



# DISABILITY, CBR & INCLUSIVE DEVELOPMENT

Formerly Asia Pacific Disability Rehabilitation Journal

Volume 32 ■ No. 3 ■ 2021

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## How Neo-colonial Are We in What We are Doing?

Dear Readers,

As Editor-in-Chief I am proud to present to you not only the 3<sup>rd</sup> (Autumn) issue of this year but share with you some more news, of which I wish to mention:

- 1) That this is the 4<sup>th</sup> issue published this year with slightly fewer manuscripts than usual, but we are back on track in terms of publishing issues quarterly. This has taken a lot of effort from the entire team involved in making this possible;
- 2) Within this issue you will see – immediately after this editorial – a **vision paper written by the editorial board**. We invite you to read this carefully and critically and we very much appreciate your feedback. Please do write to me; send me your feedback, share issues and suggestions, and do this either formally in the format of a letter to the editor or write to me more informally. Your ideas, suggestions and concerns are highly welcomed! We very much want this journal to become a platform to give you a voice and a community of collaborators and practitioners in particular! We want the journal to be of relevance to all stakeholders involved in the field of disability and development. We want the journal to be of value to academics on one hand but even more importantly, to practitioners and policymakers on the other hand.

The most recent announcement on the website of the DCID journal that may be of importance to you: see: <https://dcidj.org/announcement/>

With only asking the above question (see title of this editorial), I run a serious risk of being severely criticised by some people or groups in society. Giving answers will make me even more vulnerable. Does it then mean that we should not ask this question and even more forget to find answers that are not based on vague notions but are grounded in the reality of today's world in which we are living?

With all developments and development cooperation that is taking place in low- and middle-income countries, I often have the feeling that the voices of those living in these countries is hardly being heard and if we hear them, it doesn't mean that we listened to those voices. There are even initiatives with names that – explicitly or not so explicitly – refer to the importance of the voice of those who form the target of those programmes e.g., Power of Voices, Amplifying Voices; Voices for Power. These are excellent and nice initiatives in themselves. There

is of course nothing wrong with all these initiatives as long as it indeed leads to change, transformation and a more egalitarian society. However, when reflecting on the past three or four decades of my involvement in development cooperation, I wonder in how far the power basis in low- and middle-income countries has changed? I increasingly notice that there are a lot of subtle or no so subtle forms of neo-colonialism taking place in development cooperation by both large and not so large stakeholders. Unfortunately, and despite all good intentions, I see this happening in the disability field as well.

The divide that is so often made between those who are disabled and who are not disabled is an artificial one, which I have been referring to in one of my earlier publications in this journal. There I state that *“We cannot permit ourselves anymore a division among those who are disabled and those who are non-disabled as there are other divides among groups of people that are by far more profound and serious to the majority of disabled people worldwide. While the urban elite of people with disabilities who live in a conflict-free, open and democratic society may be well concerned with issues such as accessible tourism, Community Based Rehabilitation as an essential service provision is often unavailable for the poor rural masses and those living under illegal conditions in slums of the cities of Africa, Asia and South America. Community-Based Rehabilitation as a philosophy seeks for solidarity with those who live under appalling conditions, threatened by conflict, eviction and hunger (1)”*

Jan Pronk – former Minister of Dutch Ministry of Development Cooperation – describes in a recently published essay the need to decolonise what he calls the ‘under-world’ (2). He refers in his essay to the commitment of the United Nations to use development aid (as it was called then) as a means to end inequality, injustice and discrimination rooted in colonial oppression, and to counteract their repercussions in new world relations. He asks the reader if the practices of development cooperation contributed to reaching that goal but concludes that in fact nowadays, the contrary is happening. He wonders why it is that development cooperation has not been able to change that system. Change requires time, but if that was the only reason then the system would slowly get weaker. However, that is not the case. The system is stronger than before because Western economic powers tried to undermine the developing autonomy of former colonies by exercising control over investment, technology, and trade channels to safeguard their interests.

It is the voice of that ‘under-world’ that is usually not being heard: the majority of people with disabilities living in a poor isolated situation; often in conflict areas,

disaster-prone areas, living in semi-permanent refugee camps where the driver tells us to lock the doors of the car because it is too dangerous not to do so.

We, however, so often pay lip service to the true meaning of empowerment, and I am including myself here as well since it is all too simple to point to others. I had the privilege to travel the past couple of months to various countries and be a facilitator in advocacy and lobby training in 2 different countries. In one country we have a great group of trainees; disability activists; people with longstanding involvement in the disability sector in that country. They know the local laws and legislation related to disability and have an excellent grasp of the international scene. Almost all people have a laptop in front of them, multitask and perfectly cope with theory and praxis. A few weeks later we are training in another country with 18 people of whom only 5 have access to internet because they either work for an international organisation or work for the government. And it is those people who do well; who grasp what we say, who respond adequately; with whom we have easy contact. And yet the training is not for them per se. It is especially for those of whom we, as trainers, – and maybe all too soon – become critical and wonder if ever they will grasp even the essence of what we are saying and doing.

I have a responsibility to reflect, respond and act upon the differences that I notice in working with 2 apparently similar groups in the same programme but in 2 different countries, and thus need to adapt and take more time and listen better. Is that also not a large responsibility of bilateral, multilateral, and non-governmental organisations as well? I imagine that this should be the case and I hope that all those who are in power in the offices of the United Nations, professional boards of rehabilitation professionals, global disability organisations, international non-governmental organisations, Western universities and consultancies continuously reflect on their way of working in the interests of those who are belonging to that 'under-world'. The ones who have nothing, the millions of people with disabilities who are not (yet) being heard because...

Jan Pronk finishes his essay by stating that personal reflection is important. However, he continues by concluding that the structures of injustices in society that perpetuate institutional discrimination need to change. That requires a change in mindset and should start with the recognition that one needs to use the needs of people of the under-world as the point of departure for development.

The defeat of the West in Afghanistan among other developments in today's world shows us that there are groups of people who don't like western norms and values. The defeat was painful and terrible – not so much for the defeated West – but far more for all those Afghans who worked with western governments, organisations and agencies that tried to create a society that would be acceptable to western norms and values. Let us thus be careful in using these western norms and values as a point of departure or as that what we wish to achieve in developments. Let's rather use a critical lens for thinking about development and rehabilitation interventions. Let's have an open window towards the needs and desires of those who are least benefiting from developments that have taken place over the past decade and let's be open to local solutions to the problems and challenges which people face.

1. Cornielje H, (2009) The role and position of disabled people's organizations in community-based rehabilitation: balancing between dividing lines, APDRJ, Vol 20, No 1, pp 3-14.
2. Jan Pronk (2021), Essay: Dekoloniseer de benedenwereld, Vice Versa, 16th of August.



# Vision Paper: DCID Journal - The Future...

## Introduction

For the past 30 years the Disability, CBR and Inclusive Development (DCID) journal has played an important role in presenting debates in the area of disability, community-based rehabilitation and disability inclusive development and continues to do so. With rapid changes taking place in these and related fields, it is time to present a new vision for the future of the journal and the contribution it can make to the arena of disability inclusion within and across all sectors, particularly in low- and middle- income countries, to accelerate social justice and equity.

DCID is an open-access journal with a strong focus on communicating:

- 1) lessons from applied research in and to the fields of disability, inclusive development and rehabilitation;
- 2) experiences and learning from the field that can contribute to inclusive policy and practice; and
- 3) knowledge generated from a range of perspectives, including groups that are marginalised and oppressed.

## Towards a new vision

Through the DCID journal, we are committed to inform and influence policy processes, share best practices, contribute to promoting and facilitating inclusive practices, and to inform agenda-setting that is relevant for the field of disability inclusive development. DCID aims to inspire and influence its readership to drive the much-needed transformation of society into one where persons with disability have access to services and equal opportunities to ensure their participation and inclusion in all aspects of life in their communities.

The DCID journal intends to support and contribute to the creation and building of leadership in disability inclusion, in social justice and equal opportunities in development. The editorial board of DCID wants to be action oriented and inspire action among its readers.

The DCID journal aspires to look beyond problems and instead help with identifying solutions to the many challenges we encounter in our work in low- and middle-income countries.

The journal will continue to maintain the core focus on research (particularly practice-based research and implementation research) and research methods that can inform practice in the Global South.

The editorial board of the DCID journal strongly encourages submissions from Southern authors and those from outside academia by reaching out to those who may be new to this kind of writing but have something meaningful to share!

The editorial board of DCID seeks to be a forum for dissemination and exchange of information between academics, practitioners and other stakeholders in the disability arena. We aspire to broaden the readership both in terms of types of readers and their geographical location.

An aim of the editorial board is that the scope of the journal will be broadened and deepened; the publication of special thematic issues on a wide range of topics will be stimulated and invited. There could also be special issues dedicated to the CBR Africa/Asia/South America/Caribbean Networks, AfriNEAD, OT Africa Regional group, also OT Pacific-Asia Regional group and other specific interest groups.

Other means of communication and dissemination e.g., via social media will increasingly play a role to stimulate debate and innovation. Active dialogue between authors and readers will be encouraged for example by a section for short commentaries, letters and responses.

The journal could have a section for Masters and PhD students to submit their papers, in order to encourage and build capacity in writing papers. Such papers could be part of a possible new section of articles, for example, 'Emerging Research Digest'. The Editorial Board members could play a role here, as mentors to build capacity and ensure quality of content being published.

Similarly, we aim to encourage field-level programmes to publish their experiences, aided by members of the Editorial Board. National and International organisations (INGOs and others, for example) working on disability at community level could be asked to work on a special issue related to their work.

## **The Editorial Board**

## ORIGINAL RESEARCH

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# **/t/ before /t/ or /t/ before /t/: Emerging Trends from a Preliminary Study of Consonant Acquisition in Typically developing Sinhala-speaking Children aged 3 to 6 years**

Shyamani Hettiarachchi<sup>1\*</sup>, Mahishi Ranaweera<sup>2</sup>, R. M. W. Rajapaksha<sup>3</sup>

1. Department of Disability Studies, Faculty of Medicine, University of Kelaniya, Sri Lanka

2. Department of English Language Teaching, Faculty of Humanities, University of Kelaniya, Sri Lanka

3. Department of Linguistics, Faculty of Humanities, University of Kelaniya, Sri Lanka

### ABSTRACT

**Purpose:** *Speech and language therapists use developmental norms established for consonant acquisition to determine whether a child has age-appropriate, delayed or disordered speech skills. There are currently no established norms for the acquisition of Sinhala consonants, which have implications for accurate diagnosis. The aim of this study was to document preliminary trends observed in the trajectory of consonant sound development in Sinhala-speaking young children so as to form a set of ‘working norms’.*

**Method:** *A picture-based articulation assessment was administered to 70 typically developing children who were between 3 years and 6 years 11 months of age.*

**Results:** *Regarding the rate of acquisition and order of acquisition, the findings displayed trends comparable to general patterns of consonant mastery reported within cross-linguistic studies. In addition, a different rate of acquisition and order of mastery was observed for both uncommon Sinhala language-specific speech sounds showing ambient language effects and for a few common sounds occurring in Sinhala and other languages.*

**Conclusion & Implications:** *The convergence and divergence in the rate and order of Sinhala consonant acquisition compared to the cross-linguistic literature has important clinical implications for assessment, early identification of speech difficulties and intervention within speech and language therapy practice in Sri Lanka.*

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\* **Corresponding Author:** Shyamani Hettiarachchi, University of Kelaniya, Sri Lanka. Email: shyamanih@yahoo.com

*Key words: speech, consonants, trajectory, acquisition, norms, Sinhala*

## INTRODUCTION

For a child referred due to ‘unclear speech’ or concerns surrounding speech intelligibility, the task of a speech and language therapist is to make an informed decision on whether the child displays typical age-appropriate speech skills, delayed (meaning below age-level competence) or atypical disordered speech patterns. To do so, clinicians rely on established norms for speech sound acquisition and for typical speech error patterns in the ambient language or languages under consideration.

At present, in the absence of clearly established norms for phonetic and phoneme acquisition for Sinhala, Sri Lankan speech and language therapists are reliant on norms for English as published by Grunwell (1985) or Dodd, Holm, Zhu and Crosbie (2003), as well as on their clinical experience of diagnosis. Research studies on the trajectory of speech sound acquisition have called into question the current use of English speech norms with monolingual and bilingual speakers of languages other than English (Bowen, 1998; Fox & Dodd, 2001).

## Cross-linguistic Studies

### Rate and sequence of speech sound acquisition

Given the need for guidance in determining consonant mastery in languages that have hitherto been under-researched, attempts have been made to use cross-linguistic studies to determine potential speech acquisition trajectories for children who are monolingual and multilingual (McLeod & Crowe, 2018). While acknowledging the contested theories of Jakobson (1941/1968), Locke (1983) and Vihman (1996), McLeod and Crowe (2018) offered a review of 27 languages to determine patterns of consonant acquisition in diverse languages and document overall emergent cross-cultural patterns. This, they argued, could be a preliminary resource, relevant to languages not investigated thus far. The authors of the current study have used the review as a starting point to reflect on the emerging trends in Sinhala, given the lack of previous research.

In a cross-linguistic review of 60 articles on consonant acquisition, McLeod and Crowe (2018) found that, across 27 languages, most consonants are mastered by the age of 5 years. The review concluded that plosives, nasals and non-pulmonic

consonants are mastered early in comparison to fricatives, affricates, trills and flaps. This early acquisition pattern of nasals, plosives and approximants has been reported in languages as diverse as Japanese, Korean, Turkish and Spanish (Amayreh & Dyson, 1998; Kopkalli-Yavuz & Topbas, 1998; Goldstein & Washington, 2001; McLeod & Crowe, 2018). Conversely, fewer instances of liquids, fricatives and affricates and dorsal consonants have been reported in babbling and early childhood speech (MacNeilage, 2000; Gildersleeve-Neumann, Davis & MacNeilage, 2001). Additionally, McLeod & Crowe (2018) reported on the early acquisition of labial, pharyngeal and posterior lingual consonants in contrast to consonants requiring anterior tongue movement across the range of languages reviewed.

Of particular interest to the current study is the research on languages of the Indian sub-continent on common sounds shared across languages. For instance, one assertion within the literature is of the relatively late emergence of /r/ in Hindi (Srivastava, 1974; Lakshmi Bai & Nirmala, 1978). One explanation for the late mastery of the shared sound of /r/ is the manner of production as a trill or flap in some languages (Bortolini & Leonard, 1991). Yet another possibility proposed is the linguistic salience or ‘functional load’ of the target sound within the ambient language. Unfortunately, in the review of 60 articles of 64 studies undertaken by McLeod and Crowe (2018), none were of languages of the Indian sub-continent.

### Sinhala Language

Spoken Sinhala, an Indo-Aryan language, consists of 14 vowels and 26 consonants (Disanayaka, 1991; Karunatillake, 1992; Rajapakshe, 1993; Wasala & Gamage, n.d.). This includes 4 prenasalized voice plosives as documented in Table 1. Tak (2011) records Sinhala among a range of languages including Fijian that contains prenasalized consonants which, for Sinhala, are said to occur as a phonologically driven unitary element or phoneme, contrasting with a nasal plus consonant (NC) cluster. Table 1 below illustrates the consonant repertoire of Sinhala.

**Table 1: Consonant Repertoire of Sinhala**

Manner	Place							
	Bilabial	Labio-Dental	Alveolar	Post-Alveolar	Retroflex	Palatal	Velar	Glottal
Plosives	p b		t d <sup>l</sup>		ʈ ɖ	c ɟ <sup>2</sup>	k g	
Nasals	m		n			ɲ	ŋ	

Trills			r <sup>3</sup>					
Fricatives		b	s	ʃ				h
Approximants		w				j		
Laterals			l					
Prenasalized stops	~ b		~ d		~ d		~ g	

Sources: Rajapakshe, 1993<sup>4</sup>; International Phonetic Alphabet, 2005

There has been one study on the trajectory of phonetic and phonemic acquisition in Sinhala- speaking preschool children by Wickremasinghe and Rajapakshe (1999), which is an estimation of speech sounds mastered from 06 months to 4 years. There is no information on sample size, data collection methods, criteria of mastery or analysis undertaken suggesting the use of cross-linguistic literature instead of speech data in Sinhala to develop the norms above

### Figure 1: Acquisition of Consonant Sounds

Age	Sound
6 months- 2 years	p, b, c, m, s, w (plosives + nasals)
1 year – 3 years	t̪, d̪, t̪, k, g, ŋ, h (plosives + nasals)
2 years – 3 years	s, l, j (fricatives)
2 years – 4 years	ʃ, r (trills)

(Source: Wickremasinghe & Rajapakshe, 1999)

Sixteen of the Sinhala consonants can be geminate, /p: b: m: t: d: n: t̪: d̪: k: g: c: ʃ: s: l: j: ŋ:/occurring intervocally, contrasting phonemically with the comparable singleton (Rajapakshe, 1993), though arguably few meaningful minimal pairs are available.

1 There is no agreement among local linguists regarding the place of articulation of /t/ and /d/ with Rajapakshe (1993, 2019) identifying them as alveolar while Wasala and Gamage (n.d.) recognise the placement as dental.

2 There is no agreement among linguists on the manner of articulation of /c/ and /ʃ/. For instance, Rajapakshe (1993, p.29) identifies the sounds as plosives, which has been confirmed through spectrographic assessment (Rajapakshe, 2019) while Wasala and Gamage (n.d.) categorise these sounds as affricates.

3 There are 2 allophonic variants of /r/ as a trill /r/ or a flap/tap /r/ depending on word-position

## Objective

The main aim of this preliminary study was to determine 'working norms' for Sinhala phonetic and phoneme development in young children. Within this paper, phonetic acquisition denotes the mastery of production of individual speech sounds of the target language, in this case Sinhala, either independently or in repetition.

## METHOD

### Participants

Using a purposive sampling method, 70 typically developing Sinhala-speaking children between 3 years (3; 0) and 6 years 11 months (6; 11), belonging to seven age-ranges (3;0 to 3;5, 3;6 to 3;11, 4;0 to 4;5, 4;6 to 4;11, 5;0 to 5;5, 5;6 to 5;11, and 6;0 to 6;11), were included. A corresponding number of male and female participants were included (see Table 2).

**Table 2: Participant Details**

Age-range	Number	Mean age	Gender	Geographical region
3;0 – 3;5	10	3;3	M=5, F=5	G=3 C=6 K=1
3;6 – 3;11	10	3;7	M=4, F=6	G=1 C=4 K=5
4;0 – 4;5	10	4;3	M=6, F=4	G=2 C=4 K=4
4;6 – 4;11	10	4;8	M=5, F=5	G=3 C=5 K=2
5;0 – 5;5	11	5;1	M=7, F=4	G=2 C=4 K=5
5;6 -5;11	13	5;7	M=7, F=6	G=2 C=1 K=10
6;0 – 6;11	6	6;2	M=3, F=3	G=2 C=1 K=3

Children with a known history of speech or language difficulties, any hearing loss or visual difficulties or cognitive or psychosocial difficulties were not included.

Contact was made with preschool teachers known to the researchers through professional contact. Meetings were set up to collect data at the participants' home or pre-school, once written consent was received through the school authorities.

### **Study Tool**

A picture-based assessment tool was compiled based on the key principles of the Diagnostic Evaluation of Articulation and Phonology (DEAP) (Dodd et al, 2002). It included 23 picture stimuli with 45 target items to be named, with each target consonant appearing more than once in word-initial and medial and/or final positions as it occurs in Sinhala (Disanayaka, 1991), with a few identical and non-identical consonant clusters. Error sound stimulability was also checked in CV/VC production and in isolation in a repetition task.

### **Data Collection**

Each participant was administered the articulation subtest of the Test of Articulation and Phonology – Sinhala, and was encouraged to name the target words in the test through 'wh' questions (e.g. What is this? Who is in the picture?). The participants were seen either at their nursery/school or at home. The speech data was recorded using a SONY IC-Recorder and phonetically transcribed simultaneously using the International Phonetic Alphabet (2005). The data was collected by 6 speech and language therapists trained in phonetic transcription.

### **Data Analysis**

All the transcripts were analysed by the primary investigator, with 7 (10%) of the transcripts re-analysed by the co-investigator. The consonants were classified under three phonetic features of voicing, place of articulation and manner of articulation. The criterion for mastery of each consonant was the production of it in the assessment, either spontaneously or in imitation, in at least two word-positions as specified by Dodd and colleagues (2003). At a group level, a consonant was considered to have been 'acquired' if it was produced correctly either spontaneously or in imitation by 75% of the children in each age range at least once, as per the proposition by Dodd et al (2003). Consonant inventories indicating the presence and absence of each target consonant in 75% of children in each age range were compiled as in the review by McLeod and Crowe (2018).



## Ethical Considerations

Ethical clearance was obtained from the Ethical Research Committee of the Faculty of Medicine, University of Kelaniya (No. P/210/11/2018). The study was described to each participant's parent/caregiver with an information sheet given and written consent obtained prior to data collection.

## RESULTS

Given that the results are based on a small group of participants; the findings must be interpreted with care.

### Overall Trends

#### Phonetic Acquisition

Consonant mastery per age range is given below in Figure 2.

**Figure 2: Acquisition of Consonant Sounds in Sinhala**

Age	Present		Absent or Emerging
3;0-3;5	Plosive	p b t d k g	t d c ʃ
	Nasal	m n	ɲ ŋ
	Fricative		s f ʃ h
	Trill		r
	Tap or flap		ɾ
	Approximant	w	
	Lateral	l	
	Prenasalized stops		~ b ~ d ~ ɖ ~ g
3;6-3;11	Plosive	p b t d k g ʃ ɖ c t ɖ	
	Nasal	m n	ɲ ŋ
	Fricative	s h	f ʃ
	Trill		r
	Tap or flap		ɾ
	Approximant	w	
	Lateral	l	
	Prenasalized stops		~ b ~ d ~ ɖ ~ g

4;0-4;5	Plosive	p b t d c ʃ k g t d	
	Nasal	m n ŋ	ɲ
	Fricative	s ʃ h	f
	Trill	r	
	Tap or flap	r	
	Approximant	w	
	Lateral	l	
	Prenasalized stops	~ ~ ~ b d g	~ d
4;6-4;11	Plosive	p b t d c ʃ k g t d	
	Nasal	m n ŋ ɲ	f
	Fricative	s ʃ h	
	Trill	r	
	Tap or flap	r	
	Approximant	w	
	Lateral	l	
	Prenasalized stops	~ ~ ~ ~ b d d g	

In the youngest age-range, 75% of the children in the group accurately produced 13 of the 26 target consonants spontaneously or in imitation. With reference to the same criteria, 5 additional consonants (a total of 18) were mastered by children between the age-range of 3;6 to 3;11 years. Yet another 5 consonants were mastered by those between 4;0 to 4;5 years (23 in total). By the age of 4;6 years, the remaining 3 consonants were mastered, with all consonants acquired produced either spontaneously or in imitation.

The ‘early’, ‘middle’ and ‘late’ consonants mastered indicated the following trends:

- Early sounds (by 3;0): /t p b m d n k g h l/
- Middle sounds (3;0 – 3;11): /s j t d ŋ c ʃ w/
- Late sounds (4;0 – 4;6): /r/r ɲ ʃ f b d d g/

### Place of Articulation

Tables 3, 4, 5 and 6 present the acquisition of consonants based on place of articulation for each word-position.

**Table 3: Mastery of Bilabials and Labiodental Consonants at Word-positions by Age-range**

	Bilabial									Labiodental			
	p			b		m			~ b	f		w	
	I	M	F	I	M	I	M	F	M	I	F	I	M
3;0-3;5													
3;6-3;11													
4;0-4;5													

**Table 4: Mastery of Alveolar and Post-alveolar Consonants at Word-positions by Age-range**

	Alveolar																	Post-alveolar		
	t			d		n			~ d	l			s			r/ r			f	
	I	M	F	I	M	I	M	F	M	I	M	F	I	M	F	I	M	F	I	M
3;0-3;5																				
3;6-3;11																				
4;0-4;5																				
4;6-4;11																				

**Table 5: Mastery of Retroflex and Palatal Consonants at Word-positions by Age-range**

	Retroflex						Palatal									
	t			d			~ d	c			ɟ			ɲ	j	
	I	M	F	I	M	M	I	M	F	I	M	F	M	I	M	
3;0-3;5																
3;6-3;11																
4;0-4;5																
4;6-4;11																

**Table 6: Mastery of Velars and Glottal Consonants at Word-positions by Age-range**

	Velar						Glottal			
	k			g			ŋ	~ g	h	
	I	M	F	I	M	M	M	I	M	
3;0-3;5										
3;6-3;11										
4;0-4;5										

### Manner of Articulation

Tables 7, 8, 9 and 10 present the acquisition of consonants based on the manner of articulation for each word-position.

**Table 7: Mastery of Plosive Consonants at Word-positions by Age-range**

	Plosives																					
	p			b		t			d		t̪			d̪			c			tʃ		
	I	M	F	I	M	I	M	F	I	M	I	M	F	I	M	I	M	F	I	M	F	
3;0-3;5																						
3;6-3;11																						

**Table 8: Mastery of Plosives and Nasals at Word-positions by Age-range**

	Plosives						Nasals								
	k			g			n			m			ɲ	ŋ	
	I	M	F	I	M	I	M	F	I	M	F	M	M	F	
3;0-3;5															
3;6-3;11															
4;0-4;5															
4;6- 4;11															

**Table 9: Mastery of Approximants, Laterals and Fricatives at Word-positions by Age-range**

	Approximants				Laterals			Fricatives									
	w		j		l			f		s			ʃ		h		
	I	M	I	M	I	M	F	I	F	I	M	F	I	M	I	M	
3;0-3;5																	
3;6-3;11																	
4;0-4;5																	
4;6-4;11																	

**Table 10: Mastery of Trills and Prenasalized Stops at Word-positions by Age-range**

	Trill/Tap		Prenasalized plosives			
	r		~ b	~ d	~ ɖ	~ g
	I	M	M	M	M	M
3;0-3;5						
3;6-3;11						
4;0-4;5						
4;6-4;11						

Fifteen consonant geminates appearing in word-medial position produced by the participants showed a pattern of acquisition similar to that of its comparable singleton (see Table 11).

**Table 11: Mastery of Geminates at Word-medial Position by Age-range**

	pp	bb	mm	tt	dd	nn	ʈʈ	cc	ʃʃ	ɲɲ	kk	gg	ss	ll	jj
3;0-3;5															
3;6-3;11															
4;0-4;5															
4;6-4;11															

Six non-identical consonant clusters tested indicated an overall late mastery compared to the acquisition of consonant geminates (see Table 12).

**Table 12: Mastery of Target Non-identical Consonant Clusters by Age-range**

	mb	ŋc	tr	kr	fr	skr
3;0-3;5						
3;6-3;11						
4;0-4;5						
4;6-4;11						

## DISCUSSION

On the whole, the trajectory of Sinhala consonant acquisition uncovered in this preliminary study is in general agreement with cross-linguistic studies for common shared sounds. Divergent patterns for language-specific uncommon speech sounds, in both the order and rate of speech sound development, were also uncovered.

### Mean Age of Acquisition of Consonants in Sinhala

Overall, all Sinhala consonants were acquired by 4 years 6 months (54 months) by the children included in this study at a 75% criterion of mastery for an age-group. For Sri Lankan Tamil, 75% of the sounds of the Western coastal dialect were acquired by children between 3;6 - 3;11 years, with the exception of /ŋ, ɲ, h, ʃ, l, ɾ/ (Saleem & Hettiarachchi, 2014). There was, however, a difference in the criterion used, with Saleem and Hettiarachchi (2014) opting for a 90% criterion of mastery at least once, either spontaneously or in repetition, as per Hua and Dodd's (2000) proposition. All consonant sounds are reported by Wickremasinghe and Rajapakshe (1999) to have been mastered by 4 years, whereas in the current study complete mastery of the Sinhala consonant repertoire was only achieved by children at 4 years and 6 months. This difference may be reflective of the former study not including prenasalized stops, which were sounds acquired late within the current study.

In the systematic review of cross-linguistic research, McLeod and Crowe (2018) noted that 8.4% of data points were not acquired by the oldest age group included (a mean age of 67.26 months) at a comparable criterion of mastery. The rate of Sinhala consonant acquisition is similar to the rate of a majority of Spanish sounds acquired at 4 years (Mann & Hodson, 1994), but later than for Turkish by 3 years (Topbas, 1997) and Cantonese by 3 years 6 months (So & Dodd, 1995).

The relatively early acquisition of most sounds by 3 years 11 months, and almost all consonants of Sinhala by 4 years 3 months, is much earlier than the stipulated 5 years for mastery of most consonant sounds of the 27 languages within the review by McLeod and Crowe (2018).

The relatively early mastery of Sinhala consonants may be due to the manner of articulation, with a wide range of plosives and nasals constituting the language. The more complex prenasalized stops unique to the language and the /f/ and /ʃ/, which are sounds borrowed from English, were among the later sounds mastered. A comparably late acquisition of /ʃ/ beyond 3 years 11 months has been found for Sri Lankan Tamil compared to English (Saleem & Hettiarachchi, 2014), in which language too this is a borrowed sound. Nevertheless, this finding is comparable to the age of acquisition for /ʃ/ across 27 languages (McLeod & Crowe, 2018).

### **Age of Acquisition of Sinhala Consonants based on Place of Articulation**

Overall, bilabial, labiodental, alveolar and velar consonants were mastered earlier in Sinhala than retroflex consonants, with a mixed picture emerging for palatals. The only previous study on Sinhala speech sound development states a general trend of very early bilabials /p, b, m/ and labiodental /w/ between 6 months and 2 years (Wickremasinghe & Rajapakshe, 1999). McLeod and Crowe (2018) found that bilabial and labiodental sounds are mastered early, between 1 year 10 months and 2 years 11 months, across 27 languages, at a 75% - 85% criterion of mastery. The exception in Sinhala is the early acquisition of many of the alveolar sounds (/t, d, n, l/). This may reflect the interaction between place and manner of articulation as the four early sounds produced in contact with the alveolar ridge are plosives (/t, d/), nasals (/n/) or laterals (/l/) in Sinhala. Wickremasinghe and Rajapakshe (1999) also note /t/ and /d/ as early sounds acquired between 1 year and 2 years 6 months, though they describe the sounds as dentals, /n/ has been missed out, and /l/ is said to be mastered between 2 years and 3 years of age.

There was a comparatively late mastery of the retroflex sounds /ʈ, ɖ/ and the prenasalized voiced retroflex in Sinhala. This corresponds with the general trend of late acquisition of sounds produced using the anterior tongue (McLeod & Crowe, 2018). Comparably, a late acquisition of the voiceless retroflex sound /ʈ/ was found for Sri Lankan Tamil (Saleem & Hettiarachchi, 2014) and the late mastery of both /ʈ/ and /ɖ/ reported for Indian Tamil (Denktash, Ramasankar, Nagaraj, & Srinivasan, 2010; Kala & Lilith, 2016).

### **Age of Acquisition of Sinhala Consonants based on Manner of Articulation**

On average, plosives, nasals, approximants and lateral sounds were acquired earlier in Sinhala compared to fricatives, trills, flaps/taps and prenasalized stop sounds. This is in line with the assertion by Wickremasinghe and Rajapakshe (1999) of a trend of early plosive and nasal mastery. The most stable consonants used within Sinhala baby talk include plosives, nasals and laterals (Meegaskumbura, 1980), which may reflect the trajectory of speech sound mastery observed. The trend of early acquisition of plosives and nasals is commensurate with previous research on languages of the Indian subcontinent, including Sri Lankan Tamil (Saleem & Hettiarachchi, 2014), Indian Tamil (Denktash et al, 2010; Kala & Lilith, 2016), Hindi (Kaur, Anand & Subbarao, 2017), Malayalam (Sameer, 1998), and Telugu (Srilakshmi, 2005).

Additionally, the voiced palatal approximant /j/ was an early Sinhala sound acquired in the 3 years to 3 years 5 months age range, similar to Arabic in which it is acquired by 2 years 6 months (Amayreh & Dyson, 1998). McLeod and Crowe (2018) reported marked variability in the age of acquisition for the equivalent voiced palatal /j/ across Greek, Turkish and Xhosa, with a range from 24 to 72 months (2;0 – 6;0 years) noted. It is unclear whether this reported wide variation reflects the age- ranges included in the different studies reviewed.

The early acquisition of /c/ observed for Sinhala is an important finding, given the lack of consensus among local linguists on whether it is a plosive or affricate. The target palatal sound /c/ was acquired relatively early by the youngest group of participants in the 3 years to 3 years 5 months age group, suggestive of a relatively simpler manner of acquisition. Wickremasinghe and Rajapakshe (1999) too identify /c/ as a very early sound between 6 months and 2 years. A follow-up study to verify this trend would need to include a younger age group of children between 2 years and 2 years 11 months.

Saleem and Hettiarachchi (2014) register evidence of early mastery of both /c/ and /j/ in Sri Lankan Tamil by children between 3 years and 3 years 5 months, classifying the sounds as plosives. This early mastery noted is in spite of a 90% criterion for an age group expected in that study, though only one production was required with no analysis of production based on word-position. If the equivalent sound is an affricate in Sinhala (Wasala & Gamage, n.d.), then this early acquisition would be in contrast to the general late acquisition pattern of affricate sounds within some of the cross-linguistic literature (Amayreh & Dyson, 1998; Kopkalli-Yavuz



& Topbas, 1998). Additionally, /c/ appears in two key kinship terms within early child vocabulary: /a:cci/ (grandmother) and /appacci/ (Kandy dialect word for father) suggestive of a 'functional load' hypothesis for its early mastery (Pye, Ingram & List, 1987; So & Dodd, 1995). Further acoustic analyses of Sinhala may be beneficial to verify the characterisation of the sound as a plosive or affricate.

The children in this preliminary study had acquired /r/ in all word positions by 4 years 3 months. The late acquisition of /r/ gains support from studies of the region, such as Indian Tamil (Denktash et al, 2010; Kala & Lilith, 2016) and Hindi (Lakshmi Bai & Nirmala, 1978), Quiche (Pye et al, 1987), Portuguese (Yavas & Lamprecht, 1988), German, Swedish and Xhosa (Mowrer & Burger, 1991) and Spanish (McLeod & Crowe, 2018). One probable explanation that can be proposed is the limited frequency of occurrence of this consonant in early childhood vocabulary in Sinhala compared to a sound such as /t/. For instance, /r/ and /r/ occur in child words which are later concepts such as 'ratu' /rɔtu/ (red), while /t/ has an immediate 'functional load' appearing in kinship term of 'thaththa' /tɑ:tta/ (father), food items 'bath' /bat/ (rice) and objects such as 'toppi' /toppijə/ and shoes /sapattu/. Moreover, this relatively late acquisition of /r/ and /r/ is substantiated by Sinhala baby talk that shows an absence of this sound (Meegaskumbura, 1980).

In keeping with the findings of the cross-linguistic review of languages (McLeod & Crowe, 2018), the current study found the relatively late mastery of /r, ʈ, d/, all requiring anterior tongue placement. The target sound /r/ is produced as an alveolar trill or flap in Sinhala, as it is in Hindi (Lakshmi Bai & Nirmala, 1978; Locke, 1980), Igbo (Nwokah, 1986), Italian (Bortolini & Leonard, 1991), Portuguese (Yavas & Lamprecht, 1988), Quiche (Pye et al, 1987), Indian Tamil (Denktash et al, 2010; Kala & Lilith, 2016) and Spanish (Anderson & Smith, 1987), which may account for its late acquisition. For Sri Lankan Tamil, /r/ produced as an alveolar trill had been mastered by 3 years 11 months-old children speaking Western Coastal Sri Lankan Tamil (Saleem & Hettiarachchi, 2014). In contrast, for Indian Tamil, Sivapriya, Perumal, and Savitha (2009) noted a much later mastery of trills and flaps. The perceptually comparable /r/ sound is a late sound in many languages. This includes Arabic, in which it is mastered between 4 years and 6 years 4 months (Amayreh & Dyson, 1998), Putonghua, in which the sound is acquired between 4 years 1 month and 4 years 6 months (Hua & Dodd, 1995) and English, in which it is by 4 years 6 months (Grunwell, 1985) or 6 years (Dodd et al, 2003).

### **Acquisition of Complex Nasals and Prenasalized Stops**

Although /m/ and /n/ appeared to be acquired early, the palatal nasal /ɲ/ was mastered much later by the Sinhala-speaking children in the study. Unfortunately, the study by Wickremasinghe and Rajapakshe (1999) does not include information on the mastery of this language-specific complex sound. This is, however, in contravention to the presumed general pattern of early acquisition of nasals (McLeod & Crowe, 2018).

Regarding the velar nasal /ŋ/, which is a shared sound between Sinhala and English, the preliminary findings suggest earlier mastery of the sound in Sinhala than proposed for English by Sander (1972) at 6 years and Smit, Hand, Freiling, Bernthal, and Bird (1990) between 7 years and 9 years, although slightly later than the 3 years to 3 years 5 months age range stipulated by Dodd et al (2003). The variation in the criterion for mastery used in these studies may account for the vast discrepancy in the age-range of mastery for /ŋ/ in English (Lof, 2004).

In contrast to Sinhala, early acquisition of the palatal nasal /ɲ/ between 3 years and 3 years 11 months, and late mastery of the velar nasals has been reported for Spanish (McLeod & Crowe, 2018). This may be due to the phonetic frequency of these sounds in the ambient language. In Sinhala, arguably, the palatal nasal /ɲ/ seldom occurs in child vocabulary with a low functional load, and is infrequently observed in adult speech as well. It is assumed that the reverse may be true of Spanish. That said, this dissimilarity in findings can also be attributed to a difference in the criteria used, with the Spanish studies adopting a 90% criterion (McLeod & Crowe, 2018) in contrast to the 75% criterion of the current study. A comprehensive study incorporating the frequency of occurrence of this target sound in preschool children's vocabulary in Sinhala would be of value.

In addition, the complete mastery of all the complex nasalized sounds including 'prenasalized' stop sounds in Sinhala was only achieved after 4 years. As prenasalized stop sounds have not been included in the review by Wickremasinghe and Rajapakshe (1999), no comparison is possible. There is also no speech sound equivalent in the cross-linguistic studies consulted for prenasalized stop sounds, and thus, no comparison is possible. This finding of late mastery does comply with the general last acquisition of complex sounds (Goldstein & Washington, 2001).

## CONCLUSION

Broadly speaking, the overall pattern of early acquisition of Sinhala consonants involving lips (labial), the posterior tongue (palatal and velar) and pharynx (glottal) in contrast to sounds produced with the involvement of the anterior tongue placement (alveolar and retroflex; the latter in particular) is commensurate with the general principles from cross-linguistic studies. The rate of acquisition was rapid compared to some of the cross-linguistic literature. Data from this preliminary study indicates a comparable trend in rate and order of acquisition of shared sounds but a contrast in both for language-specific sounds. These findings can serve as 'working norms' for consonant acquisition for Sinhala within speech and language therapy clinical practice. It highlights the need to establish normative data for Sinhala without an over-reliance on established norms for English. The next phase of this study will aim to verify the trends observed using a larger sample of children from across the country, taking heed of possible dialect variations.

## ACKNOWLEDGEMENT

This study was funded by two grants offered by the Research Council of the University of Kelaniya, Sri Lanka: Grant No. RP/03/04/17/01/2012 (University Grants Scheme) and R/S/G/04/17/01/2018 (Sabbatical Leave Research Fellowship).

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# Methodological Approaches to Researching Organisations of Persons with Disabilities: a Case Study from Uttarakhand, North India

Danielle Green<sup>1</sup>, Nathan Grills<sup>2\*</sup>

1. General Practitioner and Public Health Registrar, formerly with Nossal Institute for Global Health, University of Melbourne, Australia
2. Public Health Physician and Professor, Nossal Institute for Global Health & Australia India Institute, University of Melbourne, Australia

## ABSTRACT

**Purpose:** *Organisations of Persons with Disabilities (OPDs) are promoted to encourage the inclusion of persons with disabilities in development programmes. However, there is little peer-reviewed literature on the effectiveness of OPDs in low and middle-income countries.*

*This Case Study in Uttarakhand State of North India, aimed to explore the methodological approaches used to understand and evaluate the formation and function of OPDs.*

**Method:** *The Nossal Institute of Global Health, Australia, partnered with the Uttarakhand Cluster (an NGO in India) to facilitate the development of Organisations of Persons with Disabilities. Five research studies were undertaken between 2014 and 2018 to understand their formation and function. The current Case Study has focused on these 5 studies, examined the qualitative and quantitative methodological approaches that were used in each study, summarised their findings, and analysed the advantages and limitations of the methodologies used in the context of the formation and function of OPDs.*

**Results:** *The methodologies used included: Thematic analysis; Realist Evaluation; Participatory Action Research using Videovoice; Social Network Analysis; and a Cluster Randomised Trial. By examining the 5 selected studies, rather than drawing conclusions from any individual methodology, this Case Study derived a better understanding of OPDs in Uttarakhand. OPDs were seen to have had positive impacts across a variety of domains.*

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\* **Corresponding Author:** Nathan Grills, Public Health Physician and Professor, Nossal Institute for Global Health & Australia India Institute, University of Melbourne, Australia. Email: ngrills@unimelb.edu.au

**Conclusion and Implications:** *The Case Study showed the value of multiple and mixed methods approaches to study complex phenomena such as the formation and function of OPDs. It helped in understanding the mechanisms for OPD impact.*

**Key words:** *DPO, OPD, Organisations of People with Disability, India*

## INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) highlights the importance of persons with disability being central to all aspects of decision-making that affect them (United Nations, 2006; United Nations General Assembly, 2016). This is embodied by the motto of the disability rights movement “nothing about us without us” (Callus & Camilleri Zahra, 2017). Perhaps the central mechanism advocated to achieve the involvement and participation of persons with disability has been the formation of Organisations of Persons with Disabilities or OPDs (United Nations, 2006; United Nations General Assembly, 2016). Disabled People’s Organisations or DPOs was the term used at the time of the initial studies and therefore the term is used in reference to these studies.

Organisations of Persons with Disabilities are formal groups composed of, led, and controlled by persons with disabilities and those with lived experience of disability such as families or caregivers (Deepak et al., 2013; United Nations General Assembly, 2016). The functions and characteristics of OPDs can vary, but key elements include advocacy, providing a “voice” for people with disabilities, evaluating service and systems, expressing priorities and promoting public awareness (Disabled People’s Organisations Australia, n.d).

Although disability programmes are typically required to work with OPDs, and despite being considered a fundamental right for people with disabilities (United Nations, 2006; World Health Organisation, 2011), there has been little published evidence regarding their actual impact. Similarly, methodological approaches to researching OPD functions and their impact have not been well characterised.

A literature review undertaken in 2016 by Young et al (Young et al., 2016) examined peer-reviewed literature that studied the roles, functions and impacts of Organisations of Persons with Disabilities. Eleven studies that were identified for inclusion consisted of eight qualitative studies (Armstrong, 1993; Cobley, 2013; Deepak et al., 2013; Dhungana & Kusakabe, 2010; Griffiths et al., 2009; Hemingway



& Priestley, 2006; Kleintjes et al., 2013; Miles et al., 2012), two mixed methods studies (Polu et al., 2015; Stewart & Bhagwanjee, 1999), and one quantitative cohort study (Kumaran, 2011) - the quality of which was described as poor. The qualitative studies were of variable quality. The CASP Qualitative research checklist classified 3 studies as 'High quality', 4 studies as 'Medium quality', and 3 studies as 'Low quality' (Young et al., 2016). Demographic information was minimally presented, making it difficult to judge the generalisability. The authors undertook thematic analysis and presented their findings under three themes: 1) participation (awareness of rights, increased confidence for participation, involvement in advocacy and awareness-raising activities); 2) the development of connections (creation of networks, and improved social connections); and 3) self-development (improved access to orthopaedic devices, medical and orthopaedic services, housing, training and education, microfinance).

This literature review by Young et al is the only published review of studies pertaining to the function and effectiveness of OPDs. Poor reporting and the variable levels of quality of the studies warrant further research to explore the identified functions of OPDs and their impact. In addition, each study was related to different OPDs, with consequent inability to triangulate research on any particular OPD.

Since 2007, the Nossal Institute for Global Health has supported the development of a network of community health programmes based in the northern Indian State of Uttarakhand. The Community Health Global Network, "Uttarakhand Cluster" (CHGN-UKC), now consists of fifty member organisations which cover a catchment area of more than 2 million people. In 2009, the Cluster identified that persons with disabilities were often excluded from health and development programmes. In response, the Cluster decided to focus on disability, both in terms of awareness-raising and the promotion of disability inclusive development (Grills et al., 2016).

One aspect of the work undertaken by the Uttarakhand Cluster was facilitating the development of Organisations of Persons with Disabilities, as well as researching their function and impact. Since 2015, the Nossal Institute for Global Health in partnership with CBM and the Uttarakhand Cluster have utilised five different methodological approaches to explore the formation and function of the Organisations of Persons with Disabilities that they helped facilitate.

## **Objective**

This Case Study aimed to build upon the existing literature by exploring the methodological approaches used to understand and evaluate the formation and function of these OPDs in Uttarakhand, over a four-year period. It summarised the findings from the 5 studies and examined the advantages and limitations of the methodologies used, in order to provide an in-depth exploration of Organisations of Persons with Disabilities and the utility of methodologies to research them.

## **METHOD**

### **Setting**

Between 2015 and 2019, the CHGN Uttarakhand Cluster was involved in facilitating OPD formation. Uttarakhand state, located in the Himalayan foothills of North India, is a predominantly rural state with high levels of poverty. It has a population of 11 million people, 6.8% of whom have disability (Grills et al., 2017). This involved identifying people with disability using the Rapid Assessment of Disability tool (RAD), undertaking community sensitisation, conducting training in the formalities of running a registered group, assisting in the formal registration process, and helping with various activities such as clinics and community awareness meetings.

Five studies were undertaken at different points over the course of the 5-year process of OPD formation and support for OPD activities. These studies were undertaken by the Nossal Institute for Global Health, with financial support from CBM India, and in partnership with the Uttarakhand Cluster. Each study investigated, at different time points, aspects of formation and function of Disabled People's Organisations in Uttarakhand.

This Case Study collates and analyses the findings and methodologies from these 5 studies to tell the coherent and interesting story of the Uttarakhand OPDs.

### **Study Design**

For each of these studies the methodology and findings were summarised. The summary provided key study and methodological attributes, including items such as aspects of the OPD studied (formation, function and impact), location, sample and sampling technique, outcome measures and tools utilised.

The 5 studies were analysed to compile the key findings related to OPD formation and function, and the results were descriptively tabulated detailing the study type, timeframe, research questions, and methodology used.

Where indicated, the wider literature was consulted to provide an overview of the methodological approach, including its known advantages and limitations. Consequently, the strengths and limitations of using that approach were analysed within the context of exploring the formation and function of Organisations of Persons with Disabilities in Uttarakhand State.

The discussion brings together some of the key findings about the combination of methods utilised and the overall findings from the Case Study of OPD formation in Uttarakhand.

## RESULTS

**Table 1: Summary of the Five Studies and the Methodologies Utilised**

Authors	Time frame	Study Design	Research Question/s	Methods
Leung M et al.  'With hope to help ourselves and others': The impact of Disabled People's Organisations on the lives of persons with disability in Uttarakhand, North India	2017	Qualitative Thematic Analysis	(1) To understand the impact of OPDs on the lives of persons with disabilities and their families  (2) To understand the enablers and barriers to the involvement of persons with disability within OPDs	Semi-structured interviews, Focus Group Discussions, local translators (trained), transcription, translation into English, inductive thematic analysis
Young R et al.  A realist evaluation of the formation of groups of people with disabilities in North India	2015 - 2016	Qualitative Realist Evaluation	Why and how different factors affect the development and operation of Disabled People's Groups	Context- mechanism-outcome configurations developed, tested and refined using 5 case studies; also Focus Group Discussions, Semi-structured interviews, field observations, review of key documents

Montgomery J et al.  Disabled People's Organisations grow social connectedness for persons with disability: Evidence from South Asia	2018	Mixed Methods Social Network Analysis	What impact can participation in Organisations of Persons with Disabilities have, on the social networks of persons with disability?	Mixed Methods: Network mapping survey before and after joining OPD, Focus Group Discussions (participants and staff), thematic analysis of Focus Group Discussions
Butcher N et al.  Videovoice Study Finds Transactional Benefits and Personal Impact of DPO Membership	2019	Qualitative Participatory Action Research - Videovoice	How and when do OPDs have an impact on their members?	Training followed by participant production of narrated 2- minute video product, Semi-structured interviews, Focus Group Discussions
Grills N et al.  Disabled People's Organisations increase access to services and improve well-being: evidence from a cluster randomised trial in North India.	2014 - 2018	Cluster Randomised Intervention Trial	Do OPDs improve the access to services and well-being of their participants?	Intervention group facilitated to form OPDs, non-intervention group continued with normal disability programmes, random allocation, baseline and end-line surveys using RAD survey tool

**Table 2: Summary of the Findings from the Five Studies**

Study	Findings
Leung M et al  'With hope to help ourselves and others': The impact of Disabled People's Organisations on the lives of persons with disability in Uttarakhand, North India	Positive impacts of OPDs were collated under six key themes:  <b>Social connectedness:</b> with other persons with disability and NGO staff, also for family members of persons with disabilities.  <b>Empowerment of persons with disability:</b> increased self-confidence, increased independence, improved capacity for self-advocacy.  <b>Participation within community:</b> OPDs promoted positive attitudes towards persons with disability, increased knowledge sharing by persons with disability with community, increased community awareness and increased respect from family/community.

	<p><b>Promotion of the inclusion of previously excluded groups:</b> inclusion of women and other groups although some people remained excluded, including Muslims (NGO staff needed to gain trust of Muslim community), persons with hearing disabilities (lack of use of sign language by persons with disability and NGO staff and broader community) and persons with intellectual disability (difficult to communicate with persons with disability if family or carer was not present).</p> <p><b>Access to services:</b> difficulty for persons with disability getting to meeting places (transportation) and accessibility issues at OPD venues. OPDs improved access to government programmes – help with accessing financial support such as pensions, improved access to assistive devices (eg. wheelchairs, hearing aids, etc.).</p> <p><b>Livelihoods:</b> some OPDs focussed on income-generating activities, such as agricultural work in mountain areas.</p>
<p>Young R et al.</p> <p>A realist evaluation of the formation of groups of people with disabilities in North India</p>	<p>Factors enabling formation and functioning of OPDs were grouped under three themes:</p> <p><b>External Supports:</b> group members valued NGO initial information sharing and financial support; NGO staff engaged on an equal basis, emergence of NGO champions to encourage those with disabilities and their families to join OPD, networks with other OPDs led to peer-led information and knowledge sharing and improvement in confidence of OPD members and acceleration of OPD formation.</p> <p><b>Community and physical environment:</b> increased member confidence influenced community perceptions; village leader support important, formation of OPDs led to increased village leader interest in disability issues, physical and environmental barriers limited involvement, and reliance on the NGO and family to support group involvement.</p> <p><b>Group composition:</b> promotion of equality of socially and culturally diverse members, i.e., different cultures, religions and castes able to exist in the same OPD. Often those with profound disability were more excluded. Parents played a role representing them.</p>
<p>Montgomery J et al.</p> <p>Disabled People’s Organisations grow social connectedness for persons with disability: Evidence from South Asia</p>	<p>OPDs increased the breadth of social networks for participants as well as increased the interconnectedness between participants.</p> <p>This increased social connectedness led to improved self-esteem, social acceptance, increased access to services (financial, medical care and assistive devices), opportunities for friendship and possibilities of collective advocacy, access to employment opportunities.</p> <p>Negative impacts included time burden in relation to family and work.</p>

<p>Butcher N et al.</p> <p>DPO membership has immediate transactional benefits as well as personal impact</p>	<p><b>Information and knowledge gain:</b> joining OPDs led to information and knowledge gain and positive emotions.</p> <p><b>Material benefits:</b> access to goods, government pensions, assistive devices, housing improvements.</p> <p><b>Skills:</b> direct (access to skills training) or indirect (education opportunities).</p> <p><b>Personal:</b> awareness, confidence and improved self-image and motivation (to be domestically, socially or vocationally active).</p> <p><b>Social:</b> getting to know others, creation of social networks.</p> <p>Note: social and personal were the most discussed topics (50% of dialogue), followed by information/education and material benefits (40% of dialogue), and then skills and other (10% of dialogue).</p>
<p>Grills N et al.</p> <p>Disabled People's Organisations increase access to services and improve well-being: evidence from a cluster randomised trial in North India</p>	<p>Compared to controls - OPD formation led to significant improvement in:</p> <ul style="list-style-type: none"> <li>• persons with disability participating in community consultations, social activities and OPDS;</li> <li>• improved access to toilet facilities, rehabilitation, and Government social welfare services;</li> <li>• improvement in having their opinions heard and being able to make friends;</li> <li>• Other improvements noted were not statistically significant.</li> </ul>

## SUMMARY AND ANALYSIS OF THE METHODOLOGIES USED IN THE FIVE INCLUDED STUDIES

**Study 1. 'With hope to help ourselves and others': The impact of Organisations of Persons with Disabilities on the lives of persons with disability in Uttarakhand, North India (Leung et al., 2019)**

**Study methodology: Qualitative**

**Aspects of OPD studied: Impact**

### Detailed Methodology

This study utilised Semi-Structured Interviews (SSIs) and Focus Group Discussions (FGDs) with 20 people with disability who were members of an Organisation of People with Disability and 8 of their family members. The researchers also

interviewed the 14 Uttarakhand Cluster staff who were facilitating the formation of OPDs in Uttarakhand. People with disabilities were purposively sampled, and the sample was representative across age, gender, disability type and different levels of OPD involvement. Family members were selected in consultation with the people with disability who were interviewed.

There was one day of training with the translators. Following this, SSIs and FGDs were conducted in English, with the Hindi-English translators, and recorded and analysed using inductive thematic analysis.

### **Advantages of a Qualitative Approach in this context**

This study used a qualitative approach to explore the **impacts** that OPDs had on the participating persons with disability and their families. These were described under 6 themes (see summary of themes in Table 2) which included a description of the enablers and barriers to achieving the described impact. Using this qualitative approach provided in-depth information that would have been difficult to elicit with a quantitative approach. The exploration of enablers and barriers allowed recognition of some of the features that could enhance or jeopardise the ability to achieve the identified impacts.

Utilising translators for the interviews provided the opportunity for persons with disabilities to voice their thoughts in their own language and meant that English language literacy was not an impediment to their inclusion. The small number of participants simplified the logistics and allowed in-depth exploration with each participant.

Identifying themes by using an inductive approach during analysis allowed the researcher to construct themes that may not have been identified in a deductive approach using pre-established hypotheses about the data (Bhattacharya, 2017).

### **Limitations of a Qualitative Approach in this context**

The small sample size as well as participants being members of only two OPDs within a defined geographical area may affect generalisability. To some extent this was addressed by ensuring there was demographic representation from the local area. However, to be generalisable, the impacts identified from a study of this nature would need to be correlated with those found elsewhere.

Using traditional semi-structured interviewing can exclude those with more severe disability, intellectual disability or communication disabilities.

The synthesis of the data from three distinct groups (persons with disability, family members and NGO field staff) into a single group of themes made it difficult to disaggregate differences between groups.

## **Study 2. A realist evaluation of the formation of groups of people with disabilities in North India (Young R et al., 2016) – A realist evaluation approach**

### **Study methodology: Qualitative, Realist Evaluation, 5 Case Studies**

#### **Aspects of OPD studied: Formation and Function**

#### **Detailed Methodology**

A programme theory (based on the literature, programme document synthesis, and a field visit) was developed using context-mechanism-outcome configurations to attempt to capture how an externally driven intervention promoted the formation of OPDs and led to particular outcomes. This was subsequently tested and refined by analysing the selected Cluster OPD case studies. Triangulation included a FGD with OPD members, SSIs with key informants (village leader and/ or community health worker and field manager), observation and key document review. Data was transcribed and translated into English and grouped into themes.

Context-mechanism-outcome configurations were refined between site visits and tested at subsequent sites.

What is a “realist evaluation approach?”

In contrast to conventional impact evaluation approaches where the core question is whether a programme works, the realist evaluation approach, developed by sociologists Pawson and Tilley in 1997, theorises that programmes “work for certain people in certain circumstances”(Hewitt et al., 2012) . Thus realist evaluation endeavours to explain “What works, for whom, in what respects, to what extent, in what contexts, and how?”(Westthorp, 2014). Rather than analysing the whole programme, this approach allows mechanisms to be analysed and can use quantitative and/or qualitative data to refine the theory underpinning a programme and explain the “for whom and how” components of a programme’s successes and failures (Hewitt et al., 2012).



### **Advantages of a realist evaluation approach in this context**

The use of a realist evaluation methodology contributed to a better understanding of some of the contextual factors and mechanisms that may need to be considered in terms of the **formation and function** of OPDs. It provided a structure to consider process rather than impact and provided the means of assessing some of the contributing factors, such as the physical environment and group composition, that may enhance or detract from an OPD's ability to be formed and function. Knowledge about these types of factors is essential to understand how OPDs can form, as well as be effective.

The model used within this study involved the initial involvement of an NGO, an external entity. The realist evaluation methodology allowed the researchers to unpack how and why this model was thought to be useful. Providing depth around this aspect is essential to establish which factors were instrumental in OPD formation, in order to facilitate the development of OPDs elsewhere.

As in the preceding study, the methodology had similar advantages to those already discussed in terms of utilising qualitative techniques. The process of triangulation from focus group discussions, interviews, observation and document review enhanced the validity of the context-mechanism-outcome configurations.

### **Limitations of using the methodology in this context**

This research methodology and the analysis required considerable researcher expertise, which may limit its use to places where such expertise is available.

From this study it was not possible to prioritise the importance of the mechanisms that were discussed. However, it provided a range of considerations that are at play in the establishment of OPDs by an external entity, and this can be considered in the formation of OPDs elsewhere.

The cross-sectional methodology made it difficult to differentiate the specific contextual factors involved at various stages of OPD formation.

Similar to the other qualitative study, the realist approach had difficulty including those with significant intellectual disability and communication disabilities, and it is difficult to determine if findings are generalisable to other parts of India or other countries.

This type of methodological approach tried to answer questions around

programme theory and process rather than effectiveness per se and needs to be used in conjunction with other approaches that evaluate overall impact.

### **Study 3. The impact of participation in Disabled People's Organisations on the social networks of persons with disability in Sunsari, Nepal and Uttarakhand, India (Montgomery J et al)**

**Study methodology:** Mixed Methods, Social Network Analysis with Focus Group Discussions

**Aspect studied:** Impact

#### **Detailed Methodology**

Social Network Analysis (SNA) was used to compare the social connections of OPD members prior to and several years after joining the Cluster- initiated OPD. A representative sample of 8 members was selected from the Cluster Case Study according to age, gender and type of impairment. Inclusion criteria were: OPD member and self-identified as having disability. Exclusion criteria were: <18 years of age, recently joined member (less than 12 months) or irregular attendance (<50% of meetings attended in the previous year). Modified 'position generator' surveys were developed to gather data about OPD members' social connections. Contacts were defined as acquaintance, friend or family member, and it was identified whether the relationship and type were different prior to joining OPD. Collation and analysis were achieved using NodeXL, and network maps were developed according to a Harel-Koren Fast Multiscale algorithm.

Four FGDs were done with the 16 OPD members and key staff of the Cluster-facilitating NGO. Questions covered the social aspects of OPD involvement. Trained research assistants then transcribed and translated these into English. Thematic analysis identified key themes and sub-themes.

#### **Advantages of SNA with FGDs when studying OPDs**

By using the SNA methodology, assessments and comparisons were made regarding the quantity and extent of social connections of OPD members before and after joining an OPD. It allowed differentiation of where or with whom the maximal changes in their social network occurred. For example, connections were increased between OPD members; however little change was noted in their

connections with health and community services. This methodology is specific to the issues of social connectedness that were being researched.

Combining the quantitative methodology of SNA with the qualitative approach of FGDs increased understanding of how increased connections impacted individuals, both negatively and positively, and allowed the value of social connectedness to be delineated. The mixed methods process also provided triangulation and thereby enhanced the study's overall validity.

### **Limitations of the methodology in this context**

This approach to SNA, done through single survey, relied on the recall of participants regarding changes in their relationships from when they joined the OPD, up to the period when the data was collected. This might have been difficult for participants and especially for those with cognitive disabilities. It also required participants to be able to verbalise and comprehend the extent of their relationships, which may have been difficult for people with more severe disability or intellectual disability.

Again, generalisability is an issue due to the small sample sizes used, although this is the only study (of the five included) which incorporated people from outside India (i.e., from Nepal).

Conducting and analysing SNA is complicated and requires specific expertise, potentially limiting its use as a methodology in other contexts to those where researchers have training and experience in this area.

SNA in itself specifically looks at social connectedness and does not evaluate other impacts that participation in OPDs might have.

### **Study 4. DPO membership has immediate transactional benefits as well as personal impact (Butcher et al., 2021)**

**Study methodology:** Qualitative (Participatory Action Research) - Videovoice

**Aspects studied:** Function and Impact

### **Detailed Methodology**

Purposive and convenience sampling was used to recruit 19 participants – 13 persons with disability who were OPD members and 6 carers of OPD members.

Inclusion criteria were: age > 18 years, able to follow instructions and communicate verbally, and having been OPD members for longer than 6 months.

Field staff were trained in research and video recording, interview and facilitation skills and supplied with a Videovoice manual.

The Videovoice methodology followed a modified version of Hergenrather's ten-point framework for Photovoice (Hergenrather et al., 2009) by utilising video in the place of photography. Participants were required to take 2 minutes of video footage that showed the impact that OPD membership had on their lives. Consequent interviews with field staff investigated participants' ideas and motivations within their clip. Interviews were recorded, transcribed and translated into English. Data included in the final analysis were transcripts from narrated videos, SSIs between field staff and participants, and additional FGDs. Analysis assigned the data under predefined categories which included skills, social, personal information/education and material. This was then coded, thematically analysed and validated with field staff.

### **Advantages of using this methodology-Videovoice with SSIs and FGDs**

A qualitative study of this nature helps to determine how and when OPDs might have an impact, and particularly the mechanisms and stories that illustrate these factors.

Apart from providing research data regarding the impacts of OPDs on persons with disability, this participatory video methodology enabled active involvement and an avenue for self-expression. Participants had the chance to film whatever was important to them, minimising the constraints potentially present in more conventional research methodologies.

An added by-product of using this approach was that the process of producing the videos empowered OPDs to advocate for the roles and rights of persons with disability within their communities.

### **Limitations of using Videovoice in this context**

The Videovoice methodology required significant technical and learning ability on the part of the participants, as well as the ability to construct a narrative. This may make it difficult to use where technical skills are lacking, or where people have more severe disability or intellectual disability. The use of a Smartphone video camera also requires the participant to have vision, hearing and the ability to hold and manipulate the device.

Again, the small sample sizes in qualitative research limits the generalisability of the findings.

### **Study 5. Disabled People's Organisations increase access to services and improve well-being: evidence from a cluster randomized trial in North India (Grills et al., 2020)**

**Study methodology:** Cluster Randomised Intervention Trial

**Aspect studied:** Impact

#### **Detailed Methodology**

A cluster randomised trial evaluated the impact of cluster initiated OPDs. A baseline survey was done initially in 2014, using the RAD survey tool to assess well-being, community participation and access to services. People with disability were identified in each village. This was followed by Cluster NGOs facilitating the formation of OPDs. The subsequent end-line survey was done in 2017 using the RAD tool. Thirty-nine villages were purposively selected from five areas in Uttarakhand. While 20 villages were allocated to the intervention arm where OPDs were facilitated (272 people), 19 villages were allocated to the control arm where no OPDs were facilitated but normal disability work continued (211 people).

OPDs were encouraged and supported to have weekly meetings, monthly training sessions on OPD formation, monthly visits by the research team for support, and biannual public events. Persons with disability were encouraged to visit the block and district offices and make three visits to the disability commissioner. OPD members also visited other OPDs, and livelihood initiatives were started.

#### **Advantages to using this methodology**

This is the first level II quantitative study that has been done to evaluate the impact of OPDs on persons with disability.

The advantage of a quantitative methodology in general is that not only can the degree of impact be measured, but its significance can also be calculated. In this way the impacts can be measured, quantified, and consequently evaluated against each other, and the significance of individual impacts can be determined. However, a tool to measure this was required. The development of the Rapid

Assessment of Disability (RAD) tool preceded this study (Marella et al., 2014). This validated tool measures elements across seven domains of access and participation, enabling standardisation before and after measurements of impact.

The control group provided a means to compare the measured impacts for persons with disability who were participating in OPDs, with those who were not. This gave an opportunity to measure the impact of OPDs on persons with disability and also to gauge whether OPDs provided an added advantage beyond what was previously available.

The cluster randomised approach is ideal in elucidating effects across communities where the intervention is by group.

### **Limitations to using a Cluster Randomised Intervention in this context**

Recruitment bias has been raised as an issue in cluster randomised control trials (Chan et al., n.d.). There were attempts to include all persons with disability from the selected villages in the study by using a key informant approach. However, as with the other studies in this case study, it was difficult to assess whether this approach identified all people with disability.

The generalisability of this study may again be limited, given that the intervention was only undertaken in two districts within a single area in India.

The measurement of impacts that were made was limited to those that could be identified using the RAD tool. This may not have identified all of the possible impacts. It also could not provide the depth that the qualitative, more open-ended approach provided.

## **DISCUSSION**

This Case Study has examined five research approaches used in Uttarakhand State of North India, which together evaluate the formation and function of Organisations of Persons with Disabilities. It has explored some of the advantages and limitations of using different methodologies to study the phenomena of OPDs. These five studies represent some of the most comprehensive bodies of research on a specific group of OPDs. This is significant given that Organisations of Persons with Disabilities are promoted as important in improving the participation and well-being of persons with disability (Callus & Camilleri Zahra, 2017), yet there is sparse evidence about OPD formation, function and impact in low- and middle-income countries (Young et al., 2016).

Of note, the randomised controlled trial provided the first RCT level evidence of the positive impact of OPDs, which was further supported by the qualitative studies. Within this Case Study, OPDs were generally found to have a positive effect on participation and well-being across a variety of domains (Butcher et al., 2021; Grills et al., 2020; Montgomery et al.; Leung et al., 2019). OPDs were also found to improve the social connectedness of participants (Butcher et al., 2021; Grills et al., 2020; Montgomery et al.; Leung et al., 2019), participants' self-confidence (Butcher et al., 2021; Leung et al., 2019; Young R et al., 2016), the ability for self-advocacy and persons with disability having their opinions heard (Grills et al., 2020; Leung et al., 2019), participation (Grills et al., 2020; Leung et al., 2019) and access to government services and assistive devices (Butcher et al., 2021; Leung et al., 2019; Young et al., 2016). In the formation of OPDs a number of factors were found to be important including initial NGO support, networks with other OPDs, and village leader support (Young R et al., 2016).

The inclusion of different qualitative and quantitative methodologies within this Case Study is informative. The debate around using qualitative versus quantitative methodologies is not new, with both paradigms having distinct advantages and limitations. This Case Study suggests that a mixed methods approach can be useful to study complex phenomena like a social movement- a sentiment supported by the literature (Beail, 2014; Hartley & Muhit, 2003; McVilly et al., 2008; O'Day & Killeen, 2002). Ultimately this Case Study demonstrates that the use of a variety of both qualitative and quantitative methodologies provides a rich and comprehensive understanding of how OPDs impact on persons with disabilities and their families, far more than any of the studies can provide individually. It is the quantitative study that sheds light on the statistically significant effect that OPDs have on well-being and access, but the qualitative studies give information as to how and why this occurs.

The quantitative study included in this Case Study represents the first randomised controlled cluster trial on OPDs in low- and middle-income settings. Previous to this, the one quantitative study identified in Young's literature review was a survey (Kumaran, 2011), and one mixed methods study with a questionnaire and Focus Group Discussions (Stewart & Bhagwanjee, 1999). A RCT provides quantitative data that measures the amount and type of impact that OPDs have on members. The objectivity inherent in quantitative methodology gives greater reliability and validity to the findings; however, they are more costly to run, with greater sample sizes required. They can provide measurement of impact and

incorporate statistical analysis but are not able to provide the in-depth analysis that the qualitative approach can.

Similar to the existing literature reported in the literature review by Young et al (Young et al., 2016), the majority of the studies that were included within this Case Study were qualitative. Within this Case Study, the qualitative approach of researching OPDs has a number of advantages. It provides a medium to examine what OPDs mean to members, their perceptions about how participation has made an impact on their lives, and their personal narratives and stories. The smaller numbers involved makes it an easier research method in terms of recruitment of participants and costs of completing the research. The ability to extract the salient themes that emerge means that there is more scope to design appropriate quantitative studies that do not miss important domains. In contrast, they can also function alongside existing quantitative studies to delve deeper into the aspects that a quantitative methodology is unable to provide answers to (O'Day & Killeen, 2002).

By using a variety of methods with their own inherent advantages and limitations, different information was gleaned about OPDs; this would not have been possible by using any of the methodologies in isolation. For example, the realist evaluation provided an understanding of the contexts within which and through which mechanisms an OPD works. The participatory approach of using Videovoice had the advantage of gaining participants' personal perspectives about the impact OPDs had on their lives and the network analysis used visual mapping to illustrate how peoples' networks grow through participation in an OPD.

The difficulties of representing the voices and issues of the broad spectrum of people with disability within a research context have been documented (McVilly et al., 2008). Each of the 5 research approaches included in this Case Study faced similar issues in that they excluded people with certain disabilities. Each different methodology will be more or less accessible to some over others, depending upon the nature of the disability and the features of the methodology. The inclusion of those with hearing and speech impairments, severe disabilities and intellectual disabilities remains an ongoing challenge, with more work needed to explore how to ensure these groups are represented in the published literature so that their needs are not forgotten. The quantitative survey was perhaps less problematic than the qualitative approaches that often required processing of more complex questions and the use of tools like video. Approaches from the



literature that have been used to address this problem have included involving the persons with disability in some capacity within the research team in the roles of advisors, collaborators or leaders and controllers of the research (Bigby et al., 2014), asking simple open-ended questions and ensuring questions are non-leading (Beail, 2014), using observational methodologies and collaborative approaches over longer periods of time (McVilly et al., 2008), and utilising appropriate communication aids.

Another approach to help include people with different disabilities is to incorporate the voice of their carers but, under the rights-based approach advocated by the UNCRPD, people with disability should be facilitated to speak for themselves (Callus & Camilleri Zahra, 2017). There are limitations that are determined by the extent of the disability that some people have, that make it difficult for them to have their voices heard within a research context. In these situations, this Case Study shows that incorporating the voices of carers can be informative. In effect, these carers can often play the role of interpreter or communication aid for the person with disability. None of the included studies differentiated whether the themes that were identified were more salient for those with disability or for their carers without disability. It is possible that they may not have the same views on what is actually meant by impact in the OPD context.

Interestingly, in many of the included studies, individuals under 18 years of age were specifically excluded from involvement in the research. It is not clear in the literature as to how often those under 18 participate within Organisations of Persons with Disabilities, and no groups that specifically cater to youth were identified. This is despite there being very limited research regarding youth with disabilities in developing countries (Groce, 2004). Whether there is benefit from including young people and how they should be included within OPDs would be an area of future research.

A common finding across all 5 studies was the importance of external entities (usually an NGO) in supporting the formation and function of OPDs. Importantly, the NGOs were not a member of the OPD, satisfying the accepted definition of an OPD as an organisation that is composed of, governed and led by persons with disabilities (Deepak et al., 2013; United Nations General Assembly, 2016). The realist evaluation indicated that this initial NGO support was one of the aspects that led to some of the positive impacts described. It described how this initial support was important in terms of recruiting OPD members, initial funding, and modelling of organisational and governance strategies. In the few studies in the

literature that did describe it, the OPD was either initiated by persons with disability themselves (Armstrong, 1993; Stewart & Bhagwanjee, 1999) or the development of the OPD was facilitated initially by an external entity (Polu et al., 2015).

None of the included studies were undertaken after NGO support had been withdrawn, and therefore no information was collated around the factors that might lead to the effective continuation of the OPD after NGO support is withdrawn, nor how NGOs might approach withdrawal of support to ensure that the OPD remains viable. Furthermore, it is difficult to comment on the durability of results about OPDs, given that the timeframe for these studies was over 3 years only. These would be areas that would benefit from future follow-up research.

Another factor inherent in many of the included studies, including the cluster randomised control trial, was the involvement of OPD members with other groups for the purposes of forming networks. Network approaches between OPDs have also been described in other literature (Armstrong, 1993; Coble, 2013; Deepak et al., 2013; Hemingway & Priestley, 2006; Kleintjes et al., 2013; Miles et al., 2012). The value of the Uttarakhand Cluster as a network has been reviewed in previous studies (Grills et al., 2012; Grills et al., 2016). The realist evaluation described this process of visiting other OPDs as being useful in terms of modelling group function, increasing enthusiasm, sharing knowledge, and increasing confidence, which in turn led to earlier group formation, more rapid transfer of responsibility from the NGO to the OPD members, and increased participation in society. Future studies would need to assess whether this network and linkages component is essential to the successful formation of OPDs in other contexts.

One theme that could be further explored is determining whether OPDs improved financial well-being and livelihoods. The outcome was not clear and differed between the studies. Within the RCT (Grills et al., 2020), employment was the one access indicator that did not show improvement; however the study by Butcher et al (2021) suggested access to methods of livelihood - such as raising chickens - did occur, and Leung et al (2019) found variables impact on income generation. It is possible that whilst OPDs might not have resulted in increased formal employment, they may have resulted in an increase in informal roles and self-employed activities such as subsistence farming. Either way, some form of economic analysis would help to better understand the OPD phenomena impact on livelihood and economic security.

## **Limitations**

This Case Study is based on only 5 research studies, all done in a similar context. Further research in other contexts, using additional methodological approaches would provide additional insights.

Most of the included studies either collected data at a single period in time and/or collected data in the early stages after OPDs were formed. It is not clear whether impacts identified early on, after groups formed, would be either sustained in the longer term or whether the nature of the impacts may vary and change over time. Longer term follow-up would be necessary to explore this, potentially in the form of longitudinal studies.

A limitation of a Case Study approach is that the geographic area is limited – in this case to Uttarakhand in Northern India. It is unclear whether the same impacts and factors would be apparent for other OPDs in other geographical, economic, and cultural contexts. However, the in-depth contextual data gathered from using this multi-pronged approach helps to understand what might or might not work in other contexts.

## **CONCLUSION**

This Case Study demonstrates that OPDs can be effective, and the different studies outline how and why this was so. It demonstrates the value of multiple and mixed methods approaches to study a complex phenomena such as the formation and functioning of OPDs.

It highlights the importance of using a variety of methodologies, in order to understand different aspects of OPDs. Each methodology has its own inherent strengths and weaknesses; however by utilising a spectrum of approaches it is possible to begin to construct a more comprehensive picture of Organisations of Persons with Disabilities and their application for people with disabilities.

## **ACKNOWLEDGEMENT**

The authors would like to thank CHGN Uttarakhand Cluster for hosting the research, CBM India for supporting the OPD intervention and research, and Bethany Carr of the Nossal Institute of Global Health, Australia.

No potential conflict of interest was reported by the authors.

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# Feasibility Assessment of the ICF Minimal Generic Set as a Disability Screening Tool in Rural Nepal

Paul Witte<sup>1\*</sup>, Suresh Tamang<sup>2</sup>, Christine C Groves<sup>3</sup>, Darlene R House<sup>4</sup>,  
Laxman Khadka<sup>5</sup>, Thorang Bhotia<sup>6</sup>, Jeff Hartman<sup>7</sup>

1. Independent Researcher, Tribhuvan University, Nepal

2. Senior Research Coordinator, Nick Simons Institute, Nepal

3. Physical Medicine & Rehabilitation Consultant, Spinal Injury Rehabilitation Centre, Nepal

4. Associate Professor, Clinical Emergency Medicine & Paediatrics, Indiana University School of Medicine, USA

5. Ministry of Health & Population, Nepal

6. B.P. Koirala Institute of Health Sciences, Nepal

7. Asst Professor, Physical Therapy Programme, University of Wisconsin School of Medicine & Public Health, USA

## ABSTRACT

**Purpose:** Nepal's 2017 Disability Rights law provided a new national definition of disability consistent with the UN Convention on the Rights of Persons with Disabilities (CRPD). Updated measurement methods are now indicated to assess disability, suitable for use in populations where self-report tools may be sub-optimal. This study describes the development and field testing of a screening methodology using a clinical assessment conducted by trained non-professionals to score the ICF Minimal Generic Set (MGS).

**Method:** A prospective, 2-stage assessment of disability was conducted over an eight-month period among a convenience sample of individuals aged  $\geq 18$ , admitted to a rural District Hospital in Northeastern Nepal. After 30 hours of training, non-professional assessors completed Stage 1 screening during hospital admission, with positive screening thresholds set on the basis of MGS scores. A physiotherapist completed Stage 2 assessments in the homes of participants with long-term disability, after their hospital discharge.

**Results:** Data from 161 participants was analysed, with 159 (98.8%) screening positive for either temporary or long-term disability. Stage 1 screening was completed independently by assessors in 8-12 minutes. Of the 35 participants (21.7%) with positive screening for long-term disability, 13 (37.1%) underwent Stage 2 detailed evaluation. Disability was confirmed in all Stage 2 assessments, indicating feasibility of the screening process.

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\* **Corresponding Author:** Paul Witte, Independent Researcher & Global Physiotherapist, Tribhuvan University, Nepal.  
Email: powitte@gmail.com

***Conclusion:** Disability screening conducted by trained non-professional assessors using clinical assessment to score the MGS appears to be a promising methodology, and warrants further investigation. If it is found to be valid, it could provide a powerful tool to increase the visibility of disability among some of the most vulnerable populations.*

***Key words:** disability evaluation, International Classification of Functioning, Disability and Health, Community-based Rehabilitation, literacy, minority groups*

## INTRODUCTION

The vulnerability of people with disabilities is exacerbated by their invisibility (Swartz et al, 2018). Nepal's landmark Act Relating to Rights of Persons with Disabilities, 2074 (2017) (ARRPD) marked a leap forward nationally in the process of making disability more visible. Critically, this new law provided an updated definition of a person with a disability, and established a disability identity (ID) card programme which serves as the eligibility document for the government's disability-inclusive social protection scheme (Banks et al, 2017, 2019).

Nepal now defines a person with a disability as someone with "long-term physical, mental, intellectual or sensory disability or functional impairments or existing barriers that may hinder his or her full and effective participation in social life on an equal basis with others" (Act Relating to Rights of Persons with Disabilities, 2074 [2017], 2017). This definition approximates to the language of the UN Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007).

With this internationally-recognised definition recently affirmed in a national law, updated disability assessment methods should be developed which are capable of identifying persons with disabilities, internationally-comparable, and suitable for the local cultural context. Here the word 'suitable' means that the approach must produce the best quality data possible in the population being assessed, with the fewest resources of time, finances, and high-skill personnel (Bolton & Tang, 2002).

The International Classification of Functioning, Disability, and Health -ICF (2001) developed by the World Health Organisation, has been endorsed by all UN Member States (World Health Organisation, 2001) as the conceptual framework and common language for disability statistics (World Health Organisation, 2002;



Kostanjsek, 2011). Coherent with the CRPD (Sherlaw & Hudebine, 2015), and therefore with Nepal's definition of disability, the ICF makes an ideal framework to produce data which is meaningful, internationally-comparable, and capable of accurate description of disability (Üstün, Chatterji, Bickenbach, Kostanjsek & Schneider, 2003; Kostanjsek, 2009; Madden & Bundy, 2019; Stucki, Rubinelli & Bickenbach, 2020).

ICF-derived assessment tools have been produced which depend on both self-report as well as clinical assessment. As commonly-used ICF-based disability assessment tools, both the Washington Group Short Set of Disability Questions (Washington Group on Disability Statistics, n.d.) and the WHODAS 2.0 (World Health Organisation, 2010) depend on self-report of participants to complete the tool. Unfortunately, recent research from Nepal has raised concerns about the utility of such measurement tools in low-literacy populations due to high error rates in responses with both numerical and verbal scales (Pathak et al, 2020), even though the tool they studied had been previously validated in the local language and culture (Sharma, Palanchoke & Abbott, 2018).

As an alternative to self-report tools, ICF Core Sets (ICF-CS) are typically scored by clinical assessment (World Health Organisation, 2013). An ICF-CS is a short selection from the full list of 1400 ICF categories, which is considered to be the most essential to describe functioning of a person with a certain health condition or in a certain healthcare context (Bickenbach, Cieza, Rauch & Stucki, 2012). Among the dozens of ICF-CS now available (ICF Research Branch, n.d.), the Minimal Generic Set – MGS - (Cieza et al, 2014; ICF Research Branch, n.d.) has been suggested as an efficient and user-friendly ICF-based disability assessment tool (Bickenbach, Posarac, Cieza & Kostanjsek, 2015). Although the MGS has been adopted as a generic measure of functioning in a population (Ehrmann et al, 2018), the authors of the current study are unaware of any published cases describing application of the MGS as part of a disability screening methodology.

Although ICF-CS typically relies on clinicians for scoring, there are no explicit instructions or prohibitions about who can use or score any ICF-CS (Rauch, Cieza & Stucki, 2008). With this in mind, and to satisfy the methodology criteria of 'suitability', the current authors believe that in a context with few trained clinical professionals available, non-professionals can be effectively trained to reliably collect information and score a relatively simple tool such as the MGS.

A clinical assessment strategy, especially when conducted by trained local, non-

professional assessors, would be applicable among populations with low literacy levels where self-report tools may be unreliable or among linguistic minority groups for whom self-report tools have not yet been translated and validated. These populations represent some of the world's most vulnerable people, where disability is currently the most invisible.

## **Objective**

The study aimed to:

1. Develop a disability screening methodology relying on trained non-professionals to conduct focused clinical assessments sufficient to score the MGS;
2. Field-test this methodology to determine its candidacy for further investigation as a screening tool.

## **METHOD**

### **Study Setting**

Located between China and India in South Asia, Nepal is a small, landlocked country with rugged terrain which ranges from tropical lowlands to the slopes of the Himalayan Mountains. Of the population of 26.5 million people, 82.9% live in rural communities (Nepal Population and Housing Census 2011, 2012), many of which are multicultural and multi-ethnic. Nepal is home to 125 distinct ethnic groups, speaking 123 different mother tongues (Government of Nepal, Central Bureau of Statistics, 2014). Access to high-quality healthcare is a fundamental right as per Nepal's 2015 Constitution but in reality, it remains a privilege of those who have access and means (Trägård & Shrestha, 2010; Sharma et al, 2019). With only 0.7 physiotherapists per 10,000 people, physiotherapy in particular is lacking throughout the country (Nepal Physiotherapy Association, n.d.; World Physiotherapy, 2020).

This study took place in the rural Sankhuwasabha District of Northeast Nepal. Almost 160,000 individuals live within the District's 3,480 km<sup>2</sup> area and 54% of the population speaks a language other than Nepali as their mother tongue (Government of Nepal, Central Bureau of Statistics, 2014). The literacy rate in Sankhuwasabha District is 69.4% (Nepal Population and Housing Census 2011, 2012), indicating that 30.6% of the assessed individuals between the ages of 15-49

are unable to read even part of a sentence, although rates decline significantly from that average with increasing age, female gender, and rural residence (Ministry of Health & Population, Nepal, 2017).

The District Hospital Sankhuwasabha (DHS) is a 36-bed government-run facility located in the District headquarters of Khandbari. It serves residents of the rural communities of Sankhuwasabha and neighbouring Bhojpur District. Generally, rural Nepal does not have adequate medical personnel to meet the needs of the population (Baral, Prajapati, Karki & Bhandari, 2013). Although official District-level data is not available, there are no licensed or paraprofessional rehabilitation clinicians working in Sankhuwasabha, to the best of this study team's knowledge.

### **Assessor Recruitment and Training**

Leaders of a small, local community development NGO were asked to recommend possible research assistants who:

- a) Had completed secondary education up to, but no higher than, class 11 or 12,
- b) Were lifelong residents of the District,
- c) Fluent in Nepali,
- d) With no experience in healthcare or disability, and
- e) Not currently employed.

Three candidates were recommended and, after interviews, two were selected and compensated for their time at a rate determined appropriate by leaders of the referring NGO. The acting superintendent of the DHS (author LK) independently evaluated these two candidates and confirmed their selection.

Prior to the initiation of the study, assessors were given training that involved 12 hours of lectures, discussions, and lab-based instruction (introduction to disability, the hospital environment, workflows, the clinical assessment process, the MGS tool and scoring with training with simulated cases), and an additional 18 hours working side by side with the study's principal investigator observing the screening process over the first two weeks of the study. By the end of the training, assessors were able to complete assessments independently and accurately. Subsequently, one author (PW) completed bi-weekly independent assessments of several participants for each assessor for the duration of Stage 1 data collection, scoring results were compared to assistant records, and feedback was provided

in the event of a discrepancy in scoring. There were no discrepancies in the outcome of the screening (positive or negative result), although minor variations in scoring were observed.

## Study Design

The study design was a prospective, 2-stage evaluation of disability among individuals admitted to the District Hospital Sankhuwasabha. Stage 1 involved screening to categorise participants as having no, temporary, or long-term disability. Stage 2 involved a detailed assessment of participants with long-term disabilities, in order to confirm disability screening results and determine the domain and severity of disability; this was completed at the participant's home in order to account for the environmental contribution to the disability. This design has been used to produce high-quality data with a minimum of resources (UNICEF & Bhutan National Statistics Bureau, 2012).

In order to assess disability using the MGS, Nepal's definition of disability had to be operationalised in terms of degrees of severity used by the ICF. To correspond to the lowest level of difficulty scored by the ICF's "Mild" or "Minimal" levels of difficulty (see Table 1), a person with a disability was defined as "someone who has physical, mental, intellectual or sensory impairments which, in interaction with various barriers, causes at least a 5% difficulty in some meaningful area of participation in society on an equal basis with others."

**Table 1: ICF (2001) vs Nepal Disability ID Card (Act Relating to Rights of Persons with Disabilities, 2074 [2017], 2017) Severity Categories**

ICF Category	ICF Category Definition	Nepal ARRPD Category	ID Card Colour	Nepal ARRPD Category Definition, "A person who is in such a condition that he or she":
Mild	5-24% difficulty	Mild	White	Can regularly participate in his or her daily activities and social activities if there exists no physical and environmental barrier.
Moderate	25-49% difficulty	Moderate	Yellow	Can regularly participate in his or her daily activities and in social activities if physical facility is available, environmental barrier is ended or education or training provided.

Severe	50-95% difficulty	Severe	Blue	Needs support of others continuously to perform personal activities and involve in social activities.
Complete	96%+ difficulty	Profound	Red	Has difficulty in performing his or her day-to-day activities even with continuous support of others.

## Study Population

Participants were recruited from a convenience sample of individuals admitted to the DHS between August 11, 2019 and March 23, 2020. Six days per week (excluding Saturdays) hospital census records were reviewed by research assistants and all newly-admitted individuals who had not yet been contacted were approached to discuss the study. Informed consent was solicited from potential participants as soon after hospital admission as possible, within 72 hours or less.

All admitted persons with non-maternity-related diagnoses, aged eighteen years and above, were eligible to participate in the study, unless they were discharged or referred to a higher centre of care before assessors could make contact.

## Data Collection Procedures: Adaptation and Use of the MGS

The ICF is a complex but flexible instrument, and must be adapted before deployment for any purpose. As Madden, Hartley, Mpofu and Baguwemu (2013) stated, “It is a challenge but also an advantage that the ICF does not provide a formula or strict set of rules for its use. Its use requires thought and selection. But this also means that it provides flexibility – it can be used freely to suit different uses and circumstances – as a tool, not a master”.

The ICF Minimal Generic Set (MGS) was intended to broadly describe functioning in adults using the fewest ICF codes. Consisting of only seven categories (three from ‘Body Functions’ and four from ‘Activities & Participation’), it is purposefully brief and direct (Cieza, Oberhauser, Bickenbach, Chatterji & Stucki, 2014). Although the ‘Activity & Participation’ items on the MGS presume that two qualifiers for each item will be scored—both Performance (what the individual actually does), and Capacity (what the individual would be capable of in a “neutral” or “uniform” environment)—the authors of the current study are of the view that the Capacity qualifier is too nuanced and complex (Bostan, Oberhauser, Stucki, Bickenbach & Cieza, 2014) to be scored by a non-professional, and accordingly Capacity qualifier scoring was excluded from data collection.

Scoring for the single qualifier for the 'Body Functions' items and Performance qualifier for the 'Activities & Participation' items on the MGS was conducted on a 0-4 scale according to the standard instructions in the ICF (2001).

Paper packets were used during Stage 1 screening; these consisted of the informed consent forms, form for basic demographic information, interview questions and functional assessment guide (see Supplementary Material 1), as well as a scoring sheet for the 7 items of the MGS. Assessors took notes during screening and referred to those when scoring the MGS while at the participant's bedside. While still on-site, assessors discussed each positive screening case with the participant's physician or the study's lead author, to determine whether disability should be classified as temporary or long-term according to the above criteria. After screening newly-enrolled participants, assessors transported screening packets to an off-site, locked, private office where they transcribed collected data into a spreadsheet programme with files encrypted after each use. Screening packets were then stored in a locked cabinet in the office, to which only the principal investigator and assessors had access.

Screening with the MGS was considered positive for disability if any one item was scored 2 or above, or at least two items were scored 1. This threshold was set to identify a person with a disability according to the working definition developed for this study.

As screening data was transcribed, custom algorithms copied relevant screening and demographic data of participants with positive screening for long-term disability into a separate file to create a register of participants to be scheduled for Stage 2 evaluation. When team schedules and weather/rural road conditions allowed, and between one and six months after Stage 1 screening, research assistants called participants to agree on a time the following day for the study's Principal Investigator and assistant to complete Stage 2 assessment. Researchers navigated to participants' homes by off-road motorcycle and on foot, depending on road access and conditions.

### **Data Collection Procedures: Stage 2 Enrollment Process and Assessment**

Participants with positive Stage 1 screening were considered to have a temporary disability if all difficulties identified on the screening tool:

1. Developed not more than one month prior to hospital admission; and,

2. Were related to a medical condition which was expected to fully resolve, with no residual effects, not more than one month after discharge from the local hospital. This determination was a clinical judgment made collaboratively by an experienced physiotherapist (author PW) and/or the individual's attending physician during the hospital stay.

All other participants with positive Stage 1 screenings were considered to have a long-term disability, and enrolled in Stage 2.

Between one and six months after hospital discharge, eligible participants were visited at their home, throughout Sankhuwasabha and adjoining Bhojpur District, to complete a detailed Stage 2 assessment based on the ICF checklist (World Health Organisation, 2003) but adapted for the local context. A form of free listing (Bolton & Tang, 2002) was used in community interviews to identify important activities in the local area, with key categories mapped to the corresponding ICF code (see Appendix 1 for a complete list).

A physiotherapist (author PW) completed assessments in the Nepali language, with linguistic support as needed by a local Nepali assistant. These assessments provided data on the 'Activity & Participation' levels of participants through review of relevant medical records, detailed interviews and physical assessment, and analysis of the impact of the barriers and facilitators in their specific physical and social environments. Stage 2 assessments typically lasted 45-60 minutes.

### **Data Collection Procedures: Stage 2 Assessment Scoring and Disability Categorisation**

Though disability is a complex and multidimensional phenomenon (UN General Assembly, 2007; World Health Organisation and World Bank, 2011), and a single score cannot adequately describe an individual's disability experience, assessed individuals were grouped into severity categories for the purpose of concise description and comparison with the rankings described by the National Disability ID card programme (see Table 1). The disability severity categories were based on the ICF coding convention for 'Activity & Participation' (A&P) - Performance, where a score of '0' indicates no difficulty, '1' of mild difficulty, '2' of moderate difficulty, '3' of severe difficulty, and '4' of complete difficulty. The highest score recorded from among all relevant A&P items for an individual was used to determine that individual's level of disability severity. Irrelevant items (i.e., d6506-"Caring for animals" - for a participant whose family raises no animals) were scored as 'Not Applicable' and disregarded from analysis. This

method of disability severity categorisation presents disability on a continuum of more or less (rather than a dichotomous Yes or No), consistent with the ICF's model (2001).

## Data Analysis

Data was de-identified, entered into a spreadsheet, and analysed with descriptive statistics.

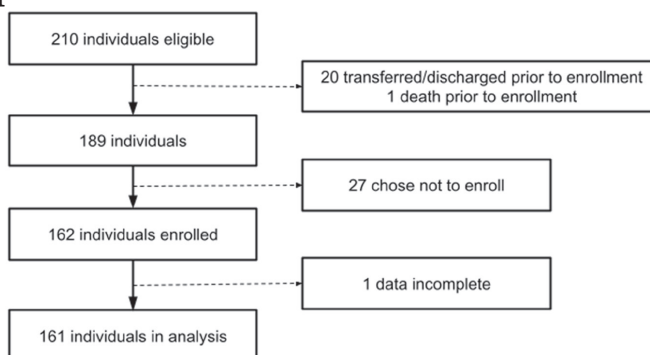
## Ethical Considerations

Applicable regulations from the Nepal Ministry of Health and District Hospital Sankhuwasabha concerning the ethical use of human volunteers were followed. The Nepal Health Research Council approved the study prior to the initiation of data collection [Ref # 3519, received 9 July 2019]. Study assistants solicited written informed consent in Nepali from all potential participants. Consent forms were read out to those unable to read comfortably, along with discussion to ensure understanding throughout the process. Thumbprints and witness signatures were collected if the participant was unable to pen a sign. No compensation or incentive was given to study participants.

## RESULTS

Though it was planned to continue data collection for one full year, due to the COVID-19-related lockdown in Nepal the study was truncated on March 23, 2020, after 32 weeks. Within the data collection period, 210 individuals admitted to the District Hospital Sankhuwasabha were eligible for inclusion (see Figure 1 and Table 2 for details).

**Figure 1: Participant Inclusion and Evaluation Flowchart**





**Table 2: Participant Demographics**

Participant Age by decade (n=161 total)	
18-29	33
30-39	22
40-49	22
50-59	20
60-69	28
70-79	25
80+	11
Median Age (IQR)	50 years (32 - 68)
Gender Ratio	42.0% male, 58.0% female

Of the 161 participants, 40 (24.8%) were not able to make a distinguishing mark on the consent form and used their inked thumbprints instead, and an additional 33 participants (20.5%) only made an 'X' on the signature line because of inability to write their name or initial. Among the 13 participants assessed in Stage 2, only 1 participant had any amount of formal education (four years).

### **Stage 1- Screening Process Findings**

The screening process typically took 10 minutes to complete, including scoring of the MGS tool after assessors had been fully trained. Bi-weekly quality checks revealed acceptable agreement with assessors on scoring, and particularly with the screening result. However, as the hospitalised population in this study generally had a high level of various impairments and the MGS assesses very high-level skills, there were few opportunities to check for agreement with negative screening results.

### **Stage 1- Screening Results**

Among 161 participants included in the analysis, 159 (98.8%) had a positive screening for disability. While 124 of the total 161 (77.0%) were categorised as having a temporary disability, 35 (21.7%) had a long-term disability. Those with temporary disability were affected by various levels of reversible impairments due to the effects of their acute illness or injury, which is known to be common in hospitalised populations (Hajjioui, Fourtassi & Nejjari, 2015; Loyd et al, 2020).

### **Stage 2- Detailed Assessment Results**

Due to weather-related adverse rural road conditions, data collection for Stage 2 could not begin until study week 12 (November 2019). Stage 2 assessments were completed on only 13 of the 35 (37.1%) scheduled participants (see Table 3) as premature termination of the study prevented assessment of 18 participants. Four additional participants could not be assessed - due to death (2), not being at home at the time of scheduled appointment (1), and inability to locate the participant's home (1).

**Table 3: Stage 2 Assessed Participant Demographics**

Assessed # Stage 2 participants (M / F)	13 (7 / 6)
Median Age (IQR)	65 years (52.5-77.5)

Eighteen participants were assessed in Stage 2; among them 10 (55.6% or 6.2% of the study population) presented with “complete difficulty” in at least one assessed ‘Activity & Participation’ item on the ICF. Mobility was the most common domain of disability for participants assessed in Stage 2 (see Tables 4 and 5).

**Table 4: Disability Category per Stage 2 Assessment Results**

Severity Category	Adult
No identified disability	0 (0.0%)
Mild disability	1 (7.7%)
Moderate disability	3 (23.1%)
Severe disability	2 (15.4%)
Complete disability	7 (53.8%)

**Table 5: Primary Domain (and Secondary, if applicable) of Disability among Participants Assessed in Stage 2**

Disability Category	Adult
Mobility	11 (84.6%)
Self-care	4 (30.8%)
Communication	0 (0.0%)
Vision	3 (23.1%)
Hearing	1 (7.7%)
Cognition	0 (0.0%)

\*Percentages do not add up to 100% due to some participants having a disability

in multiple domains. Percentages are equal to the prevalence of each disability category in each group of participants.

## DISCUSSION

### **Use of Non-professional Assessors to conduct Clinical Assessments**

The study researchers set out to develop a disability assessment methodology which is both capable of producing reliable internationally-comparable data, as well as being suitable to the local context. In the context of this study, the investigators needed to consider the lack of physiotherapists in the region. To ensure this method could be maintained after the study was completed and to reproduce it in other low-resourced communities, the methodology had to be such that a trained professional could efficiently and effectively identify and train someone in the local community. Although there is limited research on the abilities of non-professionals and paraprofessionals to conduct accurate clinical assessments outside of mental health and counselling (Durlak, 1979; Armstrong, 2010), there is a long history of relying on such workers to conduct a wide array of disability-related assessments and interventions related to Community-based rehabilitation (Werner, 1987; ILO, UNESCO, WHO, 2004; IDDC, 2012; Iemmi, Blanchet, Gibson & Kumar, 2016). According to this well-established precedent and the results of this study, the researchers have no reservations about relying on trained non-professionals to effectively complete this important work, and indeed can see no superior alternative.

### **Feasibility in Low-literacy and Linguistic Minority Groups**

Another important contextual consideration was the low-literacy rates and linguistic minority groups that are prevalent in this region and similar regions around the world. In this study, although the literacy level was not formally assessed, some information about writing competency was gained on the basis of the high number of participants who were unable to sign the consent form. Given the difficulty of individuals with low literacy in providing reliable responses to self-report questionnaires involving more than 3 response items (Flaskerud, 2012; Chaves, Reis, Pagano & Torres, 2017; Pathak et al, 2020), tools relying on clinical assessment for disability assessment may be more suitable. However, areas with lower literacy also tend to have a paucity of available clinical professionals to administer such assessments (Wilson et al, 2009). Using local, non-professional

trained assessors (who are multilingual when necessary) to administer a clinical assessment to score the MGS eliminates the barriers related to self-report response errors and the need to translate and validate a questionnaire into every spoken language. Based on the good agreement in Stage 1 screening results during quality checks by the lead author, as well as confirmation of disability in all assessed participants in Stage 2, this study demonstrated the feasibility of this potentially powerful approach.

### **The MGS as a Disability Screening Tool: Experience with Adaptation, Limitations, Future Needs**

The MGS, released in 2014, is being used as a generic measure of functioning in hospitals throughout China (Ehrmann et al, 2018). During adaptation, 'remunerative employment' (d850) was removed from scoring because clinicians were "unable to appraise this category in the inpatient setting". The authors of the current study are of the view that all MGS codes should be scored when used as a screening tool for disability according to a CRPD-based definition of disability, even if this results in a high rate of positive screenings in some settings. What is needed is some filtering and management of the resultant data, not elimination of relevant categories.

Although the CRPD considers disability only to be as a result of long-term impairments, the ICF makes no such distinction. The MGS, like any of the common ICF-based self-report screening tools (World Health Organisation, 2010; Module on Child Functioning: Questionnaires, 2016; Washington Group on Disability Statistics, n.d.), is not capable of discriminating between those individuals with temporary and chronic impairments and participation restrictions. As a screening tool, this is an acceptable and unavoidable weakness. However, if the MGS or any screening tool is being used as part of an effort to support and enable people with impairments, limitations and disabilities, it is incomplete to identify problems and not activate a successor process to identify appropriate next steps. In this study, there was reliance on assessors' consultation with a physiotherapist or the participant's physician in order to determine whether the difficulties identified during screening were temporary and resolvable, or part of a long-term condition. In most typical community-based rehabilitation (CBR) type applications, such resources would not be readily available. In order for screening with the MGS or any other tool to be efficacious as part of a community empowerment effort, appropriate successor processes should be designed according to goals

and locally-available resources to ensure the health and social service needs of participants are attended to appropriately (Cieza et al, 2020; Mont & Cote, 2020).

Overall the researchers were very pleased with the MGS and the quality of information, as Stage 2 assessments confirmed disability of varying degrees in all assessed participants. This indicates effective assessment and scoring by trained non-professional assessors and appropriate positive/negative screening thresholds. It is recommended that the MGS be further studied as a disability screening tool to ensure validity. If found to be valid, this tool may be of special use to Community-based Rehabilitation workers and others who provide essential care and support services to individuals with low literacy levels or speakers of minority languages in resource-limited settings. In light of the potential utility of the MGS for functional assessment and possibly disability screening, the current researchers recommend training in use of this tool to be part of any standardised CBR curriculum which may be developed (Gindorfer & Cornielje, 2020).

### **Limitations**

Due to a high positive screening rate in this hospitalised population, it was difficult to provide blinded independent assessments of a sample of participants to determine inter-rater reliability. However, during selected independent Stage 1 assessments, there were no discrepancies between positive and negative screens performed by the physiotherapist and the study assessors.

Stage 2 assessments were only completed on those with positive screening for long-term disability, and all assessed participants did demonstrate disability of varying degrees. Although this shows the screening process correctly identified people with long-term disabilities, it does not reveal how often participants were misclassified by the study criteria as having no or temporary disabilities. Furthermore, the sample size of those assessed in Stage 2 was limited due to early termination of the study, potentially limiting the validity of these Stage 2 results.

This study showed feasibility, but did not investigate the validity of this screening approach.

### **CONCLUSION**

Nepal's 2017 Disability Rights provided the impetus for the development of updated methods to make disability visible. Approaches based on clinical assessments have advantages over self-report tools for disability assessment,

especially among populations with low literacy levels or minority language use. This study has demonstrated the feasibility of training non-professional assessors using clinical assessment of participants to score the MGS. If future investigations further establish the validity of this method, it may provide a powerful tool for use, particularly in CBR settings, to increase the visibility of persons living with disability.

## ACKNOWLEDGEMENT

The authors would like to thank the staff and administration of the District Hospital Sankhuwasabha for accommodating this study in their facility. They also extend their appreciation to Dr. Yogendra Gurung of the Tribhuvan University Central Department of Population Studies for his assistance in study design.

The authors declare that they have no competing interests. No grants or external funding were used to conduct this study.

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## **Supplementary Material 1: Stage 1 Clinical Assessment Screening Procedure Interview Guide** (rephrasing or asking clarifying questions is acceptable)

- When did you arrive here at the hospital?
- What problem were you having when you came?
- Are you still having that problem?
- Are you having any pain, either right now, or over the last day?
- Where do you live, and with whom?
- What sorts of things did you do before you got sick with the problem that brought you to the hospital? What was your daily routine like?
- Before you got sick with the problem that brought you to the hospital, was anything in your daily life or routine difficult for you? Were you able to do everything people your age are typically able to do?

### **Functional Assessment**

Instruct the individual to do the following, and note if they are able to do it, how well, how quickly, and how comfortably. Note anything that seems to be worse than normal for someone their age.

- Lift arms up over your head

- Bend up and down at elbows
- Open and close both hands quickly 5 times
- Look up/down/left/right
- Seated marching
- Seated kicks
- Seated ankle pumps
- Stand and march in place
- Repeated stand up and sit down
- Walk back and forth across the room
- Pick something up off the floor

\*Based on this information, complete the GDS screening form according to the instructions

### Supplementary Material 2: Data Collection Items for Stage 2 Assessment

<b>Basic Demographics</b>
Age
Gender
Currently a student?
Total years of education
Marital status
Occupation
Medical diagnosis - 1
Medical diagnosis - 2
Home location
<b>Body Functions</b>
b110 - Consciousness functions
b114 - Orientation functions

b117 - Intellectual functions
b130 - Energy and drive functions
b134 - Sleep functions
b140 - Attention functions
b144 - Memory functions
b152 - Emotional functions
b156 - Perceptual functions
b164 - Higher level cognitive functions
b167 - Mental functions of language
b210 - Seeing functions
b230 - Hearing functions
b280 - Sensations of pain
b310 - Voice functions
b410 - Heart functions
b430 - Hematological system functions
b435 - Immunological system functions
b440 - Respiration functions
b515 - Digestive functions

b525 - Defecation functions
b530 - Weight maintenance functions
b555 - Endocrine gland functions
b620 - Urination functions
b710 - Mobility of joint functions
b730 - Muscle power functions
b765 - Involuntary movement functions
b770 - Gait pattern functions
<b>Body Structures (both extent of impairment and nature of change assessed)</b>
s110 - Structure of brain
s120 - Spinal cord and related structures
Chapter 2 - Eye, ear, and related structures
Chapter 3 - Structures involved in voice and speech
s410 - Cardiovascular system and related structures
s430 - Respiratory system and related structures
Chapter 5 - Digestive, metabolic, and endocrine structures
s710 - Structure of head and neck region
s720 - Structure of shoulder region
s730 - Structure of upper extremity
s740 - Structure of pelvic region
s750 - Structure of lower extremity
s760 - Structure of the trunk
Chapter 8 - Structure of skin
<b>Activity &amp; Participation (both performance and capacity assessed)</b>
d110 - Watching
d115 - Listening
d130 - Copying
d131 - Learning through actions with objects
d132 - Acquiring information

d133 - Acquiring language
d135 - Rehearsing
d140 - Learning to read
d145 - Learning to write
d150 - Learning to calculate
d155 - Acquiring skills
d160 - Focusing attention
d166 - Reading
d170 - Writing
d172 - Calculating
d175 - Solving problems
d210 - Undertaking a single task
d220 - Undertaking multiple tasks
d310 - Communicating with/receiving spoken messages
d315 - Communicating with/receiving nonverbal messages
d330 - Speaking
d335 - Producing nonverbal messages
d340 - Producing messages in formal sign language
d350 - Conversation
d410 - Changing basic body position
d415 - Maintaining a body position
d420 - Transferring self
d430 - Lifting and carrying objects
d440 - Fine hand use
d450 - Walking
d470 - Using transportation
d510 - Washing oneself
d520 - Caring for body parts
d530 - Toileting
d540 - Dressing
d550 - Eating
d560 - Drinking
d570 - Looking after one's own health
d620 - Shopping

d630 - Cooking
d640 - Doing housework
d6506 - Caring for animals
d660 - Assisting others
d710 - Greetings and "small talk"
d750 - Informal social relationships
d760 - Family relationships
d810 - Informal education
d815 - Preschool education
d820 - School education
d825 - Vocational training
d850 - Remunerative employment
d859 - Agricultural work
d860 - Basic economic transactions
d870 - Economic self-sufficiency
d880 - Engagement in play
d910 - Ceremony participation
d920 - Recreation and leisure
d930 - Religion and spirituality
d950 - Political life
<b>Environmental Factors</b>
Products and technology for:
e110 - Personal consumption
e115 - Completion of activities of daily living (ADLs)
e120 - Personal indoor/outdoor mobility and transport
e1551 - Design, construction and building products and technology for gaining access to facilities in buildings for private use
e1552 - Design, construction and building products and technology for way finding, path routing and designation of locations in buildings for private use, indoor and outdoor products
Natural environment and human-made changes to environment:

e210 - Physical geography
e225 - Climate
e298 - Local paths and roads
Support and relationships:
e310 - Immediate family
e315 - Extended family
e320 - Friends
e330 - People in positions of authority
e355 - Health professionals
Attitudes of:
e410 - Immediate family members
e415 - Extended family members
e425 - Acquaintances, peers, and neighbours
e430 - People in positions of authority
e460 - Societal attitudes
Services, systems, and policies:
e540 - Transportation
e560 - Media
e570 - Social security
e580 - Health systems
e585 - Education and training systems

# Perspectives of Caregivers on Pubertal Changes among Young Adolescent Girls with Cerebral Palsy: a Qualitative Analysis

Arathi P Rao<sup>1\*</sup>, Hitesh Shah<sup>2</sup>, Shyamala Guruvare<sup>2</sup>, Manisha Gore<sup>3</sup>,  
Kesavan Rajasekharan Nayar<sup>4</sup>, Bindhya Vijayan<sup>5</sup>

1. Prasanna School of Public Health, Manipal Academy of Higher Education, Manipal, India
2. Kasturba Medical College, Manipal Academy of Higher Education, Manipal, India
3. Faculty of Health Sciences, Symbiosis International Deemed University, Pune, India
4. Principal, Global Institute of Public Health, Trivandrum, Kerala, India
5. Public Health Professional, Central University of Tamil Nadu, India

## ABSTRACT

**Purpose:** *Girls with cerebral palsy can have limited capacity to cope with pubertal issues. It results in their parents being burdened with additional caregiving during this period. A qualitative study was undertaken among parents of girls with cerebral palsy to understand the caregivers' challenges and concerns.*

**Method:** *Twenty-one interviews were conducted among purposively selected parents and caregivers of young adolescent girls with cerebral palsy in a tertiary care referral hospital in South India. The interview questions were related to menstrual hygiene, behavioural changes around puberty, fear of sexual abuse, and perceptions about contraception. Transcripts were coded and, after data anonymisation, manual thematic analysis was done using an inductive approach.*

**Results:** *A total of 6 themes emerged, related to identification of problems, treatment-seeking patterns of the caregivers, social support and perspectives on contraception, pubertal challenges and concerns of parents for the future of their girls. Caregivers reported that puberty in girls with cerebral palsy places an additional burden on the caregivers. They were also worried about the safety of their girl children. Contraception and menstrual suppression were not considered as options. Caregivers wanted education and financial independence for their children.*

**Conclusion:** *Awareness of methods of managing pubertal issues, shared caregiving responsibility by the family, and customised approach for healthcare*

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\* **Corresponding Author:** Arathi P Rao, Coordinator, Master of Public Health Programme, Prasanna School of Public Health, Manipal Academy of Higher Education, Manipal, India. Email:arathi.anil@manipal.edu

*interventions are of paramount importance in helping caregivers deal with the transition to puberty by girls with cerebral palsy. Family counselling and therapy can help to allay the parents' fears, worries and tensions*

**Key words:** *menstruation, caregivers, developmental disorders, secondary sexual characteristics, contraception, growth hormone*

## INTRODUCTION

Adolescence is the transitional phase which helps shape a young adult (Zacharin, 2009). Cerebral palsy (CP) is one of the leading causes of disabilities, diagnosed in 1-3 per 1000 children and associated with physical and mental disability (Parthasarathy et al., 2013). Many girls with cerebral palsy have limited capacity to cope with issues like menstrual hygiene, abdominal pain (dysmenorrhoea), heavy bleeding, irregular cycles, and infections due to restricted mobility; lack of comprehension can manifest as behavioural changes. Motor disabilities along with intellectual disability influence the self-care potential of these girls as they attain puberty.

Caregivers of girls with cerebral palsy go through various phases in coping with their children's condition: refusal to accept, shock, fear, anger, loss of the ideal child, inability to fulfil normal motherhood as per the norms of the community, and so on (Devesa et al., 2010). Caregivers' efforts to cope with the challenges of rearing girls with cerebral palsy can lead to psychological problems that require counselling (Marilee et al., 2010; Novak et al., 2012; Ogunlesi et al., 2016). Parental anxiety is enhanced due to fear of sexual abuse and pregnancy, hence they are sometimes forced to opt for permanent methods of contraception (Huang et al., 2010). Evidence suggests that there is an unmet need for reproductive health services among parents and children with neurodevelopmental disabilities (Nasrin et al., 2014). There could be higher levels of parental anxiety due to lack of information (Pelchat et al., 2009). Professional guidance and support are required for caregivers, as they play an important role in the transitional care of children with cerebral palsy (Keith, 2008).

There is a paucity of literature addressing these issues and providing context-based solutions. Although healthcare interventions are universal, there is a need to address the social dimensions of parenting when a child with neurodevelopmental disability goes through puberty. Hence, an exploratory study among parents of girls with cerebral palsy was undertaken to understand their challenges and concerns.

## Objective

The primary objective of the study was to explore the concerns of caregivers regarding pubertal challenges among girls with cerebral palsy. The secondary objective was to understand the perceptions of caregivers regarding social support and the future of their girls with cerebral palsy.

## METHOD

### Study Design

This qualitative study is built on the constructs of 'An epidemiological study of gynaecological disorders among girls with cerebral palsy'. It follows a sequential exploratory design, Quantitative→Qualitative approach.

The study was conducted between April 2016 to April 2018. It revealed the growth, sexual maturity and patterns of onset of puberty among the study participants (Rao et al.,2019). Development of sexual characteristics commences at around 9-11 years of age among Indian girls, while girls with cerebral palsy can develop signs of precocious puberty earlier (Backeljauw et al., 2004; Agarwal & Agarwal, 2020).

Parents were asked open-ended questions which enabled the researchers to understand their perceptions and concerns in relation to the onset of puberty among their daughters with cerebral palsy, and the fears regarding their safety and security. The qualitative study aimed at analysing the perceptions and concerns regarding challenges which the parents foresee.

### Participants

Caregivers of girls with cerebral palsy in the age group of 6-12 years, who had admitted their children to the hospital for treatment, were selected for the study. A basic proficiency in the local dialect (Kannada) was required. Participants were purposively selected following the quantitative study to ensure broad representation of various levels of cerebral palsy as per the GMFCS-ER. The nature and purpose of the study were explained, and informed consent was obtained from the participants.

The interviews were conducted in classrooms adjacent to the orthopaedic hospital wards where the girls with cerebral palsy were admitted for treatment between April 2016 and April 2018.



## Study Tools

The interview guide consisted of the following domains:

- 1) Activities of daily life;
- 2) Menstrual hygiene;
- 3) Behavioural changes around the onset of puberty;
- 4) Parental fear of sexual abuse; and
- 5) The perceived role of contraception for the girl with cerebral palsy.

These domains were based on inputs from a review of the literature and subject experts. The interview guide was pilot-tested among 3 caregivers of girls with cerebral palsy who could speak Kannada language. Audio recording of the interviews was done during the study, using Olympus (model no – WS 812).

## Data Collection

A total of 25 parents were approached for in-depth interviews. Among them, 3 parents were not willing to participate in the study. Each interview lasted for 25 - 75 minutes. The interview commenced with an explanation of the purpose and nature of the study, after which informed consent was obtained from the caregiver. Following the introduction and the rapport-building questions, the interviews proceeded with questioning across domains decided earlier. The line of questioning followed the pattern and nature of responses by the caregivers. Probing was used where necessary. Notes were taken during the interview for non-verbal responses and other relevant field information.

## Data Analysis

A unique identification code was assigned to all audio-recording files. The identifiers were cleaned from the transcripts once the unique identification code was allocated. The transcripts were read repeatedly to identify frequently reported patterns, in terms of both similarities and differences. They were coded and extensively elaborated, followed by development of themes in keeping with the study objectives.

## Ethics

Ethical clearance from the Institutional Ethical Committee was obtained before the study commenced.

## RESULTS

Table 1 shows the characteristics of the respondents who participated in the present study. Most of the participants were mothers. Five of them were caregivers of pre-menarcheal girls with cerebral palsy. Two mothers were separated from their respective spouses because of their daughters' cerebral palsy condition. The qualitative analysis revealed 6 major themes with subthemes among each of them.

**Table 1: Characteristics of the Respondents**

Participant number	Cerebral Palsy level of child	Age	Gender	Education	Occupation	Relationship with Girl with Cerebral Palsy
1	1	42	Female	9 <sup>th</sup> std	House-wife	Mother
2	3	36	Female	Primary	House-wife	Mother
3	4	42	Male	Primary	Electrician	Father
4	5	36	Female	Primary	House-wife	Mother
5	1	38	Female	Primary	House-wife	Mother
6	1	40	Female	Graduate in Special Education	Teacher in Special School	Mother
7	3	38	Female	Graduate in modern medicine	Doctor	Mother
8	1	Parent was unaware	Female	Illiterate	Homemaker	Mother
9	2	40	Male	Primary	Coolie	Father
10	5	32	Female	Graduate	State Govt Employee	Sister
11	3	38	Female	Primary	House-wife	Mother
12	1	Parent was unaware	Female	Primary	House-wife	Mother
13	4	32	Female	Primary	House-wife	Mother
14	4	Parent was unaware	Female	Illiterate	House-wife	Mother
15	1	33	Female	Primary	Security	Mother
16	1	34	Female	Primary	House-wife	Mother
17	1	35	Female	Primary	House-wife	Mother
18	4	45	Female	Pre-primary	Tailor	Mother
19	3	40	Female	Graduate	House-wife	Mother
20	1	36	Female	Pre-primary	Labourer	Mother
21	1	36	Female	Pre-primary	House-wife	Mother
22	1	18	Female	Pre-primary	House-wife	Sister

## Theme 1

### Identification of the Disability

The caregivers shared various early childhood symptoms of their wards, such as seizures, and mentioned their visits to doctors. In one case, the child visited the doctor about 7 months after onset of symptoms in Mysore. After treatment, the symptoms started to reappear almost every month. The child was taken to a hospital in a city nearby where the doctors recommended medicines to be taken for a period of 7 years.

### Concerns about Delayed Milestones

Growth was observed to be slow among girls with cerebral palsy in comparison to their peers without disabilities. One of the caregivers revealed that her daughter started to sit only at 2 years of age. The parents bought her a 3-wheeler walker, which the child used to push around and walk a little.

In another case, the caregiver revealed that the child was advised continuous physiotherapy for six months. She was born prematurely with a weight of just 650 grams, and the parents had little hope of her survival.

About experiences with physiotherapy, one of the parents stated:

*“In our town, physiotherapy sessions are conducted but clients experience a lot of pain, and hence we brought the child to Manipal hospital”* (42-year-old father of a 6-year-old girl with cerebral palsy).

The caregiver further revealed that the child’s growth was slow even after 1 year of age, and it was then considered a problem.

### Concerns about IQ and Memory

The caregivers shared that compared to their peers, girls with cerebral palsy have low intelligence and are poor in studies; however they do remember what they watch on television and in cinema theatres. At home, they remember every word spoken but have issues with regard to grasping the lessons at school. One caregiver revealed that her daughter understands things after they are repeated twice or thrice.

## **Difficulty in Walking and Related Implications**

One parent revealed that the child was kept in the Intensive Care Unit for about 60 days after she was born. As the child grew, there was weakness in her leg and it was bent. After she started going to school, she complained of pain in her legs.

The 36-year-old mother of a daughter with cerebral palsy explained:

*“The child does everything with her legs, eating, playing games on mobile. She sweeps and mops the floor (with her legs), plays with toys, everything with legs. No power in hands at all.”*

## **Theme II**

### **Treatment-seeking for Menstrual Issues**

The treatment-seeking behaviour of the participating parents reveals that they sought immediate resolution of their children’s problems. They would not take the child for treatment to the same doctor if there was no improvement. After repeated visits to doctors and hospitals, parents expressed frustration and helplessness and some burnt their child’s clinical records. Most of them had spent lots of money, taken loans (*‘saala’*) for their children’s treatment and they said they could see only minor improvements after all the cycling and other exercises to which the children were subjected.

A 32-year-old caregiver, sibling of a girl with cerebral palsy, said that there was some improvement in the functioning of her sister’s legs:

*“Just 3 years only. Previously mummy used to bring her for physiotherapy. It seems they said there are no hopes. So they stopped coming.”*

The dependency of the children was a big worry for the caregivers. The ultimate aim of seeking treatment was to make the children independent in their daily activities.

## **Theme III**

### **Caregivers’ Perceptions on Pubertal Challenges**

The study revealed that caregivers had observed the physical changes in girls with cerebral palsy such as breast development, hair growth in the armpit and pubic areas, and onset of menstruation. A few caregivers shared that young

adolescents reported pain in the breasts if touched while bathing. Some reported that the adolescents had irregular menstrual cycles, fortnightly or monthly, white discharge and itching in the private parts.

*“Sudden development of the breasts, large in size, embarrassed my child and she became very conscious of her appearance after that”* (36-year-old mother of a young adolescent with cerebral palsy).

Most of the caregivers reported that their girls suffered painful periods with heavy bleeding during the first three days, followed by a gradual decline on the 4<sup>th</sup> and 5<sup>th</sup> days. Some of them complained of clots during menstruation, symptoms of persistent backache, abdominal pain, and leg pain. None of the caregivers had sought any professional advice for these symptoms. One respondent shared that her child’s abdominal pain was severe on the first day but would subside after that and did not require medication.

### **Use of Pads during Menstruation**

Majority of the caregivers reported the use of cloth pads rather than sanitary napkins, for different reasons. They believed that cloth pads were useful during heavy bleeding, were more absorbent than sanitary pads, and are cheaper and easily available at home. It is easy to clean cloth pads and change the cloth every alternate month. Since these adolescents sit for longer hours, staining of undergarments and seats occur; so the caregivers cut up saris and used big pieces of cloth beneath the undergarments to avoid staining. Cloth pads are used on the first three days when the bleeding is heavy, followed by the use of sanitary pads. Interestingly, one mother reported that since the men at home would not go out to buy sanitary pads, they use cloth pads even if sanitary pads are recommended by the doctor. They reported that they had to do everything by themselves to take care of their daughters.

### **Practice of Menstrual Hygiene**

For the majority of the adolescents, the caregivers took charge during their periods. Knowing the importance of hygiene, they cleaned the private parts of adolescents periodically during menstruation. Girls with cerebral palsy accept the help of the caregiver initially but learn to be independent as they grow up. The caregivers changed the pads depending on the requirement. For a few, it was changed once a day. The adolescents did not give trouble during cleaning

or changing the pads. A young adolescent shared with the caregiver that she felt cursed for having been born as a woman.

One mother specifically pointed out that she takes the adolescent outdoors so that she feels happy during this “critical phase”. She mentioned that the adolescent becomes more irritable when at home. Parents shared that it was difficult to identify the mood of their child during menstruation, as they are sometimes irritated with parents for not understanding what they want and tend to get short-tempered.

### **Responses towards the Opposite Sex**

Caregivers had observed changes in the girls’ behaviour, such as attraction to the opposite sex, anticipation of marriage proposals, and feelings of shyness to communicate with males, including relatives, especially in answering their questions and stating their names. They express and share everything only with mothers or female caregivers. One respondent said that before she matured, her daughter used to behave like a child but was now like a grown-up woman.

## **Theme IV**

### **Social Support**

Most parents did not take their daughters with cerebral palsy to social gatherings for fear of discrimination. Some of the caregivers reported that their daughters themselves hesitated to go out with their parents. Mothers preferred to stay at home with their children while fathers attended the functions. Some of them said that their relatives question them about the adolescents’ health and they prefer to avoid questions that put them in an embarrassing position. The adolescents shared with the caregivers that they do not like people staring at them during social gatherings.

A few caregivers took their daughters to all functions, without feeling any apprehension or hesitation. They were not bothered about what other people think about them. Some parents also said that they enjoy taking their daughters with cerebral palsy on motorcycle rides.

### **Support of Parents, Relatives and the Community**

Caregivers become tired of constantly caring for their adolescents. They have to

do household work, and feel very disturbed by arguments at home regarding physical exercises. While some of them reported that neighbours helped them out, a few acknowledged that some Non-Governmental Organisations were also helpful. They had been helped in paying the school fees. Some caregivers shared that distant relatives always keep in touch with their children.

*“Right from when she was young, we have showered her with a lot of love. My uncle and everyone will be calling her regularly; she is in touch with everyone, with cousins. She remembers everybody’s birthday. For everyone’s birthday, hers is the first wish. At 12 am, she wishes them”*(32-year-old sister of an adolescent with cerebral palsy).

## **Theme V**

### **Key Perspectives on Contraception**

Caregivers were aware of the different contraceptive methods but had never thought of using any precautionary measures for their daughters with cerebral palsy. Two mothers reported that their family members had suggested uterus removal for their daughters with cerebral palsy as they did not think they would be in a position to start a family and therefore menstruation would be an extra burden. However the parents were not willing to follow this advice even though it meant taking extra care during menstruation. Caregivers believed that menstruation is normal and good for health, while surgical removal of the uterus would lead to obesity or other side effects in adolescents. Some of the caregivers acknowledged that menstrual suppression would come as great relief, both to their child and for them. The majority of the caregivers were aware of contraceptives but some mothers said they were scared of intra-uterine device insertion for themselves and had opted for sterilisation after the birth of their second child.

## **Theme VI**

### **Future Concerns and Worries of the Caregivers**

#### **a) Marriage**

Most parents were very worried about the future as they wondered who would marry their daughters with disabilities. They said that getting an arranged match for their girls – a custom which is still very common in this part of the world – would

be tough at present. After marriage, mothers worry about possible pregnancy and delivery of their daughters. A few caregivers also said that financial issues are a cause of concern. They indicated that girls should be economically and socially independent before they marry.

### **b) Education**

The caregivers thought that proper academic education for their daughters would help them in securing jobs and make them financially independent. Education was prioritised even if there were financial constraints.

*"How much ever she wants to learn, whichever school she wants to go (I will send her). Her brother is going to a private school. She should not feel bad"* (42-year-old father of a child with cerebral palsy).

### **c) Security**

Parents were worried about the safety of their daughters with cerebral palsy and did not like to leave them alone. A mother revealed that she is more worried since her daughter has attained physical maturity and she hoped that her child would not be abused by any unknown person when left alone. In addition, she mentioned that she has her limitations in guarding and protecting her child throughout her life. These insecurities were not shared by others, including husbands.

### **Precautions taken for Safety of the Children**

The caregivers did not communicate with their daughters about safety issues. They felt that the children lacked the maturity to understand their fears. Parents were afraid that their daughters could be easy victims of rape because of their disabilities. A mother explained that she would lock her daughter in the house when nobody was at home. A few caregivers shared that they lived in joint families and consequently managed to take care of their daughters very well. A few of them said that villages are safer than urban areas.

## **DISCUSSION**

In the present study, parents identified early symptoms of developmental delays in their children as well as abnormal features compared to other children, and shared that they searched for medical treatment. They exhibited a strong treatment-seeking pattern and were willing to opt for surgical treatment of their



children in order to make them independent. This finding differed from a study done by Iversen et al. (2009) which reported that caregivers felt helpless and vulnerable as their children could not express their concerns to them due to their disability (Susan et al., 2021).

The current study revealed that there is a significant change in the lives of parents when a child with cerebral palsy is born. All their activities revolve around that child and they do not expect constant support from other sources for caregiving activities. These children are very dependent on their caregivers for physical help in their daily routine. It is however interesting to note that caregivers indicated that their daughters strive hard to be independent. This may be of considerable help in carrying out their daily chores.

Studies have revealed that caregivers of children with cerebral palsy experience high levels of stress and physical tiredness, anxiety and inability to complete daily tasks due to lack of time as a result of the caregiving process for their children with disability (Zuurmond et al., 2015). In the current study, parents have reported physical stress in managing their children as they grow older. Many families were economically weak, and would invest their finances in their child's health rather than spending on themselves (Ramita et al., 2016; Vivek et al., 2018).

Experience of discrimination and isolation during social functions, and avoidance of such functions by parents, are major problems in normalising the lives of these families. This is a social challenge faced by caregivers, along with limitations that they may experience in building and maintaining social relations in their communities.

With respect to menstruation, some of the parents reported that their daughters suffered with heavy bleeding during their menstrual cycles but none of them had sought treatment for this problem. A study by Zacharin et al. (2009) conducted in Melbourne revealed that there was a high level of anxiety among caregivers and more than 50% of them sought menstrual advice even before their daughters attained menarche. However, studies have also emphasised the lack of knowledge of menstrual control among caregivers and that there is an acute need to educate these families and provide them with the necessary information (Grover, 2002; Albanese & Hopper, 2007).

Parents reported that menstruation was good for their child's health and they would not think of uterus removal. In a study by Dizon et al. (2005), a few

families of girls with neurodevelopmental delay had opted for hysterectomy and sterilisation for menstrual management. However another study by Grover (2002) advised gynaecologists against giving in to the demands of the parents of such children and to opt for more conservative methods. Caregivers reported educating their girl child to be aware of strangers trying to get close to them or touching them in public places. This was observed more often in families when the girls were around pubertal age.

## **Limitations**

The study was conducted only among Kannada-speaking participants. Interviews were conducted in the hospital setting, which could have influenced the responses of the caregivers.

## **CONCLUSION**

There are several dimensions which have emerged from this qualitative study. Understanding parental concerns will help in facilitating a meaningful approach towards the challenges that they face. Parents' awareness of their children's early symptoms, deformities, low IQ, etc., is important in evolving a user-friendly treatment strategy. One of the important issues which should influence such strategy and interventions is the critical period of menarche. Behavioural changes in girls with cerebral palsy, who experience both shyness and attraction towards the opposite sex, deserve to be handled with care and support. While caregivers indicated that the pattern and onset of pubertal changes was normal, they found that dealing with their daughters' menstruation was challenging and an added burden in the task of caregiving. Economic factors also play a role in maintaining support systems. For instance, limited monetary resources and family support were some of the reasons behind inadequate menstrual hygiene practices. Discrimination and avoidance of social functions are also issues that need attention in shaping programmes and interventions directed at girls with cerebral palsy.

## **Recommendations**

Awareness of better methods for management of pubertal issues, shared caregiving responsibility by family members, and a customised approach for healthcare interventions are needed to help caregivers deal with the transition to puberty among girls with cerebral palsy. Family counselling and therapy can

help parents to deal with their fears, worries and tensions. It will also help in reinforcing their roles of supporting each other.

### Conflicts of interest:

The authors of the study hereby declare no conflict of interest.

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# The Functions of Vocational Rehabilitation Using Agriculture in Japan

Kazuaki Maebara<sup>1\*</sup>, Yukiko Goto<sup>2</sup>, Jun Yaeda<sup>3</sup>

1. Akita University, Japan

2. Tsukuba University of Technology, Japan

3. University of Tsukuba, Japan

## ABSTRACT

**Purpose:** Vocational horticultural therapy seems effective in the recovery of individuals with psychiatric disabilities; however, few studies have explored the factors underlying the effectiveness of such therapeutic intervention in the context of psychosocial vocational rehabilitation. While many jobs are available in metropolitan areas such as Tokyo, agricultural jobs are often limited, especially at sheltered workshops for individuals with disabilities (Type B Support Centres) in Japan.

**Methods:** A mail survey was conducted with 119 administrators of Type B Support Centres in Akita Prefecture, a northern area of Japan. Respondents were asked to complete the “Efficacy of Agricultural Vocational Rehabilitation” (EAVR) questionnaire which was developed by the authors of this article.

**Results:** The results of exploratory factor analysis revealed two factors: “Reassurance” and “Place of Exchange.” There was no significant difference between the perceived effectiveness of vocational horticultural therapy in farming and non-farming job categories. Support Centres that offered farming opportunities seemed to provide more direct job opportunities, preferences, and possibilities. On the other hand, Centres that did not offer farming seemed to focus more on central administration, operational management, independent handling of matters, and collaboration with other support institutions.

**Conclusion:** While Type B Support Centres in Japan offer support in farming jobs, they do not provide enough support for horticultural therapy for people with psychiatric conditions. To promote collaboration between Type B Support Centres that offer farming jobs and social welfare centres that have expertise in horticultural therapy, it is necessary to disseminate knowledge about the benefits of horticultural therapy.

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\* Corresponding Author: Kazuaki Maebara, Akita University, Japan. Email: maebara-kazuaki@ed.akita-u.ac.jp

**Limitation:** *As this study was an analysis of a survey within a limited range of the Type B Support Centres in Akita Prefecture, future studies should investigate whether the results are generalisable to other metropolitan areas and local regions nationwide.*

**Key words:** *horticultural therapy, employment support, vocational rehabilitation, farming*

## INTRODUCTION

In recent years, many welfare institutions in Japan have focused on implementing collaboration between farming and social welfare. This type of collaboration is defined as follows: “An activity that fosters the development of farming businesses and confidence and sense of purpose among persons with disabilities, made possible through collaboration between the farming industry and the social welfare sector and with the ultimate aim to realise increased social contribution” (Council for the Promotion of Collaboration between Agriculture and Welfare, 2019). In fact, the number of welfare facilities implementing collaboration between the agricultural and welfare sectors is increasing. In addition, welfare service establishments for persons with disabilities that implement collaboration between the agricultural and welfare sectors reported positive effects in terms of physical/health, mental/emotional, and life/work attitudes (Nippon-kikin, 2018).

There are reports on the welfare-like power of agriculture (Hamada, 2016) and the benefits of cooperation between agriculture and welfare (Kanda, Yoshida, Tsuda & Imanishi, 2014), along with many practical studies on agricultural and welfare collaboration (Miyabe, 2020; Kikuchi, 2020).

This collaboration is said to be a win-win solution to issues that are faced by both the farming industry and the social welfare sector. Specifically, it theoretically may contribute to resolving the lack of manpower in farming in the country. Additionally, it may resolve some of the challenges of welfare centres in offering more adequate job training opportunities for persons with disabilities. These potential promises have led to a growing interest in Type B Support Centres for Continuous Employment which offer job support in Japan.

Japan’s Type B Support Centres for Continuous Employment provide one way of offering job-related welfare support to persons with disabilities in accordance with the Act for the Comprehensive Support of Persons with Disabilities. This framework is in place to offer opportunities for employment for those people

who cannot be hired easily by regular mainstream companies. There are also Type A Support Centres specialised in employing persons with disabilities through employment contracts which are not offered by Type B Support Centres. There is no upper limit to the period one can make use of either type of Support Centre. In addition to these two types of sheltered workshops, there is another type of employment support system, namely the Transition Support System for Employment. This in fact is basically a private practice system. It offers a time-limited 2-year standard period of apprenticeship: offering skills training while working and enabling individuals with disabilities to work competitively.

Collaboration between the farming industry and the social welfare sector makes it possible to contribute to resolving issues faced by both fields in Japan. For this reason, attention paid to this development is growing. Meanwhile, to date, there have been no studies done in Japan which examine how agricultural initiatives function as vocational rehabilitation for persons with disabilities. Therefore, this study examined the impact of employment support to persons with disabilities in farming, with a focus on horticultural therapy as a way to offer employment for such persons.

Horticultural therapy is “the art and science of growing flowers, fruits, vegetables, and shrubs, resulting in the development of the minds and emotions of individuals, the enrichment and health of communities, and the integration of the ‘garden’ in the breadth of modern civilisation” (Relf, 1992). When offered through support programmes, the introduction of horticultural therapy is believed to promote the users’ understanding of self-identity, develop their social interactions, physical activities, and learning skills, and improve their vocational habits (Relf, 1981). Additionally, reports show that this therapeutic method helps persons with psychiatric disabilities in finding employment (Grahm, Pálsdóttir, Ottosson & Jonsdottir, 2017). It also helps persons with intellectual disability to improve their dexterity, emotional reactions, and social skills (Joy, lee & Park, 2020). Participants in horticultural therapy can also derive a sense of positive meaning in their work (Pálsdóttir, Grahm & Persson, 2014), relieve stress (Hayashi, 2004), foster greater interest in others (Shibatani, Harada & Washio, 2009), make clinical improvements and enhance communication skills (Uehara, 2001). Horticultural therapy also reduces psychological stress and boosts positive feelings (Sugihara, Asano, Morishima & Aoyama, 2012). These outcomes of horticultural therapy suggest it would be efficacious in supporting persons with disabilities who seek jobs in farming.

## Objective

The objective of this study was to clarify the features and functions of horticultural therapy and its role in offering employment support for individuals with disabilities at Type B Support Centres in Japan.

## METHOD

### Study Participants

The study participants were the directors and the managers of all 119 Type B Support Centres in Akita Prefecture, Japan, as of 1st October, 2019.

From 10th of January, 2019 to 20th February, 2020, self-administered questionnaires were sent to all 119 Type B Support Centres. The content included demographic information, functions of the Support Centres in providing employment support using horticultural therapy, and operational perspectives of the Centre.

### Data Collection

Participants were asked to enter the number of registered users of the Type B Support Centres by disability category (intellectual, physical, psychiatric, and others), and the status of employment support in farming (if such farming-related jobs were offered).

### Study Tool

To understand the features of employment support based on horticultural therapy, the "Efficacy of Agricultural Vocational Rehabilitation" (EAVR), which was developed by the authors, was used to determine the efficacy of support services using 11 items identified by Yamane and Sawada's discussion of the therapy's benefits (Yamane & Sawada, 2009). These include nurturing a sense of hope, exposure to universal experiences, exposure to passive experiences, experiencing compassionate acts, relaying information, assessing reality, learning by imitation and mistakes, catharsis through expression, a dense series of interactivity, shared experiences, and existential experiences. Based on discussions in the studied literature, the co-researchers created questions for each item based on their earlier research on vocational rehabilitation and practical experiences.

Each item was measured on a 5-point Likert scale: "Not achieved at all" (1 point), "Not achieved much" (2 points), "Neither" (3 points), "Partly achieved" (4 points), and "Adequately achieved" (5 points).



Views on the Operation of Type B Support Centres - Seven unique question items were created on the operation of Type B Support Centres. The importance of each item was gauged on 5 levels: "Do not consider important at all" (1 point), "Do not consider particularly important (2 points), "Neither important nor unimportant" (3 points), "Consider somewhat important" (4 points), and "Consider very important" (5 points).

### Data Analysis

Using the responses obtained from the EAVR on the impact of support services, an exploratory factor analysis was conducted and the mean score for each factor was calculated. An unpaired t-test for each factor's mean score among farming and non-farming jobs was conducted. This was followed by a Pearson correlation analysis between views on the operation of the Type B Support Centres and scores of each factor.

### Ethical Considerations

This research was approved by the Research Ethics Screening Committee targeting people in the Tegata region of Akita University (No. 1-10 on 14th December, 2019).

## RESULTS

### Respondents' Basic Attributes

Questionnaires were distributed to 119 Type B Support Centres and responses were received from 60 centres (50.4%). Table 1 shows the basic attributes of the respondents. While 29 Type B Support Centres (48.3%) were offering farming jobs, 31 (51.7%) were not.

**Table 1: Basic Attributes of the Respondents**

Item	Number of Persons
Number of Users	
Persons with Intellectual Disability	Mean: 14.1 persons (standard deviation: 10.07, range: 0-41 persons)
Persons with Physical Disability	Mean: 3.0 persons (standard deviation: 4.06, range: 0-21 persons)
Persons with Psychiatric Disability	Mean: 8.8 persons (standard deviation: 10.65, range: 0-61 persons)

<b>Persons with Other Disability</b>	Mean: 0.5 persons (standard deviation: 1.24, range: 0-6 persons)
<b>Item</b>	<b>Number of Centres</b>
<b>Main Job</b>	
<b>Farming Jobs</b>	29 Centres (48.3%)
<b>Non-Farming Jobs</b>	31 Centres (51.7%)

Farming Jobs: Farming tasks offered

Non-Farming Jobs: Farming tasks not offered

### Exploratory Factor Analysis of EAVR for Support Services

The factors were analysed using the maximum likelihood method and the number of factors extracted were regulated using a scree plot. The factors were then extracted using the maximum likelihood method and a Promax rotation was conducted. Items with a factor loading below .35 were deleted and the factor scores determined using the final extracted factors. Table 2 shows the final factor patterns and the correlation among the factors after Promax rotation. The total distribution among eight items in two factors before the rotation was 50.1%.

**Table 2: Results of Exploratory Factor Analysis (after Promax Rotation) (N=60)**

Item		1	2
<b>Factor 1: "Reassurance" (Cronbach's <math>\alpha</math>=.85)</b>			
4	The users can identify their abilities by feeling a sense of reassurance and human kindness.	.91	-.10
3	The user can derive a sense of acceptance.	.77	-.02
2	The user can derive a sense of relief by realising that s/he is "not alone" through exchange with others sharing the same disability.	.63	.12
1	The user can feel that s/he "feels at home by just coming here" or "can come and do the tasks again."	.59	.27
<b>Factor 2: "Place of Exchange" (Cronbach's <math>\alpha</math>=.70)</b>			
5	The user can have a free and casual place of exchange where many topics, like everyday life and hobbies, can be shared.	-.13	.98
11	The user can spend time in comfort to accept himself/herself.	.05	.49
7	The user can learn the skills necessary to lead a life as a member of society and respect social boundaries.	.14	.45
10	The users can share their physical experiences using their five senses with others.	.19	.35
<b>Correlation Among Factors</b>			
1		—	.49
2			—

The first factor comprises four items. The items covered aspects reflecting how the users can derive a sense of reassurance, acceptance, positive feelings and comfort, and relief. Therefore, this factor was named “Reassurance.” The second factor comprises four items. The items covered aspects on how the users can experience the Type B Support Centre as a place of exchange, derive a sense of reassurance, attain skills to respect social boundaries in professional settings, and share physical experiences. Therefore, this factor was named “Place of Exchange.”

Next, to analyse factors in the EAVR for support services, the researchers achieved sufficient values for “Reassurance” at  $\alpha=.85$ , and “Place of Exchange” at  $\alpha=.70$ . This was done by calculating the mean of items with high factor loading, which then allowed for the determination of Cronbach’s  $\alpha$  to study the internal consistency between “Reassurance” (Factor 1; mean: 3.75; standard deviation: 0.61) and “Place of Exchange” (Factor 2; mean: 3.35; standard deviation: 0.56).

### Differences in Factor Scores among Job Categories

An unpaired t-test was used to study whether there were differences between farming and non-farming tasks (Table 3). The mean values for each factor for Type B Support Centres that offer farming jobs were: “Reassurance” (mean: 3.64; standard deviation: 0.66) and “Place of Exchange” (mean: 3.38; standard deviation: 0.53). The mean values for each factor for Type B Support Centres that do not offer farming jobs were: “Reassurance” (mean: 3.86; standard deviation: 0.54) and “Place of Exchange” (mean: 3.32; standard deviation: 0.60). The differences in scores were analysed by the t-test. None of the scores showed a significant difference (“Reassurance”:  $p=.165$ , n.s., “Place of Exchange”:  $p=.686$ , n.s.).

**Table 3: Comparison of Factor Scores among Job Categories**

	Farming Jobs (n=29)		Non-Farming Jobs (n=30)		<i>p</i> Value
	Mean	Standard deviation	Mean	Standard deviation	
Reassurance	3.64	.66	3.86	.54	.165
Place of Exchange	3.38	.53	3.32	.6	.686

### Relationship between Views on Support Offered and Factor Scores

Table 4 shows the scores for the importance of views on support offered. In descending order of mean scores, the items were “Improved staff awareness of disabilities and protecting the users’ rights” (mean: 4.4); “A good Centre

environment that offers comfort and a place to have free conversations” (mean: 4.3); “Help users develop strength to be self-sufficient and motivated” (mean: 4.2); “Offer support so users can fulfil their hopes and pursue personal goals” (mean: 4.2); “Collaborate with other support institutions and leverage support systems” (mean: 4.1); “Centre support provides an opportunity for users to work” (mean: 4.0); and “Satisfactory support programme” (mean: 3.8).

**Table 4: Views on Centre Operation**

No.	Item	Mean	Standard deviation	Minimum	Maximum
1	Satisfactory support programme	3.8	.97	1	5
2	A good Centre environment that offers comfort and a place to have free conversations	4.3	.67	3	5
3	Help users to develop strength to be self-sufficient and motivated	4.2	.74	2	5
4	Improve staff awareness of disabilities and protecting the users’ rights	4.4	.70	2	5
5	Offer support so users can fulfil their goals	4.2	.76	2	5
6	Centre support provides an opportunity for users to work	4.0	.85	2	5
7	Collaborate with other support institutions and leverage support systems	4.1	.90	2	5

Next, a Pearson correlation analysis between views on Centre operation and the factor scores was conducted (Table 5). Factor 1, “Reassurance”, was significantly correlated with “Satisfactory support programme” ( $r = .449, p < .05$ ), “Improve staff awareness of disabilities and protecting the users’ rights” ( $r = .379, p < .05$ ), “Offer support so users can fulfil their hopes and pursue personal goals” ( $r = .475, p < .01$ ) and “Centre support provides an opportunity for users to work” ( $r = .509, p < .01$ ) in Type B Support Centres that offer farming jobs. In Type B Support Centres that do not offer farming jobs, Factor 1 was significantly correlated with “A good centre environment that offers comfort and a place to have free conversations” ( $r = .443, p < .05$ ), “Help users develop strength to be self-sufficient and motivated” ( $r = .506, p < .01$ ), “Improve staff awareness of disabilities and protecting the users’ rights” ( $r = .483, p < .01$ ) and “Offer support so users can fulfil their hopes and pursue personal goals” ( $r = .455, p < .05$ ). Factor 2, “Place of Exchange”, was significantly correlated with “Offer support so users can fulfil their hopes and pursue personal goals” ( $r = .530, p < .01$ ) in Type B Support Centres that offer

farming jobs. In Type B Support Centres that do not offer farming jobs, Factor 2 was significantly correlated with “Collaborate with other support institutions and leverage support systems” ( $r = .397, p < .05$ ).

**Table 5: Correlation Analysis of Views on Centre Operation and Factor Scores**

		Factor 1		Factor 2	
		Farming	Non-Farming	Farming	Non-Farming
1	Satisfactory support programme	.449 *	.271	.131	-.160
2	A good Centre environment that offers comfort and a place to have free conversations	.314	.443 *	.096	.185
3	Help users to develop strength to be self-sufficient and motivated	.216	.506 **	.314	.239
4	Improve staff awareness of disabilities and protecting the users' rights	.379 *	.483 **	.209	.278
5	Offer support so users can fulfil their hopes and pursue personal goals	.475 **	.455 *	.530 **	.225
6	Centre support provides an opportunity for users to work	.509 **	.060	.361	.195
7	Collaborate with other support institutions and leverage support systems	-.044	.168	.127	.397 *

\*\*  $p < .01$  \*  $p < .05$

## DISCUSSION

### Features of Employment Support from the Perspective of Horticultural Therapy

The analysis of the EAVR for support services offered based on horticultural therapy showed that Type B Support Centres manifested the two pillars of “Reassurance” and “Place of Exchange” as their unique features from a methodological perspective. The sampling survey conducted by Matsumoto, Imaeda & Kanno (2019) on Type B Support Centres nationwide, reports that much of the production activities at such Centres focus on providing an everyday,

daytime place for users to spend time, and many of them give priority to offering users a sense of satisfaction and an emotionally stable experience.

In this way, Type B Support Centres have been thought to offer reassurance and a place of exchange for users with disabilities. Moreover, Nakao (2017) points out that Type B Support Centres tend to prioritise the welfare aspects of the operation over vocational skill development and higher compensation, such as teaching rules and manners required in everyday social life, making self-adjustments in human relationships, and giving psychological support. The reason seems to be that these facilities are premised on their role as a place that provides social welfare, regardless of the disability type. This aspect is also very similar to the support features of horticultural therapy and shares as an underlying principle in employment support.

### **Differences among Support Services by Job Type**

Based on the results, the difference in the mean values for each factor for Type B Support Centres was analysed using the t-test. None of the scores showed a significant difference. No support service differences could be identified in horticultural therapy among farming and non-farming tasks. This may be due to inadequate understanding of the method by the Centres. Kanda et al. (2001a, 2001b) report that employment-focused welfare service centres catering to persons with disabilities lack full understanding of horticultural therapy. Another source (Toyoda & Ikeda, 2007) also argues for the need to disseminate knowledge and foster human resources about horticultural therapy. Horticultural therapy focuses on the relationship between humans and vegetation. Horticultural therapy promises to be effective by leveraging the positive aspects of vegetation in therapy. It is presumed that exposure to better knowledge of horticultural therapy would be beneficial in promoting collaboration between farming and social welfare in the future. In particular, there are only a few staff members with knowledge of the horticultural therapeutic method at Type B Support Centres in Japan.

While collaboration between farming and social welfare is moving forward, the authors of the current study believe it is necessary to build a training system to back up employment support systems that integrate farming to improve employment support, instead of simply linking the two. It is imperative to enhance initiatives to develop therapeutic skills for specialists to provide valid employment support for individuals with disabilities.

## **Relationship between Awareness of Centre Operation and Service Features**

The results of a Pearson correlation analysis between views on Centre operation and factor scores suggest that awareness of how Centres operate relates to the consideration of job categories in employment support, such as the introduction of farming. Centres with farming jobs show that support services based on horticultural therapy correlate to the Centres' awareness of their role in providing satisfactory support programmes and work opportunities, as well as fostering the users' hopes and pursuit of personal goals.

At the same time, Centres that do not offer farming jobs show that support services based on horticultural therapy correlate to the Centres' awareness of their operation in terms of their environment, users' self-sufficiency, and collaboration with other support institutions. Maebara, Goto & Yaeda (2020a, 2020b) argue that Centres introduce farming jobs as they are aware that such an ongoing employment support system is evaluated satisfactorily. Moreover, they point out that these Centres must improve compensation and employment support programmes in running their services. These suggestions offer ways to resolve issues faced by Japan's Type B Support Centres in providing employment support. Horticultural therapy promises to offer a perspective to reinforce such support services as one of the solutions.

## **Implications**

Sufficient wages may be one of the major outcomes when evaluating the effectiveness of employment support programmes, but this should not be the only outcome. More emphasis should be placed on the daily life aspects of workers with disabilities and the focus should be on assessing the degree of their happiness and peacefulness through work. To achieve this, employment support professionals must acquire sufficient knowledge and skills to adequately respond to such objectives. Utilising horticultural therapy as a professional tool to support employment could be one of the required competencies. How one has to incorporate agriculture into social welfare and vocational rehabilitation has not been specified and studied systematically. This paper focuses on agriculture and more specifically horticultural therapy as a means of providing employment support at Japan's Type B Support Centres. It is however recommended that future studies should examine the effectiveness of collaboration between agriculture and welfare into employment support in terms of achieving full self-actualisation of individuals with disabilities.

## Limitations

The generalisability of the results is limited since the present study used a sample from Type B Support Centres only in Akita Prefecture of Japan. Further investigations, including a national study, are necessary to verify the construct of the factors found in this study and determine if the results are applicable to other Centres.

## CONCLUSION

In this study, the function of employment support using agriculture in Type B Support Centres in Japan was examined from the perspective of horticultural therapy. Currently, employment support using agriculture is attracting attention in Japan, but few studies have examined the function of such support from the perspective of horticultural therapy. This study is expected to provide perspectives for practicing employment support using agriculture and contribute to the improvement of current support. In particular, there is a lack of knowledge about horticultural therapy among Japanese employment support practitioners. Therefore, considering the introduction of horticultural therapy would not only increase the effectiveness of employment support using agriculture, but also contribute to the transition to employment and as such contribute to the improvement of the quality of life of persons with disabilities who use Type B Support Centres.

## ACKNOWLEDGEMENT

This research was funded by a Health and Labour Sciences Research Grant under the title “Research on the Status of Support Given to the Persons with Psychiatric Disabilities at B-Type Centres for Continuous Employment and Development of Effective Support Programmes” (19GC1006).

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# Improving Well-Being, Academic Self-Concept and Academic Achievement of Indian Children with Specific Learning Disability by utilising Positive Psychology Intervention

Usha Tiwari Upadhyay\*

## ABSTRACT

**Purpose:** It is widely recognised that children's well-being involves not only the absence of psychological distress, but also the presence of positive indicators of optimal functioning to be mentally healthy. The aim of this study was to investigate whether a Positive Psychology Intervention (PPI) implemented in schoolgoing children with specific learning disability (SLD) would lead to increased subjective well-being (SWB), improved academic self-concept (ASC) and academic achievement (AA).

**Method:** The study followed a one group pre-test post-test design. Purposive sampling was used to select 75 children with SLD (61 boys and 14 girls) from 3 schools in Telangana State, India. Children who were between 8 – 12 years of age (in classes 3 – 7) were selected on the basis of the inclusion criteria. The main outcome measures used were Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS), Positive and Negative Affect Schedule for Children (PANAS-C) and Academic Self-Concept Scale. Academic achievement was recorded through total marks scored by the student in all the core subjects (language/s, math, science, social studies) of the semester examination. The Positive Psychology Intervention consisted of activities integrating gratitude, mindfulness and attributional style. Each class group received weekly sessions of group intervention for 12 weeks. Results were analysed using Statistical Package for the Social Sciences (SPSS Version 20.0). Wilcoxon signed-rank test was calculated to find the difference between pre-, post- and follow-up scores.

**Results:** The findings showed significant increase in the levels of subjective well-being, academic self-concept and academic achievement of children with SLD after PPI. The follow-up after 6 months found the effect was maintained

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\* **Corresponding Author:** Rehabilitation Psychologist, Special Educator, Consultant School Psychologist. Email: ushaupadhyay30@gmail.com

*on all the studied variables except academic achievement.*

**Conclusion and Implication:** *Positive Psychology Intervention has the potential to sustain significant improvements in happiness and academic self-concept of children with SLD. It also aided improvement in their academic achievement. There is a need to further investigate the applicability of these interventions to boost positive emotions and alleviate negative emotions in all children, with and without specific needs. In addition, these PPIs may be used to empower parents and teachers with positive attributes to face their challenges in dealing with other disabilities in children.*

**Key words:** *subjective well-being, life satisfaction, positive affect, negative affect, academic self-concept, academic achievement, positive psychology intervention, specific learning disability*

## INTRODUCTION

The foundation for an individual's personality and overall development is laid in early childhood. It is widely acknowledged that the child's emotional health and well-being influences cognitive, physical and social development, learning and mental well-being in the "future adult". Various emotional and social skills inculcated in childhood will not only facilitate optimal growth and development but will act as protective factors in later life. A longitudinal study (Richards & Huppert, 2011) concluded that childhood well-being predicts positive adult well-being and not merely the absence of mental ill-health.

All over the world there is a growing concern about child well-being research, with a view to understanding children's and adolescents' quality of life. Positive psychology is the study of topics as diverse as happiness, optimism, subjective well-being, psychological well-being, social well-being, personal growth and strength, flow, wisdom, creativity, imagination and characteristics of positive groups and institutions. A wide range of Positive Psychology Interventions have been devised to enhance subjective well-being, covering a wide range of theoretical approaches, intervention contexts, age groups, and targeted beneficiaries (e.g., children, parents, families, teachers and other normal and clinical populations). Seligman, Ernst, Gillham, Reivich and Lindkins (2009) proposed that well-being should be taught in schools because it can serve as an antidote to depression and as a means to increase life satisfaction; additionally, well-being may promote better learning and more creative thinking. Therefore, Positive Psychology

Intervention may act as an antidote to negative emotional experiences of children with specific learning disability, help in increasing life satisfaction, and aid better learning and more creative thinking. The current study is focused on improving Indian children's subjective well-being, academic self-concept and academic achievement by engaging them in positive intentional activities.

### **Subjective Well-being**

The science of well-being has a long history with a multidimensional phenomenon integrating biological, psychological, spiritual and social dimensions (Cloninger, 2004, 2006a, 2006b; Lyubomirsky et al, 2005; Bartels & Boomsma, 2009; McDowell, 2010). Primarily involved in the field of psychology, it is gradually spreading to other arenas like education, health, organisational and global human development. There is a conceptual overlap between various existing definitions of happiness, subjective well-being, and quality of life. The concept of "subjective well-being" (SWB) was introduced by Diener (1984) as comprising three primary components: life satisfaction (LS), positive affect (PA), and negative affect (NA). Diener (2006) has reconceptualised the concept of subjective well-being as: "An umbrella term for different valuations that people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live". It embraces the personal experiences of individuals with three separate but related dimensions: positive and negative affect (i.e., frequency of experiencing positive and negative emotions in daily life, respectively) and life satisfaction (i.e., cognitive appraisal of one's life overall) (Diener, 2000).

Researchers concluded that high levels of SWB are associated with superior outcomes across important domains, including greater school satisfaction, academic self-perception and achievement, higher quality of social relationships, and greater perceived physical health and social support (Suldo, Riley & Shaffer, 2006; Suldo & Shaffer, 2008) among children.

**Positive affect** represents pleasant moods and emotions such as contentment, pleasure, affection, interest, engagement and joy (Diener, 2006). Positive affective experiences, usually referred to as positive emotions, have been shown to be related to several contributing functions such as learning and achievement, through the promotion of creativity and flexible learning strategies (Pekrun, Frenzel, Goetz & Perry, 2007), attentional and cognitive broadening (Isen, 2003), and protective function against depression among children and adolescents (Lonigan, Phillips, & Hooe, 2003). These positive emotions are not only helpful

in enhancing children's academic achievement but also in facilitating a positive school experience.

**Negative affect** includes moods and emotions that are unpleasant and represent negative responses that people experience in reaction to their lives, health, events, and circumstances such as anger, sadness, anxiety and worry, stress, frustration, guilt, shame, envy, loneliness and helplessness (Diener, 2006). Prolonged experience of negative emotions can interfere with effective functioning and happiness.

**Life satisfaction** denotes how a person evaluates or appraises his or her life (at a particular point in time or as an integrative judgment about the person's life since birth) taken as a whole (Diener, 2006). Life satisfaction is an important factor for overall well-being because children who report higher levels of life satisfaction also report higher levels of academic performance, interpersonal relationships, and intrapersonal functioning, in comparison to students who report low levels of satisfaction (Gilman & Huebner, 2006). Gilman and Huebner (2003) reported that lower life satisfaction was linked to alcohol and drug use, depression, anxiety, and social stress.

### **Positive Psychology Intervention**

Positive Psychology Intervention (PPI) involves evidence-based specific strategies developed to promote well-being. As defined by Sin and Lyubomirsky's work (2009), Positive Psychology Intervention is a psychological intervention (training, exercise, therapy) primarily aimed at raising positive feelings, positive cognitions or positive behaviour, as opposed to interventions aiming to reduce symptoms, problems or disorders. It was stated by Seligman (2002) that people are capable of increasing their subjective well-being into the upper range of their biologically inherited set points through intentional activities. He proposed a multidimensional view of increasing happiness, including attention to past, present, and future aspects of emotional life. The "father of positive psychology" Martin Seligman (2002) popularised the happiness formula of  $H = S + C + V$  in his best-selling book 'Authentic Happiness'. This formula states that happiness is comprised of the individual's set happiness point (S), the individual's circumstances (C) and voluntary factors that are under the individual's control (V). This is similar to the architecture for sustainable change model of Lyubomirsky, Sheldon, and Schkade (2005), which states that happiness is 50% happiness set point, 10% life circumstances and 40% intentional activity. These theories acknowledge the

importance of the happiness set point and life's circumstances but propose that happiness can be actively pursued by addressing the factors that are under the individual's control. In enhancing well-being, PPIs target the 40% of variance associated with focused positive activities. Seligman suggested that feelings of satisfaction with the past can be increased through expressions of gratitude for positive events, such as journaling happenings for which one has been grateful or creating interpersonal expressions of gratitude. In terms of the present, Seligman suggested that people can improve lasting happiness by increasing gratifications through identifying their personal strengths and virtues, termed character strengths, and using them in new ways. Finally, Seligman suggested that happiness levels for the future could be increased through learned optimism, which is a cognitive behavioural method of altering pessimistic modes of thought through disputations of negative attributions, and development of an optimistic explanatory style which includes attributions of negative events as temporary, specific to situations, and related to external causes beyond one's complete control.

The current intervention is structured in three phases, including past, present, and future aspects of subjective well-being with developmentally and culturally appropriate modification. Gratitude, mindfulness and attributional style variables are selected to improve positive emotions about past, present and future respectively, within Seligman's (2002) framework of improving subjective well-being.

**Gratitude** has been conceptualised as an emotion, an attitude, a moral virtue, a habit, a personality trait, and a coping response. Gratitude is a cognitive-affective state that is typically associated with the perception that one has received a personal benefit that was not intentionally sought after, deserved, or earned but rather because of the good intentions of another person (Emmons & McCullough, 2003). Another definition of gratitude is as "a sense of thankfulness and joy in response to receiving a gift, whether the gift be a tangible benefit from a specific other or a moment of peaceful bliss evoked by natural beauty" (Peterson & Seligman, 2004). The benefit-appraisal curriculum intervention to promote gratitude in children by Froh et al. (2014) holds significant theoretical and applied implications. In the present study the gratitude curriculum is divided into three smaller steps, focusing on helping children understand a benefactor's intention in helping, the costs incurred in helping, and the benefits bestowed on the receiver - all crucial components of the gratitude experience (McCullough, 2001).

**Mindfulness** is the feeling of involvement or engagement. It is an active state of mind that is achieved by simply noticing new things. Jon Kabat-Zinn, the foremost pioneer in the therapeutic application of mindfulness, has defined mindfulness as “the awareness that emerges through paying attention on purpose, in the present moment and non-judgmentally, to the unfolding of experience, moment by moment” (Kabat-Zinn, 2003). The concept of mindfulness among children can be introduced through directing their attention to things in their environment, drawing their attention to their surroundings, and emphasising the need for mindfulness by revealing what they are and are not aware of. Once children learn to be mindful or aware of their environment, they can be taught to pay attention to their own experience, beginning with their body, such as attending the senses, mindfulness of body movement and mindfulness of breath (Hooker & Fodor, 2008). Mindfulness in children has been found to mitigate the effects of bullying (Zhou, Liu, Niu, Sun, & Fan, 2017), enhance focus in children with ADHD (Zhang et al., 2017), and reduce attention problems (Crescentini, Capurso, Furlan, & Fabbro, 2016). It is important to provide age-appropriate mindfulness practices for children to improve their mental health and well-being. Mindfulness teaches children how to pay attention, and this way of paying attention enhances both academic and social-emotional learning.

**Optimistic thinking: Attributional style** - Attributional style, sometimes known as explanatory style, refers to the ways in which people explain the cause of events (positive or negative) within their lives, which subsequently predicts future expectations. Seligman (2006) has asserted that there are two different ways in which one can explain the manifestation of the positive and negative events experienced on a daily basis: either with an optimistic explanatory style or with a pessimistic one. According to Seligman (2006), an optimist is one who believes the cause of a positive event is personal (as a result of one’s own ability), permanent (forever), and pervasive (across all domains) and conversely, an optimist believes the cause of a negative event to be unrelated to his skill or ability but to some external reason, that it is temporary, and that it will not affect all areas of his life. A pessimist will attribute the cause of a negative event to a personal trait or skill, a stable phenomenon, and one that affects across all domains. A pessimist will believe positive events to be caused by an external factor, to be transitory and unstable, and to occur only in the present sphere (Seligman, 2006).



## **Academic Self-concept**

Self-concept is the perception of oneself, involving one's attitudes, feelings and knowledge about skills, abilities, appearance and social acceptability. Academic self-concept is the perception and evaluation that a child has or does about his or her academic abilities (Marsh & Craven, 2002). High academic self-concept is crucial to develop and maintain children's self-worth, since children spend a significant portion of their lives being evaluated in school classrooms. Thus, the self-concept directly affects their learning processes and academic achievement. Additionally, it helps to create various cognitive and self-regulative strategies (Zimmerman, 2000), which reflect on academic performance (Schunk, Pintrich, & Meece, 2008).

## **Academic Achievement**

Academic achievement is defined as the level of students' ability to excel within the academic setting (Noffle & Robins, 2007). School examination marks are customarily used as a measure of achievement for social research purposes (Buch, 1988). Academic achievement refers to how well a student performs in school, and includes indicators such as grade point average (GPA), standardised reading assessment scores, school attendance, and students' perceptions of their own academic abilities. Academic achievement is important for children because it promotes their success later in life. It is considered a key criterion to judge an individual's total potentialities and capabilities. The present study describes academic achievement in terms of actual marks or scores obtained by children in one semester examination.

Most of the research studies have reported that there is a mutually reinforcing relationship between academic self-concept and academic achievement (Arefi, Naghibzadeh, & Boloki, 2014). Enhanced self-concept has a significant importance for all students, especially for students with learning disabilities. In the context of education, the academic self-concept is an important psychological construct because "it has been found to be both a cause and an effect of academic achievement" (Cokley & Patel, 2007). A higher academic self-concept has been associated with greater academic achievement among students (Marsh, 1990). Academic self-concept and academic achievement are closely linked and important during childhood and adolescence for children's cognitive, social and emotional development, as student well-being is positively related to academic performance (Durlak, Weissberg, Dymnicki, Taylor & Schellinger,

2011). The experience of positive emotions broadens one's awareness and allows the building of new skills and resources (Fredrickson, 1998, 2001) which may eventually lead to enhanced academic achievement. Indeed, positive emotions are associated with better self-regulated learning, higher motivation, and better examination grades (Mega, Ronconi, & De Beni, 2014) and have a positive effect on memory and attention processes (Fiedler & Beier, 2014). Moreover, academic self-concept, a psychological construct by mediating performance outcome (academic achievement), is thereby closely associated with children's subjective experience of well-being. Academic self-concept is affected by learning disability status, but not general social self-concept (Al Zyoudi, 2010). It is well understood that children with SLD perform poor in academic tasks when compared with children without SLD. Hence, these two concepts - academic self-concept and academic achievement - have been taken into consideration in evaluating the impact of Positive Psychology Intervention on subjective well-being of children with SLD.

### **Children with Specific Learning Disability**

Specific learning disabilities (SLDs) are defined as a "heterogeneous group of conditions wherein there is a deficit in processing language, spoken or written, that may manifest itself as a difficulty to comprehend, speak, read, write, spell, or to do mathematical calculations, and includes such conditions as perceptual disabilities, dyslexia, dysgraphia, dyscalculia, dyspraxia and developmental aphasia" (RPWD Act, 2016). Co-morbidity is common in children with SLD and is generally associated with affective disorders, particularly depression, deficits in social skills, self-esteem, peer relationship problems, feelings of lack of control and poor self-esteem (Willcutt & Pennington, 2000). Children with SLD experience repeated academic failure and attribute this failure to self-incapability. The feeling of self-incapability results in low effort and concentration, lowered expectations in future academic successes, and lower academic self-concept. The fear of failure may further cause children not to try and thus lead to poor academic outcomes.

All over the world, including in India, there is growing concern about children's well-being and quality of life. This is especially so for children with SLD. Happy children are more creative, confident and accomplished. Positive Psychology Intervention can therefore serve a twofold function for children with SLD: by first providing prevention against psychological problems, and then by enhancing their subjective well-being. The current study is an effort to investigate whether

administration of Positive Psychology Intervention would bring about a significant positive change in children's happiness as well as functioning.

## **Objective**

It is well documented that children with specific learning disability tend to have more emotional concerns, such as anxiety, depression, loneliness, and low self-esteem, than do their peers without disabilities; this results in scholastic achievement declining still further. Studies of subjective well-being in relation to children with SLD are scarce, as most studies have focused on behavioural, attentional and cognitive issues. The objective of the present study was therefore to assess the effectiveness of Positive Psychology Intervention on subjective well-being, academic self-concept and academic achievement of children with SLD.

## **METHOD**

### **Study Design**

A one group pre-test post-test design was used to study the effect of PPI on subjective well-being, academic self-concept and academic achievement of children with SLD. Pre-test, post-test and follow-up scores were compared and differences were attributed to the application of the experimental treatment, i.e., Positive Psychology Intervention.

### **Study Setting**

The researcher selected 2 CBSE schools (Central Board of Secondary Education) and 1 State Board school from the twin cities of Secunderabad and Hyderabad in Telangana state, India.

### **Study Sample**

Purposive sampling technique was used. Due to the limited sample size, all children with SLD in the selected schools, 75 in total, were included in the study. There were 61 boys and 14 girls, between 8 – 12 years of age, from Classes 3 – 7. Among them, 53% (40) were children with associated condition of ADHD and 47% (35) were children without ADHD.

Inclusion criteria:

- Children of average intelligence, with an IQ of 90 or above on Malin's Intelligence Scale for Indian children;
- Meeting ICD-10 criteria for either Specific Reading Disorder (F81.0), Specific Spelling Disorder (F81.1) or Specific Disorder of Arithmetical Skills (F81.2), Mixed disorder of Scholastic Skills (F81.3) alone or in combination with or without Disturbance of Activity and Attention (F90.0).

Exclusion criteria:

- Children with other disabilities like visual impairment, hearing impairment and loco- motor disability; co-morbid disorders like seizure, conduct and emotional disorders, and chronic medical conditions such as diabetes, heart anomalies, and kidney disorders.
- Children and parents with mental illness.

**Table 1: Demographic Variables of Children with Specific Learning Disability selected for Positive Psychology Intervention Programme**

Variables	Frequency ( <i>n</i> )	(%)
<b>Gender</b>		
Boys	61	81.3
Girls	14	18.7
<b>Class</b>		
3 <sup>rd</sup> standard	13	17.2
4 <sup>th</sup> standard	14	18.7
5 <sup>th</sup> standard	23	30.7
6 <sup>th</sup> standard	14	18.7
7 <sup>th</sup> standard	11	14.7
<b>ADHD</b>		
Present	40	53.3
Absent	35	46.7
<b>Total N</b>	75	100

### **Instruments: Outcome Measures**

- **Subjective Well-being (SWB)**

Diener (2009) postulated that subjective well-being is comprised of three primary components: life satisfaction (LS), positive affect (PA), and negative affect (NA). The LS was measured with Brief Multidimensional Students' Life Satisfaction Scale - BMSLSS (Seligson, Huebner, & Valois, 2003) - which

is a 6-item self-reported measure of students' satisfaction in the five domains of life (family, friends, school, living environment, self) contributing to youth Total Life Satisfaction (TLS) most relevantly. There is one item per domain, plus one-item rating of Global Life Satisfaction (GLLS) at the end of the BMSLSS to provide an assessment of overall life satisfaction. Children respond to items such as "I would describe my satisfaction with my school experience as..." and "I would describe my satisfaction with where I live as..." on a 7-point Likert scale, from 1(= terrible) to 7 (= delighted). In this study, five domain items are averaged to create a total life satisfaction (LS) score. Seligson et al. (2003) reported adequate internal consistency ( $\alpha = .75$ ) and evidence of strong criterion-related validity and construct validity based upon strong correlations with other life satisfaction measures.

In addition, children were administered Positive and Negative Affect Scale for Children - PANAS-C (Laurent et al., 1999) which is a 27-item measure appropriate for children in grades from 4 - 8. The 12-item Positive Affect (PA) scale assesses the respondents' frequency of experiencing various positive emotions (e.g., interested, energetic, cheerful, happy), and the 15-item Negative Affect (NA) scale assesses frequency of negative emotions (e.g., miserable, sad, angry, lonely). Children were asked to rate 27 words that describe various emotions on a 5-point Likert-like scale, to indicate the extent to which they have experienced each emotion in the past few weeks, from 1 (= very slightly or not at all) to 5 (= extremely). Laurent et al. (1999) reported internal consistency reliability of the PANAS-C at a coefficient alpha of .92 for the Negative Affect scale and .89 for the Positive Affect scale, which was similar to internal consistency reported for the PANAS at a coefficient alpha of .87 for both scales (Watson, Clark, & Tellegen, 1988). For better comprehension by children, a few words in the questionnaire were translated into simple English.

**Composite Subjective Well-being:** Bussari and Sadava (2011) postulated that there are several potential ways in which the three SWB components (LS, PA & NA) may be linked:

1. A hierarchical construct – in which a higher-order factor SWB correlates positively with PA and LS, and negatively with NA.
2. A causal system model – where, among other things, LS is influenced by PA and NA.

3. A configuration framework – which views SWB as an integrated system LS, PA, and NA, all of which are differently configured within distinct individuals (Shmotkin, 2005).
4. A composite model – wherein all three components combine to contribute to SWB together.

In the current study, SWB is conceptualised as a composite model in which all three components (LS, PA, and NA) are assessed and then combined to estimate a fourth variable, a composite (aggregate) SWB score (Busseri, 2015). In line with other recent studies (Sheldon & Elliot, 1999; Bettencourt & Sheldon, 2001; Linley, Nielsen, Gillett & Biswas-Diener, 2010), a composite subjective measure of well-being is computed by first standardising all scores and then subtracting negative affect from the sum of positive affect and life satisfaction (Diener, 1994).

- **Academic Self-concept**

Academic self-concept was measured with the Academic Self-concept Questionnaire - ASCQ (Liu & Wang, 2005). It comprises two self-report subscales, namely, academic confidence (10 items) and academic effort (10 items). Liu and Wang (2005) reported Cronbach's alpha of .82 for academic confidence, .71 for academic effort and .76 for internal consistency.

- **Academic Achievement**

Academic achievement was measured with the average marks obtained by students in core subjects in the semester examination.

## **Procedure**

Baseline assessment of children's level of SWB (LS, PA, NA) and academic self-concept was done through standardised tests, and academic achievement was assessed from students' report cards. Positive Psychology Intervention was administered to the study sample for 12 weeks. Post intervention, their levels of SWB (LS, PA, NA), academic self-concept and academic achievement were assessed, and after 6 months the follow-up data was collected on the same variables, i.e., SWB (LS, PA, NA), academic self-concept and academic achievement.

## **Subjective Well-being Intervention Programme**

The main aim of the intervention package was to enhance the SWB of children with SLD and find out whether the intervention had brought any significant

change in their level of academic self-concept and academic achievement. The subjective well-being group intervention programme was developed on the basis of Seligman's (2002) framework for increasing happiness about the past (gratitude), present (mindfulness), and future (optimistic thinking) aspects of children's emotional life, with appropriate modification in light of their development and culture.

The intervention programme had two phases. In the first phase, a pilot study was conducted on a sample of 31 children with SLD. The results showed significant improvement in the level of SWB post intervention. However, based on the observation, children's performance on home assignments and parental feedback, a few changes were undertaken in the home assignment activity. It was made more pictorial, choice-based, and more time was allotted for completion. The intervention time was extended from 1 hour to 2 hours because children needed more time and repeated explanation of concepts and activities. The second phase consisted of the administration of the programme by the researcher to the children in groups. There were totally 12 weekly group sessions, each of two hours duration, spread over a period of 4 months. Groups were formed class wise. Activities during intervention included role play, storytelling, practical demonstration, group discussion, worksheets, chalk/white board activities, audio-visual aids, one-to-one interaction and minimal home assignments. Children were motivated through social and tangible rewards. Psychoeducation and closing sessions were conducted to motivate parents to implement and continue the positive intentional activities, thereby ensuring stable future benefits. Individual sessions were conducted for students who were absent during the regular group sessions. Sample pages are attached as Annexure-1

**Table 2: Subjective Well-being Intervention Programme – Overview**

Session	Theme	Outcome
1 <sup>st</sup> session	Introduction to Intervention	Establishing a supportive group environment; increasing awareness of subjective well-being.
2 <sup>nd</sup> session	Gratitude	Introduction to gratitude - defining gratitude and how it can impact happiness; learning a method of using gratitude to create a focus on positive interpretations of past events.
3 <sup>rd</sup> session		Integrating and reviewing all the components of gratitude: intention, cost, and benefit; learning how to express gratitude.

4 <sup>th</sup> session	Mindfulness	Introduction to mindfulness - awareness of the external environment, strengthening attention to be in the present moment.
5 <sup>th</sup> session		Awareness of the self in the environment; cultivating awareness and acceptance without judgment. Breathing exercise.
6 <sup>th</sup> session	Attributional Style: Optimistic Thinking	Introducing optimistic thinking; discussing the value of optimism in happiness as related to the future; helping children to note and externalise self-talk.
7 <sup>th</sup> session		Reinforcing awareness of internal thoughts; introducing Antecedents, Behavior, Consequences (ABC) Model - Consolidating the link between thoughts and feelings.
8 <sup>th</sup> session		Teaching concepts of optimism, pessimism, and thinking styles.
9 <sup>th</sup> session		Teaching the importance of disputing thoughts; teaching the skills of disputation - thinking more accurately and flexibly about unpleasant events in life.
10 <sup>th</sup> session		Awareness about catastrophic thinking; teaching the skills of decatastrophising.
11 <sup>th</sup> session		Integrating the skills of Optimistic Thinking.
12 <sup>th</sup> session	Termination	Reviewing structure for increasing personal happiness by doing purposeful positive activities; encouraging a personal reflection and feedback on purposeful activities; appraising children's feedback on subjective well-being programme; motivating for continuation of helpful activities in future.

## Data Analysis

Statistical analysis of the data obtained with different scales was performed using the Statistical Package for Social Sciences (SPSS Version 20.0).

## Ethical Considerations

Informed consent was obtained from the respective school authorities after explaining the nature and purpose of the research study. Parents were given detailed information regarding the study and told that they could withdraw their children from participation at any time. Children could also choose whether to participate or not, and had the option to withdraw from the study at any time. At the beginning of the intervention, confidentiality issues and concerns were discussed with them and it was emphasised that the content of group discussions would remain confidential. Children were provided with the opportunity to express their opinions without compromising their safety and well-being, as proposed by Schenk and Williamson (2005). Information collected was used only for research purposes and accurate findings were reported.



## RESULTS

The aim of the study was to find the effect of Positive Psychology Intervention on subjective well-being, academic self-concept and academic achievement of children with SLD. Mean, standard deviation and Wilcoxon signed-rank test were carried out on the data to examine whether any differences were significant from pre- to post- and follow-up intervention.

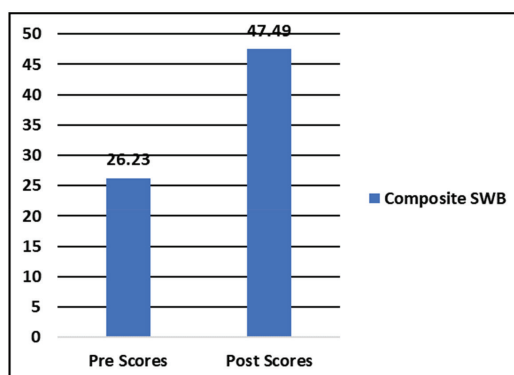
**Table 3: Pre- and Post- Intervention Mean Scores on Composite Subjective Well-Being (SWB) (N = 75)**

Variable	Pre Scores	Post Scores	Mean Difference	<i>p</i> -Value
Composite Subjective Well-being	26.23	47.49	21.27	$p < .01$

Composite subjective well-being (SWB) is a single well-being indicator computed by an aggregate measure of subjective well-being by first standardising all scores and then subtracting negative affect from the sum of positive affect and life satisfaction (Diener, 1994; Linley et al., 2010). Table 3 shows a comparison of mean scores from pre- to post- intervention yielding the mean difference of 21.2666 ( $p < .01$ ) which suggests statistically substantial level changes in composite SWB. Hence it can be concluded that there was a significant improvement in children's composite level of subjective well-being post intervention.

It is notable that Kahneman, Diener, and Schwarz (1999) considered the concept of subjective well-being to be essentially interchangeable with happiness, thus suggesting that the composite SWB of children in the study improved substantially, indicating that their happiness scaled up after intervention (Figure 1).

**Figure 1: Pre- and Post- Intervention Mean Scores on Composite Subjective Well-being**

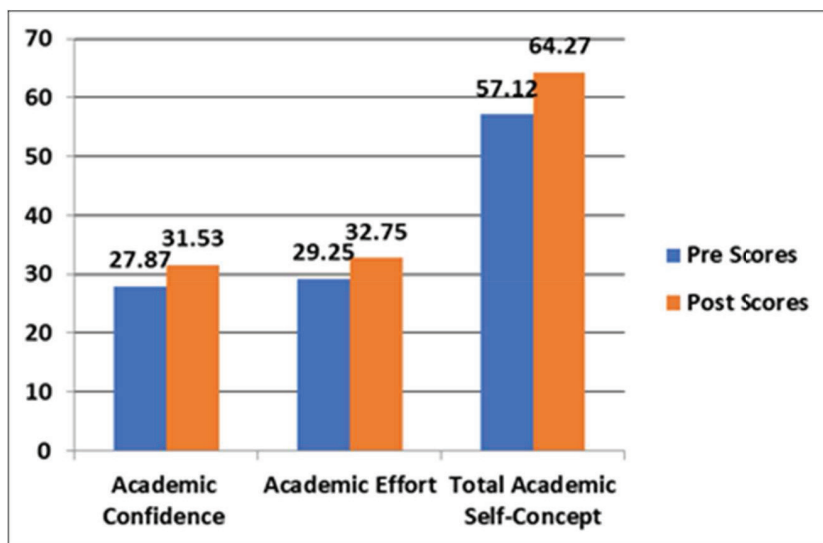


**Table 4: Pre- and Post- Intervention Mean Scores on Academic Self-concept Questionnaire (ASCQ) (N = 75)**

Domains of Academic Self-concept	Pre Scores	Post Scores	Mean Difference	<i>p</i> -Value
Academic Confidence (AC)	27.87	31.53	3.66	<i>p</i> < .01
Academic Effort (AE)	29.25	32.75	3.5	<i>p</i> < .01
Total (Academic Self-concept)	57.12	64.27	7.15	<i>p</i> < .01

Academic self-concept (ASC) consists of academic confidence (AC) and academic effort (AE). The academic confidence subscale assessed children's feelings and perceptions about their academic competence. The academic effort subscale assessed children's commitment to, involvement and interest in schoolwork. Analyses of the results of academic self-concept are presented in Table 4. An increase in AC mean scores by 3.66 ( $p < .01$ ) revealed statistically significant improvement in children's academic confidence post intervention. Similarly, results evidenced that the AE mean scores also increased by 3.5 ( $p < .01$ ), indicating statistically significant improvement in the academic effort domain. The mean scores on total academic self-concept gained by 7.15 ( $p < .01$ ), demonstrating statistically significant improvement in children's academic self-concept post intervention, as represented in Figure 2.

**Figure 2: Pre- and Post- Intervention Mean Scores on Academic Self-concept Questionnaire (ASCQ)**



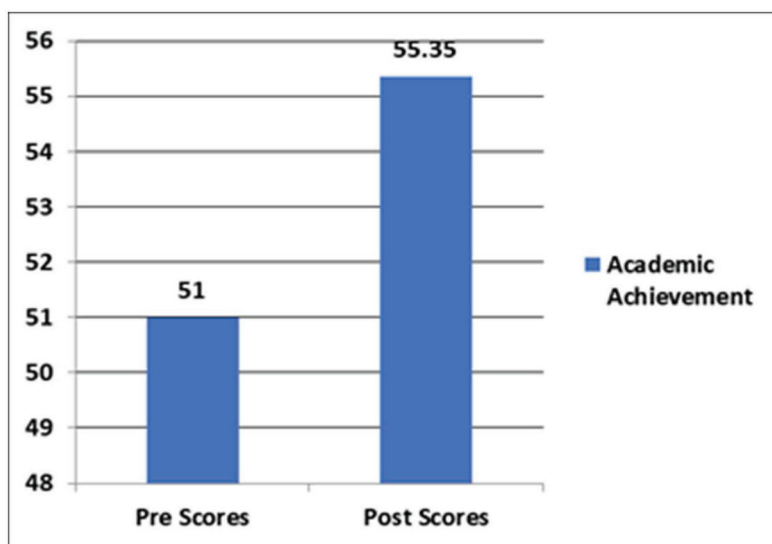
**Table 5: Pre- and Post- Intervention Mean Scores on Academic Achievement (AA)**

(N = 75)

Variable	Pre Scores	Post Scores	Mean Difference	<i>p</i> -Value
Academic Achievement (AA)	51.00	55.35	4.35	$p < .01$

Table 5 presents the mean scores on academic achievement (AA) showing the mean difference of 4.35 ( $p < .01$ ) which is statistically highly significant. This indicates that post intervention the children's academic achievement has improved distinctly, as can be seen in Figure 3.

**Figure 3: Pre- and Post- Intervention Mean Scores on Academic Achievement**



### Results of Follow-up Intervention

A follow-up assessment of all earlier studied variables was done 6 months after the intervention in order to see the retention effect on children with SLD. A Wilcoxon signed- rank test was carried out to find the mean difference between pre- and follow-up scores.

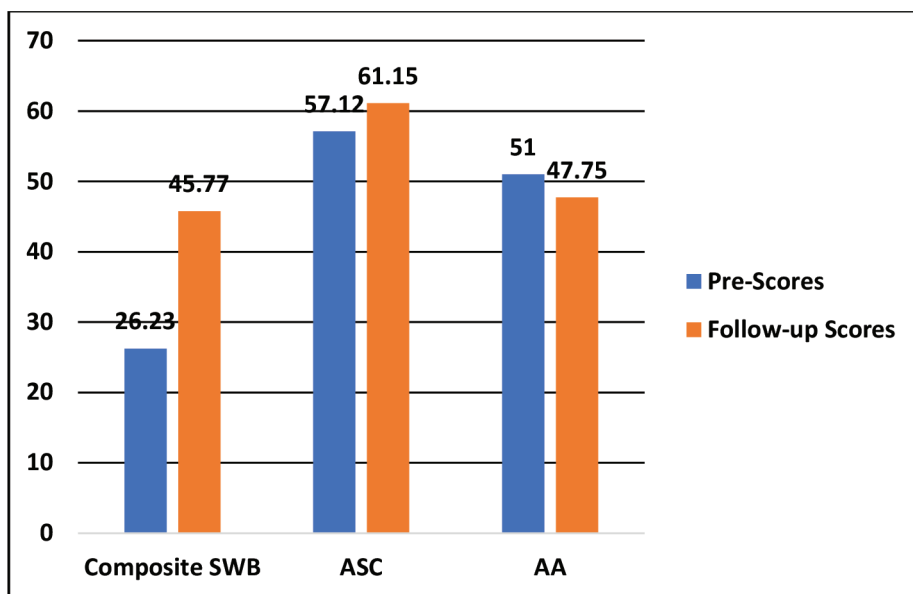
**Table 6: Pre- and Follow-up Intervention Mean Scores on Composite SWB, Academic Self-concept and Academic Achievement of Children with SLD (N = 75)**

Variables	Pre Scores	Follow-up Scores	Mean Difference	<i>p</i> -Value
Composite SWB	26.23	45.77	19.56	$p < .01$
ASC	57.12	61.15	4.03	$p < .01$
AA	51.00	47.75	-3.25	$p > .05$

Note: ASC = academic self-concept; AA = academic achievement

A statistically highly significant improvement was observed from baseline to follow-up mean difference scores of Composite SWB 19.56 ( $p < .01$ ) and ASC 4.03 ( $p < .01$ ), whereas a slight decrease in mean difference of AA -3.25 ( $p > .05$ ) was noticed which is statistically not significant (Figure 4). This probably occurred due to the increased difficulty level of the core subjects as, at the time of follow-up, the children with SLD were promoted to the next class (after the second semester). They might have encountered academic difficulties in the higher-level class and due to their SLDs did not score as well as in the junior class.

**Figure 4: Pre- and Follow-up Intervention Mean Scores on Composite SWB, Academic Self-concept (ASC) and Academic Achievement (AA) of Children with SLD**



It is evident from the follow-up results (shown in Table 6 and Figure 4) that benefits of PPI on composite SWB and ASC were retained even 6 months after

the intervention. Children's academic achievement was found to have decreased at follow-up in comparison to baseline scores. However, this reduction was not statistically significant.

## DISCUSSION

The aim of the current study was to examine whether the positive psychology group intervention incorporating gratitude, mindfulness and optimistic thinking-attribitional style contributes to subjective well-being, academic self-concept and academic achievement of children with SLD. Statistical analysis revealed a significant increase in the level of subjective well-being, academic self-concept and academic achievement post intervention. In accordance with previous research (Stiglbauer, Gnambs, Gamsjager, & Batinic, 2013; Dawood, 2014; Shoshani & Slone, 2017), this study showed that a Positive Psychology Intervention for children is effective in improving their well-being and functioning. The study results revealed that there was also significant improvement in children's academic self-concept. This is in consonance with the notion by Fredrickson (1998, 2001) that the experience of positive emotions broadens one's awareness and encourages the development of new skills and resources which may eventually lead to enhanced academic achievement. In the school context, children experienced more positive emotions through Positive Psychology Intervention, which facilitated their personal resources and classroom learning, thereby enhancing their academic-related self-concept. This shows the significance of engaging children in positive activities because their academic self-concept is affected by the learning disability status but not the general social self-concept (Al Zyoudi, 2010). There was also a significant improvement noticed in children's academic achievement post intervention. This can be explained by the broaden-and-build theory of positive emotions (Fredrickson, 1998, 2001) leading to enhanced academic achievement. Indeed, positive emotions are associated with better self-regulated learning, higher motivation, and better examination grades (Mega et al., 2014), and have a positive effect on memory and attention processes (Fiedler & Beier, 2014). In conclusion, happy children learn and perform better in a positive state of mind.

Results of a follow-up study revealed that the gains were maintained in subjective well-being and academic self-concept, but not in academic achievement. The reason for this may be the increased difficulty level of the higher class to which children were promoted at the time of the follow-up.

There are various studies targeted at either improving cognitive learning or reducing negative symptoms among children with SLD. It would be more effective to strengthen their ability to maintain a reservoir of positive attributes through Positive Psychology Intervention. These positive characteristics would be beneficial to their socialisation, emotional and cognitive learning. Park (2004) has argued that programmes aimed at youth development are more successful when they begin early, extend over time, are structured, and are guided by specific theories. In an Indian study on adolescents (Singh & Junnarkar, 2015), it was observed that positive mental health was predicted by flourishing, positive affect, physical health, psychological well-being, social relationships, and environmental health. Research indicates that positive affectivity is a major protective factor against depression among children and adolescents (Lonigan et al, 2003). Children with SLD often receive negative comments regarding their academic activities and performance from peers, teachers and parents. Inculcating positive emotions in children with SLD through intentional activities would empower them to improve their relationship with others during aversive situations and protect them against academics-related stress and anxiety. Positive affect enables adolescents to initiate and maintain relationships and show less vulnerability to negative peer influence (Mrug, Madan, & Windle, 2012). These interventions can have the dual effect of laying a foundation to support positive development and being a tool for protection, especially for children at risk.

To sum up, findings suggest that the PPI used in the current study significantly improved subjective well-being, academic self-concept and academic achievement of children with SLD by the end of the intervention. Furthermore, it is encouraging that the gains in subjective well-being and academic self-concept in the present research study were maintained at the follow-up 6 months later.

## CONCLUSION

It is evident from the findings of the present study that there was a remarkable improvement in children's level of subjective well-being, academic self-concept and academic achievement after Positive Psychology Intervention. PPIs may be used as protective and proactive measures in the rehabilitation of children with disabilities. The positive intervention activities such as gratitude, mindfulness, attributional style and others can be incorporated into school curricula and be applied in regular classrooms for holistic development of all children. Positive intervention activities cultivating positive feelings, positive

behaviours and positive cognitions can also be useful in counselling students, teachers and parents in the school set-up. Findings of the present study suggest potentially useful guidelines for the development of future interventions aimed at improving the well-being of children with SLD as well as other children. It also highlights the need for research on parents and teachers as they are the key stakeholders in children's overall development, and can be involved in future Positive Psychology Intervention processes. While further research is needed on the application of Positive Psychology Intervention tools to special needs populations, it is hoped that these recommendations will also benefit teachers and students with special needs. The study findings offer scope for prevention as well as remediation programmes based on positive psychology principles for children's overall optimal development. Children's well-being is the need of the hour; children who flourish will grow up to be citizens who contribute to the nation and the world.

## ACKNOWLEDGEMENT

The author wishes to thank all the children with specific learning disability who participated in the study. In addition, she is grateful to the school principals, teachers and the parents of children with SLD for supporting the research. Deep gratitude is extended to Dr. Saroj Arya, Associate Professor and Head (Retd.), Department of Rehabilitation Psychology, NIEPID, Secunderabad, for guidance in preparing the intervention programme and improving the quality of this research study.

The author declares there is no conflict of interest.

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## Annexure-1

### Sample pages from Subjective Well-being Intervention Programme

#### Subjective Well-being Intervention Programme

#### Session 4: Introduction to Mindfulness

#### Overview

#### Goals

- Discover students' current levels of mindfulness
- Awareness of the external environment
- Strengthening attention to be in the present moment

#### Session Procedures

- A. Group Discussion: What is mindfulness? Rate your own mindfulness. Importance of mindfulness
- B. 'Mind in Jar' Video presentation and discussion
- C. Mindful Observation Exercise
- D. Homework: Daily mindful observation exercise

#### Materials Needed

- Mindfulness – PPT
- Small paper slips for students to note self-identified ratings
- Video - 'Mind in a Jar'  
<https://www.youtube.com/watch?v=QNmMH6tqiMc>
- Objects for observation (soft ball, pen, toy, piece of cloth, clip, seed, notebook, eraser, crayon)
- Student comprehension check: Mindfulness
- Bell
- Mindful Observation Exercise Worksheet
- Tangible rewards for homework completion (stickers, pencils, ball pens)

## Session 4 Procedures Defined

### A. Group Discussion: Mindfulness and its importance

A brief introduction to mindfulness was carried out by stating that sometimes we all feel like we have a hard time focusing or paying attention. Our days are busy and there is a lot going on. Mindfulness in a simple word is awareness. It is paying attention in a specific way. It is noticing our thoughts, feelings, bodily sensations, and anything that is around us and happening right now.

#### Rate your own mindfulness:

Before further discussion children were provided with a piece of paper and stated:

*We are going to rate our own level of mindfulness. Think about your current mindfulness level (aware of your own thinking, feeling and doing). Rate it on a scale from 0 to 10 with 0 being never mindful, 5 being sometimes mindful, and 10 being always mindful.*

0 = being never mindful

10 = being always mindful

5 = being sometimes mindful

0	1	2	3	4	5	6	7	8	9	10
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Having students write their ratings on a piece of paper and handing over to therapist.

*"Today we are going to learn about what it means to be aware or attentive. Can anyone tell me what is the meaning of the phrase to be aware or attentive?"* Students' responses were discussed.

Students were explained that mindfulness is just being aware of the present moment. It is paying attention to those things in the present moment that they never noticed before. It is a skill of noticing and accepting the internal and external environment. We use five senses to be mindful i.e., sight, hearing, touch, taste and smell.

Posing these questions to the group:

- *Why is it important or not important to be mindful in your life?*
- *Do you think being mindful can increase happiness? Why or why not?*

Mindfulness can help to take a few minutes to pause and let our minds and bodies relax and refocus. It strengthens our attention and concentration, reduces worry before testing, improves classroom participation, and improves friendship and good relations with others. Mindfulness can make us feel calm, relaxed and happy. (PPT on Mindfulness was used for better understanding of the concepts)

### **B. 'Mind in Jar' Video presentation and discussion**

Prior to relaxation jar activity, children were shown the video 'Mind in Jar' and explained that when we are stressed, our mind is clouded with many thoughts and feelings and we are not able to see situation clearly. Once we focus our attention to our breath, we gradually settle down and are able to see the event clearly and take right action.

Children were explained that while we wait, the glitter does not go away. It stays at the bottom. Our thoughts and feelings and wishes are still in our minds, but they are no longer in our way, clouding our idea. Same happens to our brain.

### **C. Mindful Observation Exercise**

The concept of mindfulness was introduced to children through directing their attention to things in their environment. They were first instructed to describe everything they observed in the classroom. They were helped to observe the given environment in a manner which they have never noticed before. They were explained with the help of a soft ball how to observe mindfully – its color, size, shape, texture.

**Exercise:** They were asked to sit upright, comfortably at their desks. They were each given a single object such as, pen, toy, piece of cloth, clip, seed, notebook, eraser, unsharpened pencil, and crayon. They were asked to spend some time looking at the given object and paying attention to its

smaller and smaller details, once time starts (ringing a bell to start time), they would observe the object—noticing how it looks, feels, and smells if so, without labelling or naming it. Just noticing and describing, without judging. Helpful prompts were given to students:

- “Observe your object, notice and describe its features without labelling it”
- “Notice what it feels like in touch, is it smooth? Hard? Rough? Soft? Slippery? Can it be squeezed or not?”
- “Notice how it smells, if so.”
- “Notice how it looks, long, short, flat, big, is it sharp? is it round?”

After 2-3 minutes, their awareness was brought back to the room and their surroundings by ringing the bell to stop. Students were asked to share their observations about their objects. Reminding them to stick to observations, describing what they noticed non-judgmentally.

#### Reflection Questions:

These questions were asked to debrief after a mindfulness activity:

1. *Was this exercise hard or easy? Why?*
2. *Did you notice your mind wandering during the exercise? What strategies did you use to bring yourself back to the present or to the task at hand?*
3. *Can you be mindful or aware of your feelings, thoughts, and environment around you?*
4. *Do you think you could use a mindfulness exercise outside of the classroom? In what situation might it be helpful?*

#### **D. Homework: Mindful Observation Exercise**

Observe an object daily and record in the Mindful Observation Exercise Worksheet. Your effort will be duly rewarded. Remember to look at the object as if you are seeing it for the first time.



**E. Review Homework: Mindful Observation Exercise**

Children were asked how often they did their Mindful Observation Exercise. For students who did not comply with the daily requirement, the importance of daily effort was stressed for changes in happiness to occur. Small tangible rewards (e.g., pencil, sticker, edible) were provided for homework completion. Children were asked to share any new reflections that they had over the week.

End

## LETTER TO EDITOR

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Dear Editor,

### **COVID-19 Prevention and Difficulties experienced by Blind Persons in Low- and Middle-Income Countries**

The COVID-19 pandemic began in early 2020 and continues to be a health threat globally. The disease is caused by the emergence of a new virus, SARS CoV-9, which can induce respiratory tract infection. The disease has a wide clinical spectrum, ranging from silent asymptomatic to severe clinical symptoms. It can be easily transmitted, because a droplet generated from an individual with the pathogen can spread in the environment to many other people. After the first cases were reported in China, the disease rapidly spread to Southeast Asia and other parts of the world (Hsia, 2020). The result is a global public health crisis as well as global economic deterioration.

A large proportion of the world's population is already infected and there are millions of deaths globally. The pandemic has become an emergency in all countries. Due to lack of proven effective therapies for COVID-19, prevention against infection is the best course of action. Protection against COVID-19 is necessary for everyone, but more so for vulnerable people. Among the underprivileged groups, people with disabilities should receive special attention in COVID-19 prevention. However, as this group of people is diverse, forms a minority and often does not benefit from mainstream health interventions, it becomes difficult to reach them all. Primary prevention should cover self-protection, environmental decontamination, and practice of sanitation, as well as vaccination.

In general, facemask wearing, social distancing, environmental decontamination and vaccination are recommended as a combination of preventive actions. Since persons with disabilities are more vulnerable to infectious agents, some specific interventions need to be considered for them. In a recent publication focusing on people with autism, Araujo et al (2021) indicated that there were many challenges, such as effective communication of information about COVID-19. In fact, with people who are deaf, difficulty in communication due to wearing a facemask is expected. Here, the writers of this letter would like to share ideas and concerns regarding people who are blind and who may face many barriers in relation to information about the prevention of COVID-19. Checking for completeness

of face coverage after wearing a facemask and social distancing could also be problems for them.

Access to healthcare services in times of COVID-19 is a problem for everyone. During lockdown periods it is in general difficult for people to access eye-care services and it will be even more difficult for blind persons (Jackson et al, 2021). Difficulties in providing ophthalmological care start soon after the emergence of COVID-19. Routine eye examination is needed for the management of eye problems, but social distancing is virtually impossible in the process of ophthalmological examination. Arrigo et al (2020) noted that, "At least 1 m of distance among people is recommended; however, some clinical practices cannot allow this distance." Therefore, routine health services in clinics for people with impaired vision who may need specific care in ophthalmology clinics, can usually lead to COVID-19 transmission.

For people who are blind, correct wearing of a facemask is also sometimes difficult. The position of the facemask cannot be checked completely. One who is blind may use one's hands for orientation. This means an increased chance for contact with pathogen- contaminated objects. Use of hand sanitiser is certainly recommended. However, using a hand sanitiser could be more difficult for blind people than for people who can see. Similar problems with using facemasks can be experienced by other groups of persons with disabilities. For example, a person who has no ear pinna might not be able to wear a facemask.

Finally, COVID-19 vaccination is essential for people who are blind. The available vaccines offer hope for successful disease containment. Vaccination programmes generally focus on mass immunisation of large groups of people, with the aim of generating herd immunity. However, people who are blind may experience difficulties in accessing vaccine service points. In certain settings, such as some Asian countries, electronic internet pre-appointments via Smartphone apps may be needed but these are not always accessible to people who are blind. Hence specific public health support in getting COVID-19 vaccinations must be provided to those who are blind and to people with other disabilities. Good systems are those that offer blind persons special accessible appointments for vaccination, a walk-in service or forms of accommodation to access vaccination schemes.

It is evident that people with disabilities, in particular people who are blind, are facing serious difficulties in accessing information about (the prevention of) COVID-19 (Goudeau et al, 2021; Haupt, 2021; Shakespeare et al, 2021). Currently,

there is limited data on COVID-19 among blind persons, but it is apparent that the necessary support mechanisms are required to prevent infection among them.

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Rujittika Mungmunpantipantip<sup>1\*</sup>; Viroj Wiwanitkit<sup>2</sup>

1. Private Academic Consultant, Bangkok, Thailand
2. Honorary Professor, Dr DY Patil University, Pune, India; Adjunct Professor, Joseph Ayobabalola University, Ikeji-Arakeji, Nigeria

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\* **Corresponding Author:** Rujittika Mungmunpantipantip, Private Academic Consultant, Bangkok, Thailand. Email:rujittika@gmail.com

**NLR - until No Leprosy Remains** is a Dutch non-profit organization committed to a world without leprosy and its consequences. It tries to achieve this by supporting health authorities in countries where leprosy is prevalent. NLR promotes the independent social and economic functioning of leprosy patients and their families. By supporting scientific research NLR wants to improve the effectiveness of leprosy control.

NLR is a member of the International Federation of Anti Leprosy Associations (ILEP). NLR supports national health authorities in over twenty countries with endemic leprosy problems, collaborates with international partners in leprosy control, and works professionally and efficiently.

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**The Liliane Foundation** contributes to a world that is open to everyone and in which poor children with disabilities can develop and use their talents. The foundation collaborates with local partners in Africa, Asia and Latin America to raise awareness of the 'exclusion' of these children and to remove the barriers that they suffer because their environment is not set up to allow their participation.

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**Published by**  
Stichting Liliane Fonds  
5211 TX's-Hertogenbosch  
The Netherlands