Administrative Tools	6	Search tool		8	1	4	3
		User management	Administrative management of personas/ permissions, password/code management	21	3	6	5
		Confidentiality/security		14	2	2	2
		Payment for services*		1	0	0	0
Total	100			674	100	121	100

Note. * = feature not mentioned in any highly relevant publication

RESULTS

The initial search yielded 3,474 records of which 135 publications underwent full-text review. Selected characteristics of the included publications are listed in Table 2. The year of publication spanned from 1997 to 2021 with the majority (52%) published in 2018 or later (shown in Figure 2). There was wide variation in publication type (including conference proceedings, open-access peer-reviewed publications, and traditional peer-reviewed publications) owing in large part to the inclusion of technical papers describing the on-going development of hardware and software platforms. The largest percentage of articles were published in conferences and journals through the Institute of Electrical and Electronics Engineers (IEEE) (*n* = 25, 19%), followed by JMIR journals (*n* = 10; 7%), the International Journal of Telerehabilitation (*n* = 8; 6%), and Telemedicine and e-Health (*n* = 8; 6%). Commonly reported hardware and software components are listed in Table 3. All full-text publications included in the review are listed in the supplementary material. The remaining results will be reviewed in order of our research questions.

Table 2

Selected Characteristics of Full-Text Publications Included in the Scoping Review

	n	%
Study Design		
Randomized Controlled Trial (RCT)	2	1.5%
Proposed Design	9	6.7%
Case Study	10	7.4%
Other	14	10.4%
Review	30	22.2%
Pilot	31	23.0%
Descriptive Overview	39	28.9%
Condition Category		
Mental disorders	3	2%
Chronic respiratory diseases	3	2%
Sensory impairments	4	3%
Neoplasms	5	4%
Cardiovascular diseases	8	6%
Musculoskeletal disorders	20	15%
Neurological disorders	46	34%
Rehabilitation in general	46	34%

Note. Total *n* = 135

Figure 2

Year of Publication of Articles Included in the Scoping Review

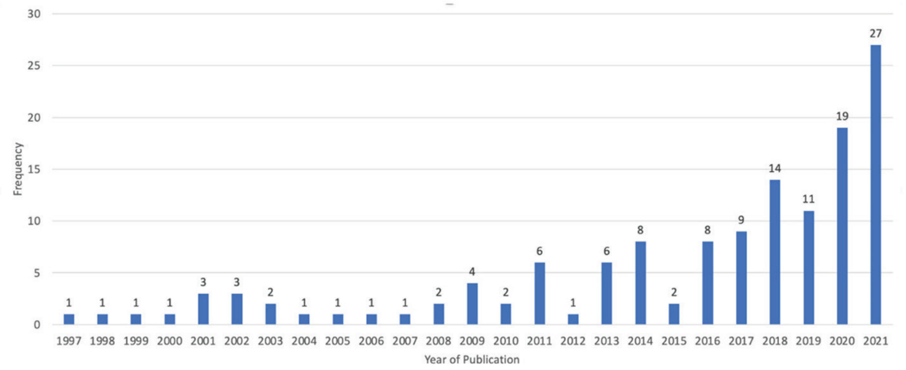


Table 3

Commonly Reported Telerehabilitation Hardware and Software Components

	Hardware	Software
Components	▪ Computer or laptop ▪ Smartphones (iOS and Android) ▪ Mobile devices (e.g., tablets) ▪ Wearable sensors (e.g., Fitbit, Apple Watch, heart rate monitoring device) ▪ Motion tracking devices (e.g., Microsoft Kinect, Nintendo Wii) ▪ Camera or webcam ▪ Microphone ▪ Speaker or headphones ▪ Internet access equipment (e.g., router) ▪ Plug-in accessory devices (e.g., joystick, mouse, keyboard) ▪ Database server ▪ Inertial sensors (in a smartphone and in a standalone device) ▪ Telephone ▪ Videoconferencing systems ▪ Video projector ▪ Biometric sensors	▪ Audio- and videoconferencing (e.g., Skype, WhatsApp, Zoom, TeamViewer, GoToMeeting, Viber, Greenlight) ▪ Email and messaging applications (e.g., WhatsApp) ▪ Internet and data sharing applications (e.g., 4G, LTE, Bluetooth) ▪ Social media applications ▪ Computer sharing (e.g., remote desktop control) ▪ Cloud computing and database management ▪ Website/software/application creation and management tools (e.g., Apache, Java, Microsoft Visual Studio, .NET) ▪ Digital telehealth platforms (e.g., Doxy.me, thera-LINK, TheraNest, Zoom, SimplePractice, Vsee, GoToMeeting, UpDox, eVisit, VA Video Connect) ▪ Comprehensive computer and web-based telerehabilitation programs (e.g., VISYTER [Versatile and Integrated System for Telerehabilitation]) ▪ Motion tracking software (e.g., Leap Motion)

Features

Our primary research question aimed to generate a list of features that have been developed and/or tested for the delivery of telerehabilitation services. A total of 29 separate features were identified and categorized, as listed in Table 1. Across all years, the most frequently mentioned feature was data collection, followed by videoconferencing, messaging, plan of care management, and patient education. When considering only publications from the past five years (2017-2022; *n* = 80), the same five features had the highest frequencies with only slight changes in rank order and with data collection remaining the most frequently mentioned feature. On the other hand, when examining studies across the first ten years of data collection (1997-2006; n = 50) videoconferencing and audioconferencing were the two most frequently mentioned features and accounted for 36% of all feature mentions. Similarly, 12 of the features (including report/statistics generation, decision support, and confidentiality/security), weren't mentioned at all until after 2006. As noted in the methods, reviewers provided subjective relevance ratings based on alignment with study objectives. Highly relevant articles provided rich and substantive descriptions of features and had to include at least three features. Studies that were subjectively rated as highly relevant (*n* = 26) spanned the years 2009-2021 and 69% of them were published after 2015. Highly relevant publications that were not a review paper (*n* = 21) mentioned an average of 7 features (ranging from 4-12), and across all 26 publications only 4 of the 29 total features were not mentioned. Features and selected characteristics of highly relevant publications are listed in Table 4.

Table 4

Selected Characteristics of Highly Relevant Articles Included in the Scoping Review

Authors	Year	Features	Condition	WHO Region	Income level
Anton et al.	2018	Plan of care management, Report/statistics generation, Scheduling, Patient instructions, Videoconferencing, Motion tracking, ePROMS	Musculoskeletal disorders	Multiple Regions	High Income Countries
Bacungan et al.	2021	User management, Plan of care management, Note recording, Messaging, Patient instructions, Confidentiality/security, Scheduling	Cardiovascular diseases	Western Pacific Region	LMIC
Caggianese et al.	2019	Motion tracking, Plan of care management, Report/statistics generation, Serious games	Neurological disorders	European Region	High Income Country
Chamorro-R et al.	2018	User management, Search tool, Messaging, Plan of care Management, Report/statistics generation, Synchronous TR	Musculoskeletal disorders	Region of the Americas	LMIC
Chiensriwimol et al.	2017	User management, Search tool, Plan of care management, Serious games, Data collection, Report/statistics management	Musculoskeletal disorders	Not specified	Not specified/ applicable
Finkelstein et al.	2011	Data collection, ePRO, Plan of care management, Patient instructions, Report/statistics generation, Patient education, Video transmission	Neurological disorders	Region of the Americas	High Income Country
Hosseiniravandi et al.	2020	Synchronous TR, messaging, Plan of care management, Scheduling, Videoconferencing, Report/statistics generation	Rehabilitation in general	Not specified	Not specified/ applicable
Houlihan et al.	2011	Data collection, patient instructions, Scheduling, Report/statistics generation, Audioconferencing	Neurological disorders	Region of the Americas	High Income Country
Jameie et al.	2019	Data collection, ePRO, Report/statistics generation, Plan of care management, Patient education, Messaging,	Cardiovascular diseases	Not specified	Not specified/ applicable
Kim et al.	2012	Fata collection, ePRO, Report/statistics generation, Search tool, Videoconferencing	Rehabilitation in general	Region of the Americas	High Income Country
Korostelev et al.	2014	User management, Confidentiality/security, Data collection, Messaging, Plan of care management	Neoplasms	Region of the Americas	High Income Country
Kringle et al.	2020	Data collection, Plan of care management, Patient instructions, Patient education, Messaging	Neurological disorders	Region of the Americas	High Income Country
Ku et al.	2021	Data collection, Video transmission, Plan of care management, Patient instructions, Scheduling, User management	Rehabilitation in general	Western Pacific Region	High Income Country
Landers & Ellis	2020	Data collection, ePROM, Report/statistics generation, Video transmission, Patient instructions, Motion tracking	Neurological disorders	Region of the Americas	High Income Country

MacKo et al.	2016	Rehab database, Patient education, Video recording, Video transmission, Plan of care management	Neurological disorders	Region of the Americas	LMIC
Marziniak et al.	2018	Plan of care management, Scheduling, Videoconferencing, Patient education, Data collection, ePRO, Report/statistics generation, Decision support, Delf-management, Motion tracking, Patient instruction, Derious games, Synchronous TR, Support group	Neurological disorders	Multiple Regions	Not specified/ applicable
Moral-Munoz et al.	2021	Data collection, Serious games, Report/statistics generation, Patient instructions, Patient education, Messaging, Self-management, RT feedback	Rehabilitation in general	Not specified	Not specified/ applicable
Parmanto & Saptono	2009	Videoconferencing, Decision support, Synchronous TR, RT feedback, Environment modeling, Support groups, Patient education, Data collection, Messaging, Serious games, Video recording, Video transmission, Self-management, Confidentiality/ security,	Rehabilitation in general	Not specified	Not specified/ applicable
Parmanto et al.	2010	Data collection, Videoconferencing, RT feedback, Synchronous TR, Scheduling, Plan of care, Decision support, Motion tracking, Audioconferencing, ePRO, Messaging, Confidentiality/security, User management	Rehabilitation in general	Region of the Americas	High & Low Income
Perez-Medina et al.	2019	Self-management, Patient instructions, ePRO, Data collection, RT feedback, Serious games, Messaging, Plan of care management	Musculoskeletal disorders	Not specified	Not specified/ applicable
Rawstorn et al.	2016	Synchronous TR, Patient education, Patient instructions, RT feedback, ePRO, Data collection, Messaging, Plan of care management, Self-management, Report/statistics generation, Support groups, Confidentiality/security	Cardiovascular diseases	Western Pacific Region	High Income Country
Rosso et al.	2018	Plan of care management, Videoconferencing, User management, Search tool, Messaging, Data collection, Rehab database, Decision support	Neurological disorders	European Region	High Income Country
Solana et al.	2015	Decision support, Plan of care management, Patient instructions, Data collection, Report/statistics generation, Confidentiality/ security, Note recording, Videoconferencing, Messaging, Support groups, Scheduling	Neurological disorders	European Region	High Income Country
Tsavourelou et al.	2016	Synchronous TR, Data collection, Patient instructions, Patient education, RT feedback, Motion tracking, Remote operation, Videoconferencing, Audioconferencing, User management, Confidentiality/security	Rehabilitation in general	European Region	High Income Country
Yue et al.	2013	User management, Plan of care management, Search tool, Report/ statistics generation, ePRO, Patient instructions, Messaging, Scheduling, Rehab database	Neurological disorders	Western Pacific Region	LMIC
Zyliski et al.	2020	Videoconferencing, Scheduling, Plan of care management, Motion tracking, ePRO, Data collection	Neurological disorders	European Region	High Income Country

Geographic Distribution

The first of our research sub-questions aimed to generate a list of features that have been used in LMICs. Geographic location and income level were extracted from full-text publications and are illustrated in Figures 3 and 4. High income countries are overwhelmingly represented in the literature, as is research focused on the Region of the Americas and the European Region. Overall, LMICs were only represented in 24 (18%) of the publications. Given the high concentration of LMICs in the African and South-East Asia Regions, it is noteworthy that only 3% of all publications referenced these regions specifically. Moreover, 17% and 22% of publications, respectively, did not include any reference to geographic location or income level. Features included in articles representing LMICs are listed in Table 1. The most frequently mentioned feature was messaging (*n* = 13), followed by data collection (*n* = 9), plan of care management (*n* = 9), and videoconferencing (*n* = 9). Of all 29 features, only five were not mentioned in articles representing LMICs.

Figure 3

Distribution of Geographic Location of Full-Text publications by WHO Region

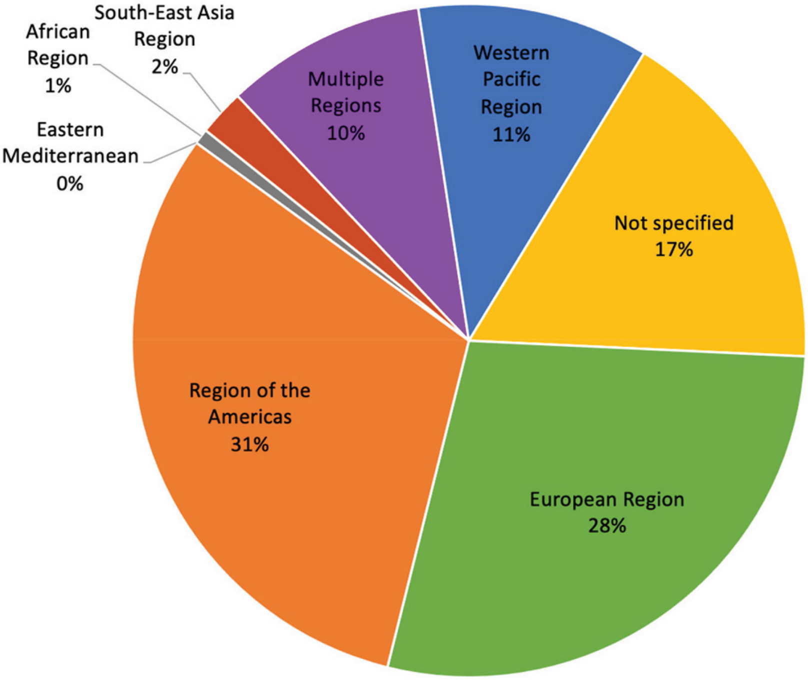
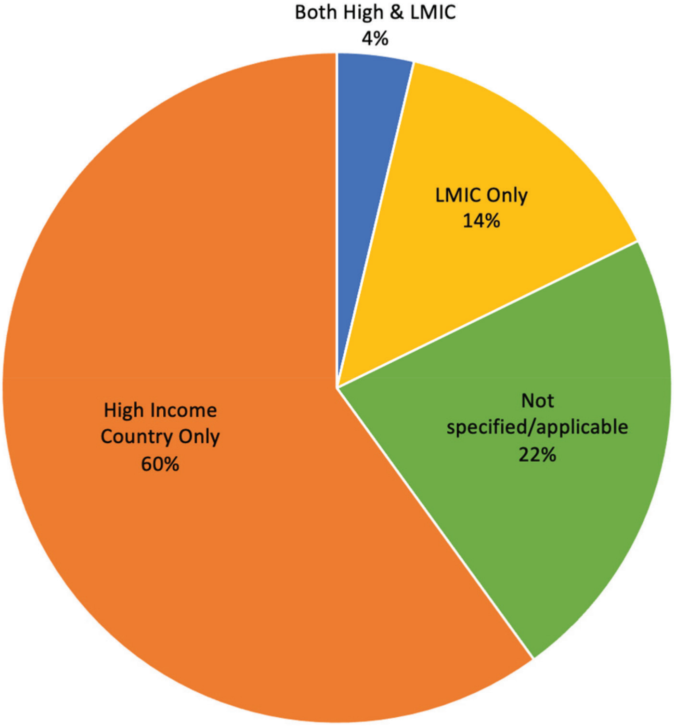


Figure 4

Distribution of Income Level Based on Geographic Location of Full-Text Publications



Features by Case Management Category

Our second research sub-question aimed to map telerehabilitation features onto healthcare delivery processes and services. We similarly noted publications that described features integration into healthcare systems. All identified features were grouped into case management categories, as described previously, and outlined in Table 1. The most frequently mentioned features overall were those within the "Implementation" category, followed by the "Assessment" category. Few papers introduced a single telerehabilitation platform or application with features spanning multiple clinical categories, though there were several notable exceptions. Only 34 (25%) publications described six or more features as part of one system or platform (e.g., Anton et al., 2018; Parmanto et al., 2010; Rawstorn et al., 2016; Ruiz-Ruano et al., 2013). Anton and coauthors (2018) described the development of a comprehensive platform (Kinect-based Telerehabilitation System [KiReS]) designed to provide telerehabilitation services to people with musculoskeletal disorders, which was tested in both Spain and Australia. The KiReS platform included more than 10 features across four clinical categories. Similarly, Rawstorn et al. (2016) described creation of a comprehensive platform (REMOTE-CR) to deliver remote cardiac rehabilitation exercise programs in New Zealand, which included more than 10 features across all clinical and administrative categories. Features commonly associated with integration into healthcare systems (e.g., decision support, scheduling, referral mechanisms, user management, and payment for services) were infrequently noted and altogether accounted for only 8% of all feature mentions.

Economics and Sustainability

Our final research sub-question aimed to identify the scope of the available telerehabilitation literature that included discussion of economic costs of implementation and factors pertaining to long-term sustainability. Across the literature, there was sparse discussion of actual economic costs or long-term sustainability. Lakhani et al. (2021) described the use of freely available mobile applications within their program of care, specifically to ensure access within their low-income context of India. Two publications included an explicit discussion of cost-benefit analysis (Solana et al., 2015; Tsavourelou et al., 2016) and both concluded that the investment was worth the cost. A separate search however did not yield any follow-up publications discussing the actual return-on-investment (ROI) of the projects. The vast majority of publications included in this review described technological innovation without explicit discussion of economic cost to the consumer, long-term financial viability, or ROI. Similarly, there was no discussion of long-term sustainability of telerehabilitation features.

DISCUSSION

Telerehabilitation offers an innovative approach to advance global health care initiatives by reducing access barriers and gaps in service delivery. Literature examining the current telerehabilitation landscape with consideration for resource-limited settings and LMICs is scarce. In this paper, we extracted and analyzed information on telerehabilitation features from 135 publications. Our broad goal was to identify and map telerehabilitation features noted in the literature to-date. We specifically sought to identify features that have been or could be implemented in LMICs, note how these features map onto healthcare delivery processes and into healthcare systems, and describe what is known about the economic costs of service delivery technologies. A total of 29 features were identified, with the three most common features being data collection, videoconferencing, and messaging. When mapping features onto clinical care categories, we found that most features contributed to implementation of rehabilitation services and clinical assessment. Gaps that were revealed in the literature included few comprehensive platforms with features across multiple phases of clinical care, limited research representation in LMICs and in certain geographic regions (e.g., the Eastern Mediterranean, African, and South-East Asian Regions), and virtually no discussion of financial costs or long-term sustainability.

Lack of Comprehensive and Integrated Platforms

Our findings highlight the need for more comprehensive telerehabilitation platforms that offer features spanning the range of clinical and administrative categories that can be easily integrated into healthcare systems. With limited exceptions, few papers in this scoping review introduced a single telerehabilitation platform with features spanning multiple clinical categories. Similarly, our review revealed that most telerehabilitation features mapped onto the clinical assessment (24%) and implementation (41%) domains. Even fewer features appear to be available to aid in the clinical aspects of diagnosis (8%) or evaluation (3%) when working with rehabilitation patients. While these particular interventions can be quite complex in standard clinical practice and pose challenges for successful translation to telerehabilitation, diagnostic and evaluation tools are crucial for identifying and resolving problems early in implementation (Finch et al., 2012). Given prominent concerns about data privacy and security in the literature (Mamdouh et al., 2020; Saptono et al., 2009), the scarcity of confidentiality and security features is also notable, particularly in relation to the frequent mention of data collection features. One meaningful feature that appeared to be lacking in the literature was that of decisional support. Decisional support features can equip frontline workers, particularly those less familiar with rehabilitation medicine, with a tool to aid in treatment decisions and consulting with specialty rehabilitation providers. In LMICs, this stands out as one of the most important functionalities for narrowing gaps in service delivery where human resources are scarce (Finch et al., 2012).

Effective implementation of telerehabilitation into health care systems likely requires a range of features and functionalities to match the diverse clinical demands inherent in rehabilitation across the care continuum. Results from a recent qualitative analysis that focused on telerehabilitation implementation emphasized the value of various support mechanisms for all individuals involved in the rehabilitation process (e.g., patient, provider, non-clinical staff; Anil et al., 2021). Other studies have similarly found a need for diverse features that can assist in various clinical categories involved in rehabilitation (Rothgangel et al., 2017). Of note, the importance of comprehensive telerehabilitation platforms can be assumed by the inherent qualities of the International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001). The ICF is a biopsychosocial model that is key in the conceptual understanding of a person's functioning, disability, and health. It provides a clear framework that highlights the necessity that services should address diverse factors, as well as dynamic relationships between an individual and their environment. To this end, telerehabilitation systems that are limited in scope (e.g., delivery of an exercise program in the absence of ongoing evaluation) or lack interactive features (e.g., message systems to facilitate patient-provider communications) are falling short of rehabilitation's overarching goal to improve functioning by attending to various factors that affect activity and participation. Solana et al. (2015) described development of a comprehensive cognitive telerehabilitation platform called the Guttman Neuropersonal Trainer (GNPT) that was built on ICF standards and taxonomy. The GNPT platform included 12 different features across all clinical categories. It was explicitly designed with interoperability in mind such that it could easily operate within and across healthcare systems and electronic health records and was tested with 887 patients across 27 different organizations and 83 patient homes. The scope of the services offered across multiple organizations is an example of what can be achieved with a thoughtfully designed comprehensive telerehabilitation platform.

Skewed Global Distribution of Telerehabilitation Research and Development

Despite intentional efforts to conduct a review that discussed features and functionalities appropriate for implementation in resource-limited settings and LMICs, very few papers were in the setting of or published by authors in LMICs (14%), which limits our knowledge about how contextual factors shape the implementation of telerehabilitation in LMICs. More than half of the papers included in the full-text review were conducted in the Regions of the Americas (31%) and European Region (28%), with an extremely scarce number of publications conducted in the Eastern Mediterranean (0%), African (1%), and

South-East Asia Regions (2%). This undoubtedly relates to an adjacent finding of ours that the vast majority of papers were published in high-income countries (60%). This aligns with a recent study that found the top five countries in number of publications relating to telerehabilitation were all high-income countries (Zheng et al., 2022). The one publication from the African Region (Teriö et al., 2019) described research evaluating a mobile phone-supported (primarily using short message service [SMS]) intervention for post-stroke rehabilitation in urban Uganda. The services included few features, but the authors did include rich information regarding barriers and facilitators unique to that cultural context. There were three publications from the South-East Asia Region (Lakhani et al., 2021; Sahu et al., 2021; Tyagi et al., 2019), which were all situated in India. These three studies again described a limited number of features but included descriptions and discussion regarding the best choice of features to ensure accessibility and feasibility for their intended populations. Overall, a significant portion of the reviewed publications (22%) did not specify or include details regarding intended or relevant geographic regions. This skewed and equivocal global distribution of telerehabilitation research raises concern for effective integration in LMICs. Literature that has examined facilitators and barriers to implementing telerehabilitation, particularly in LMICs, has consistently emphasized the need to better understand the local context and culture of a given geographic region (Binkley et al., 2020; Finch et al., 2012; Rabanifar & Abdi, 2021).

There is a dire need for telerehabilitation research and development in LMICs. Despite the overall growth in evidence and advancements of telerehabilitation, skewed representation of this work in high-income countries further disadvantages LMICs, where the impact of disability and unmet rehabilitation needs are already disproportionately greater. Gaps in rehabilitation care tend to be the widest and most prevalent in LMICs due to poor healthcare infrastructure, scarce resources, and limited transit (Neill et al., 2023). Integrating telerehabilitation in these resource-limited settings may prove most advantageous in narrowing gaps, yet the dearth of development and research in these settings may lead to even more fragile infrastructures. It is crucial that more research be conducted and tested in these contexts to obtain a comprehensive understanding of the successes and challenges of telerehabilitation integration.

Our review further highlights this necessity, as many telerehabilitation features, even those deemed relatively basic and not technically advanced (e.g., audioconferencing, electronically collected patient information), were proposed without consideration for rules, policies, and/or infrastructure of given geographic regions (e.g., privacy and security, data exchange standards, power lines, internet access). For example, one systematic review evaluated studies using SMS and mobile application-based interventions (i.e., m-health) in surgical settings and found them to be efficient and accurate in evaluating postsurgical symptoms (Lu et al., 2018). Moreover, these relatively simple m-health interventions were associated with increased patient adherence, improved clinic attendance, lower readmission rates, and high satisfaction among patients and physicians. While these interventions show potential for improving precision and personalization in healthcare, authors later identified privacy as a notable barrier for successful implementation (e.g., regular SMS cannot be encrypted) given current standards regarding protection of patient health information. To this end, specific contextual considerations are critical for practical application of telerehabilitation and, unfortunately, inadequately addressed in the literature.

One pilot study that emerged in our review was exemplary in providing a comprehensive description of a web-based tool that delivers prescribed exercise plans and education to individuals following stroke (MacKo et al., 2016). Major strengths of this study were that initial field testing of the tool was conducted in the country in which it was intended to be used (i.e., Jamaica) and tested with individuals for which the tool was designed (i.e., adults with recent history of stroke and hemiparetic gait deficits). Equally noteworthy was that the project was led by an institution that conducts research with an international perspective that considers translation in other LMICs (University of the West Indies Solutions for Developing Countries). This context-driven lens allowed for astute considerations in the initial development and pertinent recommendations for continued advancements (e.g., cost-effective model, systems level solutions to enable early referrals). Additionally, testing the tool with users who comprise the targeted rehabilitation population yielded clinically meaningful observations. For example, a subset of users (15%) experienced leg discomfort with selected exercises. This finding helped in refining the assessment process of who may be most appropriate for this telerehabilitation (e.g., functional capacity *and* pain tolerability) and emphasized the importance of regular monitoring and customization among patients. Without first identifying what and where current health systems gaps exist in LMICs and considering patient-specific characteristics, telerehabilitation is unlikely to aid in mitigating those gaps. Our findings urge the need for more context-derived telerehabilitation systems.

Lack of Financial and Sustainability Considerations

Our scoping review revealed very little inclusion of cost-benefit analysis, financial considerations, or long-term sustainability efforts. Matsumoto et al. (2021) noted that reimbursement for telerehabilitation services has traditionally been a barrier to adoption, a sentiment similarly reflected in a survey of Swiss physiotherapists regarding their use of telerehabilitation during the COVID-19 pandemic (Rausch et al., 2021). Saptono et al. (2009) described five required characteristics of a telerehabilitation infrastructure that included openness, extensibility, scalability, cost-effectiveness, and security. Only two articles, however, included explicit discussion of cost-benefit analyses. There were no articles that included prospective discussion of long-term sustainability.

Future Directions

Our review exposed several gaps and deficiencies in the literature on telerehabilitation that precluded clear recommendations for adoption of technology or implementation of existing platforms or systems. However, these findings offer some general directions. First, irrespective of geographical region, little to no papers gave mention to the very real financial constraints that intersect with developing telerehabilitation functionalities. An unstructured, post-hoc review further indicated that very few authors or developers went on to conduct a follow-up analysis of the telerehabilitation feature being implemented in local settings. The lack of meaningful discussion regarding economic costs and how telerehabilitation features might fit into existing health systems suggests that future work should consider return on investment and long-term viability at the outset of developing or presenting telerehabilitation technologies. Second, there is limited empirical evidence on telerehabilitation features and functionalities. Higher quality systematic reviews and clinical trials that focus on the integration of telerehabilitation features into existing health systems are imperative to begin bridging gaps in rehabilitation care, particularly in LMICs. In addition, well-designed mixed-method research could provide insight into how and why certain features provide value and enhance the overall quality of care.

Limitations

This scoping review has several limitations that warrant caution when interpreting findings. First, given the rapidly growing body of literature in this area, the review findings will quickly become dated. Second, our criteria specifically required provision of rehabilitation through telehealth or telemedicine services, and likely excluded features that may be relevant for telerehabilitation if they were introduced within broader domains. Third, telerehabilitation apps and platforms are continuously being updated and some features have likely changed or evolved since our literature search was concluded. Additionally, some papers included in the review were outdated and features may also be outdated and/or impractical in the current landscape. Fourth, the review excluded non-English publications, which may have excluded relevant articles published in other languages, especially those from LMICs. Finally, due to the limited availability of peer-reviewed literature focused on telerehabilitation, article quality was not formally evaluated.

Conclusion

This scoping review provides an overview of telerehabilitation features and functionalities that assist in the delivery of rehabilitation at a distance through telecommunications technology, with a specific interest in technology appropriate in resource-limited settings. Our results indicate that limited empirical evidence exists in this area of research, with the majority of papers existing in the grey literature. An important finding is the limited discussion of comprehensive platforms integrating multiple features and functionalities. Furthermore, despite our efforts to review features and functionalities that can be used in resource-limited settings, few papers conducted their research or development in LMICs. These findings can be used to inform the future development of telerehabilitation systems in LMICs to better meet the needs of the local context. Ideally, future work will focus on developing comprehensive telerehabilitation platforms designed with the context in mind, offering wide-ranging features that adequately map onto the clinical needs involved in successful rehabilitation delivery.

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REFERENCES

American Nurses Association. (2021). *Nursing: Scope and standards of practice* (4th edition.). American Nurses Association.

Anil, K., Freeman, J. A., Buckingham, S., Demain, S., Gunn, H., Jones, R. B., Logan, A., Marsden, J., Playford, D., Sein, K., & Kent, B. (2021). Scope, context and quality of telerehabilitation guidelines for physical disabilities: A scoping review. *BMJ Open*, *11*(8), e049603. https://doi.org/10.1136/bmjopen-2021-049603

Anton, D., Berges, I., Bermúdez, J., Goñi, A., & Illarramendi, A. (2018). A telerehabilitation system for the selection, evaluation and remote management of therapies. *Sensors (Basel)*, *18*(5). https://doi.org/10.3390/s18051459

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology: Theory & Practice*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Bacungan, R. B. E., Choi, K. M. C., Chua, J. P. A., Dupo, J. P., & Estrella, N. E. (2021). Sentinel: The development of a web and mobile application for the development and testing of an e-service learning interprofessional telehealth community based rehabilitation program among hypertensive clients. *2021 International Conference on Software Engineering & Computer Systems and 4th International Conference on Computational Science and Information Management (ICSECS-ICOCSIM)*, 341–347. https://doi.org/10.1109/ICSECS52883.2021.00069

Bernhardt, J., Urimubenshi, G., Gandhi, D. B. C., & Eng, J. J. (2020). Stroke rehabilitation in low-income and middle-income countries: A call to action. *The Lancet*, *396*(10260), 1452–1462. https://doi.org/10.1016/S0140-6736(20)31313-1

Binkley, J., Mark, M., Finley, J., Brazelton, A., & Pink, M. (2020). Meeting the rehabilitation and support needs of patients with breast cancer during COVID-19: Opening new frontiers in models of care. *Rehabilitation Oncology*, *38*(4), 159–168. https://doi.org/10.1097/01.REO.0000000000000237

Caggianese, G., Cuomo, S., Esposito, M., Franceschini, M., Gallo, L., Infarinato, F., Minutolo, A., Piccialli, F., & Romano, P. (2019). Serious games and in-cloud data analytics for the virtualization and personalization of rehabilitation treatments. *IEEE Transactions on Industrial Informatics*, *15*(1), 517–526. https://doi.org/10.1109/TII.2018.2856097

Chamorro-R, C. D., Caicedo-D, G., & García-M, J. I. (2018). Design, development, and implementation of an assistive technology device for shoulder telerehabilitation via the internet. *DYNA (Colombia)*, *85*(206), 95–104. https://doi.org/10.15446/dyna.v85n206.64889

Chiensriwimol, N., H. Chan, J., Mongkolnam, P., & Mekhora, K. (2017). Monitoring frozen shoulder exercises to support clinical decision on treatment process using smartphone. *Procedia Computer Science*, *111*, 129–136. https://doi.org/10.1016/j.procs.2017.06.019

Cieza, A. (2019). Rehabilitation the health strategy of the 21st century, really? *Archives of Physical Medicine and Rehabilitation*, *100*(11), 2212–2214. https://doi.org/10.1016/j.apmr.2019.05.019

Finch, T. L., Mair, F. S., O'Donnell, C., Murray, E., & May, C. R. (2012). From theory to "measurement" in complex interventions: Methodological lessons from the development of an e-health normalisation instrument. *BMC Medical Research Methodology*, *12*(1), 69. https://doi.org/10.1186/1471-2288-12-69

Finkelstein, J., Wood, J., & Shan, Y. (2011). Implementing physical telerehabilitation system for patients with multiple sclerosis. *2011 4th International Conference on Biomedical Engineering and Informatics, BMEI*, *4*, 1883–1886. https://doi.org/10.1109/BMEI.2011.6098758

Giacalone, A., Marin, L., Febbi, M., Franchi, T., & Tovani-Palone, M. R. (2022). eHealth, telehealth, and telemedicine in the management of the COVID-19 pandemic and beyond: Lessons learned and future perspectives. *World Journal of Clinical Cases*, *10*(8), 2363–2368. https://doi.org/10.12998/wjcc.v10.i8.2363

Heinemann, A. W., Feuerstein, M., Frontera, W. R., Gard, S. A., Kaminsky, L. A., Negrini, S., Richards, L. G., & Vallée, C. (2020). Rehabilitation is a global health priority. *Canadian Journal of Occupational Therapy*, *87*(2), 89–90. https://doi.org/10.1177/0008417420907804

Hosseiniravandi, M., Kahlaee, A. H., Karim, H., Ghamkhar, L., & Safdari, R. (2020). Home-based telerehabilitation software systems for remote supervising: A systematic review. *International Journal of Technology Assessment in Health Care*, *36*(2), 113–125. https://doi.org/10.1017/s0266462320000021

Houlihan, B. V., Jette, A., Paasche-Orlow, M., Wierbicky, J., Ducharme, S., Zazula, J., Cuevas, P., Friedman, R. H., & Williams, S. (2011). A telerehabilitation intervention for persons with spinal cord dysfunction. *American Journal of Physical Medicine & Rehabilitation*, *90*(9), 756–764. https://doi.org/10.1097/PHM.0b013e31820b140f

Iemmi, V., Gibson, L., Blanchet, K., Kumar, K. S., Rath, S., Hartley, S., Murthy, G. V., Patel, V., Weber, J., & Kuper, H. (2015). Community-based rehabilitation for people with disabilities in low- and middle-income countries: A systematic review. *Campbell Systematic Reviews*, *11*(1), 1–177. https://doi.org/10.4073/csr.2015.15

Institute for Health Metrics and Evaluation. (n.d.). *WHO Rehabilitation Need Estimator*. Institute for Health Metrics and Evaluation. Retrieved July 10, 2023, from https://vizhub.healthdata.org/rehabilitation/

Jameie, S., Haybar, H., Aslani, A., & Saadat, M. (2019). Development and usability evaluation of web-based telerehabilitation platform for patients after myocardial infarction. *Studies in Health Technology and Informatics*, *261*, 68–74.

Jesus, T. S., Landry, M. D., & Hoenig, H. (2019). Global need for physical rehabilitation: Systematic analysis from the global burden of disease study 2017. *International Journal of Environmental Research and Public Health*, *16*(6), Article 6. https://doi.org/10.3390/ijerph16060980

Khan, F., Owolabi, M., Amatya, B., Hamzat, T. K., Ogunniyi, A., Oshinowo, H., Elmalik, A., & Galea, M. P. (2018). Challenges and barriers for implementation of the World Health Organization Global Disability Action Plan in low- and middle- income countries. *Journal of Rehabilitation Medicine*, *50*(4), Article 4. https://doi.org/10.2340/16501977-2276

Kim, K.-Y., Kim, Y. S., & Schmeler, M. R. (2012). Remote decision support for wheeled mobility and seating devices. *Expert Systems with Applications*, *39*(8), 7345–7354. https://doi.org/10.1016/j.eswa.2012.01.083

Korostelev, M., Gong, N., Hu, A., Bai, L., & Wen, K.-Y. (2014). M2-PASS: SMS-based mobile patient support and responding to challenges of transitional care. *2014 7th International Conference on BioMedical Engineering and Informatics, BMEI*, 762–768. https://doi.org/10.1109/BMEI.2014.7002875

Kringle, E. A., Setiawan, I. M. A., Golias, K., Parmanto, B., & Skidmore, E. R. (2020). Feasibility of an iterative rehabilitation intervention for stroke delivered remotely using mobile health technology. *Disability and Rehabilitation: Assistive Technology*, *15*(8), 908–916. https://doi.org/10.1080/17483107.2019.1629113

Ku, B. P. S., Tse, A. W. S., Pang, B. C. H., Cheung, N. T., Pang, J. Y. W., Chan, J. K. Y., Hui, H. L., Chu, D., & Choi, K. H. W. (2021). Tele-rehabilitation to combat rehabilitation service disruption during COVID-19 in Hong Kong: Observational study. *JMIR Rehabilitation and Assistive Technologies*, *8*(3), e19946. https://doi.org/10.2196/19946

Lakhani, A., Sharma, E., & Khadayat, S. (2021). E-rehabilitation solution for rotator cuff syndrome in covid-19 pandemic era. *Journal of Musculoskeletal Research*, *24*(2). https://doi.org/10.1142/S0218957721500020

Landers, M. R., & Ellis, T. D. (2020). A mobile app specifically designed to facilitate exercise in Parkinson disease: Single-cohort pilot study on feasibility, safety, and signal of efficacy. *JMIR Mhealth Uhealth*, *8*(10), e18985. https://doi.org/10.2196/18985

Lu, K., Marino, N. E., Russell, D., Singareddy, A., Zhang, D., Hardi, A., Kaar, S., & Puri, V. (2018). Use of short message service and smartphone applications in the management of surgical patients: A systematic review. *Telemedicine and E-Health*, *24*(6), 406–414. https://doi.org/10.1089/tmj.2017.0123

MacKo, R. F., Forrester, T., Francis, P., Nelson, G., Hafer-Macko, C., & Roy, A. (2016). Interactive video exercise tele-rehabilitation (IVET) for stroke care in Jamaica. *2016 IEEE Healthcare Innovation Point-Of-Care Technologies Conference (HI-POCT)*, 150–153. https://doi.org/10.1109/HIC.2016.7797719

Mamdouh, M., Awad, A. I., Hamed, H. F. A., & Khalaf, A. A. M. (2020). Outlook on security and privacy in IoHT: Key challenges and future vision. In Hassanien, A. E., Azar, A., Gaber, T., Oliva, D, & Tolba, F. (Eds.), *1st International Conference on Artificial Intelligence and Computer Visions, AICV* (Vol. 1153, pp. 721–730). Springer Science and Business Media Deutschland GmbH. http://dx.doi.org/10.1007/978-3-030-44289-7_67

Marziniak, M., Brichetto, G., Feys, P., Meyding-Lamadé, U., Vernon, K., & Meuth, S. G. (2018). The use of digital and remote communication technologies as a tool for multiple sclerosis management: Narrative review. *JMIR Rehabilitation and Assistive Technologies*, *5*(1), e5. https://doi.org/10.2196/rehab.7805

Matsumoto, M. E., Wilske, G. C., & Tapia, R. (2021). Innovative approaches to delivering telehealth. *Physical Medicine and Rehabilitation Clinics of North America*, *32*(2), 451–465. https://doi.org/10.1016/j.pmr.2020.12.008

Moral-Munoz, J. A. P., Zhang, W. P., Cobo, M. J. P., Herrera-Viedma, E. P., & Kaber, D. B. P. (2021). Smartphone-based systems for physical rehabilitation applications: A systematic review. *Assistive Technology*, *33*(4), 223–236. https://doi.org/10.1080/10400435.2019.1611676

Naicker, A. S., Htwe, O., Tannor, A. Y., Groote, W. D., Yuliawiratman, B. S., & Naicker, M. S. (2019). Facilitators and barriers to the rehabilitation workforce capacity building in low- to middle-income countries. *Physical Medicine and Rehabilitation Clinics*, *30*(4), 867–877. https://doi.org/10.1016/j.pmr.2019.07.009

Neill, R., Shawar, Y. R., Ashraf, L., Das, P., Champagne, S. N., Kautsar, H., ... & Bachani, A. M. (2023). Prioritizing rehabilitation in low-and middle-income country national health systems: A qualitative thematic synthesis and development of a policy framework. *International Journal for Equity in Health, 22*(1), 91. https://doi.org/10.1186/s12939-023-01896-5

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. https://doi.org/10.1136/bmj.n71

Parmanto, B., & Saptono, A. (2009). Telerehabilitation: State-of-the-art from an informatics perspective. *International Journal of Telerehabilitation*, *1*(1), 73–84. https://doi.org/10.5195/ijt.2009.6015

Parmanto, B., Saptono, A., Pramana, G., Pulantara, W., Schein, R. M., Schmeler, M. R., McCue, M. P., & Brienza, D. M. (2010). VISYTER: Versatile and Integrated System for Telerehabilitation. *Telemedicine and E-Health*, *16*(9), 939–944. https://doi.org/10.1089/tmj.2010.0033

Perez-Medina, J. L., Jimenes-Vargas, K. B., Leconte, L., Villarreal, S., Rybarczyk, Y., & Vanderdonckt, J. (2019). EPHoRt: Towards a reference architecture for tele-rehabilitation systems. *IEEE Access*, *7*, 97159–97176. https://doi.org/10.1109/ACCESS.2019.2927461

Rabanifar, N., & Abdi, K. (2021). Barriers and challenges of implementing telerehabilitation: A systematic review. *Iranian Rehabilitation Journal*, *19*(2), 121–128. https://doi.org/10.32598/irj.19.2.1404.1

Rausch, A. K., Baur, H., Reicherzer, L., Wirz, M., Keller, F., Opsommer, E., Schoeb, V., Vercelli, S., & Barbero, M. (2021). Physiotherapists' use and perceptions of digital remote physiotherapy during COVID-19 lockdown in Switzerland: An online cross-sectional survey. *Archives of Physiotherapy*, *11*(1), 18. https://doi.org/10.1186/s40945-021-00112-3

Rawstorn, J. C., Gant, N., Meads, A., Warren, I., & Maddison, R. (2016). Remotely delivered exercise-based cardiac rehabilitation: Design and content development of a novel mHealth platform. *JMIR Mhealth Uhealth*, *4*(2), e57. https://doi.org/10.2196/mhealth.5501

Rosso, G., Frisiello, A., Trizio, M., Mosso, C. O., & Bazzani, M. (2018). Learning from professionals: Exploring cognitive rehabilitation strategies for the definition of the functional requirements of a telerehabilitation platform. *Computers in Biology and Medicine*, *95*, 288–297. https://doi.org/10.1016/j.compbiomed.2017.08.009

Rothgangel, A., Braun, S., Smeets, R., & Beurskens, A. (2017). Design and development of a telerehabilitation platform for patients with phantom limb pain: A user-centered approach. *JMIR Rehabilitation and Assistive Technologies*, *4*(1), e6761. https://doi.org/10.2196/rehab.6761

Ruiz-Ruano, J. A., Perry, J. C., Rodríguez-de-Pablo, C., & Keller, T. (2013). TeleREHA: Online/offline web platform for telerehabilitation of post-stroke arm impairment. *Biosystems and Biorobotics*, *1*, 991–995. https://doi.org/10.1007/978-3-642-34546-3_162

Russell, T. G. (2007). Physical rehabilitation using telemedicine. *Journal of Telemedicine and Telecare*, *13*(5), 217–220. https://doi.org/10.1258/135763307781458886

Sahu, D., Rathod, V., Phadnis, A., & Bansal, S. S. (2021). Telehealth for consultation and shoulder rehabilitation: A preliminary study on the perspectives of 30 patients during the COVID-19 lockdown. *Clinics in Shoulder and Elbow*, *24*(3), 156–165. https://doi.org/10.5397/cise.2021.00248

Saptono, A., Schein, R. M., Parmanto, B., & Fairman, A. (2009). Methodology for analyzing and developing information management infrastructure to support telerehabilitation. *International Journal of Telerehabilitation*, *1*(1), 39–46. https://doi.org/10.5195/ijt.2009.6012

Solana, J., Cáceres, C., García-Molina, A., Opisso, E., Roig, T., Tormos, J. M., & Gómez, E. J. (2015). Improving brain injury cognitive rehabilitation by personalized telerehabilitation services: Guttmann Neuropersonal Trainer. *IEEE Journal of Biomedical and Health Informatics*, *19*(1), 124–131. https://doi.org/10.1109/jbhi.2014.2354537

Teriö, M., Eriksson, G., Kamwesiga, J. T., & Guidetti, S. (2019). What's in it for me? A process evaluation of the implementation of a mobile phone-supported intervention after stroke in Uganda. *BMC Public Health*, *19*(1), 562. https://doi.org/10.1186/s12889-019-6849-3

Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., … Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of Internal Medicine*, *169*(7), 467–473. https://doi.org/10.7326/M18-0850

Tsavourelou, A., Stylianides, N., Papadopoulos, A., Dikaiakos, M. D., Nanas, S., Kyprianoy, T., & Tokmakidis, S. P. (2016). Telerehabilitation solution conceptual paper for community-based exercise rehabilitation of patients discharged after critical illness. *International Journal of Telerehabilitation*, *8*(2), 61–70. https://doi.org/10.5195/ijt.2016.6205

Tyagi, N., Amar Goel, S., & Alexander, M. (2019). Improving quality of life after spinal cord injury in India with telehealth. *Spinal Cord Series and Cases*, *5*, 70. https://doi.org/10.1038/s41394-019-0212-x

Uscher-Pines, L., Thompson, J., Taylor, P., Dean, K., Yuan, T., Tong, I., & Mehrotra, A. (2020). Where virtual care was already a reality: Experiences of a nationwide telehealth service provider during the COVID-19 pandemic. *Journal of Medical Internet Research*, *22*(12), e22727. https://doi.org/10.2196/22727

Winters, J. M. (2002). Telerehabilitation research: Emerging opportunities. *Annual Review of Biomedical Engineering*, *4*(1), 287–320. https://doi.org/10.1146/annurev.bioeng.4.112801.121923

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. World Health Organization. https://apps.who.int/iris/handle/10665/42407

World Health Organization. (2023, January 30). *Rehabilitation*. https://www.who.int/news-room/fact-sheets/detail/rehabilitation

Yue, W., Song, X., Tao, L., Li, W., & Fang, Q. (2013). Information management system of remote rehabilitation for stroke patients. *2013 1st International Conference on Orange Technologies (ICOT)*, 27–30. https://doi.org/10.1109/ICOT.2013.6521149

Zheng, J., Hou, M., Liu, L., & Wang, X. (2022). Knowledge structure and emerging trends of telerehabilitation in recent 20 Years: A bibliometric analysis via CiteSpace. *Frontiers in Public Health*, *10*, 904855. https://doi.org/10.3389/fpubh.2022.904855

Zyliski, M., Niewiadomski, W., Waclawek, A., Budzyska, A., Gsiorowska, A., Stpniewska, A., Becmer, A., Jagielski, M., & Cybulski, G. (2020). “Patient Station” telerehabilitation system for people with Parkinsons disease. *15th Mediterranean Conference on Medical and Biological Engineering and Computing, MEDICON*, *76*, 965–970. https://doi.org/10.1007/978-3-030-31635-8_117

Co-Design of Collaboration Monitoring Apps for Teachers to support Children with Autism in Religious Education

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ABSTRACT

Purpose: *This study proposes a collaborative model involving teachers and children, to enhance the religious learning progress of students with Autism Spectrum Disorder (ASD) in educational settings. The primary objective is to design a mobile-based assistive technology application, MyQuranic, tailored to monitor and support the learning journey of these children.*

Method: *Qualitative methods were employed to identify the needs and requirements in developing the MyQuranic application. Interviews and focus group discussions were conducted with UI designers, subject matter experts, and mobile app specialists. Thematic analysis was applied to interpret the data, resulting in the emergence of findings based on key themes. To ensure the active involvement of end-users, including individuals with autism, co-design principles were incorporated in the design process. This collaborative approach aimed to create a user-friendly, contextually relevant, and effective technology solution, emphasising the unique perspectives and needs of individuals with ASD.*

Results: *The findings are expected to contribute valuable insights to the broader community, particularly researchers focused on autism-related studies. The design principles have potential for teachers to monitor the learning engagement and interest of children with autism in religious studies using the MyQuranic application*

Conclusion: *This study underscores the significant role of assistive technology in the education of children with autism, specifically within the religious education context. By employing co-design principles, the MyQuranic application strives to enhance social interaction skills, address individual needs, and contribute to the overall advancement of educational support for individuals with ASD.*

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Key words: *mobile application, religious teachings, Autism Spectrum Disorder (ASD), co-design, assistive technology*

INTRODUCTION

In the realm of Islamic religious education, catering to the needs of children with autism spectrum disorder (ASD) poses unique challenges. These children, who are characterised by diverse developmental patterns, require tailored approaches to ensure a meaningful understanding of Islamic teachings. There is a lack of public awareness about the importance of imparting Ibadah and Quranic education to children with autism, even though Muslim students, including those with special needs, are obligated to receive Islamic education (Ahmad et al, 2019). The misconception that these children are exempt from religious obligations persists, and teachers often struggle to find suitable methods for teaching the Qur'an to them.

Recognising the difficulties in delivering Islamic education to children with autism, particularly due to their challenges with abstract thinking, this study addresses the gap by proposing a collaborative monitoring tool. This tool aims to bridge the communication and learning gap between teachers and children with autism in the context of religious education by leveraging assistive technology, such as mobile applications, which have been proven effective for children with autism (Jamal et al, 2017). As such, the provision and procurement of assistive technologies must be prioritised in order to continuously promote social inclusion and inclusive education in higher education institutions (Duma & Lydia, 2023). By developing a mobile application designed to monitor the religious learning progress of these children at school, the study seeks to enhance the effectiveness of interventions and ensure positive outcomes in educational settings. The collaborative model, which emphasises a co-design approach, integrates assistive technology to facilitate a more inclusive and tailored learning experience for children with autism in Islamic religious education.

Related Work

Social interaction is a significant challenge for children with ASD, as they often face difficulties engaging with their peers (Rogers at al, 2021). Advances in technology, particularly in the realm of co-design, offer innovative solutions to address these challenges. Co-design involves the active participation of end-users, including individuals with autism, in the design process, ensuring that the technology is tailored to their specific needs. In addition, Abdullah et al (2018) stated that it is important that technology supported approaches are developed in a collaborative process involving participation of children with ASD, along with the parents and teachers who teach and support them, because they are experts in their own lives and in the education domain respectively.

In the context of ASD, co-design technology aims to enhance social interaction skills by incorporating the unique perspectives and needs of individuals with autism. Co-design relies on partnership, with participants bringing essential knowledge of their own context and culture and designers bringing technical and design facilitation skills (Brereton et al, 2015). Several studies have demonstrated the positive impact of co-design technology on children with ASD. For example, higher engagement levels among children with ASD are a result of co-designed interventions that employ the personalised and interactive nature of this technology (Smith et al, 2018). Technology designed in collaboration with individuals with autism has been shown to improve social communication skills, fostering better interactions with peers and caregivers (Jones et al, 2020). In a similar vein, co-design allows for the customisation of interventions based on the specific needs and preferences of each child, increasing the effectiveness of the technology (Williams & Johnson, 2019).

Rosenbloom et al (2019) developed an application to monitor the learning progress of children with autism called I-Connect. It is a self-monitoring application that enables customisable prompts, recording, and data monitoring. The results indicate that each introduction of I-Connect caused an immediate increase in on-task behaviour as well as a decrease in disruptive behaviours. The implications for practice and future research were also discussed in the study. In addition, Abdullah et al (2015) developed MyCalendar, a visual calendar app intended to aid children with autism in communicating about their activities and interests at home and school. MyCalendar supported children with autism and limited verbal skills to communicate their daily activities through photos and videos, and it enabled teachers to model positive behaviours and create more relevant learning opportunities based on the children’s lives. Additionally, the app led to novel scaffolding of learning opportunities and modelling of communication in the classroom, surpassing the initial expectation of improving communication between teachers and parents.

In a similar vein, Schuck et al (2022) developed an application to support classroom behaviour management. The application is called iSelfControl, which functions to prompt students every 30 minutes to self-evaluate using a universal token-economy classroom management system focused on compliance, productivity, and positive relationships. Simultaneously, the teacher evaluates each student separately on the iPad. The researcher concludes that iSelfControl provides a platform for self and teacher evaluation, which is an important adjunct to conventional classroom management strategies. The application captures teacher/student discrepancies and significant variations throughout the day.

The principles of user-centred design (UCD) are critical in developing mobile applications that resonate with religious users. Research by Johnson et al (2021) emphasises the importance of involving the religious community in the design process. This collaborative approach ensures that the application meets the unique needs, preferences, and cultural nuances of the target religious audience. A successful mobile application design requires an understanding of the diversity within religious communities (Rahman et al, 2020). Al-Mouhamed and Al-Muhtadi (2016) stated the significance of content personalisation to accommodate various religious practices, rituals, and interpretations. Tailoring content to users with diverse religious backgrounds ensures inclusivity and fosters a sense of belonging (Johnson et al, 2017).

Technological considerations in the design of religious mobile applications include the integration of features that enhance the spiritual experience. Research by Gupta et al (2019) suggests incorporating features such as prayer time reminders, scripture readings, and virtual community engagement. Khan (2018) reported that it is crucial to ensure accessibility and inclusivity in religious mobile applications in order to reach a broad user base. Haque et al (2021) highlight the importance of designing applications that are accessible to users with varying levels of technological literacy and physical abilities. User satisfaction and engagement ultimately determine the success of a religious mobile application. Evaluation studies, such as that of Jamal et al (2021), emphasise the value of continuous assessment through user feedback, surveys, and analytics. Iterative improvements based on user input contribute to a more meaningful and effective application. Additionally, a holistic approach that integrates user-centred design, cultural sensitivity, technological innovation, accessibility, and privacy considerations is necessary in designing mobile applications for religious contexts.

Prototyping, which plays a pivotal role in the iterative design process, aids designers in visualising and refining their concepts. Two common categories of prototypes are low-fidelity and high-fidelity, each serving distinct purposes in the design workflow. Low-fidelity prototypes are characterised by simplicity, minimal detail, and a focus on basic functionality (Snyder, 2003). Paper sketches, wireframes, or digital tools that prioritise speed and ease of modification are often used to create these prototypes. A key advantage is rapid iteration, which facilitates quick adjustments and efficient exploration of various ideas (Rubin & Chisnell, 2008). Conversely, high-fidelity prototypes are more detailed and closely resemble the final product in terms of visual design and functionality (Snyder, 2003). They often involve interactive elements and realistic content and may be developed using specialised prototyping tools. A more accurate evaluation of user interactions is made possible by high-fidelity prototypes, which provide a more realistic representation of the final product (Rubin & Chisnell, 2008). They are valuable for conducting usability tests that closely simulate the actual user experience and are effective in conveying the final vision of the product to stakeholders (Ahmed et al, 2018). Both low-fidelity and high-fidelity prototypes have different roles in the user-centred design process.

MyQuranic Application

This study is positioned within the broader landscape of inclusive education for children with Autism Spectrum Disorder (ASD), focusing on the development of MyQuranic — a mobile application designed to support the religious learning progress of these unique learners based on the Religious Mobile Apps Guidelines by Zamry et al (2022). Acknowledging the distinctive needs and challenges faced by children with ASD in the context of Islamic religious education, this study underscores the imperative to adopt a User-Centred Design (UCD) approach in crafting an application that is not only technologically effective but also aligned with the nuanced requirements of its end-users.

This study identifies guidelines crucial for the development of MyQuranic, as informed by a comprehensive literature review. Leveraging the principles of User-Centred Design, a low-fidelity prototype is meticulously crafted based on the identified guidelines. However, the success of any educational tool hinges not only on technological soundness but also on its resonance with the intended users, in this case, teachers and children in specialised educational settings.

Moreover, this study actively involves teachers and children with autism in the design process by engaging in interviews and focus group discussions at Pondoku and Malaysia High Functioning Autism Association (MAHFAA) to ensure a holistic understanding of the needs and requirements for MyQuranic. Co-design principles come to the forefront as the research emphasises the importance of understanding the technological guidelines as well as appreciating the lived experiences, challenges, and preferences of those who will interact with the application on a daily basis. The combination of UCD and co-design enables this study to achieve its aim of bridging the gap between technological functionality and user expectations, fostering a collaborative and inclusive approach to the development of MyQuranic.

Eliciting requirement phase for MyQuranic

A comprehensive review of previous literature on mobile application guidelines for autism and religious mobile application guidelines was conducted. The comprehensive literature review method was used in this study to identify, evaluate, and summarise the related guidelines from previous literature. The seven steps suggested by Onwuegbuzie and Frels (2016) for a comprehensive literature review are followed in this study. These steps include exploring beliefs and topics, initiating the search, storing and organising information, selecting and deselecting information, expanding the search, and analysing and synthesising information and communication. A meta-analysis was conducted to take the findings from several studies on the same subject and analyse them using standardised statistical procedures. Patterns and relationships are detected, and conclusions are drawn using meta-analysis, which is associated with the deductive research approach.

The study aimed to gather information on mobile application guidelines for children with autism through specific search techniques. Two main categories were considered: guidelines for mobile applications for children with autism and guidelines for religious mobile applications. The search for the first category yielded 12,900 publications using keywords such as “mobile apps,” “guidelines,” and “autism spectrum disorder.” The number decreased to 8,600 after filtering was done for articles published in the last five years, with only 35 that were relevant based on the guideline criteria. Relevance was determined by the connection to mobile application guidelines for children with autism. Following that, 20% of the relevant papers were further analysed, leading to the proposal of a guideline for developing mobile applications for children with autism.

The second category of the search focused on religious mobile applications, incorporating terms like "religious" and "Islamic" in addition to "mobile apps" and "guidelines." A total of 32,200 publications were initially identified, and the number decreased to 16,800 due to the filtering results for publications in the last five years. Among these, 26 publications were analysed in the first cycle based on their relevance to religious mobile application guidelines for children with autism. Following a detailed analysis of guideline criteria, only 19% of the publications were further examined within the study domain. The study revealed two key findings: 1) multimedia elements encompassing text, images, and sounds; and 2) application features including interface, navigation, customisation, and interaction, as highlighted by Zamry et al (2022). The next section will elaborate on these findings, focusing on guidelines for mobile applications in religious contexts. The findings obtained from the comprehensive literature review are shown in Table 1.

Table 1: Religious Mobile Application guidelines for Children with Autism

Multimedia Elements	Guidelines	Features of application	Guidelines
Text	1. The text used must be clear, simple, and short. 2. Use only a maximum of two typefaces. 3. The use of text coincides with the original source.	Interface	1. The design and structure must be simple, clear, and predictable. 2. Avoid cluttered interfaces. 3. The application should be based on the elements that best symbolise Islam, which are widely recognised by the Islamic community. 4. The application should use features that present the Islamic identity.
Images	4. Provide suitable images. 5. Use images that are identical to real life. 6. Use well-mannered clothes for any character, figure, or real person. 7. The image used in the application should be relevant to the content; do not display images that are not related to Islamic elements.	Navigation	5. Applications should have simple navigation and be easy to use. 6. Navigation in the application should be consistent. 7. Use standard navigation icons that are familiar to ASD.

Sounds	8. Use clear, comprehensible, short audio expressions. 9. Avoid using disturbing and explosive sounds. 10. Use familiar sounds and voices. 11. Use audio commonly used in Islam.	Customisation	8. Allow customisation. 9. The application should have relevant customisation according to the user's preferences for the Islamic features of the application.
		Interaction	10. Avoid simultaneous tasks at one time. 11. Avoid distractions and interruptions in the application. 12. The speed of the application interaction must be consistent without any delay.

MyQuranic design interface

Based on the guidelines proposed by Zamry et al (2022), this application was designed and developed for teachers as a proxy to record the daily activities of children with autism in religious lessons. Teachers will use the mobile application to record the routines and activities of the children in school. However, there are some students who have the ability to use this application. According to the founder of this centre, students who are able to use this application will record their own daily activities or those of their friends. Students will also tend to follow and repeat the activities they have done based on the videos they watch on their smartphones. There are four main sections for this application: the homepage, the student's profile, the student's visual calendar, and the student's learning progress. An explanation of the details for each section follows.

Homepage

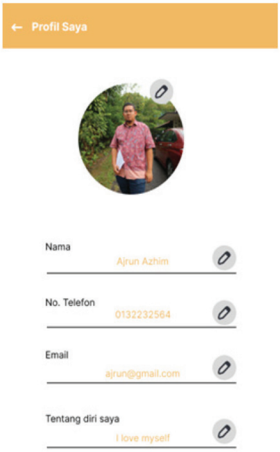
The homepage of the application features a simple and user-friendly design that adheres to the guidelines established in the literature review. The main theme is pastel colours, and students have the option to customise colours according to their preferences. In addition, customisation options for audio volume and font size are provided to accommodate children with autism. Standard navigation buttons are employed to prevent confusion and maintain focus. Recognising the importance of customisation for children with autism, the application allows individual adjustments to cater to each user's specific needs and preferences, promoting a comfortable and personalised user experience, as advocated by Lyu et al (2021) and Dattolo et al (2017). Figure 1 shows the homepage design.

Figure 1: MyQuranic Homepage

Student’s Profile

In this section, students, assisted by teachers, are required to input their personal information for effective tracking of progress. The comprehensive details, which include name, identification, age, and gender, enable teachers to identify and understand each child’s unique capabilities. An appropriate and personalised learning style that aligns with the individual needs of the students can be created based on this information, facilitating a more effective and supportive educational experience, as shown in Figure 2.

Figure 2: Student’s Profile in MyQuranic



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Tentang diri saya: I love myself

Student's Visual Calendar

The calendar feature displays the daily activities of students, organised by each day of the month. It serves as a convenient tool for teachers to use in documenting their students' religious activities at school. Teachers can record the students' learning progress through videos or photos, and easily monitor their daily activities by playing uploaded videos directly from the calendar. This streamlined process enhances the efficiency of teachers in monitoring and assessing students' learning progress more conveniently and quickly. Figure 3 shows the design of the visual calendar.

Figure 3: Student's Visual Calendar in MyQuranic

← Senarai Aktiviti

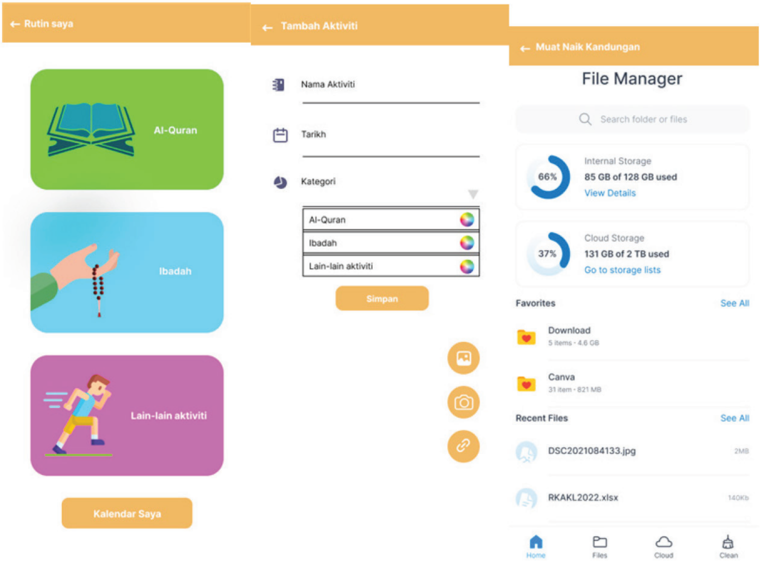
◀ September 2023 ▶

S	M	T	W	T	F	S
29	30	1 2 2 ⊕	2	3	4	5
6	7	8	9	10 1 3 ⊕	11	12
13	14 1 ⊕	15 2 ⊕	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31	1	2

Activity Update

In this section, both teachers and children can upload their daily progress. It enables video recording and picture-taking directly within the application, as well as the uploading of pre-recorded videos. The purpose is to facilitate the organised storage of images and videos of the students' activities based on the designated days and times set in the calendar. This feature simplifies the process for teachers and students to seamlessly document and archive their daily progress, as shown in Figure 4.

Figure 4: Student's Progress Update Features



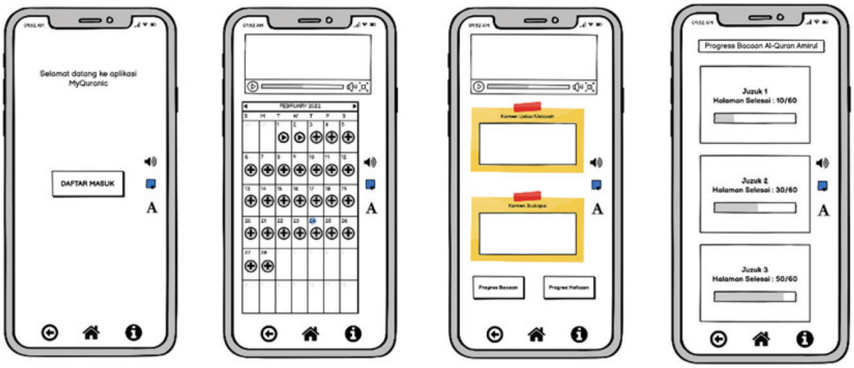
METHOD

Co-design is an ethical and pragmatic approach that involves designers engaging with those who will use or be affected by their designs from the outset in order to prioritise their agency and quality of experience (Brereton et al, 2015). Designers bring their creative and technical skills to the table, while experts contribute valuable domain-specific knowledge about the unique needs and preferences of individuals with autism. This study creates collaboration between designers and experts, resulting in several prototypes to be tested and validated before the actual application is developed. The guidelines obtained in the eliciting requirements phase led to the creation of a low-fidelity prototype. The validation process of the low-fidelity prototype came next, which was done with four user interface designers. The second version of the low-fidelity prototype was created after receiving feedback from UI designers and validated by a subject matter expert in a two-hour interview session. Then, a high-fidelity prototype was designed from the data obtained in the previous phase and validated by five subject matter experts from Pondoku and eight mobile experts. A subject matter expert from Pondoku and three special education experts from MAHFAA validated the final version of the high-fidelity prototype, which was designed from the data obtained in the previous phase. The details of each section are elaborated on in the section below.

Low-fidelity Prototype

A low-fidelity prototype was created as a result of a thorough literature review and interview sessions. The research indicates that children with autism express a preference for a straightforward and user-friendly design. Lyu et al (2021) emphasise the importance of simplicity, clarity, and predictability in design, a sentiment echoed by Dattolo et al (2017), who advocate for applications with minimal on-screen elements. Aligning with these principles, a preliminary design interface for the application was developed to present only the essential features and content required for the current user task, ensuring a simple and focused user experience. Figure 5 shows the design of the low-fidelity prototype.

Figure 5: Low-fidelity Prototype of MyQuranic



Low-fidelity Prototype Validation

The researcher conducted and moderated a one-hour focus group discussion with four experienced designers from the research team who specialise in the field of special needs. The primary focus of the discussion was on improving the prototype. The aim of this collaborative session was to ensure adherence to established guidelines and the fulfilment of user needs. The UI designer team provided valuable feedback and comments, addressing elements like multimedia usage and application features. The recorded and transcribed feedback was analysed as part of the data collection process, which helped refine the prototype to better align with user requirements. The analysed data is presented in Table 2.

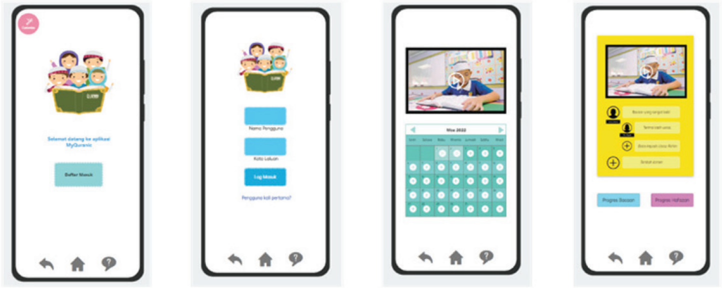
Table 2: Feedback from UI Designers on Low-fidelity Prototype

UI Designer 1	UI Designer 2	UI Designer 3	UI Designer 4
1. Avoid using capital letters in apps. 2. Need to create a section to measure the IEP goals. 3. Need to link the IEP goals section to daily activities videos. 4. Don't make it colour blind. Use colour for prototype for user to experience the colour suitability used for this application. 5. Need to add one function to identify whether the students like or dislike the apps. 6. Need to add additional parts (rating for children's learning progress).	1. Make sure the icon is visible instead of making it a hideout icon. 2. Please label each video to make it easier to trace students' progress. 3. Need to enable multiple videos upload per day. 4. No need to separate the calendar by section. One calendar can record all sections.	1. Reduce in-app usage steps. Create a button for students' direct access to the visual calendar. No need to select by year and month.	1. Use date picker for calendar instead of drop-down menu. 2. Add a rating section in apps. 3. Reduce redundant pages to make apps simpler and easier to use.

Second version of Low-fidelity Prototype

A second version of the low-fidelity prototype was developed following feedback validation from the UI designers on the initial prototype. This enhanced prototype focuses on improvements, particularly in the utilisation of multimedia elements and application features. Figure 6 depicts the design of the second prototype.

Figure 6: Second Version of the Low-fidelity Prototype of MyQuranic



Second version of Low-fidelity Prototype Validation

The validation process for the prototype involved a religious expert who is the founder of Pondoku and has extensive expertise in Islamic studies for children with autism. The application's adherence to guidelines was the main focus of the validation, and it featured a prototype for the expert to assess its suitability for fulfilling the needs of children with autism. During the session, the expert used the prototype and provided feedback, which was recorded. The received feedback will be utilised to enhance the actual application development. Table 3 depicts the expert's comments that align with the guidelines and contribute valuable insights for improvement.

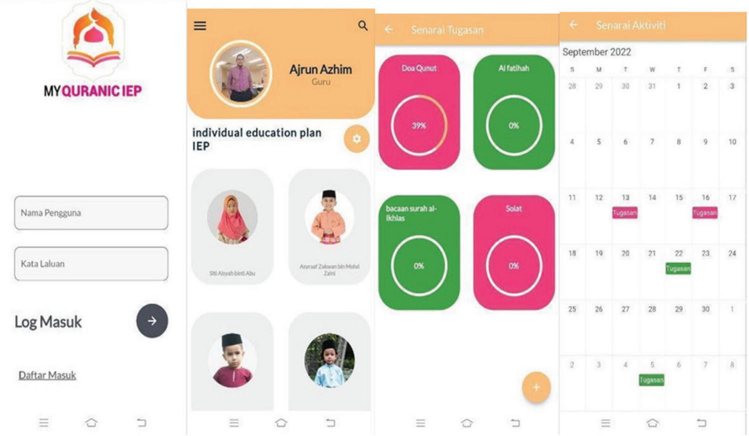
Table 3: Feedback from Religious Expert

Proposed Guidelines	Religious Expert's Feedback
Design and structure should be simple, clear, and predictable. Avoid interaction timeouts. Use familiar sounds and voices. Use audio commonly used in Islam. Allow customisation. The application should be based on the elements that best symbolise Islam, which are widely recognised by the Islamic community. The application should use features that present the Islamic identity. The application should allow relevant customisation according to the user's preferences for the Islamic features of the application.	Just a one-time log in. No need to login and logout many times. One user (parents/teachers) can register many kids. Use a familiar voice to be heard (voice of ustaz/ustazah or voice from YouTube). Need to provide options for ASD to change the theme colour. Make memorisation not focused on the Quran only; can add prayer recitation, Zikr recitation, etc. Al-Quran student progress if done by pages is too high and difficult. Try to make it customised (e.g., by line or by verse).

High-fidelity Prototype

A high-fidelity prototype was developed after two low-fidelity prototype versions were created. This iteration features increased interactivity compared to its predecessors, incorporating navigation buttons, icons, and text to enhance the user experience with the MyQuranic application. Figure 7 displays elements of the interface from the first version of the high-fidelity prototype.

Figure 7: High-fidelity Prototype of MyQuranic



High-fidelity Prototype Validation

This study conducted a focus group discussion with subject matter experts in Islamic studies, particularly teachers from Pondoku, to gather feedback on the prototype design. The participating experts, who have significant experience in instructing children with autism in religious contexts, provided valuable insights and recommendations during the discussion. The subsequent section outlines the opinions and recommendations expressed by these experts in the focus group session, as shown in Table 4.

Table 4: Feedback from Subject Matter Experts

Experts	Apps Setting	Interface
Religious Expert 1	1. I suggest adding another role which is the management of Pondoku. This makes it easier for management to monitor any issues/complaints from parents or if there are other problems that arise.	1. Tiles for the student list do not need to be too big. Makes it difficult for the user to scroll down to see the full list.

	2. I also suggest that there be a function to add a second teacher for each student. This is important as a backup if the teacher on duty is not available to teach students at that time.	2. It needs to be more dynamic in the category part. Doa dan solat can be placed under one category (Ibadah). Use the "+" button to add tasks instead of "other". 3. Change the word "add" to "update". Users may be confused between the "add tasks" and "add activities" sections. 4. Fix the order of tasks in the calendar. Customise the arrangement of tiles with many tasks. It is recommended to add the button "add" or "more" if the tiles are too full.
Religious Expert 2	1. If you can add a platform for the web, even better. This can address the problem of differences in the use of applications for Android and Apple. 2. Storage is likely to hang/lagging when there are too many videos/ pictures. Make sure these apps are able to accommodate a large database.	1. Avoid using pink. Most male students do not want to touch/interact with items that are pink in colour.
Religious Expert 3	1. Need to add a notification system to notify parents if there is a new assignment from the teacher. 2. Addition of categories for students, such as daily students, one-off students and so on will help management to easily organise the students.	1. Most male students will avoid the colour pink. It is possible that this colour looks quite feminine to them. 2. Students' pictures need to use the same style and background in order to look uniform. 3. Create a reward system after students complete a task. 4. Add a function like rating system to evaluate student activities in the task section.
Religious Expert 4	1. Need to ensure that the app has a user-friendly interface with intuitive navigation. Users should easily find key features such as prayers, religious texts, community forums, and events without confusion.	1. There are some students who have a problem when they see the colour pink, but there are also students who don't have a problem with it. 2. Students like to see their pictures the same as other friends. For example, if someone wears a vest during a picture, other students want to wear it too.

Religious Expert 5	1. Maintain a consistent design and layout throughout the app to create a cohesive user experience. Consistency helps users feel more comfortable and confident as they navigate different sections of the app.	1. If given a choice of colours when they do class activities, pink is the least favourite choice for them. It's good if you use other colours rather than pink. 2. We at Pondoku practice uniformity for autistic children. Students will feel more comfortable when they wear the same clothes among themselves.

Furthermore, a focus group discussion was conducted, involving mobile application experts, who are well-versed in areas such as mobile applications, human-computer interaction, user-interface design, and user experience. These experts, some with research experience in developing applications for children with autism and Islamic studies, provided valuable perspectives on the guidelines utilised in the prototype development. The feedback gathered from this focus group discussion, as summarised in Table 5, offers insights into the expert opinions and recommendations regarding the prototype development guidelines.

Table 5: Feedback from Focus Group Discussion with Mobile Application Experts

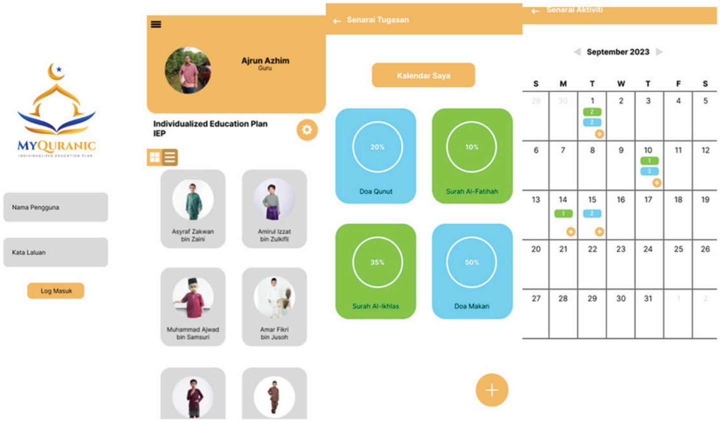
Expert	Quotes
Mobile Apps Expert 1	Children with autism feel comfortable with familiar sounds.
Mobile Apps Expert 1 and Religious Mobile Expert 1	Children with autism are more inclined towards visual communication.
Mobile Apps Expert 1	Children with autism are more likely to use mobile applications due to their comfort with touch screen-based interfaces.
Religious Mobile Expert 1	The activities of children with autism are influenced by the teachers at the centre.
User-interface Expert 1 and Human-computer interaction Expert 1	Technology supports the development of children with autism in the presence of a technology-friendly environment.
All Experts	Parents and teachers play roles in monitoring and supporting the learning progress of children with autism.
Mobile Apps Expert 1, User-interface Expert 1, Human-computer interaction Expert 1 and Human-computer interaction Expert 2	Must treat autism according to the cognitive level based on their respective autism category.
Mobile Apps Expert 2	Communication for children with autism should be personalised.

Religious Mobile Expert 1	Teachers, therapists, and doctors are involved in development/growth at different times and in different capacities.
User-interface Expert 1 and Religious Mobile Expert 2	Technology can support traditional formal communication between parents and teachers.
All Experts	There is a need for a technology-based support system alongside traditional teaching.
Mobile Apps Expert 1, User-interface Expert 1, Human-computer interaction Expert 1 and Human-computer interaction Expert 2	Technology can provide better support for formal communication and learning
User-interface Expert 1, Human-computer interaction Expert 1 and Human-computer interaction Expert 2	Monitoring and guidance are required for the use of technology by children with autism.
Mobile Apps Expert 1, Mobile Apps Expert 2 and User-interface Expert 2	Everyone has a role in ensuring children with autism's learning progress.

Second version of High-fidelity Prototype

Some improvements were made to the first version of this prototype as a result of the feedback obtained from subject matter experts and mobile application experts. Figure 8 shows the latest design for the second version of the high-fidelity prototype.

Figure 8: Second version of High-fidelity Prototype of MyQuranic



Second version of High-fidelity Prototype Validation

Interview sessions were conducted with subject matter experts from two different autism centres; these involved three experts from MAHFAA and an expert from Pondoku. Table 6 shows the feedback received from the sessions.

Table 6: Feedback from Subject Matter Experts

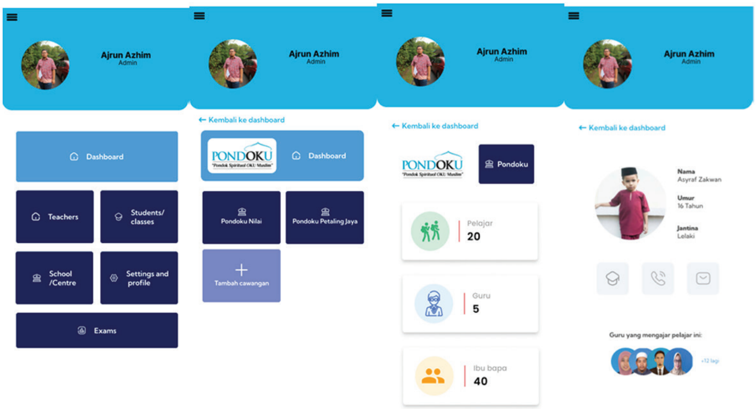
Experts	Apps Setting
Special education Expert 1	1. Can combine buttons to upload images and videos. No need for many buttons. 2. Students have no problem if there is no uniformity between them. It is not something that is mandatory to make them uniform. 3. Add special pages/dashboard for admin.
Special education Expert 2	1. There really needs to be customisation for each child because they have different preferences. 2. Students need special attention from teachers to make them more focused in learning.
Special education Expert 3	1. Add a smiley Likert scale. 2. The colours used for this application are very suitable for students.
Religious Expert 4	1. I suggest it would be good if these apps can also create a reward system to make these children have fun while using this app. 2. Customise colour on student assignments according to their preferences. 3. Each centre can set its own routine for autistic children 4. Separate the admin dashboard by centre. 5. Suggested to create a student routine list (on/off button) instead of ustaz/ustazah having to fill in the routine themselves every day. 6. For Al-Quran assignments made by individuals. 7. For worship assignments made by groups.

Final version of High-fidelity Prototype

The final version of the MyQuranic prototype was produced after it went through several validation processes from designers, subject matter experts, and mobile experts. Figures 9 and 10 show the final design for this prototype.

Figure 9: Final version of High-fidelity Prototype of MyQuranic (Teacher's dashboard)

Figure 10: Final version of High-fidelity Prototype of MyQuranic (Admin's dashboard)



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Data Collection and Analysis

Stakeholders need to be involved in the design process during co-design. In this study, interviews and focus group discussions were conducted with the stakeholders to validate the guidelines that were proposed to be used in the application. The stakeholders involved subject matter experts and mobile application experts. The subject matter experts were from two autism centres, namely Pondoku and MAHFAA. Five teachers from Pondoku and three teachers from MAHFAA were appointed as the subject matter experts for the study. A few series of interviews and focus group discussions were conducted at each centre, with every session lasting approximately two hours. In addition, eight mobile application experts were appointed for this study. All of the experts have extensive experience in the fields of mobile applications, human-computer interaction, user interface design, and Islamic studies. One out of three focus group discussion sessions was conducted for two hours. The data collected from the focus group discussion sessions and interviews was further analysed using thematic analysis.

Thematic analysis was chosen to identify patterns that exist in quotes collected from experts, designers, and teachers. Several themes emerged from the patterns that were successfully identified, providing initial themes that will be used to develop this study application. Thematic analysis unfolds in a structured cycle that commences with data immersion, where a thorough understanding of the content is established through repeated readings. Subsequently, initial codes are generated systematically, encapsulating pivotal concepts within the data. These codes then undergo a process of thematic grouping to form potential themes. Following that, rigorous review and refinement are carried out to ensure the internal coherence and distinctiveness of each theme. A coherent narrative is constructed when the refined themes are in place, interweaving them with supporting evidence from the data. The robustness of themes is consistently checked against the entire dataset to safeguard against undue influences. The process culminates in the production of a well-structured research report, delineating the analytical journey, defined themes, and supporting examples.

Ethics Approval

The Human Research Ethics Committee of Universiti Teknikal Malaysia Melaka approved the study protocol with serial number UTeM.11.02/500-25/1/4 Volume (44). Prior to the trial, written consent to involve each participant was obtained from the coordinator of MAHFAA and Pondoku.

RESULTS and DISCUSSION

The interviews with subject matter experts revealed that it is necessary to involve three key themes in designing applications for children with autism. The findings were also supported by the mobile application experts from the focus group discussion. All experts agreed that these themes needed to be emphasised in the design process for this study. The following are discussions on these themes.

Theme 1: Usability of Multimedia Elements in Religious Skills

The emphasis on usability and accessibility in a co-design approach involves actively engaging end-users, including individuals with ASD, in the design process. Co-design also encourages designers to collaborate with users to understand their preferences, challenges, and needs. The co-design principle of simplicity aligns with recommendations such as reducing redundant pages and avoiding capital letters, ensuring that the application is intuitive and easy to use for individuals with diverse abilities.

> *"…reduce redundant pages to make apps simpler and easier to use"* (Designer's comment).
>
> Feedback from the designer supports the guidelines mentioned by Zamry et al (2022).
>
> *"…Design and structure should be simple, clear and predictable"* (Zamry et al, 2022).

The resonance between these recommendations and the guidelines outlined by Zamry et al (2022), which emphasise simplicity, clarity, and predictability in design and structure, further underscores the importance of these principles. The study by Hening et al (2023) is an example of research that highlights the significance of simplicity and visibility in interface design to promote usability and accessibility, particularly for diverse user groups. This convergence of co-design insights and established guidelines, alongside the recent findings by Dawson et al (2023), serves as a robust foundation for the creation of effective, accessible, and user-centric mobile applications tailored for children with autism.

Theme 2: Personalised Religious Skills Progress Monitoring

Co-design promotes the active participation of end-users in shaping the content and features of educational tools. The co-design principle of involving users in decision-making processes is shown in the emphasis on IEP goals, student feedback, customisation, and progress tracking. Developers can create a more personalised and engaging learning experience by incorporating feedback in order to cater to the unique requirements of learners with ASD. One of the religious experts mentioned in the interview:

> *"…Al-Quran student progress if done by pages is too high and difficult. Try to make it personalised"* (Religious Expert 1).

Furthermore, Zamry et al (2022) advocated that the call for customised progress monitoring aligns with the principles of personalised learning, allowing learners to progress at their own pace and in ways that align with their individual strengths and preferences. They reported that:

> *"…the application should provide for relevant personalisation based on the user's preferences"* (Zamry et al, 2022).

This resonates with the principles of personalised learning, as presented by Zamry et al (2022), which highlight the importance of allowing learners, particularly those with Autism Spectrum Disorder (ASD), to progress at their own pace and in ways that align with their unique strengths and preferences. The researchers' report further reinforces the call for relevant personalisation based on user preferences. Additionally, the call for customised progress tracking aligns with the principles of personalised learning, which are promoted by educational theorists like Solomon (2012), allowing learners to progress at their own pace and in ways that align with their individual strengths and preferences. Similarly, Abdullah et al (2023) confirmed that technological intervention that is personalised to the needs and abilities of individuals with ASD is required for the intervention to be successful. These insights collectively emphasise the potential of personalised progress monitoring in creating a more engaging and effective educational tool, catering specifically to the diverse and individualised needs of learners within the autism spectrum.

Theme 3: Customisation Accessibility for ASD Monitoring Skills at School

This theme highlights the necessity of tailoring the application to meet the specific needs of individuals with Autism Spectrum Disorder (ASD). A fundamental aspect of co-design is tailoring the application to meet the specific needs of individuals with ASD. The incorporation of customisation options, such as theme colour adjustments and recognition of sensory preferences, aligns with the co-design principle of inclusivity. An application that is more accommodating and user-centric is produced when designers involve individuals with ASD in the design process to better understand and address their sensory sensitivities and preferences.

> *"…need to provide options for ASD to change theme colour"* (comment by Special Education Expert 2).

According to Zamry et al (2022), it is crucial to consider sensory sensitivities and individual preferences in creating environments that support the engagement and comfort of individuals with ASD. Their study also highlighted:

> *"…need to allow customisation for font type, font size, themes and colours"* (Zamry et al, 2022).

Furthermore, other researchers, such as Grandin and Duffy (2013), emphasise the importance of taking sensory sensitivities and individual preferences into account when designing environments that facilitate the comfort and participation of individuals with ASD. Similarly, Maidon et al (2023) highlighted that customised teaching can be effectively conducted by implementing an application that helps provide a variety of pedagogical approaches to teachers. This theme reaffirms that involving children with autism in the design process not only allows for a better understanding of their unique sensitivities and preferences but also leads to the creation of a more user-centric and accommodating application. It also provides guidelines for the development of educational tools that prioritise inclusivity and customisation.

In summary, these themes align with the principles of co-design by emphasising the importance of collaboration and user involvement in the design and development of educational applications. By integrating these themes into the co-design process, developers can create more effective, accessible, and user-friendly tools that cater to the diverse needs of learners, including those with ASD.

CONCLUSION

The MyQuranic application holds significant promise as an organisational and communicative tool for teachers and children with autism in religious skills development, aligning with co-design principles that emphasise user-centred solutions. The application aims to monitor religious learning skills at school and is positioned to support communication between educators and students, particularly in religious learning, by reflecting inclusivity in accommodating diverse learning environments. The call for effectiveness testing with real participants underscores a commitment to empirical validation, a key facet of co-design processes that value real-world feedback for iterative refinement. The study's intention is to provide empirical evidence that supports the application's efficacy in aiding children with autism in religious learning. This demonstrates a co-design approach focused on outcome validation and continuous improvement. The subsequent call for an evaluation process, encompassing feedback from various stakeholders, reflects co-design principles of inclusivity and iterative refinement, ensuring that the MyQuranic application is not only promising but also responsive to the dynamic needs and experiences of its user community.

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REFERENCES

Abdullah M H L (2018). Technology-based intervention for supporting the development of children with autism spectrum disorder (Doctoral dissertation, Queensland University of Technology).

Abdullah M H L, Brereton M (2015). MyCalendar: fostering communication for children with autism spectrum disorder through photos and videos. In Proceedings of the annual meeting of the Australian special interest group for computer human interaction (pp. 1-9).

Abdullah M H L, Tong B T, Zakaria M H, Daud N F N M (2023). Fostering Social Communication for Children with Autism through Augmented Reality Toy. Disability, CBR & Inclusive Development, 34(1), 64-76.

Ahmad H, Zainuddin N M M, Yusoff R C M, Azmi N F M, Hassan W A W (2019). Augmented reality model to aid Al-Quran memorization for hearing impaired students. In Intelligent and Interactive Computing (pp. 447-457). Springer, Singapore

Ahmed S, Haque R (2018). Mobile Applications for Islamic Learning: Design Principles and User Experience. In 2018 IEEE International Conference on Teaching, Assessment, and Learning for Engineering (TALE).

Al-Mouhamed M, Al-Muhtadi J (2016). Personalized Applications for Islamic Worship. In 2016 IEEE/ACM International Conference on Mobile Software Engineering and Systems.

Brereton M, Sitbon L, Abdullah M H L, Vanderberg M, Koplick S (2015). Design after design to bridge between people with cognitive or sensory impairments and their proxies. CoDesign, 11(2). doi: http://dx.doi.org/10.1080/15710882.2015.1009471

Dattolo A, Luccio F (2017). A Review of Websites and Mobile Applications for People with Autism Spectrum Disorders: Towards Shared Guidelines. 264- 273. 10.1007/978-3-319-61949-1_28.

Dawson G, Rieder A D, Johnson M H (2023). Prediction of autism in infants: progress and challenges. The Lancet Neurology, 22(3), 244-254.

Duma T, Chamane L L (2023). Epistemic access for students using assistive technology in the introduction of online teaching. Disability, CBR & Inclusive Development, 34(1), 27-45.

Gupta M, Gupta P, Kaur S, Jain A (2019). Mobile Based Smart Application for Religious Tourism. In 2019 9th International Conference on Cloud Computing, Data Science & Engineering (Confluence).

Haque M M, Rabbani M, Dipal D D, Zarif M I I, Iqbal A, Akhter S, Parveen S, Rasel M, Rabbani G, Alam F, Soron T R, Ahmed S I, Ahamed S I (2021). Grant report on mCARE: Mobile-based care for children with autism spectrum disorder (ASD) for low-and middle-income countries (LMICs). Journal of Psychiatry and Brain Science, 6.

Hening Darmasti A, Pinkwart N, Zender R (2023). User Experience Evaluation in Virtual Reality for Autism: A Systematic Literature Review. In the International Conference on Human-Computer Interaction (pp. 546-568). Cham: Springer Nature Switzerland.

Jamal S A, Qureshi S H (2017). Development of a Mobile Application for Muslim Pilgrims during Hajj. In 2017 3rd International Conference on Information Management (ICIM).

Jamal W, Cardinaux A, Haskins A J, Kjelgaard M, Sinha P (2021). Reduced sensory habituation in autism and its correlation with behavioral measures. Journal of Autism and Developmental Disorders, 51, 3153-3164.

Johnson C N, Ramphal B, Koe E, Raudales A, Goldsmith J, Margolis A E (2021). Cognitive correlates of autism spectrum disorder symptoms. Autism Research, 14(11), 2405-2411.

Johnson E D, Ali M I, Al-Mouhamed M (2017). User Centred Design of an Islamic Mobile Application for Elderly Users. In 2017 IEEE/ACM 40th International Conference on Software Engineering: Software Engineering in Society Track.

Jones R, Hoare P, Elton R (2020). Co-designing technology for children with autism: A case study approach. International Journal of Human-Computer Interaction, 36(9), 863-877.

Khan N, Shafiq M, Hassan M M (2018). Privacy in Mobile Applications: A Comprehensive Review. Journal of Ambient Intelligence and Humanized Computing, 9(6), 1905–1932.

Lyu C, Chen H, Peng X, Xu T, Wang H (2021). DailyConnect: A Mobile Aid that Assists the Understanding of Situation-based Emotions for Children with ASDs. In Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems (pp. 1-6).

Maidon F N B, Razapi N A A B M, Rozaini N S N B, Afzam N A F B S, Mokhtar A (2023). CHILDREN WITH AUTISM: THE EDUCATIONAL ASPECT. Disability, CBR & Inclusive Development, 34(1), 13-32.

Onwuegbuzie A J, Frels R (2016). Seven steps to a comprehensive literature review: A multimodal and cultural approach.

Rahman M M, Rahman M A, Almogren A, Alamri A (2020). A Comprehensive Review on Religious and Islamic Information Retrieval in the Age of Big Data. Journal of Ambient Intelligence and Humanized Computing.

Rogers S J, Vismara L A, Wagner A L (2021). A review of research on interventions for young children with autism. Topics in Early Childhood Special Education, 41(2), 69-83.

Rosenbloom R, Wills H P, Mason R, Huffman J M, Mason B A (2019). The effects of a technology-based self-monitoring intervention on on-task, disruptive, and task-completion behaviors for adolescents with autism. Journal of Autism and Developmental Disorders, 49, 5047-5062.

Rubin J, Chisnell D (2008). Handbook of Usability Testing: How to Plan, Design, and Conduct Effective Tests. Wiley.

Schuck R K, Dwyer P, Baiden K M, Williams Z J, Wang M (2022). Social validity of pivotal response treatment for young autistic children: Perspectives of autistic adults. Journal of Autism and Developmental Disorders, 1-19.

Smith J, Adams A, Shah P (2018). Co-designing with children with autism: A reflective analysis. Interaction Design and Architecture(s) Journal, 37, 22-38.

Snyder C (2003). Paper Prototyping: The Fast and Easy Way to Design and Refine User Interfaces. Morgan Kaufmann.

Solomon, R. (2012). Constructivist education: Piaget and Vygotsky. Special Education.

Williams B E, Johnson J H (2019). User-centred design of assistive technology for children with autism: A case study analysis. Journal of Usability Studies, 14(1), 39-55.

Zamry A A, Abdullah M H L, Zakaria M H (2022). A Guideline for Designing Mobile Applications for Children with Autism within Religious Boundaries. International Journal of Advanced Computer Science and Applications, 13(11).

Community-Based Rehabilitation Enhances the Functioning of General Disability Service Centres in Khon Kaen Province, Thailand

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ABSTRACT

Purpose: *To identify factors that promote the functioning of general disability service centres in utilizing local resources and community participation.*

Method: *This study selected representatives from 13 general disability service centres in Khon Kaen province, Thailand. These representatives were sourced from local governmental organizations, disability organizations, and hospitals, totalling 63 participants. They included local government, community representatives, persons with disabilities, and caregivers. Data was collected through document analysis, in-depth interviews, and focus group discussions.*

Results: *The study found 7 factors related to the operation of general disability service centres that incorporate the concepts and practices of CBR. These factors are 1) Project manager or person in charge of the general disability service centres. 2) The proportion of community representatives in the management committee. 3) Networking within and outside the community. 4) Effective utilization of local resources. 5) Development of vocational knowledge and skills. 6) Efficient database management. 7) Public relations and communication with society.*

Conclusions: *General disability service centres can emerge and operate based on the community's efforts to rehabilitate the abilities of persons with disabilities. Community engagement is crucial in utilizing local resources to enhance the effectiveness of these centres. Therefore, policies and guidelines supporting factors related to this should be established to improve the operational efficiency of general disability service centres.*

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Keywords: *community participation, local resources, persons with disabilities*

INTRODUCTION

At the present, the global population is approximately 7.7 billion persons (United Nations, 2023), with over 1 billion persons being persons with disabilities, which is roughly 15% of the total population. The World Health Organization predicts that the number of persons with disabilities will increase to 2 billion persons by the year 2050 (World Health Organization [WHO], 2023). This is due to the aging society and a rapid increase in chronic diseases. The prevalence of disability is higher in developing countries and living under difficult circumstances. Especially about the disadvantages on the social and economic dimensions that are caused by many barriers such as inaccessible physical environments and transportation, the unavailability of assistive devices and technologies, non-adapted means of communication, gaps in service delivery, and discriminatory prejudice and stigma in society (World Bank, 2023).

The World Health Organization (WHO) suggested that low-and middle-income countries (LMIC) use community-based rehabilitation (CBR) to assist persons with disabilities in accessing rehabilitation services. This is because CBR is an approach that emphasizes community involvement and providing services in the local area (Thomas M and Thomas MJ, 2003). CBR is a strategy within community development that aims for the rehabilitation, equalization of opportunities, and inclusion of persons with disabilities, it has broadened its scope from a mere strategy for access to health and rehabilitation services to include medical, education, livelihood, social inclusivity and empowerment (WHO, 2010). It’s called CBR matrix that has five dimensions.

Many LMICs, including Thailand, use this strategy to improve the quality of life for persons with disabilities because it can be a cost-effective and sustainable approach to disability services (Iemmi et al, 2015). Additionally, CBR is applied in conjunction with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and aims to stimulate the participation of people with disabilities in society. It focuses on promoting the inclusion of community stakeholders, with particular emphasis on the active involvement of people with disabilities right from the beginning of the implementation process. However, the success of these operations still depends on and needs to be adapted to the specific context of each community (Wickenden et al, 2012).

The process of implementing CBR is a cyclic and comprehensive approach that aligns with and connects various activities within the global framework of the World Health Organization. It has distinctive features designed to be suitable for the context of the community, requiring skills in applying CBR concepts in operations and assessing the needs and conditions within that specific community. CBR opens opportunities for people with disabilities, their families, community members, and various organizations, both within and outside the community, to participate in all stages of the operation. This involves integrating the work of all projects that occur, promoting and supporting traditional community practices to strengthen and gain acceptance within the community (WHO, 2004).

The CBR program operates through several stages, with a primary focus on community participation and mobilization of local resources for optimal benefits. The program aims to encourage community members to acquire knowledge and skills in rehabilitating individuals with disabilities. Particularly, it emphasizes stimulating the involvement of people with disabilities in the rehabilitation process, promoting their active participation (Kuipers et al., 2001). Therefore, the CBR program has played a foundational role in the development of persons with disabilities, fostering the enhancement of community capabilities, and elevating the quality of life for individuals with disabilities (Mannan and Turnbull, 2007).

Three decades have elapsed since Thai society adopted the concept of CBR to enhance the quality of life for persons with disabilities. This has led to the widespread implementation of CBR projects across all regions of Thailand, particularly in remote and rural areas where persons with disabilities may have limited access to various services. Several literature reviews have attempted to address the effectiveness and impact of CBR (Wanaratwichit et al 2015). This has become a significant driving force for persons with disabilities and the community as a whole, helping persons with disabilities to regain their capabilities. The outcomes of implementing CBR for persons with disabilities, their families, and communities result in changes and enhanced potential (Cheausuwantavee, 2005), which are fundamental to community development in supporting more effective disability policy initiatives, which serves as one avenue for policies aimed at promoting increased accessibility for persons with disabilities to service systems.

The service system that helps improve access for persons with disabilities is called Disability Service Centre (DSCs), established under the Empowerment of Persons with Disabilities Act, B.E. 2550 (2007). To enable persons with disabilities to access medical services, education, social assistance, professional development, and empowerment, assistance for individuals with disabilities is crucial. This includes improving living environments, and employment opportunities, and facilitating access to loans without interest. (The Empowerment of Persons with Disabilities Act, 2007), There are two types of disability service centres: general DSCs and provincial DSCs. Provincial DSCs are established as units within the Office of Social Development and Human Security in each province. They are responsible for gathering information and supporting the operations of general DSCs. General DSCs can be established on several organizations that are located at the district or sub-district level, such as local government organizations, non-governmental organizations (NGOs) or disabled' s organizations, and community hospitals. General DSCs are responsible for providing services to persons with disabilities in specialized areas where the organization has expertise or specific competence (Yokoyama, 2021).

The status of DSCs, is found that there are provincial DSCs in all 77 provinces nationwide. Additionally, there have been established a total of 3,328 general DSCs: 333 disability organizations or non-government organizations and about 2,995 local government agencies/government organizations. The functioning of general DSCs are to provide information and news about rights and benefits, advocate for the rights of persons with disabilities, offer assistance, coordinate referrals, and perform other duties as assigned by the provincial DSCs. The organizational structure involves a working committee comprised of staff from the organization and representatives from the community. Services are organized based on the mission, which depends on the capabilities and expertise of each specific general DSC. Therefore, these general DSCs, established by various organizations, undertake diverse operations based on the context and role of the founding organization (Kampempool P., et al., 2022).

The studies have shown that these centres have not been able to operate effectively in all areas. Many face budget constraints, staffing issues, and a lack of service standards hindering their ability to function efficiently. Despite these challenges, some organizations or agencies dedicated to persons with disabilities have successfully established rehabilitation centres that operate effectively (Indeesri N, 2021). There is relatively little research on DSCs in Thailand, as they have only recently been established. Some studies have examined the operation of DSCs about the CBR framework, but these studies have only focused on specific aspects of CBR, such as the social or medical dimensions (Cheausuwantavee, 2005; Yokoyama, 2021).

Disability service centres are a way to improve access to services for persons with disabilities, and their effectiveness is enhanced through community involvement. This community-based approach is the foundation of disability work in the area. This study focuses on examining the operations of general disability service centres that employ the community-based approach to promote the rehabilitation of persons with disabilities and enhance the overall functioning of these service centres. Therefore, this study uses the CBR framework, which has been implemented in Thailand for many years, particularly in rural and remote areas, to examine the operation of DSCs. This framework emphasizes community participation and is partly based on the work of CBR. To date, no studies have used this framework to examine DSCs in Thailand.

METHOD

This research is a qualitative study aimed at studying the functioning of disability services centres that utilize local resources and community support. The study is a case study design that focuses on community-based disability service centres established by local government, disability organizations, and hospitals in Khon Kaen province, Thailand. There are a total of thirteen such centres. This research has been approved by the Ethics Committee for Human Research under the reference number HE643147.

Key informants

The main sources of information, or key informants, for this research, are individuals who are directly involved in the operation of the general disability service centres and those who have a stake in their operations. The researcher used a purposive sampling technique to select key informants who were willing to provide information, had effective communication skills, possessed relevant knowledge and understanding, and were clear on the topics under study. There were a total of 63 key informants, including 7 groups of stakeholders 1) a chairman of the province DSCs 2) 8 chairmen of the general DSCs 3) 22 committee who are community health volunteers, medical personnel, community leader, disability organization leader, persons with disabilities, and caregiver 4) 11 community developer or secretary of the general DSCs 5) 11 persons with disabilities who come to use the service 6) 4 caregiver who come to use the service 7) 5 external network. Data collection took place from August 2021 to April 2023.

Research methods and tools

In this study, the researcher was a crucial tool for data collection. The research methods used include documentary study: this involved reviewing documents such as project reports, project documentation, committee appointment orders, and other relevant persons with disabilities. In-depth interviews: the researcher conducted in-depth interviews with key informants on 17 questions including the general DSCs, external context, and CBR issue. Participatory observation: the researcher actively observed the activities of the general disability service centres to gain a better understanding of their operations. Focus group discussion for an interested issue involving 13 participants took approximately 3 hours. The attendees included an organizational leader, community development specialist, public health officers, volunteers, community representatives, persons with disabilities, and caregivers.

Data analysis

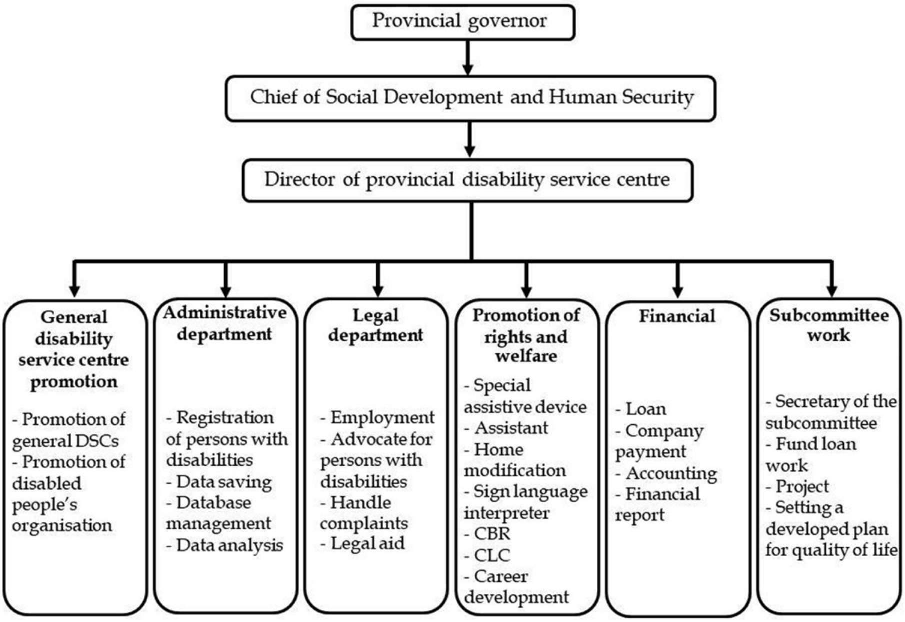
Content analysis was used to analyse the data collected. The data was organized into main- and subtopics based on the research objectives. Data triangulation was employed to ensure the accuracy and completeness of the information obtained.

RESULTS

Context of provincial disability service centre

Provincial disability service centre is managed in a way that aligns with the mission of the provincial social development and human security office. This is because they already provide comprehensive services to persons with disabilities following the policies of the disability service centres. They also coordinate with local government organizations, organizations for persons with disabilities, and government agencies. They have a broad management structure, and each division has specialized staff responsible for specific tasks due to the need for specialized expertise. The provincial disability service centre director, who is a career civil servant, is responsible for coordinating and implementing policies. The various divisions are assigned tasks according to their mission and operate under the governor of the province and the provincial social development and human security office, which is the agency directly responsible for persons with disabilities. (see Figure 1.)

Figure 1. Organizational structure of the provincial disability service centre



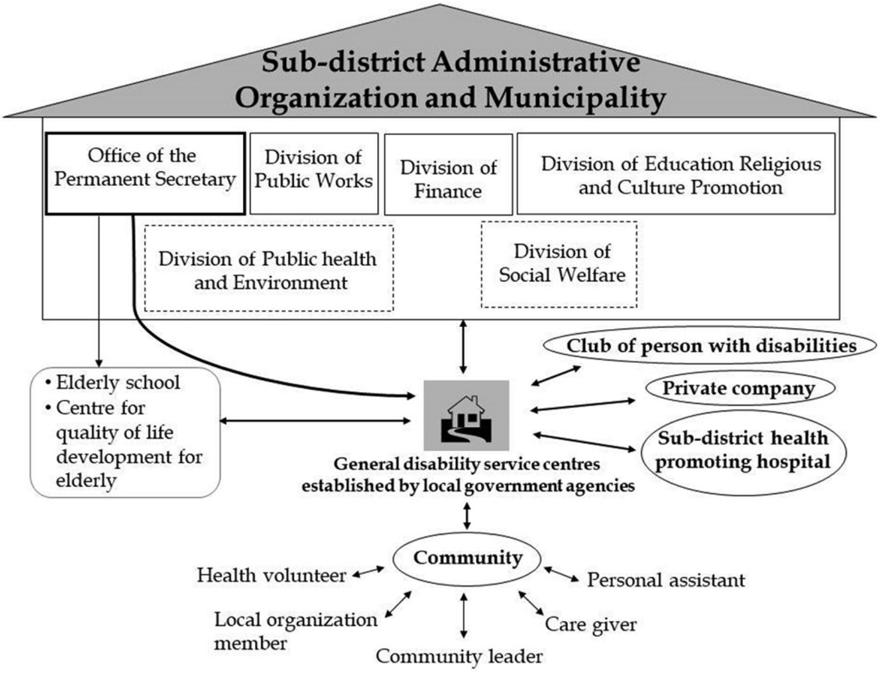
The general disability service centre in Khon Kaen province

Khon Kaen province comprises 26 districts, 198 sub-districts, 2,331 villages, and 389 communities. There are 225 local government organizations, including 1 provincial administrative organization, and 75 municipalities (1 city municipality, 6 town municipalities, and 68 sub-district municipalities), as well as 149 sub-district administrative organizations. Under the Ministry of Public Health, there are 26 hospitals, consisting of 1 central hospital, 2 general hospitals, and 23 community hospitals. There are 8 organizations for persons with disabilities certified under standards as of the year 2021. There are 85 general disabled service centres established, including 64 by local government organizations, 8 by disabled persons organizations, 5 by hospitals, and 8 by state agencies.

General disability service centres can be operated by local governments, disabled people's organizations, and government agencies. If it is a local government or government agency, it can apply to be established as a general disability service centres. However, if it is a disabled people's organization, it must be certified as a standard organization according to the criteria of the Department of Empowerment of Persons with Disabilities before it can apply to be established as a general disability service centres. Therefore, this study is divided into 3 groups as follows:

Firstly, the general disability service centres established by local government agencies, such as municipalities and sub-district administrative organizations, are state-level organizations that are closest to the communities, following the decentralization of governance. These agencies work according to the duties of the state and aim to provide public services to meet the community's needs with a focus on community participation. Therefore, the establishment of general disability service centres is another public service provided by these agencies to the community. These centres have a committee structure consisting of state officials, community representatives, and persons with disabilities who participate in the operations of the general disability service centres. (see Figure 2.) The local government organization provides care for persons with disabilities within each area. There are approximately 300-500 individuals with disabilities in each general disabled service centre, encompassing all types of disabilities.

Figure 2. The general disability service centres are established by local government agencies.



Note: the dotted line means available in some place

Secondly, the general disability service centres established by disability organizations initiate groupings of persons with disabilities or caregivers to come together to aid themselves through shared experiences of common issues. They utilize a social model concept, promoting and supporting persons with disabilities to live inclusively within society with dignity, forming strong and recognized groups. These disability organizations acknowledged as capable disability entities, are capable of providing various services to persons with disabilities through their role as general disability service centres. This study investigates the general disability service centres established by two disability organizations: the Christian Foundation for the Blind in Thailand is an organization with internal units distributed throughout the country. Providing services to approximately 30 persons with disabilities. The Khon Kaen Autism Parent Association has a network collaborating with private sector entities, representing parents of persons with disabilities in nearby provinces. Providing services to 468 persons with disabilities in the network.

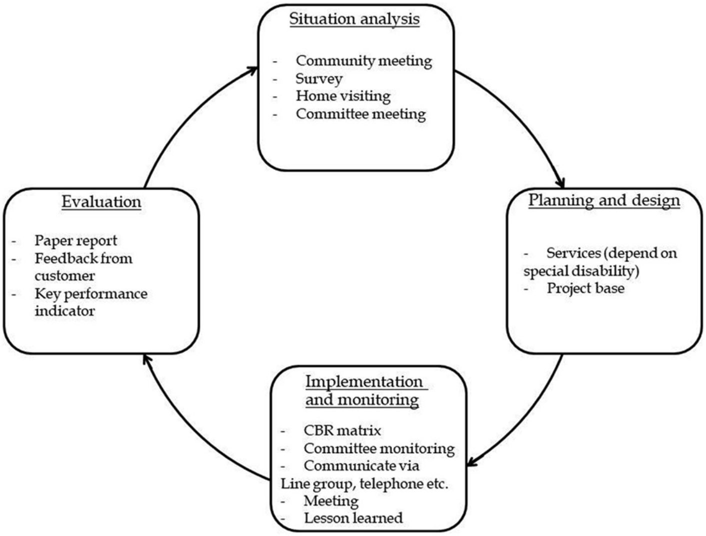
Finally, the general disability service centres established by community hospitals begins with the medical staff of the hospital working on disability-related issues at the community level, collaborating with persons with disabilities and the community. This creates a broader perspective on disabilities beyond just the medical dimension, forming a foundation for a more inclusive view. Providing services to 300 persons with disabilities in areas where some individuals may reside within the area covered by the general disabled service centres established by the local government organization, enabling them to receive services from both entities.

CBR implementation for disability service centres

Thailand has adopted the CBR concept to improve the quality of life for persons with disabilities, including community development. This is done through CBR projects in various parts of the country. These projects include pilot projects, project area expansion, and the dissemination of the CBR concept to disability practitioners in all sectors. Since the establishment of CBR-related curricula in universities, training courses, study tours, and the formation of CBR organizations, CBR implementation in Thailand has expanded to cover all areas, especially remote areas. This has enabled persons with disabilities to receive rehabilitation in physical, mental, educational, social, and living dimensions, as well as empowerment (the CBR matrix).

The visible results are the increasing number of groups and organizations of persons with disabilities. These organizations play a crucial role in driving important laws and policies for persons with disabilities. This has led to the upgrading of organizations of persons with disabilities to have standards and better disability service systems through the establishment of disability service centres. The CBR process is being used in the operation of these centres as it is a process that helps respond to the problems of persons with disabilities according to the context and integrates the work of stakeholders. (see Figure 3.)

Figure 3. Implementing community-based rehabilitation at a disability service centre.



The operation of disability service centres can be explained according to the CBR process. It begins with a situational analysis by surveying data on the problems and needs of persons with disabilities in the area. This is followed by meetings or community forums to reflect on the problems and home visits to persons with disabilities. The information gathered is then used to design and plan the implementation of projects and services by the centre's defined mission. This leads to the provision of services that cover all dimensions of the CBR matrix. The implementation is monitored by a committee through various communication channels, including follow-up meetings and work debriefings. As for evaluation, reports and evaluations are prepared by the set goals.

The findings represent factors that promote the functioning of general disability service centres in utilizing local resources and community participation. There are 7 factors as follows:

Project managers of the general disability service centres

Managers of general disability service centres, who are primarily appointed as committee members and secretaries of the committee, have the following roles and responsibilities:

- Develop project plans for approval consideration by the provincial general disability service promotion and quality of life improvement committee, including reporting on annual progress.
- Organize committee meetings approximately 3-4 times per year.
- Supervise and monitor the provision of services to persons with disabilities and projects to ensure they align with the approved plans.
- Build and maintain partnerships both within and outside the community.
- Encourage and promote the involvement of relevant stakeholders in the centre's operations, such as maintaining communication channels through online groups, holding agenda-driven meetings, and facilitating constant dialogue among committee members due to their shared presence in the same community.
- Allocate and manage resources for operations, including budgetary, and other resources in community.
- Enhance the community's capacity to address the issues of persons with disabilities.
- Create interest in the community regarding the problems faced by persons with disabilities and advocate for them to be integrated into the local development agenda. This can involve submitting proposals or issues discussed during committee meetings for inclusion in the plans of local administrative organizations, such as using the budget of sub-district administrative organizations to improve accessibility to the homes of persons with disabilities, implementing projects to enhance the capabilities of persons with disabilities, and increasing the knowledge of persons with disabilities about their rights and benefits. It involves pushing the issues related to persons with disabilities to become part of the mainstream development agenda and making local administrative organizations jointly responsible for addressing issues in their areas. As stated by the community developer in the interview

> *"We also strive to promote the formation of groups among persons with disabilities, who will engage in various activities. One such initiative is group cultivation of mushrooms, for which we have received funding from social development programs aimed at promoting inclusion. We endeavour to encourage their participation in groups as much as possible. We intend to establish a club or association for persons with disabilities in the area. Although we haven't taken action yet, we have laid out plans to involve them by forming a club in the community."*
>
> *(In-depth interview with Community Developer, January 27, 2023)*

The proportion of community representatives in the structure of the operations committee

Opening opportunities for individuals with vested interests to be part of the operations committee results in a proportional representation of the committee from community representatives. From the study, it was found that the operations committee of the general Disability Services Centres is partly composed of internal staff within the local government organization, and the other part comprises individuals with vested interests from the community who serve as committee members. This includes representatives of persons with disabilities, caregivers of persons with disabilities, community health volunteers, village chiefs, village leaders, municipal members/local administrative organization members, and representatives from local agencies. Community development workers, along with agency staff, collaborate to select committee members from the community, considering their roles and experience in working with persons with disabilities, together with the local government organization. The community representatives are invited to join the Operations Committee through formal letters or invitations to participate in the inaugural committee meeting, where roles, responsibilities, and positions within the committee are established. Due to the guidelines of the general disability services centres established by the local government organization, the committee is chaired by the local mayor or head of the local administrative organization. The majority of community representatives hold committee positions, with community development workers serving as the committee secretary, playing a key role in coordinating activities.

> *"The committee primarily consists of executives from the local administrative organization (LAO), and villagers or representatives of persons with disabilities are also invited to participate through public relations. They are informed about*

> *the benefits that general disability service centres will provide to persons with disabilities. Those who participate may possess knowledge, understanding of academic work, drive to engage in tasks, and be volunteers because sometimes there may not be allowances or compensation provided."*
>
> *(In-depth interview with Community Developer, August 04, 2022)*

Volunteerism in public health within communities is a crucial mechanism for the operation of general disability service centres distributed across all areas. Each volunteer oversees 10-15 households in the vicinity. They provide medical care dimensionally alongside public health agencies. These volunteers receive basic training in providing initial assistance regarding health. Some volunteers selected by relevant agencies undergo specialized or advanced training in caring for disabled individuals regarding health, rights, and other necessary assistance. Training is conducted based on certified courses from state agencies such as long-term care (LTC), care assistants, caregiver, etc. Trained volunteers can work alongside officials to serve disabled individuals and may be selected by the community to join the operational committees of general disability service centres to coordinate, and relay information between disabled individuals and centres, and participate in designing, planning, and monitoring the centres' operations.

> *"I'm a volunteer and have basic knowledge coming from the village health volunteers. I attended training sessions and studied. I noticed there was no one to take care of us, so we stepped in to help. I received training from the Disabled Association of Thailand in Nonthaburi province. They saw me work with public health officials and suggested to training. The training lasted about 180 hours, covering everything. I attended because I wanted to learn, and gain experience, and ended up becoming involved in this field regularly."*
>
> *(In-depth interview with care assistant, January 11, 2022)*

Working in Collaboration with Internal and External Community Networks

General disability service centres collaborate with both internal and external community networks to enhance the effectiveness of their operations. This collaboration involves coordination, seeking cooperation, and requesting support from these networks. Such networks are considered social capital, which contributes to the success of the organization by fostering positive relationships among staff within the organization and linking and coordinating the work of external networks.

The network between General Disability Service Centres

General disability service centres collaborate by participating in a network of general disability service centres and provincial disability service centres. These networks serve as channels for communication and coordination between the general disability service centres, allowing them to share information and knowledge about each centre's capabilities and strengths. If a person with disabilities requires specialized services, this network ensures that collaboration and cooperation can be established effectively.

> *"Various hospitals, when persons are sick or disabled in our area, they go to use the services. Then he has a problem He will coordinate back to us to help in various areas as well. Sometimes there is no car to go home. Like this, please contact me. Can Sila take Grandma home for me? We arrange for a rescue vehicle or any available vehicle. Pick up and send home like this. Some people live alone. If you don't have family, you'll pick them up and take them home."*
>
> *(In-depth interview with Community Developer, January 11, 2022)*

Communication between general disability service centres is not limited to within provinces but also involves coordinating services between centres across provinces. This is because all disability service centres depend on the Department of Empowerment of Persons with Disabilities, a national-level organization. Therefore, there are uniform guidelines for monitoring and supervision. Each disability service centre reports data on the number of disabled individuals, services provided, project activities, and annual budgets. Additionally, meetings are held to exchange information between the disability service centres.

External Community Networks

General disability service centres collaborate with external community networks, including governmental organizations like the Provincial Office of Social Development and Human Security, the Centres for the Rehabilitation and Occupation of Disabled Persons, and Special Education Zones in nine provinces. This collaboration typically starts with individuals with disabilities in the area expressing their needs in education, occupation, and rehabilitation. This information is then used to refer individuals to relevant agencies and organizations.

In terms of private sector networks, there are two main components: private companies and Disabled Persons Organizations (DPOs). Private companies support the community through social activities such as providing goods or budgeting through the services of general disability service centres. They also hire persons with disabilities to work in public agencies. Some general disability service centres serve as points of coordination and communication for private sector agencies or corporations engaged in social activities, such as offering goods to persons with disabilities, repairing and building homes for them, providing funds for vocational training, and hiring persons with disabilities according to the Corporate Social Responsibility (CSR) law, Article 35. For example, one community developer mentioned,

> *"We also work with a company which repairs houses for the elderly and persons with disabilities. We cooperate with the Social Security Office. But recently, there has been an impact due to COVID."*
>
> *(In-depth interview with community developer, September 29, 2021)*

Utilizing Resources in the Community for Maximum Benefit

The utilization of human resources in community operations is considered the most critical asset for driving organizations through the knowledge, skills, expertise, and experience of individuals. This is often referred to as human capital, which plays a significant role in communities, both traditional and urban. The use of human capital tends to be less in urban communities due to the rapid expansion of such communities, leading to a quicker transformation from traditional to urban settings. This transition is a result of the community's growth, and thus, the accumulation of knowledge and experience of human capital takes less time, making it preferable to employ technology or tools instead.

> *"We are the community caregivers, and we already have information in our heads, because we visit disabled persons. We have data regarding patients who are bedridden. When the service centres request information, we can respond immediately, and we will thus also be faster in given assistance. Moreover, we collaborate with caregivers and health staff who possess insights and comprehensive data, such as person with muscular disabilities, bedridden patients etc. When we work together, we can share this information among each other which benefits the entire care process."*
>
> *(In-depth interview with Village Health Volunteers and community care volunteers, September 16, 2021)*

The utilization of human capital in the CBR process involves collecting, using, and exchanging information about persons with disabilities by community representatives. These representatives have responsibilities and work closely with individuals with disabilities, allowing them to gather comprehensive data, such as the number of persons with disabilities, the nature of disabilities, and the living conditions of persons with disabilities within their areas. Additionally, community representatives, as members of the committee, have a role in presenting the issues and requirements of persons with disabilities to general disability service centres. This information is used to develop project plans and initiatives for the benefit of the community.

Development of Knowledge into Vocational Skills

General disability service centres provide specialized services based on the type of disability. Disability organizations are formed by groups of individuals with disabilities or caregivers facing similar challenges. These organizations aim to support each other by sharing expertise on disabilities, skills training, and capacity building to help individuals with disabilities lead fulfilling lives in society. Therefore, disability organizations tailor their services to their specific expertise and capabilities. These organizations possess specialized knowledge in disability-related matters and employ experts in providing services. Furthermore, they continually develop innovations and technologies for the rehabilitation of individuals with disabilities.

The services offered by general disability service centres, established by disability organizations, are tailored to specific disability types. Members or target groups of these service centres typically share the same type of disability. Consequently, the geographical scope of services provided to members may extend to different districts or even provinces, covering the residential areas of individuals with disabilities.

Efficient Database Development

Some general disability service centres have adopted the International Classification of Functioning, Disability, and Health (ICF) to categorize the work-related aspects of disability and health, which is used for analysing the issues faced by individuals with disabilities. In the past, the medical perspective viewed persons with disabilities solely as patients in need of treatment and rehabilitation. However, the contemporary medical viewpoint recognizes the multifaceted nature of disabilities. The application of the ICF framework has been instrumental in addressing the issues faced by individuals with disabilities. This framework considers not only internal and external factors but also social and environmental determinants that contribute to disabilities. Consequently, addressing medical issues is not limited to treating illnesses but involves addressing problems that are interconnected with various contributing factors. The development of ICF data, which is a hospital's dataset, can be used to design personalized assistance for individuals with disabilities.

Public Relations and Communication with Society

Engaging in public relations and communication with the community allows general disability service centres to receive financial support from society. Disability organizations also receive financial support from the private sector for their establishment. For instance, the Thai Association for the Blind, a non-governmental organization, was established by a blind teacher who donated funds, beds, land, and educational buildings to establish a school for the blind. The operations of non-governmental organizations like the Thai Association for the Blind primarily rely on donations from the private sector.

In the case of parent associations of individuals with disabilities, it is a collaborative effort among parents, most of whom possess financial means and knowledge. They collectively establish organizations in the form of associations and receive substantial support from the private sector. When organizations can establish themselves and maintain their strength, they continue to receive continuous support because donors receive tax benefits, which is one of the factors contributing to the continuous budget allocation for the operations of disability organizations.

DISCUSSION

CBR factors for enhancing the functioning of general disability service centres

Factors related to the operation of general disability service centres with the CBR approach. Found that some factors to improving the efficiency of locally established general disability service centres, working in collaboration with local government organizations and coordinating with external agencies with specialized knowledge to enhance service delivery. Additionally, it is recommended to provide opportunities for stakeholders to participate as committee members, actively involved in the decision-making process and supervision of general disability service centres.

CBR concept and principles are a key strategy in international instruments including the Convention on the Rights of Persons with Disabilities (CRPD), under heading 26, which concerns promoting capability and restoring capability, point (b) emphasizes supporting persons with disabilities to participate in and be integral parts of their communities, as well as in all aspects of society. According to the principles of CBR, the operations of general disability service centres focus on inclusive participation, particularly involving people with disabilities. This includes having people with disabilities participate as committee members and play roles in driving the operations of the centre, which is evident in disability service centres established by disability organizations providing services by and for persons with disabilities themselves.

The global organizations recommended CBR workers/stakeholders should be seven sectors including (1) persons with disabilities (2) families of persons with disabilities, (3) community members, (4) governmental organizations at local, regional, and national levels, (5) non-governmental organizations as local, regional, national and international level, (6) professionals related such as medical, educational personnel, social works and others, and (7) business sectors (ILO, UNESCO, WHO, 2004). The coordination of these individuals is crucial for the functioning of CBR. The project manager plays the role of coordinating and fostering mutual understanding among the team members. This ensures that the CBR operations follow a unified direction and work collaboratively to provide assistance and support to one another.

Stimulating and promoting empowerment within communities, including persons with disabilities, is crucial for project managers to foster inclusivity and ensure sustainable operations. As stated by a community developer who serves as the project manager of a disability service centre established by a local government organization, they have endeavoured to promote and lay out guidelines for persons with disabilities to participate in group activities or establish disability clubs in the area. This is aimed at facilitating activities and services tailored to persons with disabilities. Aligned with the transition in the process of CBR in Thailand, which emphasizes the empowerment of persons with disabilities and the principle of "nothing about us without us," it has promoted the formation of self-help groups and persons with disabilities to become project managers of CBR initiatives themselves. Furthermore, it has transformed CBR work into community development activities that decentralize power and foster collaboration between local organizations and people with disabilities.

There are studies on factors related to the operation of CBR, which include various factors that support the work of general disability service centres. It can be observed that the newly introduced factors align with the personnel and knowledge management factors, as well as the efficient database development factors. However, the factors related to public relations and communication with society have not been clearly emphasized, as the analysis in this study focuses on the organizational level. In the community-level analysis, it may highlight these factors more clearly. One study in Thailand recommended to innovative training methodology for building up the capacity of staff to work as a team and to become agents of change to set up a strategic plan for delivering CBR interventions in their settings (Tongsiri, 2022).

For example, the establishment of general disability service centres by local government organizations arises from two sectors: 1) State agencies: Local government organizations have provided services for persons with disabilities as part of their responsibilities and functions. This includes the tasks carried out by relevant personnel, meaning local government organizations engaged in disability-related activities, such as providing services for persons with disabilities. 2) Persons with disabilities: They have an awareness of their rights (capability) that enable them to access various services, including participation in disability-related activities within organizations, such as expressing opinions, participating in activities, and monitoring and evaluating outcomes. As stated by the community developer in the interview the committee primarily consists of executives from the local administrative organization, and villagers or representatives of persons with disabilities are also invited to participate through public relations.

From a study through the review of more than 33 research works and expert evaluations, it was found that the need for a CBR workforce for appropriate training, supervision, and motivation considerations within a tiered system, and the need for advocacy and empowerment skills when task-shifting to communities, respectively (Gilmore, 2017). It is consistent with the findings of this study in developing the skills, knowledge, understanding, and abilities of volunteers or individuals in roles managing the operations of general disability service centres.

Therefore, general disability service centres, established by local government organizations need to focus on the development of efficient databases regarding disabled individuals. While the use of data collected from community members may be valuable, it may not be sufficient. Given the diverse characteristics of communities in urban, rural, and semi-urban areas, which affect the data collection process, data from community representatives or community members alone may not fully meet the needs of general disability service centres. Therefore, it is important to prioritize the development of databases for disabled individuals, collected both from community representatives and through effective assessments, especially for centres established by local government organizations.

Analysing the CBR matrix through the operations of general disability service centres, which can cover all 5 dimensions, depends on the service capabilities of each general disability service centre. 1) Health dimension, services can include medical care, rehabilitation, and assistive devices, relying on the work of trained community health volunteers who have undergone skills training in collaboration with local agencies. 2) Education dimension, services mainly involve specialized organizations for disabilities, with expertise in various types of disabilities, networking with strong disability networks. 3) Livelihood dimension, the focus is on promoting and supporting the employment of persons with disabilities, hiring persons with disabilities, and providing financial services, which are the responsibilities of the disability service centres. 4) Social dimension, general disability service centres have limited capacity to respond, mainly providing individual assistance, rather than addressing broader societal issues. 5) Empowerment dimension, the involvement of persons with disabilities in disability organizations, disability networks, and participation in the operation committees of disability service centres enables direct reflection of the problems and needs of persons with disabilities.

CONCLUSION AND LIMITATIONS

The community-based rehabilitation concept is not static and allows for adaptation to respond to the changing dynamics of society, especially in the current era influenced by external factors like technology and global trends, which lead to rapid societal changes. Furthermore, it aligns with democratic principles, making it easier to analyse the operations of general disability service centres established by local government organizations. These centres are typically developed as decentralized entities and thus share a similar approach, allowing for a more straightforward analysis. This is in contrast to the analysis of service centres established by hospitals, which have a more specialized focus and may operate under the constraints of the organization. Additionally, they may involve medical professionals and specialists, which can lead to limited community engagement.

Given these constraints, the study utilized in-depth data collection to provide more detailed information, increasing the weight of the findings. It also employed suitable concepts to analyse the development of CBR for the centres, based on the operational practices and collaborative principles that are typical in CBR programs. This allows for a better understanding of how community-based practices are being applied in the general disability service centres, emphasizing collaboration, resource utilization, and community involvement. This approach enables the centres to follow CBR principles effectively.

Furthermore, this study based its analysis on the concept of CBR by studying the operations of general disability service centres. This analysis serves as a practical guideline for enhancing cooperation, increasing community participation, and utilizing local resources – principles that form the core of CBR. By employing these principles, general disability service centres can operate in a manner consistent with CBR practices, ensuring that persons with disabilities receive comprehensive support and care.

The establishment and continuous operation of general disability service centres are attributed to community involvement and grassroots work based on the concept of CBR to enhance the capabilities of persons with disabilities. When disabled persons' organizations or these units are elevated to general disability service centres, there is potential for providing services to persons with disabilities. This study thus summarizes the operational factors in CBR that promote the functioning of general disability service centres, encompassing seven factors related to data management, skills, and knowledge, management, and community involvement to enable stakeholders to collaborate effectively and provide efficient services for persons with disabilities.

The limitation of this study is that it focuses on studying the positive factors of implementing CBR that promote the operation of general disability service centres. This study selected general disability service centres which continuous functions. This limitation excludes the study of negative factors or obstacles that may affect the operation of such centres. Additionally, the study only covers one province, which may have unique contextual differences or specific characteristics of the area.

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REFERENCES

Cheausuwantavee, T. (2005). Community-based rehabilitation in Thailand: Current situation and development. Asia Pacific Disability Rehabilitation Journal, 16(1), 51-67.

Gilmore, B., et al. (2017). A study of human resource competencies required to implement community rehabilitation in less resourced settings. Human Resources for Health, 15(70), DOI 10.1186/s12960-017-0240-1.

ILO, UNESCO, WHO. (2004). Community-based rehabilitation for and with people with disabilities. Joint position paper. Geneva.

Kampempool, P. et al., (2022). Annual report 2022 [in Thai]. Bangkok: Department of empowerment of persons with disabilities

Kuipers, P., Kendall, E., & Hancock, T. (2001). Developing a rural community-based disability service: (I) service framework and implementation strategy. Aust J Rural Health, 9(1), 22–28.

Lemmi, V., Gibson, L., Blanchet, K., Kumar, K.S., Rath, S., Hartley, S., et al. (2015). Community-based rehabilitation for persons with disabilities in low-and middle-income countries: A systematic review, 3ie Systematic Review 18. London: International Initiative for Impact Evaluation (3ie).

Indeesri, N. (2019). Improving the role and duties of provincial and general disability service centres [in Thai]. http://dep.go.th/uploads/Docutents/773046a8-ec9e-4a45-b01f-946a5205e58b. Retrieved 05/06/2023

Mannan, H., & Turnbull, A.P. (2007). A review of community based rehabilitation evaluations: quality of life as an outcome measure for future evaluations. Asia Pac. 18(1): 29–45

Thomas, M., & Thomas, M.J. (2003). Manual for CBR planners. National Printing Press.

United Nations. (2023). International Day of Persons with disabilities. https://www.un.org/en/observances/day-of-persons-with disabilities. Retrieved 20/01/2023.

Wanaratwichit, C., Hills, D., Cruickshank, M., & Newman, B. (2015). A model of home-based care for persons with disabilities: Better practice in rural Thailand. Asia Pacific Journal of Health Management, 10(2), 44-51.

Wickenden, M., Mulligan, D., Fefoame, G.O., & Katende, P. (2012). Stakeholder consultations on community-based rehabilitation guidelines in Ghana and Uganda. African Journal of Disability 1(1), doi.org/10.4102/ajod.v1i1.1

World Bank. (2023). A billion persons experience disabilities worldwide - sowhere’s the data? https://blogs.worldbank.org/opendata/billion-persons-experience-disabilities-worldwide-so-wheres-data. Retrieved 20/01/2023

World Health Organization. (2004). CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities. Joint Position Paper. https://www.ilo.org/skills/pubs/WCMS_107938/lang--en/index.htm. Retrieved 05/06/2023

World Health Organization. (2010). Community-based rehabilitation: CBR guidelines. WHO Press.

World Health Organization. (2023). Disability. https://www.who.int/health-topics/disability#tab=tab_1. Retrieved 05/06/2023

The Empowerment of Persons with Disabilities Act, B.E. 2550 In: Thailand, editor. 2007. http://law.m-society.go.th/law2016/uploads/lawfile/593114244ee36.pdf. Retrieved 20/01/2023

Tongsiri, S. (2022). Scaling-up community-based rehabilitation programs in rural Thailand: the development of a capacity building program. BMC Health Services Research, 22(1), 1070. doi: 10.1186/s12913-022-08458-5.

Yokoyama, A. (2021). Institutional capacities and collaboration with communities of disability service centres in Thailand from the perspective of “Social model of disability”. Interdisciplinary Research Review, 16(4), 24–32.

Exploring the Educational Needs of Young Adults with Hearing Disability, before the Taliban Regime in Kabul, Afghanistan: A Phenomenological Study

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ABSTRACT

Purpose: *The primary aim of the study was to explore the educational needs of young adults with hearing disability in pre-Taliban administered Kabul, Afghanistan.*

Method: *A qualitative approach was utilised, specifically employing the phenomenological method. In-depth semi-structured interviews were conducted with ten participants, allowing them to articulate their experiences and perspectives in detail. Data was analysed thematically, following six key steps.*

Results: *The findings underscore the importance of facilitating a good quality educational system, employing qualified teachers, and ensuring the right to access better education for individuals with hearing disability. Addressing these fundamental components is crucial to providing a motivating and conducive learning environment, and enhancing educational opportunities to meet the unique educational needs of these individuals.*

Conclusion*: Individuals with hearing disability face many challenges in Afghanistan's education system. Despite commendable initiatives, the government's neglect and financial constraints hinder optimal development. Two proposed approaches — special education and inclusive education — highlight potential solutions, emphasising the need for teacher training and a supportive learning environment. The study also advocates for the universal right to quality education for individuals with hearing disability, calling for improved services and special classes tailored to their unique needs. However, the absence of data on individuals with hearing disability in Afghanistan, security concerns during data collection, and the unavailability of sign-language interpreters are some of the study's limitations.*

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***Key words**: access to education, good education system, educational needs, qualified teachers, young individuals with hearing disability*

INTRODUCTION

All human beings have certain needs which should first be manifested and can then be satisfied. Fulfilling these needs can indeed lead to a sense of tranquillity and peace in an individual's life (Max-Neef, 2017). Persons with hearing disability have unique needs that require specific attention and support (World Health Organisation, 2018).

Education is a need, a powerful driver of development, and one of the strongest instruments for improving health, gender equality, peace, and stability (World Bank, 2018). There are different approaches to educating individuals with special needs. Special education is designed to cater specifically to the needs of students with disabilities, ensuring they have access to education. Inclusive education emphasises the integration of students with disability into general classrooms (Hoover & Patton, 2005).

Teachers play a pivotal role in providing educational services. Their characteristics, responsibilities, and behaviours significantly impact the quality of the education system. Effective classroom management, guidance, instruction, and professionalism are among the key attributes of successful teachers. Teaching and learning are interrelated, and effective learning requires appropriate teaching methods tailored to the needs of students (Theall & Franklin, 2001). The choice of teaching methods should consider the characteristics of both the learners and the subjects being taught (Vin-Mbah, 2012).

One of the characteristics of the learners is the presence of disabilities, and there are various approaches available for educating individuals with special needs. Taking special education as an example, it is designed to cater specifically to the needs of students with disabilities, ensuring they have access to education. However, relying solely on on special education is not sufficient. Previous studies have suggested inclusive education, whichemphasizes the integration of disabled students into general classrooms (Hoover & Patton, 2005). Aligned with the social model of disability, inclusive education seeks to eliminate barriers that impede equal educational opportunities and societal participation for students with disabilities (Jenson, 2018). The social model of disability offers a comprehensive framework for understanding the social exclusion experienced by disabled individuals (Swain, Thomas, Barnes, & French, 2013). According to this model, disability is not an inherent characteristic of individuals but a consequence of societal barriers, prejudices, and exclusion. Essentially, disabled individuals are not disabled by their conditions but by the environment and societal structures surrounding them (Rakočević Uvodić, 2023). In essence, inclusive education aligns with the principles of the social model of disability by striving to create an educational landscape that is accessible, accommodating, and empowering for all, fostering a society where individuals are not defined by their disabilities but are instead enabled to participate fully in all aspects of life.

The above-mentioned arguments demonstrate that a well-structured educational system is essential for meeting the educational needs of individuals with disabilities (Sharma et al, 2013). It has been observed that the education system in Afghanistan has suffered tremendously. Numerous circumstances make the education procedure challenging for many Afghans, as for example, infrastructure, an extremist curriculum, women's education, and education against all odds (Farah et al, 2014).

In the context of Afghanistan, as well as many other countries, addressing the challenges associated with education often requires a multifaceted approach. This involves implementing policy changes, conducting awareness campaigns to counter negative attitudes, enhancing infrastructure to improve school accessibility, providing teacher training, and establishing support services for students with disabilities. These efforts are crucial to ensuring that individuals with disabilities, including females, have equitable access to high-quality education.

Objective

The unmet educational needs of young adults with hearing disability have not been tackled effectively by the authorities in Afghanistan and the reasons remain unclear. Therefore, the present study attempts to describe the educational needs of young adults with hearing disability in Kabul, before the Taliban regime in Afghanistan.

METHOD

Study Design

The study employed a qualitative research approach, specifically utilising the phenomenological method. This approach is suitable for exploring the lived experiences and perspectives of young adults with hearing disability regarding their educational needs.

Participants

The study involved 10 participants, comprising 5 males and 5 females. Participants were selected based on certain inclusion and exclusion criteria criteria.

Inclusion criteria:

- Young adults in the age range of 20 to 40 years and with a hearing disability from birth.

Exclusion criteria:

- Persons with any residual hearing through hearing aids.

The decision to include 10 participants was based on data saturation, which is reached when no new information or themes emerge from the collected data (Guest et al, 2006).

Data Collection

Data was collected through in-depth semi-structured interviews.

The interviews consisted of two parts. Part one was related to demographic information, while part two consisted of five questions aimed at exploring the educational needs of young people with hearing disability. The interviews were conducted using sign language. Each interview lasted for a minimum of 25 minutes and a maximum of 45 minutes, and the sessions were video- recorded after obtaining the participant's consent.

Data Analysis

Data analysis was performed using thematic analysis, following the six steps outlined by Braun and Clarke (2006). These steps involve familiarisation with the data, generating codes, identifying themes, searching for initial themes, reviewing themes, defining and naming themes, and finally, producing a comprehensive research report.

Ethical Considerations

Informed consent was obtained from the participants, because participants should be aware of the researcher's purpose, procedures, risks and benefits, and they should have the option to withdraw (Orb et al, 2001).

RESULTS

Three overarching themes, along with 8 sub-themes, were identified. They provide a clear and organised framework for understanding the educational needs of young individuals with hearing disability in Afghanistan.

A Good Quality Education System for Students with Hearing Disability

A good quality education system refers to a system that is tailored to the specific educational needs of students with hearing disability. For this theme, the participants highlighted the importance of teaching and learning facilities, teaching aids and materials, and the use of suitable teaching methods by teachers in the classroom.

Teaching and Learning Facilities

Most participants mentioned that teaching and learning facilities are limited, such as laboratories, computer labs, tables, chairs, libraries, special needs classes, and separate classes for boys and girls. All these facilities are essential and helpful in learning, as one of the participants recalled.

> "When I was a school student, all educational facilities, for example, a laboratory, a small library, a special classroom for professional learning were provided by those NGOs" [P4, Male, 40 years old, Diploma holder].
>
> (Key respondent).

A female participant was dissatisfied with the facilities provided by the government.

> "In all parts of Afghanistan males and females are studying separately, their schools are separated. But in this school, the classrooms for male and female students are not separated. I do not feel comfortable in the classroom" [P6, Female, 21 years old, High school Student].

The limited facilities available at school were described by another participant.

> "This is clear when a school has to be established, all facilities like library, laboratory, computer lab, and …have to be considered. But our school does not even have enough classrooms, let alone other facilities" [P9, Female, 31 years old, Bachelor Degree holder].

Teaching Aids and Materials

Teaching aids and materials refer to the tools which are used by the teachers and students to facilitate the process of learning, making lessons understandable and engaging all students in the classroom activities. These materials include pictures, cards, maps, videos, and many more items. Participants reported that teaching materials play a significant role in enhancing the learning experience.

> "When I was in the first and second semesters of the university, the curriculum was designed for general students, and almost all of the classes were lecture-based. Therefore, I was unable to learn appropriately. However, in the third semester, most of our classrooms were having projectors, videos, and some other materials in the classroom, and this was the time I learned and enjoyed" [P9, Female, 31 years old, Bachelor Degree holder].

Many participants indicated that the utilisation of simple teaching materials in the classroom is beneficial to them.

> "When I was in grade 4, the borderlands of Afghanistan were taught by a geography teacher. Although the teacher repeated many times, I could not understand which countries we were surrounded by; then, the teacher brought the map. First, she showed Afghanistan and then all the countries that we have borders with. I still remember all and will never forget" [P7, Female, 25 years old, Bachelor Degree holder].

Teaching Methods

A teaching method is an instructional approach employed by educators to convey the content of a subject to students. While educators use various methods, the most effective one is chosen based on the context. A participant with a Bachelor's degree emphasised that selecting teaching methods tailored to students' situations is crucial.

> *“To learn better, as a student with hearing disability, I needed some specific methods. For example, hands-on sessions, based on the group or individual”* (*[P5, Male, 31 years old, Bachelor Degree holder].*

The participants reported that the demonstration method, which is based on observation, is one of the most suitable methods for teaching students with hearing disability.

> “I was in class 7, and my biology teacher was teaching blood circulation to human beings. For this, he showed us a video. I watched a 3-minute video in the classroom and learned the most important topic with all processes”[P6, Female, 21 years old, High school Student].

On the basis of the participants’ perspectives, it may be concluded that the learning process is greatly enhanced by the availability of effective teaching and learning facilities. Teaching materials play a pivotal role in making lessons comprehensible and engaging all students in classroom activities. For students with hearing disabilities, the most suitable method is the demonstration method.

Qualified Teachers

Based on the study findings, the qualities of teachers encompass various aspects of their personal and professional lives. These include professionalism, a positive personality, positive attitudes, level of education, and relevant teaching experiences. Two sub-themes emerged: teacher characteristics and teacher-student interpersonal relationships, which provide detailed insights into the qualities of teachers.

Teacher Characteristics

In general, teacher characteristics encompass elements such as knowledge, level of education, skills, attitudes, behaviour, and professionalism. According to the study participants, a teacher’s knowledge of psychology, proficiency in sign language, and teaching experiences are pivotal characteristics.

> “When I was in school, all of the teachers understood sign language. But at the university, most of our lecturers did not understand sign language; therefore when they were teaching, translators were needed to convey the lecture to the students. But the sign language translators were not professional to translate the lecture of the lecturers with better

> understanding and details" [P8, Female, 28 years old, Bachelor Degree holder].

Another participant believed that the teacher's attitude towards students is a crucial characteristic.

> *"When I was at the university, I used to study with hearing people. When I wanted to ask something, the teacher would answer 'when you cannot go along with hearing students, please go to a special class, I have no extra time to repeat it for you' " [P1, Male, 39 years old, Bachelor Degree holder].*

One participant emphasised the importance of teachers having knowledge of psychology.

> *"I read in a book that a teacher must be a psychologist but it is not necessary for a psychologist to be a teacher. I think, in addition to the teachers' skills and experiences their knowledge of psychology is also important. Some teachers punish their students without thinking 'why students do not study or why they are looking sad in the classroom'. It is directly linked to the lack of knowledge regarding psychology" [P6, Female, 21 years old, High school Student].*

Another participant expressed a preference for teachers with hearing disability to teach students with hearing disability in primary and secondary schools. However, in high school and university, both hearing teachers and teachers with hearing disability were considered suitable.

> *"I have the experience of studying with both hearing teachers and teachers with hearing disability. Therefore, teachers with hearing disability in an elementary classroom are helpful because they could understand the situation of the students. But hearing teachers are better at high school and higher education levels because they have more information and knowledge compared to teachers with hearing disability" [P1, Male, 39 years old, Bachelor Degree holder].*

Teacher-Student Interpersonal Relationships

Teacher-student interpersonal relationships denote the connection between a teacher and students during the learning process. The majority of participants indicated that such relationships encompass qualities like kindness, positive behaviours, love, respect, support, and helpfulness.

> *"Although lecturers were experts and professionals in the first year of the university, I failed, just because of our lecturers who were not supportive and* helpful*" [P9, Female, 31 years old, Bachelor Degree holder].*

> *"Most of the teachers at the university were trying to avoid our questions. It was rarely that we got our answers, sometimes they were getting angry with us. To be clear, the main reason could be their fewer experiences and less professionalism which was affecting the teacher-student interpersonal relationship" [P5, Male, 31 years old, Bachelor Degree holder].*

Therefore the second identified theme regarding educational needs was the importance of having qualified teachers. According to participant responses, a teacher is recognised as the most influential figure in students' learning. If a teacher possesses the characteristics highlighted by the participants, it implies that almost half of the educational needs of students with hearing disability will be fulfilled.

The Right of Access to Better Education

Education is a fundamental human right, regardless of any differences. Three sub-themes are identified that include equality of educational opportunity, capacity building, and a conducive learning environment to explain the right of access to better education in detail.

Equality of Educational Opportunities

Equality of educational opportunities pertains to the legal, fair, and equal access to quality education regardless of one's abilities. The majority of participants emphasised that having access to quality education is their right.

> *"I went to a mainstream school, and I failed two times, back to back, because there was no school for people with hearing disability. After 3 years, my family found a newly established special school in Kabul city, then I went there and started my first class again. I faced many challenges, although access to equal education with others, was my right" [P9, Female, 31 years old, Bachelor Degree holder].*

Another participant stated that people with hearing disability need high-level and high-quality education.

> *"We have the right to have the opportunities for acquiring a high level of education. I have finished my Bachelor's, and I want to continue my education* (Masters, PhD)*" [P1, Male, 39 years old, Bachelor Degree holder].*

Capacity Building and Essential Skill Development

Capacity building refers to a systematic plan for positive change in beliefs, attitudes, skills and educational programmes, via training, workshops, access to technology, and certain other specific occupations such as tailoring, carpentry, painting, carpet weaving, make-up artist, and mechanic, to name a few.

A significant number of participants indicated that many of these skills are obtained through participation in workshops, attending occupational classes, and undergoing training.

> "When I newly started my job as a teacher, I had to attend many workshops. It was the time when there were many foreign organisations and NGOs which were providing training and workshops to people with disability which are now very minimal, even equal to nil" [P1, Male, 39 years old, Bachelor Degree holder].

Another participant responded that the value of learning some skills is the same as learning the subjects taught in schools.

> *"When people with hearing disability are skilled in some occupations they can support themselves and their family. I am a tailor; I have some income, through that I can support my family" [P10, Female, 38 years old, Diploma holder].*

Conducive Learning Environment

A conducive learning environment refers to an environment in which all students enjoy learning, feel secure, comfortable and valued. One of the participants shared her school experiences.

> *"In my school, I felt comfortable in most of the classes with all teachers because all students and most of the teachers were with hearing disability. The system, methods, teachers and classmate behaviour was convenient and acceptable for students with hearing disability. In my opinion that was a conducive learning environment" [P6, Female, 21 years old, High school Student].*

Based on the insights provided by a few participants, the ideal number of students in a classroom for students with hearing disability should not exceed 10 to 15.

> *"I studied in a special school and the number of students in each class was eight to fifteen students. At the university, the number of students was above twenty-five in each class. For me, it was difficult to learn in a crowded place. Therefore,*

> *my activities and achievements turned into zero as I failed in the first semester" [P5, Female, 31 years old, Bachelor Degree holder].*

Therefore, the right to access better education emerged as the third theme for the educational needs of young individuals with hearing disabilities. The findings indicate that access to quality education is a fundamental right for people with hearing disabilities. Additionally, the study participants expressed a need for skills that could be acquired through participation in workshops, attending occupational classes, and undergoing training.

DISCUSSION

The first theme shows that people with hearing disability require good teaching and learning facilities. According to the participants, those facilities are vital to the process of learning but are not being offered by the government. They did acknowledge that some NGOs provided such facilities. The participants also confirmed that teaching materials have a positive impact on learning. The right materials make learning fun and easy, and allow teachers to convey the learning message in a better way. They also mentioned that the demonstration method of teaching is one of the best methods for individuals with hearing disability as it allows learning through observation and sight. Thus there are three sub-themes from this theme.

The theme's findings confirm the findings of the study by Obiakor et al (2010) who have pointed out the significance of a conducive environment wherein classes should be equipped with modern technologies to make the lessons easy. Some participants did mention how easily they learned the lesson by watching the video and looking at the map shown by their respective teachers.

The study findings indicate that the government neglects the education of people with disability in Afghanistan (Pajhwok, 2012). The United Nations has urged governments worldwide to create a conducive environment for individuals with hearing disabilities (Youngs, 2010). While there have been commendable initiatives to address the issues faced by people with hearing disability in Afghanistan, the majority of participants expressed dissatisfaction with the current state of development.

Two possible approaches are suggested for engaging and developing individuals with hearing disability (Alfawair & Tobi, 2015). First, the implementation of special education involves enrolling only individuals with hearing disability and providing them with all necessary facilities to maximise their potential. This approach has proven successful, as demonstrated by the positive impact of the special education department in Oman, which arranges and provides essential facilities for people with hearing disability (Alfawari & Tobi, 2015).

The second approach involves inclusive education, where special-needs students are enrolled alongside regular students and the curriculum is designed to accommodate everyone, offering equal value and opportunities for participation and growth (Mittler, 2012) Welsh Government, 2019).

Along with the inclusiveness policy, the United States has developed a specific study plan (Individualised Education Plan) for special students where their strengths and weaknesses both have been taken care of (Kisanji, 2003) considering the philosophy behind inclusive education which offers people with disability the opportunity to mix with others and push themselves hard to shine brighter.

In addition, the social model of disability has offered a comprehensive framework for understanding the social exclusion experienced by disabled individuals (Swain, Thomas, Barnes, and French, 2013). This model has been successful in facilitating the inclusion of individuals with disabilities in society by confronting prejudice and exclusion, fostering civil rights and political engagement, and empowering disabled individuals to assert their rightful position within society (Owens, 2015). Even though it was once obscure, the social model of disability is now widely accepted in the field of disability studies (Samaha, 2007). It led to the development of inclusive education, which strives to provide equal opportunities for everyone regardless of disability (Terzi, 2014).

Second, the implementation of special education involves enrolling only hearing-disabled individuals and providing them with all necessary facilities to maximize their potential. This approach has proven successful, as demonstrated by the positive impact of the special education department in Oman, which arranges and provides essential facilities for hearing-disabled people (Alfawari & Tobi, 2015).

Even though the social model of disability is now widely accepted as a modern approach considering disability (Samaha, 2007), and inclusive education is generally viewed as a holistic concept for disabled people (Landorf & Nevin, 2007), the participants' personal experiences indicate that, due to unfriendly environment, non-standardized examinations, a shortage of professional and expert sign language teachers, and an insufficient sign language interpreters, special schools are considered preferable to regular schools in Kabul, especially for individuals with hearing disabilities..

These findings align with previous studies, which stated that even in developed countries, not all educators have adopted the inclusive philosophy, and a few are opposed to the concept (Brantlinger, 1997; Freire & César, 2002; Fuchs & Fuchs, 1994). Some disability-focused organizations continue to advocate for separate services that are tailored specifically for individuals with disabilities. Particularly, numerous organizations that represent the Deaf community argue that separate educational facilities are essential to ensuring their right to education in sign language and their ability to fully engage with Deaf culture (Freire & César, 2003).

The financial problem of the Afghanistan government where it becomes difficult and more expensive for it if it starts establishing especial schools, and curriculum separately, thus Afghanistan government should accommodate both students in the same building along with individualised study plan (NCERT, 2006). There is a possibility that some students may find it difficult in the beginning but as time passes things will change, and it will lead to the creation of a healthy and progressive society.

This overarching theme encompasses two sub-themes: teacher characteristics and teacher-student interpersonal relationships. The findings underscore the importance of teachers possessing not only general teaching qualities but also specific attributes to effectively educate disabled students. Effective teaching of disabled students requires teachers to be aware of psychology, understand sign language, and exhibit positive behavior towards students. These findings align with studies by Antia (1985) and Antia, Kreimeyer, and Eldredge (1993), which identified factors affecting the education of hearing-disabled students, including communication barriers, teacher experiences, awareness, and knowledge of teachers about deafness, psychology, and sign language, as well as the interaction of hearing-disabled students.

The study findings reveal a preference among students with hearing disability for teachers who share their disability, especially at the primary and secondary levels. This preference is rooted in the belief that these teachers better understand the characteristics, needs, expectations, communication methods, and interactions of students with hearing disability. This aligns with studies carried out by Davis (2005) and Ward (2015), emphasising that individuals with hearing disability feel comfortable to learn when the teacher knows sign language.

Additionally, the findings emphasise the importance of teachers possessing positive attitudes towards students and their learning, effective communication skills, and expertise in the subjects they teach, in line with Grieve's (2010) ideas about the characteristics of a great teacher.

Given the current situation in Afghanistan, it is suggested that the government organise numerous workshops for teachers. These workshops should focus on equipping teachers with necessary knowledge related to people's learning styles and challenges. Additionally, teachers should be encouraged to be kind and pleasant with their students, providing support and making them realise the significant responsibility they hold in shaping the future of the nation.

The third theme is the right of access to better education. There are three sub-themes that include equality of educational opportunities, capacity building and essential skills development, and a conducive learning environment. The findings revealed that hearing-disabled people require high-level and high-quality education and they consider it from elementary school to higher education as their basic right.

The right to education is enshrined in the Child Rights Convention (1989) and the Disability Rights Convention (2008), and extends to all children, youth and adults with disability. It is also discussed in many important international documents, including the 1990 World Declaration on Education for All, the 1994 UNESCO Statement and Mechanism for Action, and the 2000 Dakar Framework for Action (UNESCO, 2009). In 2012, Afghanistan ratified the Convention on the Rights of Persons with Disability and its Optional Protocol. In 2013, the Afghan Parliament approved the Law on Rights and Privileges of Persons with Disabilities, ensuring the rights of persons with disabilities to participate actively in all aspects of society.

However, there are limited education-related services to assist people with disability in Afghanistan. Johnson and Seaton (2012) indicated that students who have hearing disability do not have access to sufficient schooling. Thus, students with hearing disability require special services in order to meet their needs and to help them achieve their maximum potential (Johnson & Seaton, 2012).

Based on the current study participants' experiences, it would appear that the government is using different platforms to make sure everyone gets a full and unbiased opportunity for learning. However, participants commented that in today's world, along with theoretical knowledge people have to have some skills and special capabilities that help them secure better job opportunities, and these skills can be learned through workshops and special training. Therefore, they need special classes to learn such skills.

In addition, the number of students per class should not be more than 15 because people with hearing disability focus and understand better when the class is small. Molnar et al (1999) recommended 15 students per class as an ideal setting. The author of the current research believes that the US Individualised Study Plan, which considers the strengths and weaknesses of people, must be taking this point into consideration as well.

From experience, study participants found that special school was better than regular school which has neither a friendly environment nor teachers who are well-versed in the sign language. Gudyanga et al (2014) stated that in the Netherlands many students with hearing disability who were attending regular classes wanted to return to their special schools after suffering from stigma and isolation. They also noted that the pattern was in line with some studies in developed countries (Mushoriwa & Gasva, 2008), which had found negative attitudes towards inclusion were held by regular teachers and pupils.

CONCLUSION

In conclusion, the study underscores the critical challenges regarding access to quality education faced by individuals with hearing disability in Afghanistan.

The first theme highlights the inadequacy of teaching facilities provided by the government and the positive impact of inclusive teaching methods, echoing the importance of a conducive learning environment as emphasised by international studies.

The second theme delves into the pivotal role of teacher characteristics and interpersonal relationships in the education of students with hearing disability. The preference for teachers who share their disability and possess positive attitudes aligns with global research, urging the Afghan government to prioritise workshops for teachers to enhance their understanding and communication skills.

The third theme emphasises the universal right to better education for individuals with hearing disability, as enshrined in international conventions and Afghan legislation. However, the discrepancy between policy and practice is evident, with limited services hindering access to quality education. The call for special classes, smaller class sizes, and specialised skills training resonates with global best practices, pointing towards the need for tailored educational strategies.

Ultimately, the study recommends two approaches — special education and inclusive education — while considering the financial constraints of the Afghan government. Striking a balance between these approaches and addressing the concerns raised by participants can pave the way for a more inclusive, supportive, and progressive educational landscape for individuals with hearing disability in Afghanistan.

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REFERENCES

Alfawair A, Al Tobi A (2015). Special needs education in the Sultanate of Oman: Past, present and future. *Schol J Arts Hum Soc Sci*, *3*, 415-22.

Antia S (1985). Social integration of hearing-impaired children: Fact or fiction? *The Volta Review*.

Antia S D, Kreimeyer K H, Eldredge N (1993). Promoting social interaction between young children with hearing impairments and their peers. *Exceptional Children*, *60*(3), 262-275. https://doi.org/10.1177/001440299406000307

Braun V, Clarke V (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Davis J (2005). Code choices and consequences: Implications for educational interpreting. *Sign language interpreting and interpreter education*, 112-141.

Farah K, Fauzee O M S, Daud Y (2014). Teacher training education programme in three Muslim countries -Afghanistan, Iran and Pakistan. *Journal of Education and Human Development, 3(2), 729-741.*

Fredriksson P, Öckert B, Oosterbeek H (2012). Long-Term Effects of Class Size. *The Quarterly Journal of Economics,* 249-285. https://doi.org/10.1093/qje/qjs048

Grieve AM (2010). Exploring the characteristics of 'teachers for excellence': teachers' own perceptions. *European Journal of Teacher Education*, *33*(3), 265-277. https://doi.org/10.1080/02619768.2010.492854

Gudyanga E, Wadesango N, Hove E, Gudyanga A (2014). Challenges Faced by Students with Hearing Impairment in Bulawayo Urban Regular Schools. *Mediterranean Journal of Social Sciences*, 445-451

Hoover J J, Patton J R (2005). *Curriculum Adaptations for Students with Learning and Behaviour Problems* (3rd ed.) Austin, TX.: Pro-Ed, Inc.

Jenson, K. (2018). Discourses of disability and inclusive education. He Kupu, 5(4).

Johnson C D, Seaton J B (2020). *Educational audiology handbook*. Plural Publishing.

Max-Neef M (2017). Development and human needs. In *Development ethics* (pp. 169-186). Routledge.

Mittler P (2012). *Working towards inclusive education: Social contexts*. David Fulton Publishers.

Molnar A, Smith P, Zahorik J, Palmer A, Halbach A, Ehrle K (1999). Evaluating the SAGE Program: A Pilot Program in Targeted Pupil-Teacher Reduction in Wisconsin. *Educational Evaluation and Policy Analysis.* https://doi.org/10.3102/016237370210021

Owens, J. (2015). Exploring the critiques of the social model of disability: the transformative possibility of Arendt's notion of power. *Sociology of health & illness*, 37(3), 385-403. https://doi.org/10.1111/1467-9566.12199

NCERT. (2006). *Position Paper: National Focus Group on Education of Children with Special Needs.* New Delhi: National Council of Educational Research and Training.

Orb A, Eisenhauer L, Wynaden D (2001). Ethics in qualitative research. *Journal of nursing scholarship*, *33*(1), 93-96. https://doi.org/10.1111/j.1547-5069.2001.00093.x

Pajhwok Afghan News (2012).

Hashtaddarsadnabenayanwanashinawayanbakhidamattalemedastrasenadarand.Retrieved from: November 25, 2018 https://www.pajhwok.com/ %B1%D9%86%D8%AF

Rakočević Uvodić, M. (2023). Hard of hearing and Deafblind users: from adopting Social Model of Disability to Accessibility, Equality and Inclusion.

Riseman N, Rechter S, Warne E (Eds.) (2010). *Learning, teaching and social justice in higher education*. UoM Custom Book Centre.

Samaha, A. M. (2007). What good is the social model of disability?. *The University of Chicago Law Review*, 74(4), 1251-1308.https://doi.org/10.2307/20141862

Sharma U, Forlin C, Deppeler J, Yang G X (2013). Reforming teacher education for inclusion in developing countries in the Asia Pacific region. *Asian Journal of Inclusive Education*, *1*(1), 3-16.

Swain, J., Thomas, C., Barnes, C., & French, S. (2013). Disabling barriers-enabling environments. Disabling Barriers-Enabling Environments, 1-376.

Terzi, L. (2014). Reframing inclusive education: Educational equality as capability equality. *Cambridge Journal of Education,* 44(4), 479-493. https://doi.org/10.1080/0305764X.2014.96091

Theall M, Franklin J (2001). Looking for bias in all the wrong places: A search for truth or a witch hunt in student ratings of instruction? *New directions for institutional research*, *2001*(109), 45-56. https://doi.org/10.1002/ir.3

United Nations Economic Social and Cultural Organisation - UNESCO (2009). *Teaching Children with Disabilities in Inclusive Settings.* Bangkok: UNESCO Bangkok.

Vin-Mbah F I (2012). Learning and teaching methodology. *Journal of Educational and Social Research, 2*(4), 111-118.

World Health Organisation (2018). Deafness. Retrieved from: August 20, 2018. http://www.who.int/features/factfiles/deafness/en/

Youngs M (2010). *Real people, real needs: Deaf Education in Dadaab refugee camp in Kenya* (Doctoral dissertation).

Challenges faced and Strategies used by Teachers to enhance Academic Performance among Learners with Autism Spectrum Disorder (ASD) at a School in Zimbabwe: A Quantitative Descriptive Study

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ABSTRACT

Purpose: *The study aimed to investigate the challenges that teachers encounter when teaching learners with autism at a high school in Zimbabwe, and to identify strategies to enhance the academic performance of these students.*

Method: *Twenty teachers participated in the study. A cross-sectional survey was used to collect data from them with the help of a questionnaire. Descriptive statistics were used to analyse the data.*

Results: *Key challenges reported by the teachers were: time management, meltdowns, difficulties in coping with routine changes, obsessive compulsive tendencies and being easily distracted. Their confidence levels when teaching learners with autism were reported as: 5% not confident at all; 15% slightly confident; 65% fairly confident; 10% more confident; and 5% extremely confident. Most of the strategies currently employed in school relate to the use of visual teaching materials like colour coding, objects, videos, and worksheets. Participants recommended the adoption of new strategies such as provision of therapies at the school, advocacy to raise awareness on the educational needs of children with autism, and changes to curriculum delivery.*

Conclusion: *Despite using a range of strategies to support learners with autism, the results imply a significant need for the teachers to be trained on autism and how to better support these learners to enhance their academic performance. However, the findings may not be generalisable to other schools as the study focussed on only one high school in an urban area of Zimbabwe.*

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***Key words:** neurodiversity, education, Autism Spectrum Disorder, Zimbabwe, teaching and learning strategies*

INTRODUCTION

Students with autism spectrum disorder (ASD) have unique needs and consequently face challenges in learning, social skills and interpersonal communication. These students are not a homogenous group and have differences in the way they develop and process information (Dwyer, 2022). There is limited research on the prevalence of ASD in Zimbabwe; hence, although the actual figure is not known, they are estimated to be 200,000 out of a population of over 14 million people (Chitiyo et al, 2017).This figure remains questionable as diagnostic services are limited and often inaccessible to many people who could potentially meet the criteria for ASD. Fleury et al (2014) noted that the number of students with ASD who are now being included in mainstream classrooms in Zimbabwe has increased over the past few years. This presents teachers with the responsibility to meet the social, behavioural, and academic needs of these students.

According to a study on the trends, practices and challenges of ASD in Zimbabwe, there is a lack of qualified personnel specially trained to meet the needs of learners with ASD (Chitiyo and Chitiyo, 2019). There appears to be a gap in meeting the needs of the rising numbers of children needing the services (Majoko, 2016). Evidence shows that meeting the needs of educational professionals will benefit both the professional and the student with ASD, as it makes teaching and teacher-student interactions easier (Steen et al, 2020).

Therefore, the focus of the current study was to identify useful strategies to enhance the academic performance of students with ASD at a school in Zimbabwe. No local study has been conducted on the subject and anecdotal evidence shows that different teachers use different approaches to support learners with ASD at the school. Since the different strategies have not been documented and the perceptions of teachers in terms of their competence to educate learners with ASD are not known, this study was needed to address the identified gaps.

Objective

This study investigates the challenges encountered by teachers when teaching students with ASD at a high school in Zimbabwe, as well as the teachers' perceived level of knowledge about ASD. The study also aimed to identify strategies recommended by the teachers to enhance academic performance of learners with ASD at the school.

METHOD

Study Setting

The study was carried out at a high school in an urban setting of Harare Province in Zimbabwe. The school provides mainstream education and enrols students with ASD.

Study Design

A cross-sectional survey study design was used.

As the study aimed at investigating multiple factors that affect academic achievement among learners with ASD and to propose solutions based on perceptions of the teachers, a self-reported type of survey was used. This type of survey allows researchers to get valuable information from the participants in a quick and efficient way, eliminating the risk of participant attrition (Wang and Cheng, 2020).

Participants

The study population consisted of the 33 teachers at the school.

The inclusion criteria were:

- Teachers who had been at the school for at least one year, and
- Involved in teaching at least one learner with ASD in their class/es.

A total of 20 teachers met the inclusion criteria and the researchers decided to include all of them in the study as the number was not too big to require any sampling strategy.

Data Collection

A questionnaire consisting of predominantly closed questions and Likert scale type of questions, as well as a few open-ended questions, was used. The questionnaire captured demographic information of the participants and was designed to elicit responses that directly addressed the aim of the study. Before it was finalised, the questionnaire was piloted with 3 teachers who were not part of the main study but understood the processes and procedures at the school and had previously taught learners with ASD. Following this, adjustments were made by adding the challenges faced by the teachers when teaching children with ASD.

Data Analysis

All completed questionnaires were labelled with code numbers, as for example 'A1' instead of the participant's name, to ensure anonymity. All twenty questionnaires were returned with all questions answered, giving a 100% retention rate. Descriptive statistics were used to analyse the data.

Ethical Considerations

Approval to conduct the study was obtained from Zimbabwe Open University and written permission to collect data from the teachers was obtained from the headmaster of the school. All the study participants gave their informed written consent. Ethical principles of autonomy, beneficence, non maleficence, and justice were adhered to throughout the research process.

RESULTS

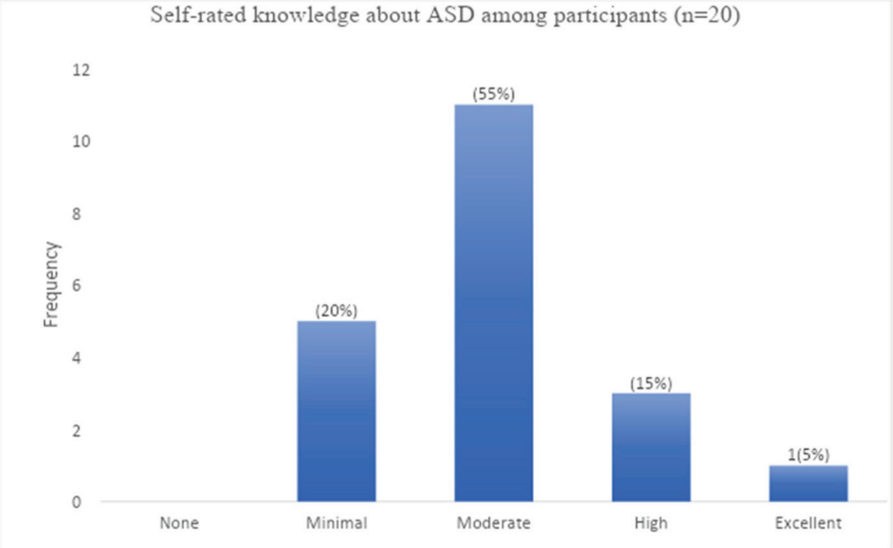
More female teachers (65%; n=13) than males (35%; n=7) participated in the study Majority of the participants (45%; n=9) were between 40 and 49 years of age, followed by the age group of 21-39 years (30%; n=6). There were 15% (n=3) of participants between 50 and 59 years of age and another 15% (n=3) aged 60 years and above.

With regard to years of teaching experience, 30% (n=6) had between 10 and 15 years of experience at the school. Teachers with 4 - 6 years of teaching experience at the school represented 25% (n=5) in the sample. Teachers with 15 years or more experience, those with 7 - 9 years and those with 1 - 3 years of experience had a representation of 15% (n=3) for each category. Majority of the participants (40%; n=15) taught learners at Forms 3- 4 level (senior secondary school), followed by 30% (n=6) who taught Forms 1- 2 level (junior secondary school). Seven (19%) were Advanced Level teachers and the remaining 11% (n=4) taught other classes, but these were not specified. However, the responses showed that some teachers taught across the provided categories of year groups.

Teachers' Self-rated Knowledge about ASD

A total of 55% (n=11) of the participants had moderate knowledge about ASD. While 20% had minimal knowledge, 15% (3) considered that they had high knowledge. Only 1 participant gave the self-rating of excellent knowledge about ASD. Figure 1 shows how the participants rated their knowledge about ASD.

Figure 1: Self-rated Knowledge about ASD



Six (30%) of the participants did not know of any specific type of ASD, while the remaining 70% (n=14) correctly mentioned at least one type of ASD. Asperger's Syndrome was mentioned by 11 participants, followed by classic ASD mentioned by 3 participants.

Some of the conditions that were mentioned are not types of ASD, for example Down's Syndrome was mentioned by 1 participant. A condition like ADHD which was mentioned by 2 participants may occur together with ASD but it is a distinct diagnosis from ASD. Rett Syndrome, autistic disorder and pervasive developmental disorder not otherwise specified were listed as a type of ASD, but each of these was only mentioned once. However, it is important to highlight that the Diagnostic and Statistical Manual of Mental Disorders (DSM),

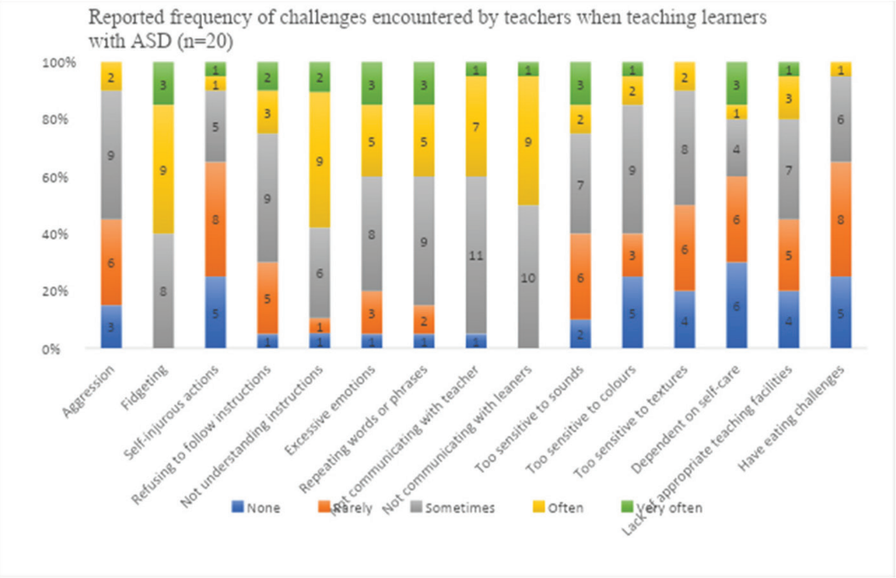
5th edition, consolidated the different categories of autism into one umbrella, i.e., ASD (American Psychiatric Association, 2013).

Level of Confidence when Teaching Learners with ASD

Thirteen (64%) of the participants reported that they were fairly confident to teach learners with ASD in the classroom. Three (15%) of the participants indicated that they were slightly confident when teaching students with ASD, two (10%) indicated that they were more confident, and one (5%) indicated not having the confidence to teach learners with ASD. Only 5% (n=1) indicated that they were extremely confident to teach learners with ASD.

Participants were asked to rate frequency of the commonly encountered challenges when teaching learners with ASD in their classes. Challenges such as aggression, self-injurious behaviour, difficulties with eating, being dependent on self-care and hypersensitivity to textures were either not or rarely encountered by most of the participants. The challenges most often encountered included not communicating with other learners, not understanding instructions and fidgeting. Between 20% and 55% of the participants were reported to have encountered all the challenges at some time. Figure 2 shows the reported frequency of the challenges encountered by the participants.

Figure 2: Reported Frequency of the Challenges Encountered by the Teachers



In addition to the challenges listed in the Figure above, participants were asked to list other challenges that learners with ASD encounter. Responses to this question yielded the following as key challenges: time management, meltdowns, difficulties in coping with routine changes, obsessive compulsive tendencies, and being easily distracted. Other challenges they mentioned related to other people and not to the learners directly; for example, disagreements between the parent and teacher, difficulties of other children in understanding their peers with ASD, as well as the coping strategies that they use during lessons.

The open-ended question which asked participants to mention the social skills that they thought their learners lacked, yielded a wide range of responses. The responses were analysed thematically and resulted in four key areas, all centred on difficulties with communication, namely, difficulties with both expressing and interpreting non-verbal communication, avoidance of eye contact, limited verbal communication, and emotional disturbances such as anxiety or mood changes.

Level of Support required by Learners with ASD

In response to the question regarding how much support the teachers felt was required by learners with ASD, two (10%) of the participants indicated that their learners with ASD did not require any support during their lessons. Two (20%) of the participants said learners with ASD in their classes required minimal support, six (30%) stated that learners with ASD in their classes required moderate support, and another six (30%) of the participants indicated that the autistic learners in their classes required substantial support during lessons. Four (20%) of the participants felt that autistic learners in their classes required very substantial support.

Participants were asked to list any therapies being offered at the school to provide additional support for the learners. Seven participants (35%) reported that there were none and two (10%) mentioned that counselling was being provided. Other participants listed the following approaches but stated that they were not sure if these are being used at the school: cognitive behaviour therapy, humanistic approach (see Table 1), behavioural and cognitive approaches, psychosocial support and early intensive behavioural intervention.

Strategies currently being used by Teachers when teaching Learners with ASD

Participants were asked to list strategies that they currently use to enhance academic performance of learners with ASD. Responses from participants were grouped into three areas of approach which are summarised in Table 1.

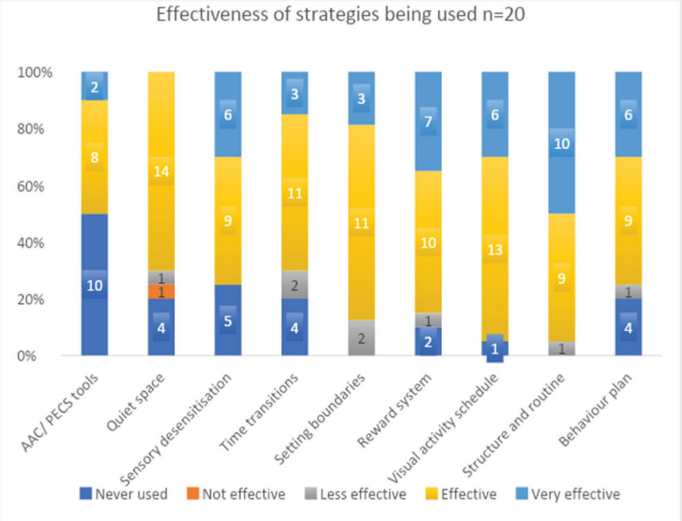
Table 1: Strategies currently used by Participants when teaching Learners with ASD

Approaches	**Strategies listed by the Participants**
Teaching materials	Colour coding questions and answers; Larger font size; Objects to manipulate; Multiple choice questions on computer; Use games; Use handouts; Use of technology; Worksheets; Visually appealing teaching aids; Videos; Music; Cartoons
Humanistic and attitudinal approaches	Treating them as individuals; Learner-centred approach; Differentiated teaching strategy for each child; Providing warning and preparation for changes; Peer-to-peer interaction; Life skills to boost confidence; Encouragement; Reward system
Structured approach	Teach at a slow pace; Small breaks in between sessions; Maintain structure and routine; Repetition; Task simplification; Providing fewer choices; Avoiding sensory overload

Participants were provided a list of strategies used by teachers when educating learners with ASD, based on published evidence, and were asked to rate the perceived effectiveness.

The rating on effectiveness of each strategy is provided in Figure 3. Fifty percent of the participants had never used Augmentative and Alternative Communication (AAC) tools such as sign language and Picture Exchange Communication Systems (PECS). However, those who had used AAC and PECS reported these strategies to be either effective or very effective at the school. Among all the listed strategies, having structure and routine was reported as the most effective approach.

Figure 3: Perceived Effectiveness of Strategies



As shown in Figure 3, most of the strategies were rated as either effective or very effective. A few participants identified some strategies such as 'Time transitions' and 'Setting boundaries' to be less effective, and only one reported that use of 'Quiet space' was not effective.

New Strategies proposed for Improving Academic Performance

Based on their experiences, participants were asked to provide new suggestions for improving academic performance among learners with ASD at the school. The responses were grouped into five areas of focus as presented in Table 2. Recommendations were made for the adoption of new strategies such as provision of therapies at the school, advocacy to raise awareness, capacity building and training for teachers on teaching learners with ASD, use of modern technology and some changes to curriculum delivery.

Table 2: Proposed New Solutions for Improving Academic Performance

Area of focus	New solutions proposed by Participants
Offer professional therapies at school	Occupational therapy; Physiotherapy; Speech and Language therapy; Applied Behavioural Analysis
Advocacy	Advocacy for the school; Advocacy for the learners; Communication with parents to encourage reading at home; Raising awareness about ASD; Cultivate a passion for reading at an early age; More interaction with mainstream students; Create a community environment
Training teachers on ASD	Staff training; Workshop for teachers on ASD; Teachers should be made aware of the needs of learners with ASD; Refresher courses for teachers; Educating the mainstream educators; Pointers on what to expect would help; Inviting visiting speakers would help
Use of technology and modern resources	Technological literacy; Colourful media; Use of media in lessons; Modern technology; More resources; Reading materials that stimulate desire to read; More specialised facilities
Curriculum delivery suggestions	Academic support programme; Bigger space and more teaching aids; Use of more teaching assistants; Improve teacher-pupil ratio; Enough learning space to accommodate learners with ASD; Improve socio-emotional learning skills; Use of textbooks tailor- made for ASD; Brief synopsis for the teacher about what each child's problem is

DISCUSSION

Autism spectrum disorder is a complex disorder and there is no single approach to meet the needs of all students with ASD. Hence, teaching strategies need to be adapted based on a student's individual needs, the resources available and the educational setting (National Institute of Mental Health, 2018). The concept of neurodiversity acknowledges that people's brains are wired differently and as a result people learn differently, especially those with developmental conditions such as ASD. The concept helps to avoid viewing ASD as pathological; instead children with ASD are viewed as having brains that think, learn and process information differently and therefore require different approaches to enhance their learning (Dwyer, 2022). This concept also allows children with ASD to view themselves in a positive way.

Findings show that a good mix of teachers participated in this study, as they were from different age groups, with varied years of teaching experience, and there was representation across age groups taught. There were more females than males, which follows the expected distribution within the school. As expected from this heterogeneous group of participants, there were different levels of knowledge about ASD. Majority had a moderate knowledge about ASD, meaning that they have some ability to support the learners. There is potential for the three teachers who had high knowledge and one teacher who had excellent knowledge to provide peer support to their colleagues with minimal or moderate knowledge. It is however, important to note that the responses were self-rated, so there is a possibility that some teachers could have either overrated or underrated their knowledge (Demetriou, 2015).

Asperger's Syndrome was commonly stated as a type of ASD. The percentage of teachers (30%) who did not know any type of ASD was higher than expected, considering that they are already teaching learners with ASD at the school. However, the DSM-V combines the different categories of autism into one umbrella (American Psychiatric Association, 2013). Down Syndrome was wrongly identified as a type of ASD; such misconceptions need to be addressed to avoid teachers using strategies that are contraindicated for children with ASD. There is a need for teachers to be educated about neurodiversity, including the different presentations of ASD, the signs and symptoms as well as the unique learning support strategies that can be used (Segall and Campbell, 2012).

A correlation can be deduced between the teachers' level of knowledge about ASD and the level of confidence when teaching children with ASD. Hart and Malian (2013) point out that teachers need to have a comprehensive knowledge of ASD disability and be able to manage the manifested overt behaviours. While the majority of the participants had moderate knowledge of ASD, the majority were fairly confident about teaching learners with ASD. Only one teacher was extremely confident about teaching learners with ASD and only one teacher reported having excellent knowledge about ASD. The teachers who reported being slightly confident or not confident imply the need for support and more knowledge to possibly increase their level of confidence when teaching learners with ASD.

Learners with ASD often present with a variety of learning challenges that interfere with their academic performance (Ruble and Robson, 2007; American Psychiatric Institution, 2013; Franz et al, 2017). Additionally, Segall and Campbell (2012) state that the realisation of inclusion in education with regard to students with ASD requires teachers to possess comprehension of ASD as well as to be thoroughly prepared to meet the needs of learners with the condition.

The challenges faced by teachers at the school when teaching learners with ASD follow the same pattern reported in literature (Leekam et al, 2011; Franz et al, 2017). The most common challenges were limited communication, inability to understand instructions and fidgeting. Furthermore, the lack of certain social skills among the learners posed a challenge to the teachers; for example, avoidance of eye contact, expressing and interpreting non-verbal communication, and emotional disturbances such as anxiety. Apart from some teachers having limited knowledge about ASD, some teachers reported finding it difficult when other students do not understand the behaviours of learners with ASD. Over 80% of the participants reported that their learners required moderate to very substantial support. This implies that the teachers need to be adequately trained and have adequate resources to provide the education required by these learners. It should be noted that there was a mention about challenges of dealing with disagreements between parents and teachers.

Different professional therapies are known to help learners with ASD to manage self-regulation, improve communication and acquire new skills (Edwards et al, 2018; Hatch-Rasmussen, 2021; McAnuff et al, 2023). The availability of such therapies within the school could be of valuable support to the learners and teachers alike. Most of the strategies currently being used at the school relate to visual teaching materials such as use of colour coding, objects, videos, and worksheets. The teachers also value approaches that focus on life skills and respecting each child as an individual. This aligns well with the concept of neurodiversity. The academic performance of students with ASD is highly dependent on the extent to which the educational programme can be individualised (Lynch and Irvine, 2009).

Providing structured learning such as the use of small breaks, maintaining routine, slow pace, and task simplification are some approaches that are commonly used. There were varied strategies reported by the teachers; this is to be expected, as each learner with ASD is a unique individual and there cannot be a one-size-fits-all approach in teaching them. This means that enhancing academic performance among learners with ASD would require a combination of strategies.

A wide range of suggestions for improving academic performance among learners with ASD was proposed by the teachers. However, some of the suggestions were not new as other teachers had reported having used them and rated their perceived effectiveness. Apparently some teachers were unaware of the strategies that other teachers at the school were employing. This could be linked with the variance in knowledge levels among the teachers. These approaches were mainly Augmentative and Alternative Communication tools, sign language and Picture Exchange Communication System, sensory desensitisation, and behaviour plans. All teachers had used 'Setting boundaries' as well as 'Structured routines'; these were mainly rated as effective or very effective. Despite many strategies being rated as effective, it should be noted that effectiveness depends on the learner's uniqueness and knowledge, and skills of the teachers on these strategies (Dwyer, 2022).

The proposed strategies show that teachers consider other broad factors to have an impact on the learners' academic performance, and need aspects such as advocacy and awareness-raising to be addressed. There was a significant call for teachers to be provided with training about ASD, and this links well with the findings on their knowledge and confidence levels when teaching learners with ASD. Steen et al (2020)alluded to the fact that it is essential to provide teachers with adequate support so that they are able to meet the needs of their learners with ASD.

Offering of professional services such as occupational therapy, physiotherapy and speech and language therapy within the school could enhance learning and also help teachers to know the different ways to support their learners with ASD using direct and specific advice from the therapists (McAnuff et al, 2023). This approach could also be helpful in maintaining daily school routines for the learners, without the need to go for therapy appointments away from the school. Participants suggested the use of modern technology but did not specify the type of modern technology or facilities they meant. Important curriculum delivery suggestions were provided, as for example, the introduction of an academic support programme also known as an individual education plan, which helps to ensure that each learner is provided with optimal support to realise his/her full learning potential.

Implications and Limitations

The study results imply a significant need for the teachers to be trained on ASD and for the learners with ASD to be better supported in order to enhance their academic performance. Many strategies have been rated as effective but, considering that learners are different, the strategies need to be appropriate for each individual learner. In addition, all teachers were not familiar with all strategies so the effectiveness of the strategies could not have been fully examined.

Generalisation of the findings from the study could be limited. The study focused on one private high school in an urban area which cannot be considered a true representation of all schools in Zimbabwe or elsewhere. Nevertheless, the study adds to the currently slender body of knowledge on education of learners with ASD in Zimbabwe and other developing countries.

CONCLUSION

The study has clearly shown that teachers at the school are using a wide range of strategies to support learners with ASD, despite some teachers feeling less confident and having moderate knowledge about ASD. Given their understanding of the setting and awareness of the needs of the students that they support, the teachers have identified new approaches that could potentially ensure enhanced academic performance of learners with ASD. Introduction and consistent implementation of individualised academic support programmes or individual education plans could enable streamlining the support provided to learners with ASD in the school.

REFERENCES

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

Chitiyo J, Chitiyo A (2019). Autism Spectrum Disorder in Zimbabwe: A Brief Review of Trends, Conditions, Challenges, and Intervention Practices.

Chitiyo M, Zekele W, Mutemeri A, Dzenga C G, Siddiq S A, Chen X (2017). 'Views of Zimbabwean parents of children with autism in relation to the process of diagnosis and access to services,' African Journal of Educational Research, 29(3), 33

Demetriou C, Ozer B U , Essau C A (2015). Self-Report Questionnaires. The Encyclopedia of Clinical Psychology. John Wiley & Sons, Inc., 1–6. DOI: 10.1002/9781118625392.wbecp507

Dwyer P (2022). The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers? Hum Dev. 66(2):73-92. doi: 10.1159/000523723. Epub 2022 Feb 22. PMID: 36158596; PMCID: PMC9261839.

Edwards C K, Landa R K, Frampton S E, Shillingsburg M A (2018). Increasing Functional Leisure Engagement for Children with Autism Using Backward Chaining in Behaviour Modification, 42(1), 9–33. https://doi.org/10.1177/0145445517699929

Fleury V P, Hedges S, Hume K, Browder D M, Thompson J L, Fallin K, Zein F E, Reutebuch C K, &amp, Vaughn S (2014). Addressing the academic needs of adolescents with Autism Spectrum Disorder in secondary education. Remedial and Special Education, 35(2), 68–79. https://doi.org/10.1177/0741932513518823

Franz L, Chambers N, von Isenburg M, de Vries P J (2017). Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism research: Official Journal of the International Society for Autism Research, 10(5), 723–749. https://doi.org/10.1002/aur.1766

Hart JE, Malian I (2013). A state-wide survey of special education directors on teacher preparation and licensure requirements in autism spectrum.

Hatch-Rasmussen C (2021). Sensory Integration in Autism Spectrum Disorders | Autism

Research Institute. Autism Research Institute. https://www.autism.org/sensory-integration/

Leekam S R, Prior M R, Uljarevic M (2011). Restricted and repetitive behaviours in autism spectrum disorders: A review of research in the last decade. Psychological Bulletin, 137, 562–593. doi:10.1037/a0023341

Lynch S L, Irvine A N (2009). Inclusive education and best practice for children with autism spectrum disorder: An integrated approach. International Journal of Inclusive Education, 13, 845-859. doi: 10.1080/13603110802475518

Majoko T (2016). Inclusion of children with autism spectrum disorders: Listening and hearing to voices from the grassroots. Journal of Autism and Developmental Disorders, 46(4), 1429-114

McAnuff J, Gibson JL, Webster R, Kaur-Bola K, Crombie S, Grayston A, Pennington L (2023). School-based allied health interventions for children and young people affected by neurodisability: a systematic evidence map, Disability and Rehabilitation, 45:7, 1239-1257, DOI: 10.1080/09638288.2022.2059113

National Institute of Mental Health (2018). Autism Spectrum Disorder. https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd

Ruble L A, Robson D M (2007). Individual and environmental determinants of engagement in autism. Journal of Autism and Related Disabilities, 37, 1457–1468. doi: 10.1007/s10803-006-0222-y

Segall MJ, Campbell JM (2012). Factors relating to education professionals' classroom practices for the inclusion of students with autism spectrum disorders. Research in Autism Spectrum Disorders, 6, 1156-1167.

Setia MS (2016). Methodology Series Module 3: Cross-sectional Studies. Indian J Dermatol. 61(3):261-4. doi: 10.4103/0019-5154.182410. PMID: 27293245; PMCID: PMC4885177.

Steen van der S, Geveke C, Steenbakkers A, Steenbeek H (2020). Teaching students with Autism Spectrum Disorders: What are the needs of educational professionals? Teaching and Teacher Education, 90, [103036]. https://doi.org/10.1016/j.tate.2020.103036

Wang X, Cheng Z (2020). Cross-Sectional Studies: Strengths, Weaknesses, and Recommendations Chest. 158(1S):S65-S71. doi: 10.1016/j.chest.2020.03.012. PMID:32658654.

REVIEWS

'Manasadhara': a Day-Care Rehabilitation Programme for Persons with Mental Disorders in South India

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ABSTRACT

Purpose: *Started in 2014, the Manasadhara programme in Karnataka State, South India, offers community-based psychiatric rehabilitation services (PRS) through day-care centres. Although funded by the Health and Family Welfare Services (H&FWS) of the State government, little research has been conducted on the need, scope and challenges the programme faces. The present study aimed to understand challenges related to the psychiatric rehabilitation services delivery and the beneficial effects of the Manasadhara programme on service users.*

Method: *Various government documents that were available to the public were reviewed, concerning the funding and the number of service users. The authors relied on their personal experience of supervising the PRS delivery at one day-care centre for 18 months, in collaboration with the HDK. The experiential accounts of the staff at the centre were also noted.*

Results: *The Health and Family Welfare Services spends INR 16,14,000 (US$ 19,834) per annum per centre. Implementing this programme across the State costs INR 48,420,000 (US $ 595,022) per annum. Data suggests that INR 73.1 million (US $ 9 million) was spent between 2014 and 2020. The authors observed a range of beneficial effects to persons with mental disorders availing of day-care services, and to their family caregivers.*

Conclusion: *The Manasadhara programme appears to offer structured engagement and rehabilitation services for those who are able to access it. However further methodical research is required.*

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Key words: *day-care, mental disorder, rehabilitation, community-based*

INTRODUCTION

Day hospital, day services, day treatment, day centres and day programmes are terms used to describe a range of outpatient treatment interventions for persons with mental disorders (Matzner et al, 1998; Marshall et al, 2001; Weir & Bidwell, 2000). However, more recently, day-care centres (DCCs) for persons with mental disorders are equated to places to keep them engaged in meaningful and stimulating activities by mental health professionals during day time (Bright et al, 2015); places that they can visit voluntarily from their homes whenever they choose to. Engagement of persons with mental disorders at day-care centres differs from the clubhouse model for them (Bouvet et al, 2015), in which the aim is to support the individuals in finding jobs. Structured occupation therapy at day-care centres is reported to reduce readmission in persons with severe mental disorders (Yoshimasu et al, 2002; Engelbrecht et al, 2019). Self-esteem and quality of life in persons with schizophrenia improved after attending rehabilitation programmes at a day-care centre (Štrkalj-Ivezić et al, 2013). Structured engagement of persons with mental disorders at day-care centres is reported to positively affect the emotional well-being of these individuals and their caregivers (Makharadze et al, 2010; Agarwal et al, 2015; Strandenæs et al, 2018 ; Rokstad et al, 2019). Similarly, engaging older people at day-care centres reduces stress in their caregivers (Zarit et al, 2011). This may be due to increased personal time and space for the family caregivers while the elderly are kept engaged.

The range of beneficial effects to persons with mental disorders who attend day-care centres depends on various influencers. Less psychopathology was associated with better occupational engagement (Tjörnstrand et al, 2015). Even so, the transition back into the community is challenging. Worries about potential challenges for transitioning into a community-based workplace are reported by some, even after engaging at a day-care centre for about six years (Phutane et al, 2012). From this it is evident that structured engagement of persons with mental disorders at day-care centres, under the supervision of mental health professionals, is likely to improve their self-esteem and well-being. An additional and extended benefit observed is the reduction in caregiver stress. Possibly, acknowledging the importance of this, the Indian Mental Health Care Act (MHCA) 2017, Sections 18 and 19, mandates that governments establish appropriate community-based day-care centres and other necessary mental health services for the care of persons with mental disorders (Mental Health Care Act, 2017).

In 2014, to improve community-based rehabilitation (CBR) in the mental health sector, the Karnataka Health and Family Welfare Services started a State-funded programme titled “Manasadhara”, with a vision to establish at least one day-care centre (DCC) per district (About Mental Health Programme in Karnataka - National Mental Health Programme 2022). Karnataka is a South Indian State, estimated to have a population of 61 million spread across 30 districts, with significant variations in the spread. While Kodagu district is spread across 4100 square kilometres and has only about 600,000 people, Bengaluru district which is spread across 2196 square kilometres has about 10 million people (Karnataka Population Sex Ratio in Karnataka Literacy Rate Data 2011-2022). One credible Non-governmental Organisation (NGO) in each district is selected by a committee chaired by the District Commissioner, to run this programme. A district project officer (DPO) from the Health and Family Welfare Services (H&FWS) would supervise the quality of programme implementation by the NGO. NGOs offering day-care psychiatric rehabilitation services (PRS) under Manasadhara would be reimbursed an amount of up to Indian Rupees (INR) 134,500 (approximately equivalent to US $1654) per month, corresponding to INR 16,14,000 (US $19,834) per annum per centre. Implementation of this programme across the State costs the exchequer INR 48,420,000 (US $595,022) per annum. Systematic examination of the implementation of Manasadhara offers insights into its usefulness to mental health and rehabilitation professionals. The information and evidence obtained has implications for public health policy and funding. The government orders for implementation of the Manasadhara programme indicate that a maximum number of 6 staff may be recruited per centre; each enrolled person with mental disorders should not be engaged for more than three months continuously; and the budgetary grant towards the recurring expenditure would be offered to the NGOs only on a reimbursement basis under various heads, as described below in Table 1.

Table 1: Budget Allocation under the Manasadhara Programme, including Staff Salaries

	Staff, infrastructure and budget allowed for the recurring expenses	**Allocated maximum budget per month in Indian Rupees (US $)**
1	One social worker salary	15,000 INR (184.3 US $)
2	Transport allowance for social worker	5,000 INR (61.4 US $)
3	Staff nurse or occupational therapist or physiotherapist salary: only one staff member can be recruited in centres that have less than 25 service users	12,000 INR (147.5 US $) per staff & 24,000 INR (295 US $) for two persons

4	Housemaid or Ayah honorarium	6,000 INR (73.7 US $)
5	Security honorarium	6,000 INR (73.7 US $)
6	Rent for the building, Maintenance of building (including electricity, telephone charges, etc)	20,000 INR (245.8 US $)
7	Food and refreshments for service users	30,000 INR (368.7 US $)
8	Transport of service users	20,000 INR (245.8 US $)
9	Recreational needs or services	3,000 INR (36.8 US $)
10	Medicines	500 INR (6.1 US $)
	Total (maximum)	134,500 INR (1654 US $)

Considering the potential usefulness in improving the functionality of persons with mental disorders through occupational engagement under Manasadhara and the mandate for establishing similar centres under the MHC Act 2017, there are as yet only a limited number of such centres across the country. However, it is essential to examine the implementation and usefulness of this programme to service users as this is associated with a significant amount of funding to the State government, i.e., about INR 45 million (US $ 552,984) every year.

Objective

The study aimed to investigate the utilisation of the Manasadhara programme by persons with mental disorders, to learn about the quality of service delivery from the experiential accounts of the staff, and to understand the practical and administrative challenges involved in running this programme.

METHOD

Study Setting

Three authors supervised the running of one Manasadhara day-care centre in Chikkaballapur District of Karnataka. Synthesis of information is based on their observations after supervising the Manasadhara programme for 18 months (April 2019 - September 2020).

The Covid-19 pandemic shutdown impacted the functioning of the day-care centres. As psychiatric rehabilitation day-care centres were considered non-essential services, the centre was closed in September 2020.

Data Collection

A series of interactions with the Chikkaballapur day-care centre staff elicited their observations about the utility of the day-care centre's services to persons with mental disorders and their family caregivers, and their experiential accounts of challenges for the delivery of services. The authors also recorded their own observations on the recruited staff's motivation to work, and their competencies in delivering services.

To understand more about these issues, during a state-wide meeting organised by the Health and Family Welfare Services, the authors interacted with staff members working in other day-care centres. Information on Manasadhara implementation, the budget spent, number of service receivers, etc., was obtained from the Karnataka State Health and Family Welfare Services which maintains this data.

Ethics Approval

Permission to conduct the study was obtained from the National Institute of Mental Health and Neurosciences (NIMHANS) Ethics Committee.

RESULTS

Table 2: Year-wise Budget granted and spent for this Programme by Karnataka Government

S. No.	Financial Year	Number of districts with DCCs	Number of persons with mental disorders attending DCCs across the State	Approved budget in millions of INR	Spent budget in millions of INR	Estimated budget spent per person with mental disorders in INR (US $)
1	2016-17	14	2175	24.3	17.8	8,133 (100)
2	2017-18	14	1439	18.0	17.1	11,883 (146)
3	2018-19	13	1605	24.3	13.8	8,598 (105)
4	2019-20	17	2084	25.8	14.2	6,814 (84)
5	2020-21	15	385	25.8	3.5	9,090 (111)
	Total/ Average	-	7,688	128.3	73.1	8,903 (109)

DCC = Day-care Centre; INR = Indian Rupee; US $ = United States of America dollar

As described in Table 2, the Health and Family Welfare Services allocated INR 128.8 million (US $ 1.58 million) and spent an amount of INR 73.1 million (US $ 9 million) on providing day-care services to 8903 persons with mental disorders, from 2014-2020. On average, Health and Family Welfare Services spent INR 8903 (US $ 109) per person with mental disorders, with amounts ranging from INR 6814 (US $ 84) to INR 11,883 (US $ 146) per person.

Table 3: Observed Beneficial Effects of Engaging Persons with Mental Disorders at Manasadhara

S. No.	Stakeholders	Method of Data Collection	Observed Impact
1	Beneficial effects to persons with mental disorders	Direct observation by the investigators	1. Offers a structure to the day and a purpose to spend time beyond their homes with rehabilitation professionals. 2. Offers them a sense of attending a workplace on par with others.
		Interaction with Manasadhara staff, persons with mental disorders and their family caregivers	1. Improves socialisation and socially appropriate conversational abilities. 2. Improves self-esteem. 3. Improves workplace behaviour. 4. Improves compliance with medication. Some persons with mental disorders consume medication at the day-care centre under the supervision of the nurse. 5. Improves follow-up rates with treating psychiatrists following the prompts by PRDCC staff.
2	Beneficial effects to the family caregivers of persons with mental disorders	Direct observation by the investigators	1. Offers respite care, personal space and time. 2. Reduces the facial contact and interaction time between persons with severe mental disorders and their family members, possibly influencing the negatively expressed emotions. 3. It helps them identify with others with similar mental health problems.
		Interaction with Manasadhara staff, persons with mental disorders and their family caregivers	1. Increases interaction with mental health professionals to find solutions related to the dysfunctionality in persons with severe mental disorders. 2. Increases awareness about disabling impacts of mental illness by observing other clients. 3. Interaction and identification with similar family caregivers. 4. Improves knowledge and awareness about disability certification and access to disability welfare benefits.

Table 4: Challenges in Delivering Services under Manasadhara

S. No.	Method of Data Collection	Observed/ Reported Challenges
1	Direct observation by the investigators	1. Staff recruited are less likely to have prior training/ work experience in engaging persons with mental disorders in day-care settings. 2. Lack of formal induction training and materials for the staff on "how to engage persons with mental disorders at day-care centres?" 3. Poor expertise and competencies of recruited nursing staff/ social workers for engaging persons with mental disorders. 4. Limitation in the range of stimulating activities that may be offered. Only simple exercises, play, recreational activities, art and craft activities, paper cover making, etc., are offered. Staff nurses and social workers have to learn skills for engaging persons with mental disorders. 5. Recruiting and retaining the staff who can do task shifting, due to less attractive salaries. 6. Task shifting is needed during the leave of absence of some staff. 7. Reluctance of family caregivers to send persons with mental disorders to PRDCC without dedicated and free transport. 8. Observed need for engaging persons with mental disorders at PRDCCs for a longer duration to improve their day structure and work behaviour, in contrast to laid-down regulation under Manasadhara that each person with mental disorders should not be engaged for more than three months. 9. Staff's poor motivation to continue under this programme due to poor scope for their career progression. 10. Access and ease of travel to the PRDCC location.

As detailed in Table 3, the authors observed various beneficial effects on persons with mental disorders and their family caregivers while the former were attending day-care services. Within a few weeks of enrolling the persons with mental disorders at PRDCC, their caregivers and staff observed a significant change in the daily routine. Persons with mental disorders were keen on getting ready in the morning to reach the centre on all working days and were interested in spending time there. Activities at this centre start with simple group exercises. This is followed by newspaper reading, paper cover making, colouring the page activities, play activities, and group interactions with staff on day-to-day and social issues in the community. The staff reported that engaging persons with mental disorders in a non-judgmental environment at PRDCC and appreciating their participation was a critical determinant of their interest in visiting the centre.

At the day-care centre the nurse would monitor their medication adherence and next appointment with the psychiatrist, and would coordinate their consultations when the need arose. The social work professional would explore the individual strengths, challenges, ambitions, past work experiences, and familial, social and economic background to discuss an individually- tailored rehabilitation plan.

Family caregivers often accompany the persons with mental disorders to drop them off and interact with the staff about their concerns. Within a few weeks of regular engagement of persons with mental disorders at the centre, several caregivers reported that they had some respite, and were happy to have some space and time to themselves while their family member was occupied at the centre. Interaction with the staff increased the caregivers' awareness about disability certification for persons with mental disorders and about various disability welfare benefits under the department of social justice. Family caregivers also reported improvement in their ward's motivation to dress appropriately and observe hygiene. A few caregivers observed that there was a reduction in behavioural issues like verbal aggression against caregivers and non-cooperation in completing household chores assigned to them, and a few caregivers said that attending PRDCC offered their person with mental disorders a purpose to go out of the house, equating it to attending formal work.

DISCUSSION

Overall, psychiatric rehabilitation services under Manasadhara is somewhat similar to a programme operational in Kerala, another Indian state (Swayamprabha, 2019). Money spent by the Health and Family Welfare Services suggests that community-based psychiatric rehabilitation is considered to be an integral part of mental health care by the Health Department. The intention of the government to offer psychiatric rehabilitation services as part of community-based mental health care deserves appreciation. The difference between the allocated budget and spent budget, as summarised in Table 2, is due to variability in the number of PRDCCs operational in a year. While there were only nine in 2014, a maximum of 17 were offering psychiatric rehabilitation services in 2019.It is unclear why the PRDCCs were not functional in all the 30 districts of Karnataka, which could have led to more service utilisation and expenditure of all the allocated budget. It is possible that either NGOs were not available to partner with the Health and Family Welfare Services in some districts. The impact of Covid-19 on the utilisation of Manasadhara has been felt across the State, as described in Table

2, and there has been a seven-fold reduction in the number of service users – dropping from 2084 in 2019/20 to 385 in 2020/21.

The staff and a few caregivers of service users attending the PRDCC informed the authors that the poor availability of logistic support is an area of concern, making it difficult to attend the PRDCC on a regular basis as per the timings of the centre. A range of observed beneficial effects to the service users availing of psychiatric rehabilitation services at the State-funded PRDCC are summarised in Table 3. The authors observed an improvement in the day structure of service users within a few weeks of their enrolment, with regard to their socialisation, interest in attending the centre, and improved medication compliance. During the informal information-gathering meetings, these observations were corroborated by the staff working at the day-care centre. Another observed benefit was the respite afforded to the caregivers when their persons with mental disorders were engaged at the PRDCC. Informal interactions with some of the caregivers and PRDCC staff further revealed that family caregivers had more time for themselves and were able to look after other family responsibilities. However, these observations need to be confirmed further by in-depth qualitative interviews and follow-up research.

During supervision of the service delivery at one PRDCC in partnership with the Health and Family Welfare Services, the authors observed a series of challenges for quality psychiatric rehabilitation services delivery under the Manasadhara programme. The recruited staff were qualified nurses and social workers, but without any formal exposure and training in the area of mental health care and psychiatric rehabilitation. The authors therefore facilitated a three-day observation session for the Chikkaballapur day-care centre staff at the day-care centre for persons with mental disorders operated by the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore. A few sessions on the role of day-care services in improving the functionality of persons with mental disorders, and "how to engage persons with mental disorders at the day-care centre" by NIMHANS mental health professionals, were reported to be immensely useful. Subsequently the authors observed a significant change in the approach and strategies used by the staff. Lack of any developed manuals or structured induction training programmes for the recruited and inexperienced staff can be a significant limitation to maintain the quality and uniformity in the psychiatric rehabilitation services delivered through PRDCC.

Another challenge that was observed was task shifting, as these centres had limited human resources. Since there are only two professional staff available at the centre, whenever either the nurse or the social worker was absent, task shifting and fulfilling the responsibilities of the absentee was observed to be a significant challenge.

Staff at Chikkaballapur and other centres, in their informal interactions with the authors, reported reluctance and poor motivation to work at PRDCC in the long term, citing less attractive wages, the contractual nature of jobs with poor job security, and poor scope for career progression. As psychiatric rehabilitation services delivery requires a reasonable amount of expertise and experience, attrition of experienced staff like social workers and nurses, and recruitment of new staff can interfere with the quality of service delivery. However, some staff reported their desire to continue despite low wages, due to work satisfaction and the feeling that they are part of a process aimed at improving the functionality of persons with mental disorders.

Limitations of the Study

The observations made after supervising one PRDCC cannot be generalised. Recollection of the authors' experiential accounts could be prone to recall and selection bias. There is also the possibility that staff could have highlighted the beneficial effects of attendance at the day-care centres while minimising the lack of improvement in the persons with mental disorders. The authors' observations have not been substantiated by the staff, persons with mental disorders and their family caregivers through a systematic research.

Strengths of the Study

This report is the first of its kind on a publicly-funded community-based mental health care rehabilitation programme for persons with mental disorders, on which millions of rupees are being spent by the Health and Family Welfare Services of Karnataka. The authors had first-hand experience in observing the running of a PRDCC under Manasadhara for 18 months. Their observations suggest that psychiatric rehabilitation services delivered through day-care centres have a range of positive public mental health implications but more methodical research is required.

CONCLUSION

Health and Family Welfare Services of Karnataka spent INR 73.1 million (US $ 9 million) on providing day-care services to 7688 persons with mental disorders for six years, with an average expenditure of INR 8,903 (US $ 109) per service user. Overall, this programme helps meet the mental health care needs of a proportion of persons with mental disorders whose day structure is poorly organised and who are not otherwise engaged in any occupational activity. Engaging persons with mental disorders at PRDCCs offers respite to their family caregivers. Guidelines for running PRDCCs, systemic support to the recruited staff at the time of their recruitment and throughout their tenure, and logistic challenges at a few centres are the areas that require attention in order to increase the reach and utilisation of this programme. Beneficial effects to the persons with mental disorders who avail of day-care services, and to their family caregivers as reported by the day-care centre staff, add preliminary evidence to support funding for the programme. It is also essential to develop training materials and modules for the recruited staff.

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The authors declare there is no conflict of interest.

REFERENCES

About Mental Health Programme in Karnataka—National Mental Health Programme. (2022.). Retrieved 22 July 2022, from https://mentalhealth.karnataka.gov.in/new-page/About%20Mental%20Health%20Programme%20In%20Karnataka/en

Agarwal AK, Rai S, Upreti MC, Srivastava A K, Sheeba (2015). Day-care as an innovative approach in psychiatry: Analysis of Lucknow experience. Indian Journal of Psychiatry, 57(2), 162–164. https://doi.org/10.4103/0019-5545.158157

Bouvet C, Battin C, Le Roy-Hatala C (2015). The Clubhouse model for people with severe mental illnesses: Literature review and French experiment. L’Encephale, 41(6), 477–486. https://doi.org/10.1016/j.encep.2014.09.001

Bright FAS, Kayes N M, Worrall L, McPherson K M (2015). A conceptual review of engagement in healthcare and rehabilitation. Disability and Rehabilitation, 37(8), 643–654. https://doi.org/10.3109/09638288.2014.933899

Engelbrecht R, Plastow N, Botha U, Niehaus D, Koen L (2019). The effect of an occupational therapy mental health day treatment centre on the use of inpatient services in the Western Cape, South Africa. Disability and Rehabilitation, 41(16), 1974–1980. https://doi.org/10.1080/09638288.2018.1453873

Karnataka Population Sex Ratio in Karnataka Literacy rate data 2011-2022 (2022). Retrieved 24 September 2022, from https://www.census2011.co.in/census/state/karnataka.html

Makharadze T, Kitiashvili A, Bricout J C (2010). Community-based day-care services for people with intellectual disabilities in Georgia: A step towards their social integration. Journal of Intellectual Disabilities: JOID, 14(4), 289–301. https://doi.org/10.1177/1744629510393186

Marshall M, Crowther R, Almaraz-Serrano A, Creed F, Sledge W, Kluiter H, Tyrer P (2001). Systematic reviews of the effectiveness of day care for people with severe mental disorders: (1) acute day hospital versus admission; (2) vocational rehabilitation; (3) day hospital versus outpatient care. Health Technology Assessment (Winchester, England), 5(21), 1–75. https://doi.org/10.3310/hta5210

Matzner FJ, Silvan M, Silva RR, Weiner J, Bendo J, Alpert M (1998). Intensive day program for psychiatrically disturbed truant adolescents. The American Journal of Orthopsychiatry, 68(1), 135–141. https://doi.org/10.1037/h0080278

Mental Health Care Act, 2017 (2017). Ministry of Law and Justice. Retrieved 24 September 2022, from https://egazette.nic.in/WriteReadData/2017/175248.pdf

Phutane V H, Thirthalli J, Sivakumar P T, Mathew V, Kumar A, Antony A, Gangadhar B N (2012). Barriers to discharge of patients from a government-run day-care psychiatric rehabilitation center in India. Asian Journal of Psychiatry, 5(1), 34–37. https://doi.org/10.1016/j.ajp.2011.11.010

Rokstad AM M, McCabe L, Robertson JM., Strandenæs MG, Tretteteig S, Vatne S (2019). Day Care for People with Dementia: A Qualitative Study Comparing Experiences from Norway and Scotland. Dementia (London, England), 18(4), 1393–1409. https://doi.org/10.1177/1471301217712796

Sayamaprabha major initiatives 2018-19 (2019). Social justice department, Government of Kerala. Retrieved from http://sjd.kerala.gov.in/DOCUMENTS/Downloadables/IEC_Materials/30791.pdf

Strandenæs M G, Lund A, Rokstad AMM (2018). Experiences of attending day care services designed for people with dementia—A qualitative study with individual interviews. Aging & Mental Health, 22(6), 764–772. https://doi.org/10.1080/13607863.2017.1304892

Štrkalj-Ivezić S, Vrdoljak M, Mužinić L, Agius M (2013). The impact of a rehabilitation day centre program for persons suffering from schizophrenia on quality of life, social functioning and self-esteem. PsychiatriaDanubina, 25 Suppl 2, S194-199.

Tjörnstrand C, Bejerholm U, Eklund M (2015). Factors influencing occupational engagement in day centres for people with psychiatric disabilities. Community Mental Health Journal, 51(1), 48–53. https://doi.org/10.1007/s10597-014-9765-0

Weir RP, Bidwell SR (2000). Therapeutic day programs in the treatment of adolescents with mental illness. The Australian and New Zealand Journal of Psychiatry, 34(2), 264–270. https://doi.org/10.1080/j.1440-1614.2000.00722.x

Yoshimasu K, Kiyohara C, Ohkuma K (2002). Efficacy of day care treatment against readmission in patients with schizophrenia: A comparison between out-patients with and without day care treatment. Psychiatry and Clinical Neurosciences, 56(4), 397–401. https://doi.org/10.1046/j.1440-1819.2002.01028.x

Zarit SH, Kim K, Femia E E, Almeida DM, Savla J, Molenaar PCM (2011). Effects of adult day care on daily stress of caregivers: A within-person approach. The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 66(5), 538–546. https://doi.org/10.1093/geronb/gbr030

New Horizons in Addressing Fear of Falling among the Elderly: a Narrative Review

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ABSTRACT

Purpose: *Fear of falling is experienced by a sizeable percentage of the elderly, a segment of the population that is increasing in most of the countries across the world. A review was therefore undertaken of the current literature on fear of falling, evaluation and management of this fear.*

Method*: Extensive literature search was conducted in PubMed, Science Direct, and Ovid databases, using the keywords 'Fear of Falling', 'Fall Fear', 'Fall Efficacy', 'Elderly', 'Senior', 'Older', and 'Elders', in various combinations. The search was restricted to articles in the English language, published between 2016 and 2021.*

Results: *Out of 478 retrieved articles, only 46 met the inclusion criteria of the current review. The abstracts were reviewed initially and the studies which met the inclusion criteria were then used for the review.*

Conclusion: *Fear of falling is reported by up to 65% of the non-fallers and 92% of fallers among the elderly. Fear of falling arises due to various biopsychosocial factors. The measuring tools are classified into those that measure fear of falling and those measuring fall efficacy. The two main management strategies are physical interventions and psychological interventions, and a combination of these two interventions is more effective in the management of fear of falling.*

Key words: *evaluation, management, fall, fall efficacy, aged*

INTRODUCTION

By 2020 the number of elderly persons above 60 years of age will outnumber the number of children below 5 years old in the world. The proportion of elderly

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in the world population will increase to 22% by 2050, with 80% of them living in low-and middle-income countries like India (World Health Organisation, 2018). Concerns about falls, also known as fear of falling, are common among community-dwelling elderly, with prevalence reportedly as high as 50% regardless of the fall history (Dorresteijn et al, 2016).Fear of falling is reported by up to 65% of non-fallers and 92% of fallers among the elderly (Chen et al, 2019). The level of fear of fall is reported to be higher among elderly women (Schoene et al, 2019), with a fear of falling prevalence rate of 63% reported among the elderly who sustained a hip fracture (Visschedijk et al, 2013). According to reports, fear of falling is high among people with neurological conditions, with 67% found among persons with stroke, 59% among persons with Parkinson’s Disease, 64% among persons with Multiple Sclerosis, and 46% among persons with spinal cord injury (Peterson et al, 2007; Grimbergen et al, 2013; Schmid et al, 2015; Butler Forslund et al, 2019).

Objective

Fear of falling is a modifiable risk factor restricting mobility among the elderly (Chen et al, 2019). It is therefore of paramount importance to understand fear of falling, its causes, methods of identification, and intervention strategies. The current review aimed to do this.

METHOD

Extensive literature search was conducted in PubMed, Science Direct, and Ovid databases, with keywords ‘Fear of Falling’, ‘Fall Fear’, ‘Fall Efficacy’, ‘Elderly’, ‘Senior’, ‘Older’, and ‘Elders’ used in various combinations. The search was restricted to articles in the English language, published between 2016 and 2021.

RESULTS

Of the 478 articles retrieved, only 46 met the inclusion criteria of the current review. The abstracts were reviewed initially and the full texts of the studies which met the inclusion criteria were used for the preparation of the review.

DISCUSSION

This review discusses the current understanding of fear of falling, the factors contributing to it, the negative consequences of fear of falling, the tools and techniques used for evaluating fear of falling and various management strategies.

Fear of Falling

Fear of falling is an umbrella term for the psychological and social consequences of falls. It is a significant and common predictor of future falls (Adams et al, 2018). It was initially reported as a fear-related "Post Fall Syndrome" (Schoene et al, 2019) because in the early days it was felt that it was experienced only by those who fell; later it was realised that even those who had not fallen experience fear of falling. Hence, the term "Post Fall Syndrome" is no longer in use. It is also suggested that fear of falling may be like any other fear or a reflection of generalised anxiety reported among the elderly (Schoene et al, 2014).

Defining Fear of Falling

Fear of falling is defined as "a lasting concern about falling that leads to an individual avoiding activities that he/she remains capable of performing" (Tinetti & Powell, 1993). It is fearful anticipation of falls (Liu et al, 2018). Fear of falling can also be defined as the "apprehension felt when a person senses the potential or immediate threat of sustaining a fall" (Payette et al, 2016). Another definition is, "a persistent feeling related to the risk of falling during one or more activities of daily living" (Kumar et al, 2016).

Fear of Falling and Fall Efficacy

Fear of falling and fall efficacy are often considered to be the same. Yet, they are described as distinct but related independent entities. Fall efficacy is described as a more sophisticated operationalisation of fear of falling (Adamczewska & Nyman, 2018). It is related to one's perceived ability to undertake activities without falling. A higher level of fear of falling leads to low fall efficacy (Adamczewska & Nyman, 2018).

Negative Effects of Fear of Falling

Negative effects of fear of falling include loss of balance confidence, reduced balance performance, fear-avoidance behaviour, social isolation, self-imposed activity restriction, depression, anxiety, physical frailty, falls, increased dependence, reduced quality of life, and risk of institutionalisation (Dorresteijn et al, 2016; Adams et al, 2018; Liu et al, 2018; Schoene et al, 2019). Thus fear of falling has many physical and psychological consequences.

Emotions like fear and balance control are closely related and any upset to this leads to maladaptive avoidance behaviours. Fear of falling has a negative influence on bodily reflexes and behaviour leading to balance impairment during ambulation and transferring activities, thus increasing fall risk (Hadjistavropoulos et al, 2011; Payette et al, 2016). The fear of falling and related maladaptive reflexes and behaviours are exaggerated when anxiety and cognitive demand increase. A strong association of fear of falling was seen with physical function, physical mobility, body pain, and general health perceptions (Schoene et al, 2019).Besides, these physical components are closely related to the quality of life. Elderly persons with poor physical functioning are found to have low health-related quality of life and fear of falling (Li et al, 2014; Esbrí-Víctor et al, 2017).

Causes of Fear of Falling

Fear of falling is caused by various biopsychosocial factors like previous falls, diminished gait speed, balance impairment, functional limitations in activities of living, polypharmacy, low self-rated health, poor life satisfaction, and depression (Chua et al, 2019). A proposed psychological concept is related to the maladaptive "stiffening strategy" adopted by the elderly. There occurs reflexive co-contraction of tibialis anterior, gastrocnemius, and soleus resulting in the low amplitude of ankle movements and increased postural sway. The difficulties are enhanced when simultaneous cognitive demand is present (Young & Williams, 2015). A visual behaviour change in the elderly has been linked to increased fear of falling. It was found that the elderly with high fear of falling tend to look away from the area intended for foot placement 400ms before the foot contacts the target area (Young & Williams, 2015). This premature gaze transfer may be due to age-related deterioration in the central nervous system processing. Another concept proposed to explain the development of fear of falling is "re-investment". In motor control development, earlier phases of motor task learning need significant cognitive involvement. Later, the cognitive involvement gets reduced as the motor task improves. However, in the elderly, due to fall-related concerns, the reverse happens; they start to invest more cognitive involvement in motor tasks that have become subconscious (Masters & Maxwell, 2008).

Balance impairment develops in the elderly as a result of age-related deterioration of sensory systems, sedentary life, obesity, and physical limitations (Montero-Alía et al, 2016). Visual impairment is one of the independent risk factors for falls. Poor visual acuity, depth perception, contrast sensitivity, and reduced visual field are the common visual impairments leading to falls and fear of falling (Adams et al, 2018). Inactivity is recognised as a strong predictor of physical disability (de Carvalho Fonseca et al, 2018).

Evaluation of Fear of Falling

There are tools that generally evaluate fall-related concerns of the clients. The tools which measure fall-related concerns are categorised into (1)Tools measuring fear of falling and (2)Tools measuring fall efficacy or balance confidence (Jørstad et al, 2005).

Tools measuring Fear of Falling

Fear of falling can be understood by measuring the fearful anticipation of future falls. The commonly used strategy is to ask the question, "At present are you very fearful, somewhat fearful, or not fearful that you may fall?" (Schoene et al, 2019). This method closely evaluates the psychological factors related to fear of falling (Eckert et al, 2020).The most frequently used tools for measuring fear of falling are Mobility Efficacy Scale (MES), adapted Falls Efficacy Scale (aFES), Survey of Activities and Fear of Falling in the Elderly (SAFFE or SAFE), and the University of Illinois, Chicago, Fear of Falling Measure (UIC FFM) and the Falls Efficacy Scale–International (FES-I) (Payette et al, 2016).

Fall Efficacy Scale-International (FES-I) comprising 16 items is a modified version of FES which has shown high validity (Cronbach's a=0.96) and high test-retest reliability (r=0.96) (Dias et al, 2006). A short version of Fall Efficacy Scale-International containing 7 questions is also available, known as Short Fall Efficacy Scale-International (Short FES-I)(Kempen et al, 2007). Fall Efficacy Scale or its modified versions are most frequently used for assessing fear of falling (Whipple et al, 2018). FES-I, the Short FES-I and the SAFE show good psychometric properties for community-dwelling elderly. These scales measure concern or worry about falling during simple to more complex activities, which are of great relevance for the functional independence of the elderly. The reliability, validity, and cut of scores are established for both FES-I and Short FES-I (Delbaere et al, 2010; Payette et al, 2016).

Another method used for measuring fear of falling is the Visual Analog Scale. A person is considered to have fear of falling if the score is '1' or higher. A score of '5' and above is considered as having severe fear of falling (Jansen et al, 2015).

Tools measuring Fall Efficacy or Balance Confidence

Another evaluating approach is related to Bandura's theory of self-efficacy (Bandura, 1977). In this approach, the person's level of self-confidence in doing some tasks in daily life without causing a fall, termed fall-related efficacy, is measured (Schoene et al, 2019). Self-efficacy is a resilience factor that protects a person from developing fear in the face of a threat. The tools used to measure fall efficacy or balance confidence comprise Falls Efficacy Scale (FES) developed by Tinetti, the Falls Efficacy Scale revised (rFES), the modified FES (mFES), the FES United Kingdom (FES-UK), the Activities-specific Balance Confidence (ABC) developed by Powell and Myers, the ABC United Kingdom (ABC-UK), Perceived Ability to Manage Falls Scale and the Confidence in maintaining Balance Scale (ConFbal) (Tinetti et al, 1990; Powell & Myers, 1995; Lawrence et al, 1998; Payette et al, 2016). FES, mFES, ABC, and CONFbal demonstrated good psychometric properties for measuring balance confidence or fall efficacy among community-dwelling elderly. As the ABC scale measures confidence during both simple and more challenging activities, it is more ideal for measuring fall efficacy(Payette et al, 2016). Using of fall efficacy is being criticised, stating that people who are confident in doing various activities may still experience fear of falling (Jung, 2008).

Many subjects with fear of falling may have underlying anxiety disorders. Hence, screening for general anxiety is recommended (Scheffers-Barnhoorn et al, 2021).

Management of Fear of Falling

Various systematic reviews and meta-analyses pointed towards 2 main management approaches that are effective in addressing fear of falling. One is a physical intervention strategy comprising mainly of balance and strengthening exercises, and the other is a psychological approach using Cognitive Behaviour Therapy (Zijlstra et al, 2007; Kumar et al, 2016; Liu et al, 2018).There is evidence to show that common neural networks work behind cognitive, balance, and gait activities. Deficits in the functioning of the neural network lead to cognitive changes, balance impairment, and gait deviations, resulting in falls and fear of falling. Hence, it was found that challenging these neural networks through cognitive behaviour therapy, balancing exercises, strengthening exercises and gait training helps to alleviate the fear of falling and aids in fall reduction (Segev-Jacubovski et al, 2011; Hagovská & Olekszyová, 2016).

Physical Intervention Strategy

Exercise

Exercise helps in reducing fear of falling by improving balance confidence and fall efficacy (Chua et al, 2019).It has been reported that improvement in balance leads to a reduction in fear of falling (Scheffer et al, 2008). Guidelines recommend at least 36 hours of exercise, over 12 weeks, which equals 3 hours per week for addressing fear of falling (Adams et al, 2018).A systematic review and meta-analysis were done to find the dose-response parameters of balance training leading to balance improvements in young adults. The results suggested that for improving steady-state balance, a training period of 11-12 weeks was needed, consisting of 3-6 sessions per week, with each training session lasting for 11-15 minutes. A training session should have at least 4 exercises and involve 2 sets of each exercise. The duration of a single balance training exercise should be of 20-40 seconds. Due to a lack of studies, the meta-analysis could not determine the dose-response parameters for improving proactive and reactive balance among young adults(Lesinski et al, 2015). Exercise has been shown to reduce fear of falling in the short- term period, but its effect in the long term was inconclusive in systematic reviews (Kendrick et al, 2014; Kumar et al, 2016).

The exercise interventions found to be effective in reducing fear of falling among community-dwelling elderly persons include strengthening exercises, balancing exercises, agility exercises, and flexibility exercises, as a single component or in combination (Whipple et al, 2018). Other specific exercises that showed effectiveness were walking, hydrotherapy, and Tai Chi (Whipple et al, 2018). Virtual reality training and guided relaxation also yielded positive results in addressing fear of falling (Whipple et al, 2018). A non-randomised control trial involving 3 months of balance training using the Nintendo Wii video console showed a reduction in fear of fall among community-dwelling healthy elderly, but the effect was not present during follow-up after 1 year (Montero-Alía et al, 2019) .Contrary to this, a randomised control trial with 12 weeks of Multi-System Physical Exercise Intervention showed a significant reduction in fear of falling among pre-frail elderly. The effect was sustained during follow-up at 24 weeks (Chittrakul et al, 2020). High-Intensity Interval Training (HIIT) using lower limb suspension exercises was found effective in reducing fear of falling among the elderly (Jiménez-García et al, 2019). It has been shown that intensive endurance exercises showed variations in balance control, increasing the risk of fall, likely through exercise-induced respiratory and muscle fatigue (Donath et al, 2013).

Structured exercises have been shown to cause improvements in cognitive and physical functioning, leading to a reduction in fear of falling and enhancing the quality of life(Schoene et al, 2019). Fall-related self-efficacy significantly improved in the intervention group (−15%, p<0.001) who received a 12-week intervention programme consisting of balance, strength, and jumping over a mini-trampoline in a randomised control trial conducted among clients with osteopenia(Posch et al, 2019).A Hedge's g effect size of -0.77 was found for FES-I after a challenging balancing exercise programme of 12 weeks, revealing a reduction of fear of falling among elderly with Parkinson's Disease (Sparrow et al, 2016).

Falls Management Exercise (FaME) programme included 12 weeks of 1-hour weekly sessions. The exercises comprise individualised balance-specific targeted training for improving dynamic balance, strength, endurance, flexibility, gait, and balance retaining (Adams et al, 2018). Home-based gait training with Rhythmic Auditory Stimulation (RAS) showed significant improvement in ankle dorsiflexion and concomitant reduction in fear of falling among subjects with Parkinson's Disease(Thaut et al, 2019).Slacklining, an exercise programme involving static body postures, showed promising results in reducing fear of falling among elderly with Parkinson's Disease(Santos et al, 2017). Chair elastic-band muscle strength exercises (CSE) programme among elderly women was found to be effective in reducing fear of falling. This 14-week progressive elastic band-based strengthening exercise was provided 2 times a week on non-consecutive days. The exercise programme consisted of 5 minutes for warm-up, 35 minutes of elastic band-based strengthening exercises, and 5 minutes for cool down. Upper limb strength, lower limb strength, and dynamic balance also increased significantly among these elderly women (Rieping et al, 2019). Fear of falling reduced significantly after an exercise programme of 6 months in women having osteoporosis-related vertebral fractures (Marini et al, 2019). A 12- week intervention with balance and resistance exercise showed a significant reduction in fear of fall among elderly women with osteoporosis and a history of vertebral fracture (Stanghelle et al, 2020).

A randomised controlled trial was conducted among elderly with fall-related hip fractures, to evaluate the effect of adaptability treadmill training. A treadmill with visual context projected on its belt was used for providing gait training, including stepping. The intervention did not show significant changes as compared to conventional treadmill training and usual physiotherapy in general walking ability, fear of falling, and general health status (van Ooijen et al, 2016). A recent systematic review and meta-analysis found that for reducing fear of falling, gait and balance training was effective among elderly with Parkinson's Disease, and home-based exercise and leisure activities were effective among persons with Multiple Sclerosis (Abou et al, 2021).

Mind-Body Interventions are exercises that involve less muscle work and energy expenditure. Meditative attention is an integral component along with physical movement in MBI. The various forms of MBI include Tai Chi, Yoga, Gigong, Feldenkrais and Pilates (Payne & Crane-Godreau, 2013). Tai Chi exercise programme of 12 weeks caused significant changes in fear of falling among elderly with multi-site pain by increasing their fall efficacy (You et al, 2018). Hatha yoga intervention of 8 weeks reported significant changes in fear of falling among the elderly. However the results cannot be generalised, owing to the small sample size (Nick et al, 2016). According to a systematic review and meta-analysis, Mind-Body Interventions (MBI) are showing promising effects in reducing fear of falling (Weber et al, 2020). A systematic review and meta-analysis of randomised controlled trials for reducing fear of falling among community-dwelling elderly found that holistic exercises like Pilates and Yoga lead to a greater reduction in fear of falling. Supervision by a Tai Chi instructor and delivery in a community setting showed positive effects in fear of falling reduction (Kruisbrink et al, 2020).

Psychological Intervention Strategy

The most common psychological intervention approaches used are Cognitive Behaviour Therapy (CBT), A Matter of Balance(AMB), and FIT-HIP intervention. Systematic review and meta-analysis showed that cognitive and behavioural treatments have a positive effect in improving fear of falling and fall efficacy among the elderly, both in the short term and long term (Papadimitriou & Perry, 2020).

Cognitive Behaviour Therapy (CBT)

Cognitive Behaviour Therapy (CBT) is a psychotherapeutic intervention used to positively influence a person's thoughts and behaviour. CBT is based on the assumption that a person's emotions and behaviour rely heavily on how one perceives an event (Chua et al, 2019). It was found that people with the fear of falling are over-pessimistic regarding the consequences of falling and have lower fall efficacy. CBT helps in adopting acceptable health behaviours and alters maladaptive behaviours. CBT interventions address the fear of falling, modifying self-efficacy beliefs related to physical activity and falling (Payette et al, 2016). The motivational interviewing techniques used as part of CBT help the elderly to identify healthy behaviour and plan their implementation (Dorresteijn et al, 2016). A meta-analysis found that Cognitive Behaviour Therapy is effective in reducing fear of falling among the elderly (Liu et al, 2018). The CBT programme comprising goal setting, promoting physical activities, and cognitive restructuring had an immediate effect in reducing fear of falls, and it was maintained for 1 year. Besides, there was gradual improvement in balance performance too. Another meta-analysis evaluated the effect of cognitive behaviour therapy-based multi-component intervention on fear of falling among community-dwelling elderly. The results showed that Cognitive Behaviour Therapy is effective in reducing fear of falling (Chua et al, 2019). A pilot randomised controlled trial found brief Motivational Interviewing (MI) effective in reducing fear of falling among elderly in acute care settings.

A Matter of Balance

'A Matter of Balance' (AMB) is a community-based intervention approach that matches the activities to the level of physical capabilities. It is multipronged, covering cognitive and behavioural aspects grounded in adaptive and realistic appraisal (Dorresteijn et al, 2016). The programme has been found to reduce fear of falling and subsequent activity avoidance among community-dwelling elderly in previous studies (Tennstedt et al, 1998; Zijlstra et al, 2009). Initially it was developed as a group-based programme but later an individualised home-based version was also developed termed "AMB –Home" to address the need of frail elderly in home settings and to cater to those who prefer individuality (Dorresteijn et al, 2011).The randomised controlled trial among community-dwelling elderly with concerns of falling aimed to enhance self-efficacy beliefs and the feeling of locus of control through realistic appraisal of fall risk and changing of behaviour. The strategies used for the purpose were to do away with misconceptions regarding falls, the setting of safe and realistic activity-level goals, and promotion and self-challenging to do previously restricted daily life activities due to fear of falling (Dorresteijn et al, 2016). The results showed that the fear of falling reduced significantly in the intervention group. Also, reduction in indoor falls, reduction of activity avoidance and disability were reported (Dorresteijn et al, 2016). Various researchers had reported the cost-effectiveness, efficacy, and feasibility of the Matter of Balance programme (Zijlstra et al, 2009;Ullmann et al, 2012; van Haastregt et al, 2013).

FIT-HIP Intervention

The Fear of falling Intervention in HIP fracture geriatric rehabilitation (FIT-HIP) is a multi-component cognitive-behavioural intervention used for reducing fear of falling in hip fracture clients. The cognitive behaviour components of the “A Matter of Balance” programme have been modified to suit the inpatient rehabilitation setting in the FIT-HIP programme. It is an individually tailored programme conducted by physiotherapists, considering their preferences, capacities, and needs (Scheffers-Barnhoorn et al, 2017). It involves graded exposure to fear-inducing activities. The fear ladder concept is used to depict the hierarchy of fear. Six steps in the fear ladder form each goal, which is specific, measurable, attainable, realistic, and timely defined (Scheffers-Barnhoorn et al, 2017). The subjects were provided regular physiotherapy exercises along with the following cognitive behaviour components: psycho-education, motivational interviewing, guided exposure to feared activities, cognitive restructuring, and relapse prevention. A cluster randomised controlled trial showed that the programme is not effective in reducing fear of falling and functional recovery among elderly with hip fractures. A low level of fear of falling at the baseline and a lack of experience of physiotherapists in cognitive restructuring are identified as barriers to its effective implementation (Scheffers-Barnhoorn et al, 2021).

Combination of Physical and Psychological Interventions

A combination of exercises and Cognitive Behaviour strategies were reported to be most effective in various reviews (Kempen et al, 2007; Jung et al., 2009; Whipple et al, 2018). The Activity, Balance, Learning, and Exposure (ABLE) programme is one such programme provided in the home setting by physiotherapists. The components of the ABLE programme are evidence-based fall prevention exercises, cognitive restructuring, home safety assessment, and exposure to feared situations (Wetherell et al, 2016, 2018). The exercise component was based on Otago Exercise Programme to Prevent Falls in Older Adults, having flexibility, strengthening, and balance exercise contents, supervised by a physiotherapist. The ABLE programme of 8 weeks helped reduce fear of falling, but the effect got worn off at a 6-month follow-up. A Randomised Control Trial(RCT) among cognitively impaired elderly proved that a combination of balancing exercises with selective exercises from the CogniPlus programme is more effective than balancing exercise alone (Hagovská & Olekszyová, 2016). A systematic review found that CBT was one of the main elements in multi-component interventions found effective in reducing fear of falling among community-dwelling elderly

(Whipple et al, 2018). A geriatric rehabilitation programme complemented with Cognitive Behavioural Therapy showed significant changes in fear of falling in elderly with hip and pelvic fracture (Pfeiffer et al, 2020). 'Step by Step' treatment protocol developed for addressing fear of falling among subjects with hip and pelvic fracture include the following components: relaxation, meaningful activities, and mobility-based goals, falls-related cognitions, and emotions, coping with risk involving tasks and situations, individualised exercise programme, planning and implementation of exercises and activities, and identification of fall risks and hazards. The intervention contained 8 individual sessions within a span of 3 to 5 weeks in inpatient settings, followed by 4 telephone calls of 30-60 minutes duration, and 1 home visit at the 2-month post-discharge period. The protocol was found feasible to implement (Kampe et al, 2017).

A 3-arm randomised control trial evaluated the effect of 3 individual interventions: cognitive behaviour therapy, postural control exercise, and Tai Chi, in reducing fear of falling among the elderly. The 8-week-long RCT among ambulatory elderly found that all 3 interventions were effective in reducing fear of falling (Dueñas et al, 2019).

Other Approaches

Other interventions effective in reducing fear of falling among community-dwelling elderly were motor training, whole-body vibration, vitamin D supplementation, and fall prevention education as a combination (Whipple et al, 2018). A prospective randomised controlled trial found that wearing custom-made Angle Foot Orthosis (AFO) and walking shoes led to a reduction in fear of falling. The intervention group showed a reduction in postural sway by 54.9% after daily use of AFO and walking shoes for 6 months. The balance improvement might have resulted from increased proprioception and supplementary sensory inputs to intact tissues through AFO, an increase in the contact area of the foot as well as mechanical support to the ankle(Wang et al, 2019).Motor imagery is a treatment strategy in which movements are only imagined but not done physically. It was found that the same motor areas involved in physical movement are activated by motor imagery. A pilot randomised controlled trial showed promising results of motor imagery in reducing fear of falling (Oh & Choi, 2021).

CONCLUSION

The long-term effect of interventions in fear of falling is not known. Hence, interventions of adequate length and longitudinal repeated follow-ups are recommended. Well-designed clinical trials need to be conducted, comparing the effect of specific exercises in reducing fear of falling. This will help in making evidence-based exercise recommendations. Clinical trials exploring the effect of exercise on fall prevention in the elderly should include fear of falling as one of the outcome variables. This will help in finding the exercise regimen that effectively reduces the fear of falling.

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REFERENCES

Abou L, Alluri A, Fliflet A, Du Y, Rice L A (2021). Effectiveness of Physical Therapy Interventions in Reducing Fear of Falling Among Individuals With Neurologic Diseases: A Systematic Review and Meta-analysis. *Archives of Physical Medicine and Rehabilitation*, *102*(1), 132–154. https://doi.org/10.1016/j.apmr.2020.06.025

Adamczewska N, Nyman S R (2018). A New Approach to Fear of Falls From Connections With the Posttraumatic Stress Disorder Literature. *Gerontology and Geriatric Medicine*, *4*, 233372141879623. https://doi.org/10.1177/2333721418796238

Adams N, Skelton D A, Howel D, Bailey C, Lampitt R, Fouweather T, Gray J, Coe D, Wilkinson J, Gawler S, de Jong L D, Waterman H, Deary V, Clarke M, Parry S W (2018). Feasibility of trial procedures for a randomised controlled trial of a community based group exercise intervention for falls prevention for visually impaired older people: the VIOLET study. *BMC Geriatrics*, *18*(1), 307. https://doi.org/10.1186/s12877-018-0998-6

Bandura A (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, *84*(2), 191–215. https://doi.org/10.1037/0033-295X.84.2.191

Butler Forslund E, Jørgensen V, Skavberg Roaldsen K, Hultling C, Wahman K, Franzén E (2019). Predictors of falls in persons with spinal cord injury—a prospective study using the Downton fall risk index and a single question of previous falls. *Spinal Cord*, *57*(2), 91–99. https://doi.org/10.1038/s41393-018-0175-y

Chen S K, Voaklander D, Perry D, Jones C A (2019). Falls and fear of falling in older adults with total joint arthroplasty: a scoping review. *BMC Musculoskeletal Disorders*, *20*(1), 599. https://doi.org/10.1186/s12891-019-2954-9

Chittrakul J, Siviroj P, Sungkarat S, Sapbamrer R (2020). Multi-System Physical Exercise Intervention for Fall Prevention and Quality of Life in Pre-Frail Older Adults: A Randomized Controlled Trial. *International Journal of Environmental Research and Public Health*, *17*(9), 3102. https://doi.org/10.3390/ijerph17093102

Chua C H M, Jiang Y, Lim D S, Wu V X, Wang W (2019). Effectiveness of cognitive behaviour therapy-based multicomponent interventions on fear of falling among community-dwelling older adults: A systematic review and meta-analysis. *Journal of Advanced Nursing*, *75*(12), 3299–3315. https://doi.org/10.1111/jan.14150

de Carvalho Fonseca R G, Silva A M, Teixeira L F, Silva V R., dos Reis L M, Silva Santos A T (2018). Effect of the Auricular Acupoint Associated with Physical Exercise in Elderly People: A Randomized Clinical Test. *Journal of Acupuncture and Meridian Studies*, *11*(4), 137–144. https://doi.org/10.1016/j.jams.2018.05.003

Delbaere K, Close J C T, Mikolaizak A S, Sachdev P S, Brodaty H, Lord S R (2010). The Falls Efficacy Scale International (FES-I). A comprehensive longitudinal validation study. *Age and Ageing*, *39*(2), 210–216. https://doi.org/10.1093/ageing/afp225

Dias N, Kempen G I J M, Todd C J, Beyer N, Freiberger E, Piot-Ziegler C, Yardley L, Hauer K (2006). [The German version of the Falls Efficacy Scale-International Version (FES-I)]. *Zeitschrift Für Gerontologie Und Geriatrie : Organ Der Deutschen Gesellschaft Für Gerontologie Und Geriatrie*, *39*(4), 297–300. http://www.ncbi.nlm.nih.gov/pubmed/16900450

Donath L, Zahner L, Roth R, Fricker L, Cordes M, Hanssen H, Schmidt-Trucksäss A, Faude O (2013). Balance and gait performance after maximal and submaximal endurance exercise in seniors: is there a higher fall-risk? *European Journal of Applied Physiology*, *113*(3), 661–669. https://doi.org/10.1007/s00421-012-2471-0

Dorresteijn T A C, Zijlstra G A R, Ambergen A W, Delbaere K, Vlaeyen J W S, Kempen G I JM (2016). Effectiveness of a home-based cognitive behavioral program to manage concerns about falls in community-dwelling, frail older people: results of a randomized controlled trial. *BMC Geriatrics*, *16*(1), 2. https://doi.org/10.1186/s12877-015-0177-y

Dorresteijn T A, Zijlstra G R, Delbaere K, van Rossum E, Vlaeyen J W, Kempen GI (2011). Evaluating an in-home multicomponent cognitive behavioural programme to manage concerns about falls and associated activity avoidance in frail community-dwelling older people: Design of a randomised control trial [NCT01358032]. *BMC Health Services Research*, *11*(1), 228. https://doi.org/10.1186/1472-6963-11-228

Dueñas E P, Ramírez L P, Ponce E, Curcio C L (2019). Efecto sobre el temor a caer y la funcionalidad de tres programas de intervención. Ensayo clínico aleatorizado. *Revista Española de Geriatría y Gerontología*, *54*(2), 68–74. https://doi.org/10.1016/j.regg.2018.09.013

Eckert T, Kampe K, Kohler M, Albrecht D, Büchele G, Hauer K, Schäufele M, Becker C, Pfeiffer K (2020). Correlates of fear of falling and falls efficacy in geriatric patients recovering from hip/pelvic fracture. *Clinical Rehabilitation*, *34*(3), 416–425. https://doi.org/10.1177/0269215519891233

Esbrí-Víctor M, Huedo-Rodenas I, López-Utiel M, Navarro-López J L, Martínez-Reig M, Serra-Rexach J A, Romero-Rizos L, Abizanda P (2017). Frailty and Fear of Falling: The FISTAC Study. *The Journal of Frailty & Aging*, *6*(3), 136–140. https://doi.org/10.14283/jfa.2017.19

Grimbergen Y A M, Schrag A, Mazibrada G, Borm G F, Bloem B R (2013). Impact of falls and fear of falling on health-related quality of life in patients with Parkinson's disease. *Journal of Parkinson's Disease*, *3*(3), 409–413. https://doi.org/10.3233/JPD-120113

Hadjistavropoulos T, Delbaere K, Fitzgerald T D (2011). Reconceptualizing the role of fear of falling and balance confidence in fall risk. *Journal of Aging and Health*, *23*(1), 3–23. https://doi.org/10.1177/0898264310378039

Hagovská M, Olekszyová Z (2016). Impact of the combination of cognitive and balance training on gait, fear and risk of falling and quality of life in seniors with mild cognitive impairment. *Geriatrics & Gerontology International*, *16*(9), 1043–1050. https://doi.org/10.1111/ggi.12593

Jansen S, Schoe J, van Rijn M, Abu-Hanna A, Moll van Charante E P, van der Velde N, de Rooij S E (2015). Factors associated with recognition and prioritization for falling, and the effect on fall incidence in community dwelling older adults. *BMC Geriatrics*, *15*(1), 169. https://doi.org/10.1186/s12877-015-0165-2

Jiménez-García J D, Hita-Contreras F, de la Torre-Cruz M, Fábrega-Cuadros R, Aibar-Almazán A, Cruz-Díaz D, Martínez-Amat A (2019). Risk of Falls in Healthy Older Adults: Benefits of High-Intensity Interval Training Using Lower Body Suspension Exercises. *Journal of Aging and Physical Activity*, *27*(3), 325–333. https://doi.org/10.1123/japa.2018-0190

Jørstad E C, Hauer K, Becker C, Lamb S E (2005). Measuring the psychological outcomes of falling: A systematic review. In *Journal of the American Geriatrics Society* (Vol. 53, Issue 3, pp. 501–510). https://doi.org/10.1111/j.1532-5415.2005.53172.x

Jung D (2008). Fear of Falling in Older Adults: Comprehensive Review. *Asian Nursing Research*, *2*(4), 214–222. https://doi.org/10.1016/s1976-1317(09)60003-7

Jung D, Lee J, Lee S M (2009). A meta-analysis of fear of falling treatment programs for the elderly. *Western Journal of Nursing Research*, *31*(1), 6–16. https://doi.org/10.1177/0193945908320466

Kampe K, Kohler M, Albrecht D, Becker C, Hautzinger M, Lindemann U, Pfeiffer K (2017). Hip and pelvic fracture patients with fear of falling: development and description of the “Step by Step” treatment protocol. *Clinical Rehabilitation*, *31*(5), 571–581. https://doi.org/10.1177/0269215517691584

Kempen G I JM, Yardley L, Van Haastregt J C M, Zijlstra G A R, Beyer N, Hauer K, Todd C (2007). The Short FES-I: a shortened version of the falls efficacy scale-international to assess fear of falling. *Age and Ageing*, *37*(1), 45–50. https://doi.org/10.1093/ageing/afm157

Kendrick D, Kumar A, Carpenter H, Zijlstra G A R, Skelton D A, Cook J R, Stevens Z, Belcher C M, Haworth D, Gawler S J, Gage H, Masud T, Bowling A, Pearl M, Morris R W, Iliffe S, Delbaere K (2014). Exercise for reducing fear of falling in older people living in the community. *The Cochrane Database of Systematic Reviews*, *11*, CD009848. https://doi.org/10.1002/14651858.CD009848.pub2

Kruisbrink M, Delbaere K, Kempen G I J M, Crutzen R, Ambergen T, Cheung K-L, Kendrick D, Iliffe S, Zijlstra G A R (2020). Intervention Characteristics Associated With a Reduction in Fear of Falling Among Community-Dwelling Older People: A Systematic Review and Meta-analysis of Randomized Controlled Trials. *The Gerontologist*. https://doi.org/10.1093/geront/gnaa021

Kumar A, Delbaere K, Zijlstra G A R, Carpenter H, Iliffe S, Masud T, Skelton D, Morris R, Kendrick D (2016). Exercise for reducing fear of falling in older people living in the community: Cochrane systematic review and Meta-Analysis. *Age and Ageing*, *45*(3), 345–352. https://doi.org/10.1093/ageing/afw036

Lawrence R H, Tennstedt S L, Kasten L E, Shih J, Howland J, Jette A M (1998). Intensity and Correlates of Fear of Falling and Hurting Oneself in the Next Year. *Journal of Aging and Health*, *10*(3), 267–286. https://doi.org/10.1177/089826439801000301

Lesinski M, Hortobágyi T, Muehlbauer T, Gollhofer A, Granacher U (2015). Dose-Response Relationships of Balance Training in Healthy Young Adults: A Systematic Review and Meta-Analysis. In *Sports Medicine* (Vol. 45, Issue 4, pp. 557–576). https://doi.org/10.1007/s40279-014-0284-5

Li C-I, Lin C-H, Lin W-Y, Liu C-S, Chang C-K, Meng N-H, Lee Y-D, Li T-C, Lin C-C (2014). Successful aging defined by health-related quality of life and its determinants in community-dwelling elders. *BMC Public Health*, *14*(1), 1013. https://doi.org/10.1186/1471-2458-14-1013

Liu T-W, Ng G Y F, Chung R C K, Ng S S M (2018). Cognitive behavioural therapy for fear of falling and balance among older people: a systematic review and meta-analysis. *Age and Ageing*, *47*(4), 520–527. https://doi.org/10.1093/ageing/afy010

Marini S, Leoni E, Raggi A, Sanna T, Malavolta N, Angela B, Maietta Latessa P, Dallolio L (2019). Proposal of an Adapted Physical Activity Exercise Protocol for Women with Osteoporosis-Related Vertebral Fractures: A Pilot Study to Evaluate Feasibility, Safety, and Effectiveness. *International Journal of Environmental Research and Public Health*, *16*(14), 2562. https://doi.org/10.3390/ijerph16142562

Masters R, Maxwell J (2008). The theory of reinvestment. *International Review of Sport and Exercise Psychology*, *1*(2), 160–183. https://doi.org/10.1080/17509840802287218

Montero-Alía P, Miralles-Basseda R, López-Jiménez T, Muñoz-Ortiz L, Jiménez-González M, Prat-Rovira J, Albarrán-Sánchez J L, Manresa-Domínguez JM, Andreu-Concha C M, Rodríguez-Pérez M C, Martí-Cervantes J J, Sañudo-Blanco L, Sánchez-Pérez C A, Dolader-Olivé S, Torán-Monserrat P (2019). Controlled trial of balance training using a video game console in community-dwelling older adults. *Age and Ageing*, *48*(4), 506–512. https://doi.org/10.1093/ageing/afz047

Montero-Alía P, Muñoz-Ortiz L, Jiménez-González M, Benedicto-Pañell C, Altimir-Losada S, López-Colomer Y, Prat-Rovira J, Amargant-Rubio J F, Jastes S M, Moreno-Buitrago A, Rodríguez-Pérez M C, Teixidó-Vargas C, Albarrán-Sánchez J L, Candel-Gil A, Serra-Serra D, Martí-Cervantes J J, Sánchez-Pérez C A, Sañudo-Blanco L, Dolader-Olivé S, Torán-Monserrat P (2016). Study protocol of a randomized clinical trial evaluating the effectiveness of a primary care intervention using the Nintendo™ Wii console to improve balance and decrease falls in the elderly. *BMC Geriatrics*, *16*(1), 8. https://doi.org/10.1186/s12877-015-0178-x

Nick N, Petramfar P, Ghodsbin F, Keshavarzi S, Jahanbin I (2016). The Effect of Yoga on Balance and Fear of Falling in Older Adults. *PM & R : The Journal of Injury, Function, and Rehabilitation*, *8*(2), 145–151. https://doi.org/10.1016/j.pmrj.2015.06.442

Oh D S, Choi J D (2021). Effects of motor imagery training on balance and gait in older adults: A randomized controlled pilot study. *International Journal of Environmental Research and Public Health*, *18*(2), 1–13. https://doi.org/10.3390/ijerph18020650

Papadimitriou A, Perry M (2020). Systematic Review of the Effects of Cognitive and Behavioral Interventions on Fall-Related Psychological Concerns in Older Adults. *Journal of Aging and Physical Activity*, *28*(1), 155–168. https://doi.org/10.1123/japa.2017-0408

Payette M-C, Bélanger C, Léveillé V, Grenier S (2016). Fall-Related Psychological Concerns and Anxiety among Community-Dwelling Older Adults: Systematic Review and Meta-Analysis. *PLOS ONE*, *11*(4), e0152848. https://doi.org/10.1371/journal.pone.0152848

Payne P, Crane-Godreau M A (2013). Meditative movement for depression and anxiety. In *Frontiers in Psychiatry* (Vol. 4, Issue JUL). https://doi.org/10.3389/fpsyt.2013.00071

Peterson E W, Cho C C, Finlayson M L (2007). Fear of falling and associated activity curtailment among middle aged and older adults with multiple sclerosis. *Multiple Sclerosis (Houndmills, Basingstoke, England)*, *13*(9), 1168–1175. https://doi.org/10.1177/1352458507079260

Pfeiffer K, Kampe K, Klenk J, Rapp K, Kohler M, Albrecht D, Büchele G, Hautzinger M, Taraldsen K, Becker C (2020). Effects of an intervention to reduce fear of falling and increase physical activity during hip and pelvic fracture rehabilitation. *Age and Ageing*, *49*(5), 771–778. https://doi.org/10.1093/ageing/afaa050

Posch M, Schranz A, Lener M, Tecklenburg K, Burtscher M, Ruedl G, Niedermeier M, Wlaschek W (2019). Effectiveness of a mini-trampoline training program on balance and functional mobility, gait performance, strength, fear of falling and bone mineral density in older women with osteopenia. *Clinical Interventions in Aging*, *14*, 2281–2293. https://doi.org/10.2147/CIA.S230008

Powell L E, Myers A M (1995). The Activities-specific Balance Confidence (ABC) Scale. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, *50A*(1), M28–M34. https://doi.org/10.1093/gerona/50A.1.M28

Rieping T, Furtado G E, Letieri R V, Chupel M U, Colado J C, Hogervorst E, Filaire E, Teixeira A M M B, Ferreira J P (2019). Effects of Different Chair-Based Exercises on Salivary Biomarkers and Functional Autonomy in Institutionalized Older Women. *Research Quarterly for Exercise and Sport*, *90*(1), 36–45. https://doi.org/10.1080/02701367.2018.1563272

Santos L, Fernandez-Rio J, Winge K, Barragán-Pérez B, Rodríguez-Pérez V, González-Díez V, Blanco-Traba M, Suman O E, Philip Gabel C, Rodríguez-Gómez J (2017). Effects of supervised slackline training on postural instability, freezing of gait, and falls efficacy in people with Parkinson's disease. *Disability and Rehabilitation*, *39*(16), 1573–1580. https://doi.org/10.1080/09638288.2016.1207104

Scheffer A C, Schuurmans M J, van Dijk N, van der Hooft T, de Rooij S E (2008). Fear of falling: measurement strategy, prevalence, risk factors and consequences among older persons. *Age and Ageing*, *37*(1), 19–24. https://doi.org/10.1093/ageing/afm169

Scheffers-Barnhoorn M N, van Eijk M, Schols J M G A, van Balen R, Kempen G I J M, Achterberg W P, van Haastregt J C M (2021). Feasibility of a multicomponent cognitive behavioral intervention for fear of falling after hip fracture: process evaluation of the FIT-HIP intervention. *BMC Geriatrics*, *21*(1), 224. https://doi.org/10.1186/s12877-021-02170-5

Scheffers-Barnhoorn M N, van Haastregt J C M, Schols J M G A, Kempen G I J M, van Balen R, Visschedijk J H M, van den Hout W B, Dumas E M, Achterberg W P, van Eijk M (2017). A multi-component cognitive behavioural intervention for the treatment of fear of falling after hip fracture (FIT-HIP): protocol of a randomised controlled trial. *BMC Geriatrics*, *17*(1), 71. https://doi.org/10.1186/s12877-017-0465-9

Schmid A A, Arnold S E, Jones V A, Jane Ritter M, Sapp S A, Van Puymbroeck M (2015). Fear of Falling in People With Chronic Stroke. *American Journal of Occupational Therapy*, *69*(3), 6903350020p1. https://doi.org/10.5014/ajot.2015.016253

Schoene D, Heller C, Aung Y N, Sieber C C, Kemmler W, Freiberger E (2019). A systematic review on the influence of fear of falling on quality of life in older people: is there a role for falls? *Clinical Interventions in Aging*, *Volume 14*, 701–719. https://doi.org/10.2147/CIA.S197857

Schoene D, Valenzuela T, Lord S R, de Bruin E D (2014). The effect of interactive cognitive-motor training in reducing fall risk in older people: a systematic review. *BMC Geriatrics*, *14*(1), 107. https://doi.org/10.1186/1471-2318-14-107

Segev-Jacubovski O, Herman T, Yogev-Seligmann G, Mirelman A, Giladi N, Hausdorff J M (2011). The interplay between gait, falls and cognition: Can cognitive therapy reduce fall risk? In *Expert Review of Neurotherapeutics* (Vol. 11, Issue 7, pp. 1057–1075). https://doi.org/10.1586/ern.11.69

Sparrow D, DeAngelis T R, Hendron K, Thomas C A, Saint-Hilaire M, Ellis T (2016). Highly Challenging Balance Program Reduces Fall Rate in Parkinson Disease. *Journal of Neurologic Physical Therapy*, *40*(1), 24–30. https://doi.org/10.1097/NPT.0000000000000111

Stanghelle B, Bentzen H, Giangregorio L, Pripp A H, Skelton DA, Bergland A (2020). Effects of a resistance and balance exercise programme on physical fitness, health-related quality of life and fear of falling in older women with osteoporosis and vertebral fracture: a randomized controlled trial. *Osteoporosis International*, *31*(6), 1069–1078. https://doi.org/10.1007/s00198-019-05256-4

Tennstedt S, Howland J, Lachman M, Peterson E, Kasten L, Jette A (1998). A Randomized, Controlled Trial of a Group Intervention to Reduce Fear of Falling and Associated Activity Restriction in Older Adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *53B*(6), P384–P392. https://doi.org/10.1093/geronb/53B.6.P384

Thaut M H, Rice R R, Braun Janzen T, Hurt-Thaut C P, McIntosh G C (2019). Rhythmic auditory stimulation for reduction of falls in Parkinson's disease: a randomized controlled study. *Clinical Rehabilitation*, *33*(1), 34–43. https://doi.org/10.1177/0269215518788615

Tinetti M E, Richman D, Powell L (1990). Falls Efficacy as a Measure of Fear of Falling. *Journal of Gerontology*, *45*(6), P239–P243. https://doi.org/10.1093/geronj/45.6.P239

Tinetti Mary E, Powell L (1993). Fear of Falling and Low Self-efficacy: A Cause of Dependence in Elderly Persons. *Journal of Gerontology*, *48*(Special_Issue), 35–38. https://doi.org/10.1093/geronj/48.Special_Issue.35

Ullmann G, Williams H, Plass C (2012). Dissemination of an Evidence-based Program to Reduce Fear of Falling, South Carolina, 2006-2009. *Preventing Chronic Disease*, *9*(5), E103. https://doi.org/10.5888/pcd9.110093

van Haastregt J C M, Zijlstra G A R, Hendriks M R C, Goossens M E J B, van Eijk J T M, Kempen G I J M (2013). Cost-Effectiveness of an Intervention to reduce Fear of Falling. *International Journal of Technology Assessment in Health Care*, *29*(3), 219–226. https://doi.org/10.1017/S0266462313000275

van Ooijen M W, Roerdink M, Trekop M, Janssen T W J, Beek P J (2016). The efficacy of treadmill training with and without projected visual context for improving walking ability and reducing fall incidence and fear of falling in older adults with fall-related hip fracture: a randomized controlled trial. *BMC Geriatrics*, *16*(1), 215. https://doi.org/10.1186/s12877-016-0388-x

Visschedijk J, van Balen R, Hertogh C, Achterberg W (2013). Fear of Falling in Patients With Hip Fractures: Prevalence and Related Psychological Factors. *Journal of the American Medical Directors Association*, *14*(3), 218–220. https://doi.org/10.1016/j.jamda.2012.10.013

Wang C, Goel R, Rahemi H, Zhang Q, Lepow B, Najafi B (2019). Effectiveness of Daily Use of Bilateral Custom-Made Ankle-Foot Orthoses on Balance, Fear of Falling, and Physical Activity in Older Adults: A Randomized Controlled Trial. *Gerontology*, *65*(3), 299–307. https://doi.org/10.1159/000494114

Weber M, Schnorr T, Morat M, Morat T, Donath L (2020). Effects of Mind–Body Interventions Involving Meditative Movements on Quality of Life, Depressive Symptoms, Fear of Falling and Sleep Quality in Older Adults: A Systematic Review with Meta-Analysis. *International Journal of Environmental Research and Public Health*, *17*(18), 6556. https://doi.org/10.3390/ijerph17186556

Wetherell J L, Bower E S, Johnson K, Chang D G, Ward S R, Petkus A J (2018). Integrated Exposure Therapy and Exercise Reduces Fear of Falling and Avoidance in Older Adults: A Randomized Pilot Study. *The American Journal of Geriatric Psychiatry*, *26*(8), 849–859. https://doi.org/10.1016/j.jagp.2018.04.001

Wetherell JL, Johnson K, Chang D, Ward S R, Bower E S, Merz C, Petkus A J (2016). Activity, balance, learning, and exposure (ABLE): a new intervention for fear of falling. *International Journal of Geriatric Psychiatry*, *31*(7), 791–798. https://doi.org/10.1002/gps.4393

Whipple M O, Hamel A V, Talley K M C (2018). Fear of falling among community-dwelling older adults: A scoping review to identify effective evidence-based interventions. *Geriatric Nursing*, *39*(2), 170–177. https://doi.org/10.1016/j.gerinurse.2017.08.005

World Health Organisation (2018). *Ageing and health*. https://www.who.int/news-room/fact-sheets/detail/ageing-and-health#:~:text=Between 2015 and 2050%2C the,- and middle-income countries.

You T, Ogawa E F, Thapa S, Cai Y, Zhang H, Nagae S, Yeh GY, Wayne P M, Shi L, Leveille SG (2018). Tai Chi for older adults with chronic multisite pain: a randomized controlled pilot study. *Aging Clinical and Experimental Research*, *30*(11), 1335–1343. https://doi.org/10.1007/s40520-018-0922-0

Young W R, Mark Williams A (2015). How fear of falling can increase fall-risk in older adults: Applying psychological theory to practical observations. *Gait & Posture*, *41*(1), 7–12. https://doi.org/10.1016/j.gaitpost.2014.09.006

Zijlstra G A R, Van Haastregt J C M, Ambergen T, Van Rossum E, Van Eijk J T M, Tennstedt SL, Kempen G IJM (2009). Effects of a Multicomponent Cognitive Behavioral Group Intervention on Fear of Falling and Activity Avoidance in Community-Dwelling Older Adults: Results of a Randomized Controlled Trial. *Journal of the American Geriatrics Society*, *57*(11), 2020–2028. https://doi.org/10.1111/j.1532-5415.2009.02489.x

Zijlstra G A R, Van Haastregt J C M, Van Rossum E,Van Eijk J T M, Yardley L, Kempen GI JM (2007). Interventions to reduce fear of falling in community-living older people: A systematic review. *Journal of the American Geriatrics Society*, *55*(4), 603–615. https://doi.org/10.1111/j.1532-5415.2007.01148.x

Conceptual Analysis on Inclusive Education for Students Labelled with Severe Disabilities: A Critical Disability Studies Approach

Haley Clark*

ABSTRACT

The literature on inclusive education rarely focuses on students labelled with severe disabilities. Severe disabilities consist of a range of impairments requiring extensive daily support. This analysis examines the three pillars or impacts of inclusive education for students labelled with severe disabilities: proximity, social, and academic.

The critical disability studies (CDS) perspective in education is described to examine the root of inclusive education and the historical, cultural, and social factors that impact educational settings and outcomes for students with disabilities more generally. The analysis applies the critical disability studies framework in an educational context to promote systemic change and anti-ableist pedagogy in education. As systemic ableism is built into educational pedagogy and curriculum, this analysis applies the established CDS framework to students labelled with severe disabilities in inclusive education.

Future research should examine the root of systemic ableism and work towards deconstructing ableist systems that oppress students labelled with severe disabilities.

***Key words**: students labelled with severe disabilities, critical disability studies, systemic ableism, inclusive education, academic outcomes*

INTRODUCTION

Within the field of disability education, there is a tendency to highlight the overwhelming benefits of inclusive education. The broadest and the most agreed upon definition of inclusive education integrates all students into the same programme - socially, academically, and physically (Paseka and Schwab, 2020).

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This definition includes various elements of inclusive education in instructional time, accommodations, and social skill development. It is important to note that the definition of inclusive education varies across disciplines and research fields, but the overarching bodies of literature focus on three fundamental areas: physical proximity, social impact, and academic impact.

Severe disabilities consist of a range of impairments such as physical, sensory, or cognitive impairments that require extensive support for daily living. Students labelled with severe disabilities commonly have an impairment that limits their ability to perform tasks of daily living.

The research questions the study addresses are:

1) Where does the literature on inclusive education land on inclusive education for students labelled with a severe disability?

2) More specifically, how does the literature describe academic success for students labelled with a severe disability in inclusive settings?

The study begins with an overview on the literature surrounding proximity and social impact. It goes on to outline the debate within the literature on academic impacts to inclusive education for students labelled with a severe disability by applying the critical disability studies perspective.

Proximity

There is a body of literature centralised on proximity of students with disabilities to other able-bodied students. Although this literature is dated, the discussion on inclusive education relies heavily on ensuring that students with disabilities are in physical proximity to those without disabilities (Feldman et al, 2016). The framework surrounding proximity is rooted in inclusive education but does not encompass the larger picture of inclusive education. As Feldman et al (2016) state "interactions with general education classmates are impossible if students with disabilities are not physically present in these classes" (p.193). Unless they are in the same space with their peers without disability, students labelled with severe disabilities will not be able to interact, socialise and develop strong relationships. Carter et al (2005) also suggest that proximity is a predictor to students developing quality relationships with their peers. Heir et al (2016) highlight that this is the nature of inclusive education: proximity, interactions, and awareness.

Morningstar et al (2017) found that students with significant disabilities including autism, intellectual disability, deaf- blindness, and multiple disabilities are only included academically for about 40-60% of the day. This varies across disability, but the general trend suggests that students with significant disabilities are not being included academically at the same rate as less significant disabilities (Morningstar et al, 2017). The general proximity to their peers outside of the academic context was much lower at 40.72% (Feldman et al, 2016). The interactions varied from task-related communication and socially related interactions with their peers in proximity. Moreover, proximity alone can act as a support for positive social and academic facilitation (Giangreco, 1997). Proximity as a singular element does not warrant many benefits as most of the benefits are interrelated to social facilitation or academic outcomes (Kozleski et al, 2014). In addition, Carter et al (2016) highlight the use of peer support arrangements in inclusive settings to increase proximity, social interactions, and academic engagement. Proximity is an important aspect in inclusive education but is not exhaustive of educational programming.

Social Impact

Discussion on the social benefits of inclusive education is found in many bodies of literature and can vary from children with disability feeling part of the community to playing more with peers. Social benefits refer to the students' feelings of belonging, communication, sociability, and social skills. Downing et al (2007) highlight the preference for inclusive education by parents, teachers, and para-educators. Within their study, 89% of parents, 100% of teachers and 94% of para- educators noted the superiority of inclusive education over specialised formats (Downing et al, 2007). The rationale for and benefits of inclusive education overly discuss social benefits. More specifically, students in inclusive education were found to have increased self-esteem, received a more balanced education, and were viewed as valued members of society (Downing et al, 2007). Moreover, inclusive education promptly offers students with disabilities communication and social skills (Kefallinou et al, 2020). Downing et al (2007) note the importance of consultation and collaboration in inclusive settings and social skill and communication development.

Not only is general classroom placement beneficial for students with disabilities, but Florian (2019) argues that having peers with disability within the classroom and having them actively involved facilitates the acknowledgement of difference for students. The shift towards more understanding and awareness can grow from the social exposure to various learners (Florian, 2019). Alquraini and Gut (2012) highlight that students with severe disabilities in inclusive education commonly have stronger communication skills as compared to their stand-alone classroom peers. This is attributed to the increased opportunity to interact and communicate with their peers in the classroom.

Academic Impact

The core academic instruction impact of inclusive education can range from positive or negative impacts on students' comprehension, grades, attitude towards learning, and collaboration with peers. Despite the social benefits for all students in the classroom, the approach to inclusive education can sometimes be primarily socially-oriented which limits support towards academic outcomes (Mitchell 2005; Booth and Ainscow 2011; Haug, 2017). This is problematic as students with disabilities are expected to not only be included in the regular classroom and in discussions, but also receive individualised support and assessments (Haug, 2017). There is a chance that the academic requirements of students with disabilities are overshadowed by the focus on physical integration and social inclusion (Haug, 2017, Kauffman, 2021). Kauffman (2021) is skeptical of the "all means all model" of inclusive education and expresses the disservice inclusive education does to students with disabilities in academic success. The analogy used is, "If you can dig a ditch, it matters little whether you are digging a trench for a sewer line or a water line. Ditch-digging requires no special training depending on what is to be put in the ditch" (Kauffman, 2021, p. 2). Kauffman (2021) emphasises that inclusive education does not account for individualised instruction that some students with severe disabilities require. The current analysis emphasises that the ditch for some students requires special training and design, and this is something that inclusive education, or the universal ditch cannot account for.

Ayres et al (2012) highlight some of the concerns with inclusive education, such as it may water down academic standards rather than offering more specific curriculum that is specialised and meaningful to a student's future independence and community engagement. Their study offers a quote from a parent that is the basis of their argument - *"My son can identify Saturn, but he still can't request a snack or even wipe his ass"* (Ayres et al, 2012, pg.12). As the focus for these students is centred less around academic prosperity and more on life skill development and independence, the curriculum should reflect this. Ayres et al (2011) maintain that education not individualised to the students' needs is a poor form of education. This would mean identifying the skills students require to be independent and fulfilled through community engagement and employment (Ayres et al, 2011) and paying heed to individualised student needs in terms of programming, curriculum and enrichment, based on the student's trajectory and future goals. This strategy centralises the instruction to the students' trajectories and capacities.

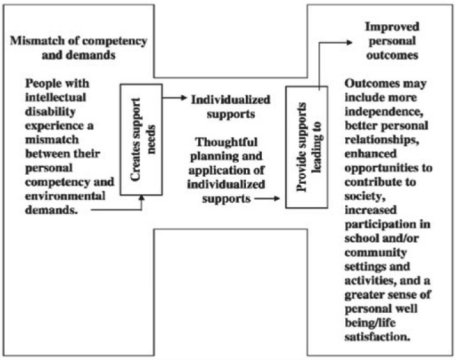

Figure 1: Supports Model created by Thompson et al (2009)

This strategy centralises the instruction to the students' trajectories and capacities. In response to some of these concerns, Thompson et al (2009) describe a model of support to improve future support in the community for those with severe disabilities and show how educational support can be more practical. This is the distinction between support and support needs. According to Thompson et al (2009), supports are strategies that promote individual well-being, development, education, and future enhanced functioning. Support needs are the patterns of support and the intensity of support deemed necessary for normative human functioning (Thompson et al, 2009). These support needs are not intended to lessen human capacity; rather they are centred on support based on the limitation in human functioning related to disability (Thompson et al, 2009). Figure 1 highlights the mismatch between the environmental demands that educational systems perpetuate and the individual capacity of the student. Thompson et al (2009) suggest that there needs to be individualised, thoughtful and intentional support needs based on an individual's capabilities rather than on mainstream standards. For example, instead of providing broad support based on a diagnosis, educational workers should be intentional towards the student's support needs.

Although some researchers highlight the failures of inclusive education in terms of academic success, many others suggest the contrary. York et al (2015) define academic success in six factors: academic achievement, persistence, attainment of learning outcomes, satisfaction, acquisition of skills and competencies, and career success. Students with disabilities who attended inclusive programming for most of the day warranted higher scores on math and language abilities compared to their segregated peers (Wagner et al, 2005; Heir et al, 2012). In fact, Blackorby et al (2007) reflected that students with an intellectual disability who were involved in inclusive education read 23-43 more words than their less integrated peers. In terms of academics, it is also important to note that students in inclusive education on average attend more school per year and are more involved in school groups (Newman et al, 2003).

Moreover, for students with severe disabilities, Dessemontet et al (2012) examined the academic effect based on placement in special schools or inclusive schools. They compared the groups and found that students with severe disabilities in inclusive settings perform stronger in literacy than those in special schools (Dessemontet et al, 2012). Adaptive behaviours and math skills were the same across the inclusive and special programming groups. According to Downing et al (2007) segregated settings disable students from pursuing academic goals by limiting creativity and reducing their ambitions. Outside of this, parents noted that students in segregated settings are commonly not challenged and receive minimally accepted academic instruction (Downing et al, 2007; Braunsteiner and Mariano-Lapidus, 2014). Similarly, Cole et al (2004) studied sixteen inclusive education programmes in comparison to special classrooms and found that students with severe disabilities in the inclusive programmes performed better academically. Alquraini and Gut (2012) highlighted that for students with severe disabilities, an integrated environment with their peers increases their likelihood of meeting their Individualised Education Programme (IEP) goals. By facilitating inclusion, the cooperative learning environment promotes academic success in areas of math and reading in particular, for students with severe disabilities (Cole et al, 2004; Alquraini and Gut, 2012). Heir et al (2016) also suggest that typically developing children stand to benefit from learning in a flexible environment tailored to students' individual strengths and needs. In addition, Browder et al (2012) provide detailed intervention strategies to support students with severe disabilities in math in inclusive settings. As scholars move towards diverse teaching styles and Universal Design for Learning (UDL), it becomes more achievable and practical for all students to receive the support they require.

There is also a gap in the resources and supports that teachers have while implementing inclusive education (Curcic, 2009; Oswald & Swart, 2011; Chiner & Cardona, 2013). Scholars suggest that educators do not have the adequate support, assistive technology, or knowledge of curriculum modification to support students (Heir et al, 2016). If adequate support and resources are not there, inclusive education is not operating to its full capacity of delivering appropriate outcomes as it implies. Aside from this, Horn et al (2019) stress that parental-teacher partnerships are crucial for the success of inclusive education. For students with severe disabilities in particular, it is crucial for academic goals to be functional, discipline-free and to facilitate meaningful outcomes (Horn et al, 2019).

Therefore, outside of these critiques of academic-focused inclusion for students with severe disabilities, it is important to note that many authors have discussed the failures in implementing inclusion and this may be a barrier. Florian (2019) argues that the policies and procedures leading inclusive education are powerful but require systemic change in attitudes and systems.

Dymond et al (2007) suggest that the problem with inclusive education is not structure, but funding. The authors note that there is space to discuss community and social locations in inclusive education, but nothing is possible or successful without adequate funding and implementation. Positive outcomes for students cannot be accessed without proper funding and education to continuous funding (Dymond et al, 2007; Curcic, 2009). There is a large body of literature around funding disability education and inclusive education programming or the lack thereof (Tones et al, 2001; Dymond et al, 2007; Aron & Loprest, 2012). Inclusive education provides opportunities and space for students with disabilities to practice self-determination in their academic journey (Mittler, 2000), but without funding this is not possible. Dukes et al (2020) also highlight that there are these key differences in theorising programming and practice for students with severe disabilities.

There is a consensus on this element, but the divide in inclusive education is regarding academic benefits and whether inclusive education can effectively educate students labelled with severe disabilities. Moreover, the divide is more prevalent when discussing students labelled with severe disabilities. The movement towards proximity is examined from the critical disability studies approach and highlights the relationality between systems of marginalisation and oppression and systemic disablement for students labelled with severe disabilities.

While reflecting on the objectives of publicly funded education, it is important to note the outlined goals and policy promises. On a larger Canadian scale, quality education is a vast objective to build knowledge, skills, and a prosperous world (United Nations, 2022). Education is a fundamental aspect of economic, social, and political development across the globe and Canada is no different. The Constitution Act of 1867 outlined the expectations of classical federalism and the responsibility of education to be exclusively controlled by the provincial jurisdiction under Section 92. This led to the development of the Education Act in Ontario. The Education Act is a provincial document that outlines the responsibilities of educational staff, structures of school boards, and the rights of students and parents. The Education Act (2009) outlines the purpose of education on page 12:

> “(1) A strong public education system is the foundation of a prosperous, caring, and civil society. (2) The purpose of education is to provide students with the opportunity to realise their potential and develop into highly skilled, knowledgeable, caring citizens who contribute to their society. (3) All partners in the education sector, including the Minister, the Ministry, and the boards, have a role to play in enhancing student achievement and well-being, closing gaps in student achievement, and maintaining confidence in the province’s publicly funded education systems” .

To reflect further on this critical piece of policy development, it is important to examine the purpose and goals of the system and the traditional trajectories that may be influencing attainment of these goals. This bears the critical reflection on how does inclusive education fit into these policy objectives and goals and how do students labelled with severe disabilities potentially differ in this framework?

Most of the research examined above focuses on academic success, separate from social success or the overarching social benefits. In some manner, the social benefits are amplified within the literature, and this overshadows the larger academic worries, specifically when discussing students labelled with severe disabilities. In some ways, the divide generates a larger argument about what is more important - academic success or social success. Although the current study would not view these as separate entities and the author values the work of Carter et al (2016) and their proposition of social development improving academic participation and engagement, there is a divide when the discussion begins on how schools and teachers can individually include students with disabilities socially, without suffering academically.

Critical Disability Studies in Education

Critical disability studies (CDS) offer a crucial perspective on educational programming based in the historical, social, and political understanding of disability from a macro-systems level approach. CDS examines the larger institutions and social structures that systemically oppress or 'disable' individuals (Hall, 2019). Through the reproduction of ableist attitudes and promoting the individual as the root of the problem, the education system marginalises and 'disables' students with impairments (Goodley, 2007; Oliver, 2013). Based on the social model of disability studies, the larger systems and institutions are using the medical model to exert power and systemically exclude and discriminate against those with disabilities. Some individuals prefer the terminology of 'disabled' because of these feelings of marginalisation and oppression that is disabling them from participation, actions, and inclusion (Goodley, 2007). The impairment is one aspect, but the discrimination, exclusion and lack of access disables them further (Titchkosky, 2011).

In the educational context, Iannacci (2018) highlights the reproduction of ableist attitudes through educators and the larger institution of curriculum. Since educators are also subjected to the systematic ableism involving students with disabilities and accommodations through society and education, Iannacci (2018) calls for the critical examination of educators' pre-existing understandings of disability and possible pre-existing biases. As there are historical predispositions, discourses and problematic procedures built into systems of education, it is crucial to be cognisant and aware of prejudices and the reproduction of these attitudes through larger social systems and institutions. As Dolmage (2017) points out, some mainstream movies such as Monsters University even attempt to conceptualise disability and diversity in education. The movie begins to recognise students' diversity or differences, but rather than altering the system to be accessible or accommodating, the institution does not adapt and students learn to conform to the larger macro-level structures such as standardised testing (Dolmage, 2017). Dolmage (2017) highlights the abundance of ableist attitudes built into the educational system, including pressure to conform to able-bodied standards of behaviour, such as sitting still, a considerable attention span, and learning without additional supports or resources. These subtle forms of ableism are not only built into systems and institutions, but also reproduced by curriculum standards and educators' compliance.

Baglieri and Lanvani (2020) offer some strategies and worksheets for critical reflection on systemic ableism and how educators can undo ableism in K-12. To critically engage with the systems that are oppressing or limiting students with disabilities, self-reflection and positionality are key elements. As educators, Baglieri and Lanvani (2020) suggest making a list of the ways in which an individual has power as a teacher. From here, the individual can reflect on what pedagogical changes can be made to change the dynamics and improve the pedagogical framework for students with disabilities. Also, make a list of what power young people have in the classroom and what pedagogical changes they can change independently (Baglieri and Lanvani, 2020). Now review these lists and reflect on the intersections between teachers and students and how they can influence or impact one another. In addition, Baglieri and Lanvani (2020) prompt educators to think about how our constructions or deconstructions of normalcy, ableism, and disability can help grow a community of learners. This question helps educators reflect on the practices they engage in that could be altered to be more inclusive and contributing to deconstructing systemic ableism.

CDS and Inclusive Education for Students Labelled with Severe Disabilities:

There are a few strategies that educators and researchers alike can take forward from this critical reflection. First, oppression, discrimination, and marginalisation for students labelled with severe disabilities (all disabilities and impairments moreover) is built within and reproduced by the current education system, curriculums, and policies more generally. The standards within education and the expectations, or the illusion of the 'normal child' as Baglieri et al (2011) refer to it, systematically disable students from their full potential and their ability to fully participate in the classroom. This disablement of students is built of relationality, social standards and power imbalances within education that are generated through colonialism and policy structures (Titchkosky, 2007; Baglieri et al, 2011). To be truly inclusive and implement inclusive education properly, Ballard (1999) highlights the need for larger systemic change by stating that "inclusive education is about confronting all forms of discrimination as part of a concern to develop an inclusive society based on 'social justice, equity and democratic participation' ". To be fully inclusive means to remove barriers for all students, not just students with disability, and to strive towards the intersectionality of identity in education

(Baglieri et al, 2011). This approach would be rooted in a social justice approach to education that involves the recognition of injustices and barriers, and addresses them. Finn (2021) proposed a theoretical framework to turn theory into practice in terms of social justice in education. The 'Just Practice' framework addresses five key concepts: meaning, power, context, history, and possibility. These concepts call for action and critical reflection, but also challenge power dynamics through the curriculum and the ways educators approach teaching and learning (Finn, 2021). The first step towards social justice is understanding the key concepts and addressing them in individual practice and work.

Within the field of critical disability studies there are goals of removing able-bodied standards and dismantling systems that reproduce systemic ableism including academic curriculum and physical spaces. In the instance of severe disability, the goal should be removing the stigma and systemic ableism that these students are problematic or a burden to the educational system. Rather than embracing diversity or the social construction of abnormal or divergent, the educational system and some individuals in education see their needs as problematic; this is where a change is needed. If the student with the severe disability is regarded as the problem, it reproduces systemic ableism that presumes students' capabilities, trajectory, and abilities. Rather, if larger macro-level structures evaluate their ableist and problematic dis-abling processes, this can switch the onus away from the student and towards the systems that are regenerating oppression, marginalisation, and discrimination.

The educational goal towards inclusive education, including social and academic efforts, is demonstrated in the Education Act as "the purpose of education is to provide students with the opportunity to realise their potential and develop into highly skilled, knowledgeable, caring citizens who contribute to their society" (p.12). By enacting effective and culturally responsive pedagogy into inclusive education, this could work towards the goal of education more generally and orient itself towards social justice frameworks. For example, Baglieri and Lanvani (2020) suggest that young children should be intentionally taught about disability and the social construction of disability through a variety of work sheets and self-reflections. As is, there is no formal educational pedagogy for discussing disability with children, let alone students in higher education. If the intention is to make students realise their potential, work must first be done towards educating the community away from ableist and bias perceptions about disability and capacity.

Students in the community can act against ableist tendencies, but so can professionals and educators who are working within the system. Whether one is an activist, self-advocate or ally, assumptions about other disabilities work towards the reproduction of ableist attitudes (Baglieri and Lanvani, 2020). The more people categorise, label and push individuals into diagnoses, the more this limits their lived experiences and can reproduce stereotypes about those who have disability. By being an advocate for support, learning and equal access for all students, one is playing a part in dismantling systems of oppression and marginalisation (Baglieri and Lanvani, 2020).

In practice, there are a few different strategies to start this process or conversation of systemic change. O'Brien (2014) suggests the use of a person-centred approach to system reform. One of the key insights that O'Brien (2014) provided was the success of system reform through community consultation. Those with severe disabilities are commonly left out of policy decisions and community support initiative decisions, but by giving them a seat at the table this allows for individuals to have power in the decision making about their future and exercises their democratic rights (O'Brien, 2014). The top-down approach to policy decisions is outdated and should be reformed to actively communicate and consult the communities that are directly impacted by these decisions. What can this look like? In the classroom this can be by simply asking one's students what they prefer, or which approach works best for them. For example, communicating with the student about what math manipulative they feel is the most 'fun' or 'engaging' for them. Each student with the same disability may differ, but this is centering the person at the root of learning, and they become autonomous over their education.

The Individual Education Plan (IEP) programme in Ontario attempts to fulfill O'Brien's person-centred approach. IEPs outline the manner in which the student's needs can be met through programming, accommodations, or alternative expectations. The Identification, Placement, and Review Committee (IPRC) assesses the student's "strengths, needs and ability to learn and demonstrate learning" (Government of Ontario, 2022). Although IEPs appear to be person-centred or student focused, they are rooted in an ableist system that fails to recognise their part in dis-ability. Commonly, students that received an IEP are categorised by behaviour or diagnosed (Government of Ontario, 2022), which inherently relies on the medical model that problematises students with disabilities and not the systems that dis-abled them from learning. The accommodations and solutions proposed to students are also routed in systems that understand these students as problematic and do not engage with these communities to develop policies and procedures. Moreover, IEPs are based on systemic solutions to accommodate disability and not inherently generated, co-produced or consulted with, as O'Brien (2014) suggests in a person-centred approach.

Although this suggestion seems individual and does not consider the systems that are dis-abling students, O'Brien (2014) suggests that changes in practices, monitoring, training, and assistance can generate transformation. These types of procedural changes at the individual level mobilise change into the larger policies that govern all bodies. This can also assist in self-determination for students labelled with severe disabilities. As Agran and Hughes (2014) suggest, self-determination is critical for students labelled with severe disabilities. Self-determination allows for students to determine their own educational desires and directs their education (Agran and Hughes, 2014). This can alleviate some of the concerns that Ayres et al (2011) highlight with the disparities in curriculum and equity in educating for life skill development. If students (and indirectly parents) had the choice to determine the courses they take with more freedom and self-determination, this could empower students in their own education and consider the injustices that Ayres et al (2011) discuss. Moreover, courses surrounding 'life skills' do not need to be centralised to only students labelled with severe disabilities. These courses can be beneficial to all students to become autonomous and learn practical skills such as personal banking and taxes.

DISCUSSION and CONCLUSION

While examining the literature on inclusive education for students labelled with severe disabilities, the three prominent themes of impact were proximity, social and academic. In response to the research questions, the literature highlights the large social impacts of inclusion for students labelled with and without disabilities. Inclusive education is coined for promoting acceptance and belonging, increasing exposure, and improving social skills for those labelled with severe disabilities (Carter et al, 2016; Florian, 2019; Kefallinou et al, 2020). There is a smaller body of literature that discusses the academic impact for students labelled with severe disabilities. The literature debates the academic impact and highlights that the academic requirements of some students with disabilities are being overshadowed by the focus on physical integration and social inclusion (Kauffman, 2021). Ayres et al (2011) and Kauffman (2021) emphasise that inclusive education performs a disservice for students labelled with severe disabilities as it lessens the importance of student trajectories and does not teach them appropriate skills. On the other side, Heir et al (2012) and Wagner et al (2005) highlight that those inclusive settings produced higher scores in math and language abilities for students compared to their segregated peers.

The policies in Canada, and Ontario more specifically, support the move to fully inclusive programming for all students. This is evident through the Constitution Act of 1867 and the Education Act (2009) which outlines the purpose of education for all and the overarching goal of academic participation and reaching individual potential. When applying the critical disability studies in education framework, scholars in this field examine the systems, institutions and standards built within the educational context that can dis-able or generate barriers for students labelled with severe disabilities. Many scholars including Baglieri et al (2011) and Ballard (1999) have critiqued the individualistic approach to removing ableism and point towards the systems that perpetuate injustice, oppression, marginalisation, and discrimination. Moreover, to be fully inclusive is to strive towards the intersectionality of identity in education and remove barriers for all students (Baglieri et al, 2011). Therefore, the inclusive education system discussed above and the key impacts of inclusive education must be broadened to remove barriers for all students, not just those that have disability.

Based on the CDS framework, the author of the present analysis would argue that these classes do not need to be segregated to only those with disabilities and the systematic advertisement and promotion of these courses stream a particular population to these courses. Students labelled with severe disabilities may be impaired from completing an advanced algebra class, but the system is perpetuating that this makes them less intelligent, worthy, or important in society. The general education system may not ever become centralised to be universally accessible for all, including those with severe disabilities, but the system can be altered to alleviate some of the ableist attitudes towards specific courses and the value of these courses more generally. The construction of high academic success as desirable further divides society's structure into two tiers, which is detrimental to societal growth and systemic development. The removal of systemic ableism is not a simple solution; it requires growth, expansion, and development through systems.

REFERENCES

Agran M, Hughes C (2014). Promoting Self-Determination and Self-Directed Learning. In Agran, M., Brown, F., Hughes, C., Quirk, C., and Ryndak, D. (Eds).*Equity and Full Participation for Individuals with Severe Disabilities* (75-98). Paul Brooks Publishing.

Ainscow M, Booth T, Dyson A (2006). *Improving Schools, Developing Inclusion.* Routledge.

Alquraini T, Gut D (2012). Critical components of successful inclusion of students with severe disabilities: Literature review. *International journal of special education, 27*(1), 42-59.

Anastasiou D, Kauffman JM (2011). A Social Constructionist Approach to Disability: Implications for Special Education. *Exceptional Children, 77*(3), 367–384. Retrieved from: https://doi.org/10.1177/001440291107700307

Aron L, Loprest P (2012). Disability and the Education System. *The Future of Children 22*(1), 97-122. doi:10.1353/foc.2012.0007.

Ayres KM, Lowrey K A, Douglas K H, Sievers C (2011). I Can Identify Saturn, but I Can't Brush My Teeth: What Happens When the Curricular Focus for Students with Severe Disabilities Shifts. *Education and Training in Autism and Developmental Disabilities, 46*(1), 11–21.

Ayres K M, Lowrey K A, Douglas KH, Sievers C (2012). The Question Still Remains: What Happens when the Curricular Focus for Students with Severe Disabilities Shifts? A Reply to Courtade, Spooner, Browder, and Jimenez (2012). *Education and Training in Autism and Developmental Disabilities, 47*(1), 14–22.

Baglieri S, Lalvani P (2020). Undoing Ableism: Teaching About Disability in K-12 Classrooms. *Routledge.*

Baglieri S, Bejoian L M, Broderick A A, Connor D J, Valle J (2011). [Re]claiming "Inclusive Education" toward Cohesion in Educational Reform: Disability Studies Unravels the Myth of the Normal Child. *Teachers College Record, 113*(10), 2122–2154. https://doi.org/10.1177/016146811111301001

Baglieri S, Valle J W, Connor D J, Gallagher D J (2011). Disability Studies in Education: The Need for a Plurality of Perspectives on Disability. *Remedial and Special Education, 32*(4), 267–278. https://doi.org/10.1177/0741932510362200

Ballard K (Ed.) (1999). *Inclusive education: International voices on disability and justice.* Falmer Press.

Blackorby J, Knokey A-M, Wagner M, Levine P, Schiller E, Sumi C (2007). What Makes a Difference? Influences on Outcomes for Students with Disabilities. *Menlo Park, CA: SRI International*. Retrieved from http://www.seels.net/designdocs/SEELS_W1W3_FINAL.pdf

Braunsteiner M L, Mariano-Lapidus S (2014). A perspective of inclusion: Challenges for the future. *Global Education Review, 1*(1).

Browder D M, Jimenez B A, Spooner F, Saunders A, Hudson M, Bethune K S (2012). Early Numeracy Instruction for Students with Moderate and Severe Developmental Disabilities. *Research and Practice for Persons with Severe Disabilities, 37*(4), 308–320. https://doi.org/10.2511/027494813805327205

Carter E W, Asmus J, Moss C K, Biggs EE, Bolt D M, Born T L, Brock ME, Cattey GN, Chen R, Cooney M, Fesperman E, Hochman JM, Huber HB, Lequia JL, Lyons G, Moyseenko KA, Riesch LM, Shalev RA, Lori B. Vincent LB, Weir K (2016).Randomized evaluation of peer support arrangements to support the inclusion of high school students with severe disabilities. *Exceptional Children, 82*(2), 209-233.

Carter E W, Hughes C, Guth C B, Copeland S R (2005). Factors influencing social interaction among high school students with intellectual disabilities and their general education peers. *American Journal on Mental Retardation, 110*, 366–377

Chiner E, Cardona M C (2013). Inclusive education in Spain: how do skills, resources, and supports affect regular education teachers' perceptions of inclusion? *International Journal of Inclusive Education, 17*(5), 526–541. http://doi.org/10.1080/13603116.2012.689864

Cole C M, Waldron N, Majd M (2004). Academic programs of students across inclusive and traditional settings. *Mental Retardation, 42*(2), 136-144.

Curcic S (2009). Inclusion in PK-12: an international perspective. *International Journal of Inclusive Education, 13*(5), 517–538.

Dolmage J (2017). *Academic Ableism*. University of Michigan Press. https://www.press.umich.edu/9708722. pp. 140

Dukes C, Berlingo L (2020). Fissuring Barriers to Inclusive Education for Students with Severe Disabilities. *Research and Practice for Persons with Severe Disabilities*, *45*(1), 14–17. https://doi.org/10.1177/1540796919895968

Dymond S K, Orelove F P (2001). What constitutes effective curricula for students with severe disabilities?*Exceptionality, 9*(3), 109-122.

Dymond S K, Renzaglia A, Chun E (2007). Elements of Effective High School Service Learning Programs That Include Students with and Without Disabilities. *Remedial and Special Education, 28*(4), 227–243. https://doi.org/10.1177/07419325070280040301

Feldman R, Carter EW, Asmus J, Brock M E (2016). Presence, proximity, and peer interactions of adolescents with severe disabilities in general education classrooms. *Exceptional Children, 82*(2), 192-208

Finn J L (2021). *The just practice framework in action: Contemporary case studies*. Oxford University Press.

Giangreco M F (1997). Key lessons learned about inclusive education: Summary of the 1996 Schonell Memorial Lecture. *International Journal of Disability, Development and Education*, 44(3), 193-206.

Goodley D (2013). Dis/entangling critical disability studies. *Disability & Society*, *28*(5), 631 644.

Government of Ontario (2022). Individual Education Plan. *Ministry of Education*. Retrieved from: https://www.ontario.ca/page/individual-education-plans

Hehir T, Grindal T, Eidelman H (2012). *Review of special education in the Commonwealth of Massachusetts.* Massachusetts Department of Elementary and Secondary Education. Retrieved from: http://www.doe.mass.edu/sped/hehir/2012-04sped.pdf

Horn E, Parks S, An Z (2012). Inclusive Special Education for Young Learners with Severe and Multiple Disabilities. *Special Education for Young Learners with Disabilities Advances in Special Education, 34*, 119-137.

Iannacci L (2018). *Reconceptualizing Disability in Education*. Lexington Books.

Kozleski E, Artiles A, Waitoller F (2014). Equity in inclusive education: A cultural historical comparative perspective. *The SAGE handbook of special education, 2,* 231-249.

Morningstar M E, Kurth J A, Johnson P E (2017). Examining national trends in educational placements for students with significant disabilities. *Remedial and Special Education, 38*(1), 3-12.

Newman L, Davies E, Marder C (2003). *School Engagement of Youth with Disabilities. In The Achievements of Youth with Disabilities During Secondary School: A Report from the National Longitudinal Transition Study-2 (NLTS2).* Menlo Park, CA: SRI International.

O'Brien J (2014). Person Centered Planning and the Quest for System Change. In Agran, M., Brown, F., Hughes, C., Quirk, C., and Ryndak, D. (Eds).*Equity and Full Participation for Individuals with Severe Disabilities* (57-74). Paul Brooks Publishing.

Oliver M (2013). The Social Model of Disability: Thirty Years On. *Disability & Society 28*(7), 1024–26.

Oswald M, Swart E (2011). Addressing South African Pre-service Teachers' Sentiments, Attitudes and Concerns Regarding Inclusive Education. *International Journal of Disability, Development and Education, 58*(4), 389–403. http://doi.org/10.1080/1034912X.2011.626665

Paseka A, Schwab S (2020). Parents' attitudes towards inclusive education and their perceptions of inclusive teaching practices and resources, *European Journal of Special Needs Education, 35*(2), 254-272.

Thompson J R, Bradley V J, Buntinx W H, Schalock R L, Shogren K A ,Snell ME, Wehmeyer ML, Borthwick-Duffy S, Coulter DL, Craig EP, Gomez SC, Lachapelle Y, Luckasson RA, Reeve A, Spreat S, Tassé MJ, Verdugo MA, Yeager MH. (2009). Conceptualizing support and the support needs of people with intellectual disability. *Intellectual and developmental disabilities, 47*(2), 135-146.

Titchkosky T (2007). *Reading and Writing Disability Differently: The Textured Life of Embodiment.* University of Toronto Press.

Wagner M, Kutash K, Duchnowski A J, Epstein M H (2005). The Special Education Elementary Longitudinal Study and the National Longitudinal Transition Study Designs and Implications for Children and Youth with Emotional Disturbance. *Journal of Emotional and Behavioral Disorders, 13*(1), 25–41. http://doi.org/10.1177/10634266050130010301

United Nations (2022). *The Sustainable Development Goals Report 2022*. Quality Education. Retrieved from: https://www.un.org/sustainabledevelopment/education/

York TT, Gibson C, Rankin S (2015). Defining and measuring academic success. *Practical assessment, research, and evaluation, 20*(1), 5.

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