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Editorial

The Global Research on Developmental Disabilities Collaborators have recently published an article on developmental disabilities among children younger than 5 years in 195 countries and territories, between 1990 and 2016 (www.thelancet.com/journals/langlo/article/PIIS2214-109X(18)30309-7/fulltext).

The study has highlighted the disproportionately high burden of developmental disabilities in low and middle income countries, and details the underlying causes of disabilities: refraction and accommodation disorders leading to vision loss; otitis media and congenital anomalies leading to hearing loss; congenital anomalies and neonatal disorders, including preterm birth complications, infections, and birth asphyxia leading to intellectual disability; and neonatal disorders leading to epilepsy. The study recommendations include the urgent need for identification of the major causes and effects of developmental disabilities in regions with the largest prevalence, especially those with low resources. The study concludes that “the global burden of developmental disabilities has not significantly improved since 1990, suggesting inadequate global attention on the developmental potential of children who survived childhood as a result of child survival programmes, particularly in sub-Saharan Africa and south Asia”.

Along similar lines, the 2017 WHO meeting on “Rehabilitation 2030- A Call for Action”, drew attention to the profound unmet rehabilitation need around the world, especially in low and middle income countries, and pointed out that the demand for rehabilitation services will continue to increase due to changing health and demographic trends related to ageing, disease and injury.

The Charter for Change from the Global Disability Summit held in the UK in July 2018 (www.gov.uk/government/publications/global-disability-summit-charter-for-change) has 10 action points, two of which are relevant to the issue of childhood developmental disabilities. Point 8 states “‘Leave no one behind’ and put the furthest behind first. We will champion the rights of the most underrepresented and marginalised persons with disabilities, of all ages, affected by any form of multiple discrimination, and notably women and girls with disabilities”, while point 9 is about “Gather and use better data and evidence to understand and address the scale, and nature, of challenges faced by persons with disabilities, using tested tools including the Washington Group Disability Question Sets”.

www.dcidj.org
In this context, it is important to consider how CBR has been and can continue to be, an appropriate response to address early identification and intervention in relation to children with developmental disabilities. The 2011 World Report on Disability (Chapter 3 on General Health Care) recognises the role of CBR in promoting and facilitating access to health care services for people with disabilities and their families in low-income and lower middle-income countries. The Report also recommends (Chapter 4 on Rehabilitation) that in low-resource, capacity-constrained settings, efforts should focus on accelerating the supply of services in communities through CBR, complemented with referral to secondary services. Experiences in countries in the Asia-Pacific region (for example, China, Vietnam, Laos, India) have shown that CBR can play a significant role in activities such as early identification and intervention.

With the UNCRPD and the SDGs providing the frameworks and action points, stakeholders from governments and civil society need to pay urgent attention to address the needs of children with disabilities, especially those from resource-poor regions.

Maya Thomas
Editor-in-Chief
Disability, CBR and Inclusive Development
Lived Experience of Psychosocial Disability and Social Inclusion: A Participatory Photovoice Study in Rural India and Nepal

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ABSTRACT

Purpose: This study aimed to investigate the experiences of people living with a psychosocial disability in rural India and Nepal, and to highlight key barriers and enablers for inclusion.

Method: Participatory action research approaches and Photovoice methodology were employed to investigate the lived experience of 32 participants in rural India and Nepal. There were 12 participants and 4 caregivers of people with psychosocial disability from each of the two countries. Semi-structured interviews with study participants were transcribed and analysed thematically to answer the study question.

Results: The findings revealed themes related to various supports, meaningful engagement in activity, and community awareness. Among these categories were both enabling and impeding factors to inclusion, the presence or absence of which was typically associated with improvements or worsening of symptoms respectively.

Conclusions and Implications: This study underscores the need for integrated community-based approaches that are multisectoral, inclusive of family, and strengthen community responses. Photovoice was also shown to be a feasible research methodology for providing insights into the lived experience of people with psychosocial disability and for fostering their empowerment.

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Key words: psychosocial disability, lived experience, inclusion, participation, Photovoice, natural supports, family, community advocates

INTRODUCTION

The inclusion of people with disabilities is increasingly being prioritised in development programmes and national agendas (Saran et al, 2018). While the inclusion of people with mental illness and psychosocial disabilities tends to be lower on the agenda, the World Health Organisation’s Mental Health Gap Action Programme (World Health Organisation, 2018), the Sustainable Development Goals (Votruba et al, 2014; Izutsu et al, 2015; Mills, 2018) and the Global Mental Health Movement are helping to raise its profile.

There is now a well-recognised body of evidence about the importance of shaping services and programmes according to consumer voices and aspects of lived experience, and the value of participatory process in recovery and inclusion (Rose et al, 2011; Evans et al, 2012; Sweeney et al, 2012; Ennis & Wykes, 2013; Salzer & Baron, 2016). This evidence has been predominantly in high-income countries however, and there is very little documented evidence of the experiences of people and families affected by psychosocial disability in low- and middle-income countries (LMICs) (Semrau et al, 2016). Accompanying this evidence gap, there is also a practice gap in as much as community-based programmes in LMICs could play a role in modelling inclusion and engagement of people with psychosocial disabilities (Menil & Glassman, 2016; Salzer & Baron, 2016).

Photovoice methodology has traditionally been used as an investigative research tool for a range of public health and social concerns. The utilisation of Photovoice in the area of mental health is reasonably recent and, to date, relatively uncommon. A scoping review of the use of Photovoice in mental illness was published in 2016, with only 7 studies fitting the inclusion criteria of primary data collection investigating the lived experience of mental illness (Han & Oliffe, 2016). Photovoice has been used to identify mental health concerns in participants post-disaster (Annang Ingram et al, 2018); to investigate the experience of using mental health services (Tang et al, 2016); and to explore factors that contribute to inclusion and wellbeing (Reid & Alonso, 2018). However, all published Photovoice and mental health studies to date have been completed in high-income countries, with a dearth of literature on lived experience of mental illness in low- and middle-income contexts.
Creating platforms for people with psychosocial disabilities to have a voice in their communities increases general understanding about mental illness, reduces stigma, and improves outcomes for people with psychosocial disability (Mathias et al, 2015; Carroll et al, 2016). Photovoice has been shown to be a robust method for achieving these aims (Han & Oliffe, 2016). Thus, the authors of the current study undertook a participatory action research utilising Photovoice to explore the lived experience of people with psychosocial disability in Nepal and India.

Building on the existing qualitative literature, and acknowledging the gap in such literature in LMIC settings, this paper discusses how the voices of those with lived experience can inform development programmes and promote inclusion.

**Ethical Considerations**

The research was undertaken by TEAR Australia in partnership with the University of Melbourne’s Nossal Institute for Global Health, Emmanuel Hospital Association (EHA) in India, and the Centre for Mental Health and Counselling (CMC) in Nepal. Approval for the research was obtained from University of Melbourne’s Human Research Ethics Sub-Committee, the Nepal Health Research Council and Emmanuel Hospital Association Institutional Ethics Committee.

**METHOD**

**Setting**

The study was conducted in locations where Emmanuel Hospital Association (EHA), India, and the Centre for Mental Health and Counselling (CMC), Nepal, currently implement community-based mental health projects. The study took place over four rural field sites in the two countries, following Hergenrather's ten-point framework for Photovoice (Hergenrather et al, 2009).

Photovoice is a qualitative participatory action approach that combines photographic images with narrative, and recognises local knowledge and the experiences of those most affected by the issue in question (Reid & Alonso, 2018). In this research, Photovoice methodology was employed to answer the research question: “What are the key barriers and enablers for social inclusion in rural north India and Nepal?”
Sample
Thirty-two research participants were selected through purposive and convenience sampling. They were 12 people with lived experience and 4 carers, from each country.

Selection criteria:

- over 18 years of age;
- ability to follow instructions and communicate verbally;
- lived experience of psychosocial disability for 6 months or more;
- for carers, more than 6 months of experience of caring for a person with psychosocial disability.

While 32 people were invited to participate, two declined. Written informed consent was obtained and two more participants later withdrew due to personal reasons. Participants were trained in using a digital camera and photography, and then instructed to take photos, over a four-day period, of perceived barriers and enablers to community inclusion.

After the four days, researchers interviewed participants, using an approved interview guide. Participants nominated their six most representative photos – three barriers and three enablers. Researchers asked participants to identify the two most significant pictures from those six (one key enabler and one key barrier). Participants discussed these two with the researchers, and gave a descriptive title to the remaining four photos. The interviews were audio-recorded, transcribed and translated.

Data Analysis
Thematic analysis of the data utilised a multi-stage grounded theory approach. The data was collated into response type (e.g. “India participant primary barriers”, “Nepal carer secondary enablers”), and codes were developed. Two researchers coded the data independently. A high degree of inter-researcher consistency allowed the team to arrive at the final themes.

RESULTS
Thematic analysis revealed three categories of response: supports, meaningful engagement, and stigma and community awareness/attitudes. Under each
category, a number of themes emerged as enablers and barriers to social inclusion. The themes are captured in Table 1.

Table 1: Themes denoting Enablers and Barriers to Social Inclusion

<table>
<thead>
<tr>
<th>Category</th>
<th>Enablers to Inclusion</th>
<th>Barriers to Inclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Supports</strong></td>
<td>Family, friends’ and neighbours’ emotional and practical support promotes mental health</td>
<td>Mental health of individuals affects other family members’ wellbeing and participation</td>
</tr>
<tr>
<td></td>
<td>Nature, religion and safe places enable recovery and mental health</td>
<td>Economic stress exacerbates psychosocial disability</td>
</tr>
<tr>
<td></td>
<td>Access to treatment is important for recovery</td>
<td>Barriers to treatment inhibit wellbeing and inclusion</td>
</tr>
<tr>
<td><strong>Meaningful Engagement</strong></td>
<td>Engagement in meaningful activity facilitates positive emotions, meaningful time use, self-efficacy and economic contribution</td>
<td>Limited contribution to family and community life is a barrier to inclusion</td>
</tr>
<tr>
<td><strong>Stigma &amp; Community Awareness/Attitudes</strong></td>
<td>Community awareness and acceptance enhance participation</td>
<td>Stigma and discrimination hinders inclusion</td>
</tr>
<tr>
<td></td>
<td>Advocates promote awareness and inclusion</td>
<td>Decreased sense of wellbeing and self-worth limits inclusion</td>
</tr>
</tbody>
</table>

1. Supports
Supports were natural, medical and economic in nature. Here ‘natural supports’ is defined as the natural environment, religion, home and family and friends (Sidebotham, 2014).

**Family, friends’ and neighbours’ emotional and practical support promotes mental health**
The positive support of family members was the most significant enabler to inclusion. Many photos portrayed family members who had supported the
person with lived experience in emotional and practical ways. These were spouses, children, parents and grandparents, siblings and uncles. Emotional support encompassed caring for, helping and listening to the person with psychosocial disability. Practical support included help to purchase medication, to take medication on time, to access treatment, and financial contributions.

“This is a photo of my son. He is the one who took care of me and the family throughout my illness and also took responsibility of the medical expenses.” (NUMA06)

In some cases, support was perceived to promote positive mental health outcomes.

“The support of my wife helped improve my situation. I was able to deal with my illness because of her support. If she had behaved badly like all the others, our family would have broken up. With her support, our bad situation had a positive outcome.” (KANK09)

Several carers recognised the importance of their own role in providing support, with one carer taking a photo of herself and adding the caption:

“Only a mother can take care of her son… no matter how hard it is.” (HUSH06)

Though less frequent a response, the support of friends and neighbours was perceived as valuable for reasons similar to family support.

“It is very easy to participate, as friends have accepted me and they listen to my feelings and support me.” (NSP6)

Conversely, the lack of family support created a barrier to inclusion and participants perceived the absence thereof to exacerbate symptoms and negative emotions, and as a barrier to accessing treatment.

“Due to the false beliefs and unsupportive behaviour from my family members, I was not permitted to get treatment.” (NSP3)

Absent family support or negative family responses in the form of violence or restraint was also present in some participants’ captions.

**Economic stress exacerbates psychosocial disability**

Participants with lived experience said that stress, negative emotions and symptoms were exacerbated by economic factors. Carers and participants expressed household economic stress due to the inability to work of both/either themselves and/or the person they were caring for.
“When I am sick, I can’t work and can’t earn money. I need work to earn money, but I don’t have either.” (KASK09)

Economic stress was also linked to access to treatment and services, and the associated expense. Participants spoke of the financial burden and the extensive efforts required to obtain effective treatment.

“We face financial difficulties in affording the medical treatment required for both of us – my husband and myself – because we both have mental illness.” (NDP6)

“…My parents are the ones who … took me to India for my treatment, spending two million rupees. They got that money from selling gold and buffaloes. When all our assets were used for my treatment, my mother would cry a lot. Despite all these difficulties they continued my treatment and made me well.” (NDP5)

Mental health of individuals affects other family members’ wellbeing and participation
Participants noted that mental illness affected the lives of family members and carers.

“My children’s school studies are hampered by my mental illness… I was afraid that my situation would create depressive symptoms in my daughter when there was very much depression and sadness. Probably this time she was studying at grade 5 or 6, she used to be afraid and cry a lot and sometimes she used to study. Due to my illness there was disturbance in her study.” (NSP1)

“I got depression because my husband has mental illness.” (NDP6)

Nature, religion and safe places enable recovery and mental health
Participants felt that feelings of peace, happiness and safety result from experiences in nature, religion/religious practice and safe places.

“Happiness after seeing the greenery and blooming flowers.” (NDP3)

Religious rituals were associated with peace and receiving strength.

“I feel peace after chanting the Gayatri mantra (a devotional song). … As far as I know I should meditate this mantra to be relaxed and fresh.” (NDP4)

Home and places of worship were both mentioned specifically as safe spaces. However, there were also several exceptions wherein the home was identified as an unsafe place of restraint and exclusion.
Access to treatment is important for recovery

Treatment support is defined here as including availability of medical services, transport, treatment affordability and supply, and support in taking medication. Participants expressed that treatment support helped to reduce symptoms, increase positive emotions and therefore promote social inclusion.

“In improvement in my mental illness after taking medication regularly.” (NDP6)

Barriers to treatment inhibit wellbeing and inclusion

The absence of treatment was among the most significant barriers to inclusion. Many participants described difficulties in access, citing varying reasons such as environmental barriers.

“In our village, there is no treatment available for mental illness and the available treatment is far away, and without access to proper transportation I was unable to take proper treatment. The road is also bad and it is difficult to travel. If I had my own vehicle, it would have made my life easy. I had to depend on others when I fell sick as well.” (KASK09)

However, barriers to treatment were also compounded by lack of family support to access medication, by economic factors and by lack of awareness of treatment options. These compounding barriers have been discussed under other theme headings, but reiterate the value participants placed on accessing treatment.

2. Meaningful Engagement

Meaningful engagement included activities such as parenting and caring roles, livelihood activities, household tasks and participation in religious and community events. Participants pointed to a number of benefits of engaging in meaningful activity.

Engagement in meaningful activity facilitates positive emotions, meaningful time use, self-efficacy and economic contribution

Meaningful engagement helps participants deal with symptoms and promotes positive emotions such as ‘enjoyment’, ‘accomplishment’ and ‘feeling at peace’.

“Taking care of my child helps me and keeps me happy.” (SASD09)

“Working has helped me forget my problems at least for that short time and focus on the work. This also gave me happiness.” (BESA10)
Participants drew direct links between livelihood activities and community insofar as running a business helps participants meet and interact with others, for example. Moreover, livelihood activities, along with study, were tied to future-related prospects, which alleviated financial stress, increased motivation and helped participants “move ahead in life”. Such benefits engendered a sense of self-efficacy.

Meaningful engagement also had benefits such as the perception of time well spent. For example,

“We two brothers used to travel to different places and this helped me to utilise the time of my sadness in the right way.” (NSP1)

Livelihood or gainful employment also fostered increased economic security.

“This business has helped me to increase my self-esteem and my motivation in life. It is one of the important parts of my life which helped me to move ahead while I was in financial crisis.” (NSP5)

Limited contribution to family and community life is a barrier to inclusion

On the other hand, suspended livelihood activity exacerbated financial stress, symptoms and exclusion. Being unable to engage in activities that participants felt were meaningful was linked with negative emotions.

“I did not have a livelihood and my mind was empty and hence I started thinking about various things which further added to my stress and mental illness. If I am busy and involved in livelihood activities, it would reduce my stress.” (KANK09)

“I feel bad that I am unable to do a lot of work in the house. Since I am not able to do the housework, the burden falls on other members of the family.” (SASD09)

3. Stigma and Community Awareness and Attitudes

This category of response encompasses self-stigma as well as knowledge, attitudes and discrimination by the community.

Decreased sense of wellbeing and self-worth limits inclusion

Participants identified a decreased sense of self-worth as being a barrier to inclusion and affecting interactions with family and friends, self-perception and motivation to participate.
“My illness isolated me from everyone. … I always prefer to be alone and not even interact with my family even when they want to talk to me.” (NUMA06)

Symptoms affected how participants felt about themselves, whether lonely, ‘better off dead’ or useless to society. Thoughts of one’s value or one’s achievements relative to others caused self-stigma. Often symptoms prevented participants from involvement in activities that they valued, such as socialising, housework and enjoying nature.

“I am not able to interact with other women…When a lot of women are sitting and talking, I am unable to interact properly. Sometimes I say inappropriate things which affect other people. I feel bad that I am not able to talk to people properly, especially with relatives and guests when they visit.” (HAME09)

Community awareness and acceptance enhance participation
Participants placed value on community awareness and described how it promoted acceptance, which enabled inclusion. For example,

“…the society should be encouraged to involve (people with mental illness). As a result, mentally ill people can feel part of the society.” (NSC1)

Several participants further articulated the enabling role of support/self-help groups for economic and social support.

“This group has helped me in interacting with other people and has provided an opportunity and created a forum to listen to the difficulties of others.” (NSP6)

“The saving and credit co-operatives have supported building good rapport in the community by collecting and utilising cash. Whenever I need a loan, the group members support me to pass the loan (test), which provides assistance in my work.” (NDC1)

Stigma and discrimination hinders inclusion
The most pervasive barrier to inclusion was social distance. Most participants expressed this, describing feelings of criticism, judgement, discrimination or isolation.

“… people in the community are humiliating me and making fun of me, so this makes me feel unacceptable … (and it is) one of the most significant barriers to inclusion in my community.” (NDP1)
The social distance experienced by participants was often the result of the behaviour of an unnamed individual or group of individuals in the community.

“This picture reminds me of a person who always created obstacles to stop me receiving treatment and participating in the community.” (NSP4)

Some participants related exclusion to specific community events.

“When there was a market fair in this place, I was not allowed to go there.” (NSP5)

Social distance was linked to negative traditional beliefs and practices, and a perceived lack of awareness about mental illness in the community. Some participants described the negative traditional beliefs and practices that they believed caused worsening mental health, recurrence of the mental illness, and/or reduced access to treatment pathways.

“Due to the false beliefs about mental illness, it is difficult (for me) to participate in society. A broom is shown in this photo. And there is an ancient belief that if the body is swept by a broom then the person will be cured but, in my case, it didn’t work at all. I tried this method (under) the influence of ancient belief. This tradition has aroused many difficulties during my mental illness.” (NDP4)

Advocates promote awareness and inclusion

Throughout the collected data, respondents identified key advocates who facilitated inclusion. Advocates were people who were valued for their knowledge about mental illness and for support provided to the participant and their family. Advocates included family members, NGO staff and volunteers, health clinic or community health workers, traditional healers and sometimes neighbours. Advocates provided support by raising awareness, bringing people together in groups, strengthening networks of people with psychosocial disability, facilitating access to treatment, as well as listening and understanding. For example,

“(These are) the right people who provided the right information at the right time to take treatment for my mental illness. They are my neighbours and the volunteers from the project, and they helped me go to the hospital. They helped me at the right time and took me to the right place.” (KASK09)

Participants described the importance of NGO staff or volunteers’ work in creating community action and awareness about mental health. For example,
“He is the first person who (shared) …with our society that the mental illness can be treated. He visited every area, every house and provided information that this can be treated and this is not due to God or ghost but this is an illness which can be cured with treatment. He raised awareness on this issue…” (NDC2)

DISCUSSION

The photos and accompanying narratives gathered through this study point to the importance of natural supports, access to treatment, stable household economics, meaningful activity, community awareness and advocates who promote inclusion. They describe exclusion through stories of stigma and discrimination stemming not only from negative traditional beliefs and practices in the community, but also from poor mental health generating self-stigma and self-discrimination.

Internal and External Contributors to Inclusion

While this study yielded a range of responses to the research question, the key themes raised by participants were highly consistent among those experiencing psychosocial disability and among carers, both in Nepal and India. The role of symptoms was central. Many of the identified barriers and enablers related to a person’s state of mental health, which contributes to or infringes on one’s self-worth and associated propensity for inclusion. The social environment (community attitude and awareness, advocates) was also identified as a significant factor in inclusion, confirming the understanding that inclusion is derived both from within an individual and from the environment. Indeed, the framework for the International Classification of Functioning, Disability and Health highlights the non-linear, dynamic and complex interactions between impairment, function, environment and participation (WHO, 2001; Sánchez et al, 2016). The voices of those with lived experience of psychosocial disability in this study have conveyed the importance of ensuring both specific supports for people with psychosocial disability to strengthen internal factors which influence inclusion, as well as the importance of addressing existing environmental barriers.

The Importance of Natural Supports and Treatment

A requirement to be noted is the need to assure specific supports in order to promote inclusion. One of the most significant of these is access to treatment, which was expressed in terms of the consequences of its unavailability, i.e.,
without treatment, symptoms worsen and the individual loses the capacity to engage in family and community life. Kermode et al (2010) acknowledged that the exacerbation of symptoms can increase stigma and psychosocial disability, stressing therefore that access to effective treatment is still a vital issue for many people with psychosocial disabilities. This issue of access to treatment, however, was more complex than unavailability of services, and included the family’s role, transport issues, economic factors, awareness and community acceptance of treatment options. These results reiterate the importance of understanding the different factors preventing or enabling access, and of developing tailored programmes which frame access to culturally-appropriate healthcare as a human right, which contributes to full social participation (WHO, 2013). Appropriate treatment should be seen through a rights-based lens that promotes participation, contextual understanding, choice and person-centred approaches (Eaton, 2018).

Social and Economic Outcomes of Meaningful Activity and Livelihood
The notion of meaningful engagement is closely tied up with life in the home, livelihood and family roles. It commonly links with economic contributions to family and society. As such, participants portrayed the cyclical relationship between financial hardship and mental health: financial hardship was a cause of mental ill-health, and mental ill-health resulted in lost productivity and/or associated treatment costs. This finding aligns with growing international evidence that mental ill-health and poverty interact in a negative cycle in LMICs (Lund et al, 2010; Patel et al, 2010; Lund et al, 2013). According to the findings, participation in gainful employment, livelihood or economic activities as well as household responsibilities and support groups, enables wellness and inclusion. Livelihood activities create opportunities for positive social connection, and generate positive emotions, a sense of meaningful use of time, self-efficacy and a positive orientation towards the future. These broader benefits of including livelihood and income-generating activities in inclusion approaches have also been documented elsewhere (Raja et al, 2012; Tew et al, 2012; Lund et al, 2013; Carroll et al, 2016).

Family-centred Approaches
The study also found that reducing exclusion starts in the home. The support of family and significant others was frequently mentioned as important for inclusion. However, not only did those with lived experience need the support
of family, but family and other caregivers also required support. The narratives in this study unveiled family members’ experience of family disruption, social disconnection, compounded economic stress, and mental health changes of their own. Multiple other studies on the effects of mental illness on families from diverse low- and middle-income settings note these effects (Shibre et al, 2003; Corrigan et al, 2006; Lauber & Rössler, 2007; McDaid et al, 2008), underscoring the need for family involvement in support and recovery initiatives (Tew et al, 2012). These data highlight the central role of relationships in recovery and the imperative of building mutual understanding and supportive environments for families and households (Wyder & Bland, 2014; Foster et al, 2016; Price-Roberts et al, 2016). The evidence suggests that this support could be offered through individual and family-based counselling, peer support groups, self-help groups and advocacy group membership (Tew et al, 2012; Price-Robertson et al, 2016; Mathias et al, 2017).

Community Mental Health Literacy

Beyond the home is a further identified sphere of concern, where carer-participants in particular placed emphasis on building community mental health literacy for inclusion. They intimated that raising awareness through information sharing helps communities understand mental health in a different way, and helps counter harmful traditional beliefs and practices, stigma and social distance. Mathias et al (2015), Metha et al (2015), Patel et al (2011) and Pinfold et al (2005) agree that emphasis must be placed on increasing awareness of mental health and associated services/treatment, and positive community attitudes. Kermode et al (2010) also suggest incorporating efforts to support access to treatment alongside efforts to address societal attitudes. They meanwhile warn that an excessively bio-medical, illness-focussed approach may worsen stigma and lead to disease labelling. Notwithstanding this, community-based models that integrate awareness and interventions that address upstream determinants of mental health have a positive impact on clinical and social outcomes (Lund et al, 2010; de Menil & Glassman, 2016; Reid & Alonso, 2018). Therefore, programmes could promote inclusion through integrating community mental health literacy alongside rights-based approaches to treatment, while promoting inclusive activities which address multi-dimensional poverty stressors (Lund et al, 2010; Davis et al, 2013; Lund et al, 2013; Trani et al, 2015; Eaton, 2018).
Strengths and Limitations
This study allowed people with lived experience of psychosocial disability to capture and express their lived experience. Participants said that taking the photos and telling their stories was a positive experience, as they felt heard and supported. Consistent with other Photovoice studies, this methodology appears to have been empowering and capable of enhancing self-efficacy, self-reflection and self-awareness (Han & Oliffe, 2016; Reid and Alonso, 2018). While the study results are important for community-based organisations, programmes and services, the process itself has also been a valuable exercise for participants. This suggests that Photovoice is a feasible methodology as both a tool for research and as an intervention in itself.

This study has limitations as to its broad applicability due to the localised focus. As participants were recruited through the work of local mental health projects, results may differ in other settings where there is less awareness of mental illness and access to support. Despite this, the data adds in-depth understanding of a little-studied population and the themes are reflective of the broader literature.

CONCLUSION
Persons affected by psychosocial disability and their carers highlighted the important role of natural supports (family, friends, access to treatment, nature, religion and safe spaces), meaningful engagement, and community attitudes in supporting or deterring mental health, wellbeing and inclusion. These findings align with literature from the region, placing emphasis on the need for multi-faceted holistic approaches to mental health promotion, recovery and inclusion. It is evident that community-based mental health programmes will have greatest impact by taking an integrated approach that accounts for the three categories of response highlighted in this study – supports, meaningful engagement and broader societal knowledge and attitudes.

ACKNOWLEDGEMENT
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Barriers and Facilitators for Wheelchair Users in Bangladesh: A Participatory Action Research Project

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ABSTRACT

Purpose: People who use wheelchairs face a range of physical, social, and economic barriers to regular participation in their communities. These barriers may be more acute in countries such as Bangladesh which are affected by poverty and often lack the physical infrastructure or resources necessary to create inclusive or accessible environments. This research aimed to identify: (a) the barriers and facilitators to accessibility faced by wheelchair users in Bangladesh; (b) how these barriers affect the inclusion of wheelchair users in Bangladeshi society; and (c) what could be done to improve accessibility and inclusion for wheelchair users in Bangladesh.

Methods: This participatory action research (PAR) project used Photovoice and semi-structured interviews to identify barriers and facilitators to accessibility for people who use wheelchairs in Bangladesh.

Results: Participants mentioned a number of barriers in public spaces, such as roads, missing or inadequate ramps, inaccessible restrooms, and negative attitudes. There were also participants who had made their home environments more accessible with accommodations such as ramps, arrangement of space, and low countertops/work spaces. Women wheelchair users seemed to face greater barriers to access, as compared to men, in a range of community spaces and activities. Participants’ recommendations for improvement targeted government stakeholders and included greater focus on road infrastructure, particularly during flooding in the rainy season, and modifications to the public transportation system.

Conclusion: A key goal of the study was to identify barriers and facilitators, and use the information gathered to promote social change on the ground. Future
research and action should encourage more people to get involved in removing barriers for people with disabilities, in Bangladesh as well as globally.

**Key words:** wheelchair users, participatory action research, Bangladesh, Photovoice, accessibility

## INTRODUCTION

The World Health Organisation (2010) indicates that approximately 65 million people worldwide require the assistance of a wheelchair. Strong evidence from around the world demonstrates that people who use wheelchairs face a range of physical, social, and economic barriers to regular participation in their communities (e.g. Schonherr et al, 2005; Balbale et al, 2017). These barriers may be even more acute in countries affected by poverty, such as Bangladesh, as these countries often lack the physical infrastructure or resources necessary to create inclusive or accessible environments for wheelchair users.

Global human rights treaties, such as the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) have emphasised the importance of “identification and elimination of obstacles and barriers to accessibility” (United Nations 2006, Article 9) for persons with disabilities. Many countries have espoused this commitment to identification and removal of barriers at the national and local levels through national policies on disability. In spite of policy commitments, disparities remain for wheelchair users globally, particularly in the developing world (Burns and O’Connell, 2012). In order to translate policy commitments to action, research may assist in the identification of barriers at a local level and in the communication of these barriers and remedies to policy-makers and other relevant stakeholders. People with disabilities themselves are in the best position to identify these factors, as they encounter the barriers and facilitators to inclusion on a daily basis (Newman and SCI Photovoice Participants, 2010).

This manuscript details the results of a participatory action research (PAR) project that aimed to identify barriers and facilitators to accessibility for people who use wheelchairs in Bangladesh, and to take action to remedy barriers and promote facilitators identified. Specifically, answers were sought to the following research questions:

(a) What are the barriers and facilitators to accessibility faced by wheelchair users in Bangladesh?
(b) How do these barriers affect the inclusion of wheelchair users in Bangladeshi society?

(c) What could be done to improve accessibility and inclusion for wheelchair users in Bangladesh?

Bangladesh is one of the most densely populated countries in the world (1070 population/km²). Recent reports indicate it has a gross national income (GNI) per capita of US$1,314 (National Institute of Population Research and Training and International -NIPORT, Mitra and Associates, 2016). Bangladesh has a relatively high incidence of spinal cord injuries and other disabilities - due to falls from heights, traffic accidents, and physically demanding and hazardous occupations - that require the assistance of a wheelchair for mobility (Rahimi-Movaghar et al, 2013; Villanueva et al, 2017). The Government of Bangladesh has demonstrated strong public support for the inclusion of persons with disabilities in mainstream society. This support includes a national policy on disability, the Persons with Disabilities’ Rights and Protection Act 2013, which is in line with the principles of the UN CRPD (Women with Disabilities Development Foundation, no date). Additionally, Prime Minister Sheikh Hasina has made numerous public proclamations related to the rights of persons with disabilities, including outlining government efforts for greater identification of people with disabilities and provision of social protections and financial support, along with access to health and education facilities (News Bangladesh, 2016).

In spite of a promising political environment for people with disabilities, research still indicates that many people with spinal cord injury (often wheelchair users) in Bangladesh rarely leave their homes, have reduced opportunities for employment, experience poverty, and have secondary conditions such as pressure ulcers (Hossain et al, 2016). Additionally, evidence demonstrates that people with spinal cord injury in Bangladesh report low total community integration and life satisfaction (Ahmed et al, 2017). Researchers have also indicated that people with spinal cord injury, many of whom use wheelchairs, have moderate rates of depression and report limited quality of life (Hossain et al, 2016) as well as lower self-efficacy (which has been linked to depression) (Villanueva et al, 2017). In the light of this situation, there is a necessity for better identification of barriers in the hope that policy-makers and service providers may then direct their attention to facilitate effective interventions and improve the quality of life for this population (Hossain et al, 2016; Ahmed et al, 2017).
METHOD

Study Setting
This study was conducted in different urban and rural regions in Bangladesh.

Study Design
In alignment with participatory action research practices of actively involving representatives of the participant population in all phases of the research process (e.g., Chevalier and Buckles, 2013; Wickenden and Kembhavi-Tam, 2014), Bangladeshi wheelchair users were engaged in all components of the research, from study design and method selection, to data collection, data analysis, and dissemination. It was determined that Photovoice (adapted from Wang and Burris, 1997) would be an appropriate first phase to gather information relevant to the research questions. To expand upon and verify findings in Phase 1, and to gain a richer, detailed description of experiences of wheelchair users, the Photovoice phase was followed by semi-structured interviews in Phase 2.

Phase 1: Photo Taking and Protocol Development

Data Collection
Data for Phase 1 was collected by the three members of the research team who use wheelchairs themselves. Prior to commencing data collection, researchers received training on research ethics and safety, digital camera use, and strategies for taking successful photos. Then, over a period of approximately four months, they took their cameras with them and photographed any barriers and facilitators they encountered in daily life. They would ask for permission before taking photos where any other person was identifiable. Often, photos were not of people but of situations or items (e.g., ramps). Sometimes the researchers would hand over their cameras to a friend or bystander to take pictures of the researchers demonstrating a barrier or facilitator (e.g., trying to wheel up a particularly steep ramp).

During data collection for Phase 1, the team held weekly (and in later months, bi-weekly) meetings to discuss progress of photo taking and to solve any issues as a group. At these meetings, each team member would display his or her favourite photos, on an overhead projector, to the group, and describe: (a) what is depicted in the image, and (b) why they took the image and/or why they believe the image
is relevant to the study research questions. As the meetings progressed, the team identified and documented themes that they saw commonly emerging across photos and across researchers. They would also identify and discuss gaps or experiences that were not yet depicted in the photos but which they believed would be important to capture in the days to come.

**Data Analysis**

On completion of the photo-taking period, the research team met for a final review of the photos that were identified as the “best” or most representative photographs over the previous weekly or bi-weekly team meetings. They worked as a group to sort and categorise all the images. At the end of this exercise, they had identified nine major categories: Roads, Leisure, Toilets, Transportation, Household Accessibility, Gender, Impact of Inaccessible Space, Ramps, and Sidewalks. These categories guided the development of questions for inclusion in a semi-structured interview protocol that would be used in Phase 2 of the research.

**Phase 2: Semi-structured Interviews**

**Data Collection**

Team members who use wheelchairs conducted semi-structured interviews with other wheelchair users. Interviewer choice was intentional, in the belief that interview respondents might be more comfortable or could speak more openly and frankly with people who were also wheelchair users. Before conducting the interviews, team members received training in research ethics, interviewing and interview techniques. Once they were comfortable with the interview questions and confident about their interview technique, the three interviewers went into the community to conduct approximately 6-8 interviews each with other people who use wheelchairs. Participants were included in the study if they (a) used a wheelchair on a daily basis; (b) were older than 16 years of age; (c) spoke Bangla fluently; and (d) were willing to provide informed consent to participate in the study.

Participants were recruited using the network of the Centre for the Rehabilitation of the Paralysed (CRP) in Savar, Bangladesh. CRP is a multi-service centre that specialises in providing support to people with spinal cord injury, and has a range of both inpatient and outpatient services for those who use wheelchairs.
Interviews were conducted at a time and location most convenient to the respondents (at CRP-Savar, Chapain, Arapara, Mirpur, Dhaka). Interviews lasted from 20 - 60 minutes, and were conducted, audio recorded and transcribed in Bangla. Interviewers asked respondents to reflect on their experiences related to the themes from Phase 1 as well as any additional barriers or facilitators not identified in the initial themes. Table 1 presents the interview protocol.

**Table 1: Interview Questions**

1. Could you please tell me about your experience with disability?
   → (probe) When did you get your disability? How long have you lived with a disability?

2. Could you please tell me about how you manage your daily activity and movement as a person with a disability?

3. Tell me about your experience on the roads that you use in your day-to-day life.
   → (probe) What is the type of surface of road that you use regularly (e.g., mud, brick, cement)? How does the type of surface impact you?
   → (probe) Can you tell me about how you use the roads during monsoon season?

4. What about travelling on the sidewalks/footpaths – how do you use these?
   → (probe) What barriers do you face to using footpaths/sidewalks?

5. Tell me about your experience using ramps in your daily life?
   → (probe) How do you use ramps in indoor situations? How do you use ramps in outdoor situations?
   → (probe) Have you ever encountered ramps that you couldn’t use? Could you tell me about that?

6. Tell me about your experience using washrooms?
   → (probe) What do you need to be able to access a restroom? How often do you get this? Where?
   → (probe) Could you talk about using washrooms outside of the home?
   → (probe) Have you ever not attended a location or participated in an activity because you knew you couldn’t use the washroom?

7. Tell me about your experience using public transport?
   → (probe) What kind of transportation do you use?

8. What are the differences between male wheelchair users and female wheelchair users for activities of daily living?

9. How easy is it for you to navigate your home?
   → (probe) What makes it easy/hard for you?

10. Could you tell me about any effects that your disability has on accessing leisure activities?

11. How does accessibility in your environment impact your life?

12. Is there anything else about accessibility that we haven’t already talked about but you would like to share with me?
Data Analysis
The community researchers first participated in two workshops on how to conduct data analysis. These workshops included practice exercises related to categorisation and coding of content. As researchers conducted semi-structured interviews, the research team would come together in regular meetings to share progress, problem-solve any challenges, and identify interesting points or emerging themes. Once all the interviews were transcribed, the Bangla-speaking research team members met to code the transcripts together in Bangla. The research team reached consensus on preliminary themes identified in the coding, and these were then applied independently by four Bangladeshi researchers to all of the transcripts. They met again to discuss their findings, and further reflect on the codes assigned and themes that had emerged. After the group came to a consensus, one Bangladeshi researcher assigned final codes to all Bangla transcripts. During the write-up of the results, the researchers identified a representative quote in Bangla, had this translated into English, and then back translated from English to Bangla to confirm accuracy of the translation.

Ethical Considerations
Prior to conducting this study, ethical approval was obtained from the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB), Queen’s University, Canada and CRP’s Ethical Review Board.

RESULTS
In total, 20 wheelchair users (10 male, 10 female) were interviewed. Participants were between 20 and 48 years of age, and had all been educated to at least secondary school level. While some reported that they had a disability for at least 3 years, there were others with disability for as many as 29 years. The majority of participants (14) were living in urban areas. Most of the participants lived with family members (e.g., husband, wife, father, mother, sister, brother, children), and most of them were assisted by their relatives in activities of daily living. Details of participants’ demographic information are provided in Table 2 below. The results have been organised along three major themes: Major Accessibility Barriers and Facilitators, Effect of Barriers on Daily Life, and Recommended Improvements.
<table>
<thead>
<tr>
<th>Age (in Years)</th>
<th>Gender (M/F)</th>
<th>How long with disability (in years)</th>
<th>Highest level of education achieved</th>
<th>Location of home (rural or urban)</th>
<th>Profession</th>
<th>Who do you live with? (Do they provide assistance in ADL to you?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>32 F</td>
<td>19</td>
<td>HSC</td>
<td>Urban</td>
<td>Service</td>
<td>Husband. (Sometimes.)</td>
<td></td>
</tr>
<tr>
<td>28 F</td>
<td>19</td>
<td>Class-VIII</td>
<td>Urban</td>
<td>Service</td>
<td>Mother and husband. (Both help her in household work.)</td>
<td></td>
</tr>
<tr>
<td>24 F</td>
<td>6</td>
<td>Bachelor</td>
<td>Urban</td>
<td>Student</td>
<td>Living in student hostel. (Sometimes roommates help her.)</td>
<td></td>
</tr>
<tr>
<td>20 M</td>
<td>3</td>
<td>HSC</td>
<td>Rural</td>
<td>Student</td>
<td>Father and mother. (Manages ADL by himself)</td>
<td></td>
</tr>
<tr>
<td>23 M</td>
<td>21</td>
<td>HSC</td>
<td>Rural</td>
<td>Jobless</td>
<td>Father, mother and brother. (Everyone helps in activities of daily life.)</td>
<td></td>
</tr>
<tr>
<td>28 M</td>
<td>6</td>
<td>Bachelor</td>
<td>Urban</td>
<td>Student</td>
<td>With sister and sister-in-law. (Friends and family members help.)</td>
<td></td>
</tr>
<tr>
<td>27 M</td>
<td>10</td>
<td>SSC</td>
<td>Rural</td>
<td>Jobless</td>
<td>By himself.</td>
<td></td>
</tr>
<tr>
<td>25 M</td>
<td>20</td>
<td>HSC</td>
<td>Urban</td>
<td>Business</td>
<td>Father and mother. (They help him with his ADLs.)</td>
<td></td>
</tr>
<tr>
<td>26 M</td>
<td>9</td>
<td>HSC</td>
<td>Rural</td>
<td>Business</td>
<td>By himself.</td>
<td></td>
</tr>
<tr>
<td>22 F</td>
<td>7</td>
<td>HSC</td>
<td>Urban</td>
<td>Student</td>
<td>By herself.</td>
<td></td>
</tr>
<tr>
<td>23 F</td>
<td>8</td>
<td>HSC</td>
<td>Urban</td>
<td>Service</td>
<td>Living with her husband. (Her husband helps her with ADLs.)</td>
<td></td>
</tr>
<tr>
<td>28 M</td>
<td>27</td>
<td>HSC</td>
<td>Urban</td>
<td>Service</td>
<td>Living with his family.</td>
<td></td>
</tr>
<tr>
<td>21 F</td>
<td>9</td>
<td>SSC</td>
<td>Urban</td>
<td>Jobless</td>
<td>Living with her family.</td>
<td></td>
</tr>
<tr>
<td>48 M</td>
<td>29</td>
<td>MBA</td>
<td>Urban</td>
<td>Service</td>
<td>Living with his family. (Everybody in the family helps him.)</td>
<td></td>
</tr>
<tr>
<td>33 M</td>
<td>22</td>
<td>Class-VIII</td>
<td>Rural</td>
<td>Jobless</td>
<td>Mother. (Everyone helps him.)</td>
<td></td>
</tr>
<tr>
<td>33 F</td>
<td>31</td>
<td>Class-VIII</td>
<td>Urban</td>
<td>Student</td>
<td>Mother and brother. (Everyone helps her.)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Sex</td>
<td>Education</td>
<td>Occupation</td>
<td>Residence</td>
<td>Status</td>
<td>Notes</td>
</tr>
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</tr>
<tr>
<td>28</td>
<td>F</td>
<td>12</td>
<td>Class-VIII</td>
<td>Urban</td>
<td>Service</td>
<td>Husband. (Everyone helps her.)</td>
</tr>
<tr>
<td>40</td>
<td>M</td>
<td>13</td>
<td>Class-VIII</td>
<td>Urban</td>
<td>Service</td>
<td>Wife and son. (Everyone helps him.)</td>
</tr>
<tr>
<td>35</td>
<td>F</td>
<td>29</td>
<td>Class-V</td>
<td>Rural</td>
<td>Tailoring</td>
<td>Husband (Everyone helps her.)</td>
</tr>
<tr>
<td>27</td>
<td>F</td>
<td>5</td>
<td>HSC</td>
<td>Urban</td>
<td>Service</td>
<td>Mother, father and brother. (Everyone helps her.)</td>
</tr>
</tbody>
</table>

**Major Accessibility Barriers and Facilitators**

Accessibility barriers identified by the interview participants primarily included barriers within the built environment. Participants confirmed the findings of Phase 1 of the research and identified barriers in infrastructure related to roads, sidewalks and ramps, transportation, and restrooms.

**Roads, Sidewalks and Ramps** - Participants reported that they experienced the greatest challenges to accessibility during the rainy season, when many roads became flooded. They stated that flooded roads make it “difficult to move” in their wheelchairs. Moreover, they said they did not want to navigate when the water on the roads was deep as they could get wet, dirty, or sick as a result. Participants also reported that flooded roads concealed great hazards to wheelchair users – such as open holes, broken tarmac, or uneven pathways that could lead to falls and/or injuries.

> “Many of our roads are flooded when it rains. We cannot get out from our homes. When water drains away from the road, the sticky mud will remain. Those roads become inaccessible for wheelchair users as there are holes and many different problems arise.”

Apart from challenges related to roads in the rainy season, one participant shared that she did not feel she was in control of her wheelchair on uneven roads. A number of other participants pointed out challenges on busy roads where there were both big (trucks) and small (rickshaws) vehicles to be avoided and limited to nil access to sidewalks (“footpaths”) to help the wheelchair users stay out of harm’s way. On the subject of sidewalks, participants complained that these were elevated above street level, making it impossible to roll onto in a wheelchair. Others complained that shop owners set out their wares on the sidewalk, so that it was not possible to roll through on a wheelchair.
Although participants mainly shared barriers, some of them also mentioned how roads were facilitators for their accessibility. In particular, concrete urban roads were seen to be conducive to accessibility.

“Since I was inside a municipality, I had no problem with the road. As we used to travel in a van, it was not a problem. The road was absolutely good, not too bad. Being home inside a municipality, I used concrete roads.”

Additionally, many participants stated that they were able to move and navigate inaccessible roads with help from others, such as family members or paid helpers.

Ramps - Linked to road infrastructure, many participants also reported the importance of ramps to help them navigate their environments.

“Suppose I go somewhere where I need to say in a guest house. If there is no ramp or if they accommodate me in a room on the 1st or 2nd floor, then it will be almost impossible for me to stay there.”

Participants not only noted the presence or absence of a ramp as a facilitator or barrier, but they also remarked that not all ramps are created equal: they lamented about ramps that were in “poor condition” or too steep to wheel up independently.

“The ramp made at City Centre (shopping mall) is too high. It needs two people to go up the ramp, one in the front and one in the back. The ramp needs to be wider and start much further back.”

Inappropriately constructed ramps were a major feature pictured in many of the photos taken by the researchers in Phase 1 of the study.

Transportation - Participants reported using a range of transportation options to navigate their daily lives: from rickshaws to CNGs (auto rickshaws), to public buses and private vehicles. A majority of participants reported that they “cannot use” public transportation, either because of physical inaccessibility, such as needing a ramp to get up into the bus independently, or due to negative attitudes, such as when a transport conductor ignores the wheelchair users or refuses them entry even when there are vacant seats on the bus.

“I can’t use public transport. Sometimes it is seen that public transport does not even stop for people who use wheelchairs like us, don’t give time for us to get in. If we get in, we need help to be lifted up to get in.”
Participants reported that large crowds of people were also a great barrier, as it became near impossible to compete with people pushing to access the bus and they would be left behind.

Participants mentioned their preference for using private vehicles to move around the community; however, a number of them reported that they did not have the financial means to be able to do this. Some participants reported that they were able to use rickshaws and autorickshaws/CNGs, whereas others reported that they could not get into these forms of transportation with their wheelchairs.

As with the use of roads, many participants stated that getting help from others, either from a family member or hired ‘helper’ or from the driver or conductor of a public transport, was an important facilitator in their being able to get around and use transportation.

“To use public transportation, I need the help of others. I can’t get in without the help of others. There are many problems. I can’t get in by myself. The wheelchair needs to lift after folding, it is very difficult. I need to take help of others all the time to get in. The vehicles are crowded so it is difficult to get in.”

Although many participants stated that getting help from others was a facilitator, for one participant the fact that she always needed help from others to get into public transportation was actually a barrier to going out of her home.

“To go anywhere, I need public transportation but I cannot use public transportation. It is very difficult… and to go anywhere, I create a burden for other people. They also have their work. They can’t help me all the time.”

Toilets - Most participants stated that the restrooms in their homes were accessible due to adjustments and adaptations such as adding ramps, bringing in stools, and widening the doorway.

“I have an accessible bathroom. I can do everything myself. When I am at home, I usually do not face any problems.”

Outside their homes however, accessing toilets was a challenge for every participant. It was commonly reported that many toilets were impossible to access, either because there were stairs or a step up into the restroom without any ramp, or because the door was too narrow for the wheelchair to fit through. If they were able to get through the door, participants reported that common lower commodes (“squat” toilets) were more difficult to use than the high commodes.
Challenges related to restrooms not only included physical inaccessibility, but also the level of cleanliness within. Participants reported that when the restrooms were physically inaccessible, they needed to lower themselves onto the floors, but the lack of cleanliness made it unsanitary and unhygienic.

“Get down directly from the wheelchair seems risky to me… Bathrooms are very dirty and my wheelchair gets stuck at the door.”

Most participants could clearly and easily identify the features of restrooms that were facilitators in terms of accessibility. Many participants identified that access to restrooms with ramps, wide doors, high commodes, and ample space for moving about within, greatly facilitated their willingness and ability to participate in their community. Participants also reported the convenience of toilets that had low taps and wash basins for easy hygiene. A number of participants specifically mentioned the Mirpur National Stadium and the CRP as locations where they found environments particularly accessible for persons with disabilities both in terms of toilets and ramps.

**Attitudes -** Going beyond the categories identified in the photographs, interview participants also discussed attitudes as being a major barrier to accessing society. Some participants reported that attitudes vary, with some people treating them just like everyone else, and others treating them differently because they use a wheelchair.

“I live in a village. There are some people who do respect me as a person with disabilities and some people who treat me like ‘who are they, they are disabled, are they human?’ Some people give value, some not.”

A couple of participants described pitying attitudes as barriers to their participation in the community: They stated that they avoided going out of their homes and to public places like the market because they did not want to face people who treated them with pity. Others reported that people around them discounted their perspectives and point of view, and this became a barrier.

“We face obstacle both in movement and in speaking – no one wants to accept our opinions. They always dishonour recommendations by saying ‘a disabled person cannot say anything meaningful’.”

Many participants lamented that attitudes created a barrier for them in terms of accessing opportunities for education and employment. For example, one participant shared that her family blocked access to education for her, because
they did not think it was an appropriate use of resources for the future of a wheelchair user. Another participant believed that attitudes were a barrier for wheelchair users to procure employment or to advance in the workplace if they are employed.

“If a person in a wheelchair goes for an interview, the authority does not take it positively. They think wheelchair means beggar or something like that... If a disabled person does get a job, they are deprived of a promotion. They are doing excellent performance but they are treated negatively.”

Sadly, a participant who was self-employed stated that because he was a wheelchair user, people in the community would steal from him, making assumptions about his incapability to demand payment and effectively denying him access to dignity and income.

“My business has become bad... Those who eat, don’t pay. I could not go to them. If they are willing to pay, then I get the money. Otherwise, I have no ability to get my money back.”

These then are the major barriers and facilitators, and participants went on to discuss the effect these had on their daily lives.

**Effect of Barriers and Facilitators on Daily Life**

Participants reported a range of issues connected to the barriers they identified.

A couple of participants stated that they sometimes remained in their homes for up to 4 days at a stretch, and one participant mentioned only leaving home once or twice a week in the rainy season. A number of participants referred to being “trapped” or “prisoners” due to the road conditions.

“In the rainy season, I do not leave my home. From morning to evening, evening to night, night to morning, I spend all the time in my room. It feels like years later when I am able to see the sky, take a breath of fresh air. I always say that I am a prisoner surrounded by walls. Cannot see the sky, cannot feel the sunshine.”

Apart from road conditions, almost all the participants reported that inaccessible toilet facilities caused significant isolation from their communities in a range of different sectors. Finding an accessible toilet would be a major preoccupation during any outing outside the home. Some participants reported missing education or employment opportunities due to inaccessible toilets. One participant reported that he was unable to attend school regularly due to the
inadequate restroom facilities, and only turned up for exams; even so, it was challenging. Another participant reported dropping out of school at eighth grade due to accessibility issues.

“I studied up to the eighth grade. I did not continue my studies because our school is not accessible to wheelchairs. Also, there is no ramp. My school is far away from my home. When I entered my classroom, there are stairs. It is very tough for me… In these circumstances, I don’t feel any interest to continue my studies.”

Participants mentioned that they missed out on a range of social and leisure opportunities in their communities, including attending concerts, going to shopping malls, visiting relatives, and participating in cultural events, largely due to inaccessible toilets.

“I do not go outside. I mean, I don’t go to my relatives’ house. I don’t go anywhere, I don’t travel anywhere. I have three sisters, they invite me to go but I don’t. Because I have one problem: if I need to use the toilet, then where do I go? … My brother does not come to see me, but he phones me and asks me to go to his place but I don’t go.”

Some participants shared instances where inaccessible toilets had caused them health problems such as urinary tract infections.

“I went to a programme related to people with disabilities and I went there in the morning. I became too restless because I couldn’t go to the toilet there. Later, I returned at 8 pm. My urine got stopped that time and then I need to spend 3000 taka (US$36.15) for medical treatment…”

In addition to losing opportunities for education and employment due to poor toilet facilities, some participants also blamed the missed opportunities on a lack of ramps in these community spaces.

It was revealed at the interviews that wheelchair users also face barriers that are related to their gender. Some participants raised issues of gender-based violence and personal security for women wheelchair users, reporting that they believed women in wheelchairs were at greater risk for violence. One participant also observed that female peers would be left by their husbands on getting injured, but “if a man became disabled, then he is still in the village, his family is still with him”. In Bangladesh, it is not typical for non-related males to touch women. Therefore, women wheelchair users faced even greater challenges when going out of home because if they needed assistance to be lifted or transferred, they could not ask the people around them for help.
this reason, women wheelchair users seemed to be doubly disadvantaged in the matter of navigating their communities.

“(For) a female, it is not possible to move in the road, which is easy for me (a male). Our society’s system is like this… You can see that when any person in a wheelchair gets into the roads, others stare at him with questions in their eyes and this will normally be double for females.”

***

“The problem of women is more than men. If she wants to go somewhere, she cannot go without her own people. In this situation, a male person can take any person to go somewhere. A male disabled person can complete his toilet anywhere but a female cannot do so.”

As alluded to in the above quote, a number of participants highlighted how females face even greater barriers, in particular when it relates to toilet accessibility. Barriers relate to biological differences, which make it easier for some men in wheelchairs to relieve themselves discreetly and from a sitting position, unlike women, or to issues of modesty for women which are more tied to gender norms. This means that even though both men and women experience reduced access in the community, for women this reduction is often even more acutely experienced.

“I do not go to social events because I have difficulty accessing them. Once, I visited an event but faced many problems in using the toilet. In an emergency situation I soiled my dress. So, now I don’t take part in programmes.”

Interestingly, on the subject of facilitators, a large number of participants reported experiencing greater independence and accessibility in their home environments, as they had made modifications and removed barriers to make life “easy”. Modifications often related to construction, creating accessible toilets, and using ramps to help access different spaces in the home.

“In my home, I am independent. I do all my tasks like move around, use the toilet, use the tube well, etc. By setting up a ramp, it is very easy for me to do my work.”

Home modifications ranged from very simple arrangements such as ensuring clear spaces and limited clutter and creating simple ramps, to more complex or expensive modifications including renovating or constructing new homes or moving spaces to create a more accessible home environment.
“I made my house terraced so I can move alone. Before, I did not have a concrete house. That time I was facing lots of problems. Last ten years I was living in one room. I could not move to another room... But now my home is accessible for people with disabilities to move easily. Besides, I made a ramp also. So it is very easy for me. I feel happy.”

Coping

In spite of the many challenges, participants also reported developing a range of strategies to cope with the barriers, thereby enabling them to navigate daily life outside their homes. These strategies included personal adaptations, requesting help from others, and explaining accessibility in utilitarian terms to others.

In relation to personal adaptations, one participant remarked that although his movements are restricted in the rainy season, “but, if any kind of need arises (when he needed to get out), I just carry some water to wash my hand and start my journey again”.

A number of participants reported coping with inaccessible restrooms by using a urine bag.

“I buy a small plastic bag. When I go out, I urinate in the bag. In this way, I manage to solve the problem of going outside. I couldn’t enter the restroom many times. I might get stuck and have to urinate at the door. I mean, this is a bad situation to get into and there are many restrooms like this.”

Another noted that she takes off her shoes and puts them on her hands to navigate dirty restrooms. Yet another participant reported that he fasts when he goes outside the home so as to avoid using the restroom.

“When I go outside, I do not take food. I fast. I try not to eat food outside. Always, I think if I get any pressure then what will I do because the toilet is not accessible for a person who uses a wheelchair. If I face any problems, it is very embarrassing. That is why I usually won’t take any meals.”

To try to overcome and navigate barriers, many participants reported that they need to interact with people in the wider community. To that end, participants discussed accessibility and their needs for accessible environments with the community, using language related to universal design, noting that accessible environments are good for all people, not just people who use wheelchairs.
“I would like to say that a person without disabilities goes up stairs and I use a ramp to go up. But the person without disabilities can go up the ramp so it is not necessary to build separate stairs… then he can go up and I can also go up, I will not be disadvantaged.”

Furthermore, participants counteracted actions emanating from pity or sympathy by standing up for themselves and explaining to people that they were fine, and that people with disabilities can do just as well in life as anyone else.

“Everybody used to ask about my disability and show their sympathy. It would be hard for me. But now, if anybody comes to show their sympathy, I tell them that there are lots of people like me. Still, they are alive, some of them are working in very good positions. I am inspired from them. I believe we can work even better than a non-disabled person.”

DISCUSSION

This article shared the results of a participatory study that sought to understand barriers and facilitators to accessibility for wheelchair users in Bangladesh, and the effects of those barriers on daily life. Participants mentioned a range of barriers in public spaces, such as roads, missing or inadequate ramps, inaccessible restrooms, and negative attitudes. They also experienced living in highly accessible home environments, by making accommodations such as ramps, arrangement of space, and having low countertops/work spaces. Women who used wheelchairs seemed to face greater accessibility barriers as compared to men, in a range of community spaces and activities.

The findings of this study indicate that people who use wheelchairs in Bangladesh are denied access to basic human rights, as enshrined in the UN CRPD (United Nations, 2006), such as accessibility (Article 9), living independently and being included in the community (Article 19), personal mobility (Article 20), and education (Article 24), among others. Given that the Bangladeshi government is a State Party of the CRPD, future action must seek to remedy and address these gaps in the implementation of the CRPD in the country. This study also provides empirical evidence and concrete examples of how women with disabilities experience dual disadvantage, often termed “double discrimination” (Habib, 1995) by gender and disability scholars. This study’s findings indicate that future government and civil society efforts to improve and promote the rights of persons with disabilities in Bangladesh must take on a gendered perspective in order to effectively address the challenges of the whole population.
Global literature indicates that many people who use wheelchairs, such as those with spinal cord injuries, will require varying degrees of assistance to perform activities of daily living, such as eating, dressing, and mobility (Nas et al, 2015). Many of those who provide caregiving duties are often family members who engage in caregiving and assistance to their family member, with little training or support (Nogueira et al, 2013). In this study, many participants highlighted the need to rely on others to help navigate their environments. This reliance on others was sometimes communicated in terms of it being a facilitator (e.g., “if I have someone to help me, I don’t experience any challenges”) and sometimes a barrier (e.g., “if I need to rely on or bother someone in order to move around, I will simply avoid moving around”). This indicates a tension as well as a potential future area of exploration, as interventions to support inclusion and social participation of wheelchair users must not only focus on the built environment, but also on personal assistance, assistive technology, and health promotion and fitness (Myers et al, 2002). Future research could seek to understand the role of informal and formal caregivers and helpers for persons who use wheelchairs in Bangladesh, including how personal assistants, aides, and carers are recruited, supported, financed, trained, etc., as well as understanding their experiences, perspectives and needs as it relates to supporting persons with disabilities.

It is interesting to note that although many of the themes of the study were captured in the initial phase of the study (Photovoice), one major theme – attitudes - was only uncovered during the second phase of the study, after researchers had an opportunity to probe deeper into the experiences of wheelchair users in Bangladesh. This may indicate that although Photovoice is an important and useful tool for participatory research approaches, it may be necessary for studies using this tool to probe more deeply and integrate different data collection methods to provide a holistic perspective of the issue under study.

Finally, in discussing the results of the current study, it is of utmost importance to highlight the agency and ingenuity of participants in creating accessible home environments. Many people discussed the specific accommodations and adaptations they were able to make in the environments over which they had control, such that they were able to live, participate, and interact at home on an equal basis as peers who did not have disabilities. In the light of this, it is suggested that any future efforts to improve public accessibility in Bangladesh should actively and meaningfully involve wheelchair users in the development and implementation of solutions – indeed they are the true experts and many
have already proven that they are able to successfully and sustainably identify, remove, and mitigate barriers that they face in their environments.

**Limitations**

First, although this study was conducted among participants from urban and rural regions in Bangladesh, most of the participants were recruited based on their connection with CRP (e.g., service user, employee, former client). Thus, the population studied may be skewed towards people who are familiar with disability rights and accessibility by virtue of their engagement with this organisation and the services it provides. Additionally, although recruitment was structured to include a diversity of perspectives, many participants came from the capital city of Dhaka, and thus the perspectives of city-dwellers may predominate. Also, because photos guided the questions that were selected for interviews, this study may have been skewed towards the more observable environmental issues, rather than less tangible barriers and facilitators. In spite of this limitation, interview responses were still able to uncover some intangible components (e.g., attitudes, gender).

**CONCLUSION**

This study provides an insight into some of the barriers and facilitators faced by wheelchair users in Bangladesh and the effect that these barriers have on their lives. However, this study is only the initial effort, since the goal was not only to identify and study these issues but also to use the gathered information to promote social change on the ground. In addition to sharing the results with an academic audience, the plan is to disseminate the results of this study in a range of accessible formats for stakeholders and change-makers, including people with disabilities, community members, and policy-makers, through a series of photo exhibitions, posters, and discussions in Dhaka and surrounding areas. It is hoped that future research and action will encourage more people to get involved in removing barriers for people with disabilities in Bangladesh and globally. Everybody has a responsibility to act.

**ACKNOWLEDGEMENT**

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REFERENCES


A Cross-sectional Survey of Rehabilitation Service Provision for Children with Brain Injury in Selangor, Malaysia

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ABSTRACT

Purpose: Rehabilitation services in Malaysia are provided by both governmental and non-governmental agencies but there are challenges, such as the lack of integration between agencies, and accessibility barriers to services especially for the population of urban poor and people in the rural areas. With the help of a survey, this project aimed to gain a better understanding of rehabilitation services provided for children with brain injury within the state of Selangor and Federal Territories of Kuala Lumpur and Putrajaya.

Method: A list of 205 organisations that provide rehabilitation services for children with neurological injuries was compiled. The researchers attempted to verify the services by visiting the facilities or via telephone or email communication if visits were not possible.

Results: The researchers were able to verify 83% of the organisations identified. There are 40 hospitals and 17 service providers for acute and/or chronic physical rehabilitation services for persons with disabilities of all ages, including children.

Conclusion: Findings showed the unequal distribution of rehabilitation service provision by districts. Service providers were concentrated in the urban areas. Setting up new healthcare facilities is one of the solutions but the costs for development, construction, and manpower could be high. An alternative solution is proposed, namely, the use of a home-based virtual rehabilitation programme.

Key words: availability, accessibility, unequal distribution

INTRODUCTION

Effective physical rehabilitation requires active and repetitive training (Ministry of Health, 1999; Galvin et al, 2011) although the training parameters in various
rehabilitation programmes differ in terms of intensity, types of therapy, duration of training, and training conditions. Hellweg and Johannes (2008) concluded from their systematic review that intensive rehabilitation programmes result in earlier and better functional abilities among clients with traumatic brain injury or TBI. The guideline from Virginia Health System (Virginia Commonwealth University Medical Centre, 2014) suggests that acute rehabilitation should involve 30 - 90 minutes of therapy per day, five to seven days a week, and outpatient therapy should involve 30 - 120 minutes of therapy per day, three days a week. This would necessitate frequent professional inputs and many contact hours to achieve the optimum outcome. Unfortunately, this kind of intensive rehabilitation is not always achievable given the current rehabilitation resources.

This paper focusses on the provision of physical rehabilitation services in Malaysia. The following section discusses the current situation of rehabilitation service provision, specifically about what the public and private healthcare sector can offer. Subsequently, the issue of availability is illustrated through the gap between the demand for services and the restrictions within the health workforce; while the issue of accessibility to healthcare services is exemplified by the physical barriers such as distance to healthcare facilities and lack of transportation.

**Service Provision in Malaysia**

Rehabilitation services in Malaysia are provided by both governmental and non-governmental agencies. Public and private hospitals, health clinics, Community-based Rehabilitation (CBR) centres, and non-government organisations (NGOs) provide various levels of services - from consultation, treatment, acute and chronic interventions to home-intervention. The challenges pertaining to these service provisions are the lack of integration between agencies, the availability of services and skilled professionals, accessibility barriers to services especially for the urban poor population and people living in rural areas, and affordability of services (Amar, 2008; Balakrishnan and Kumaresan, 2014; Dzalani and Shamsudin, 2014). This paper lays emphasis on the availability and accessibility of the rehabilitation services. Availability of healthcare refers to the adequacy of the supply of services and resources to meet the needs of clients (Penchansky and Thomas, 1981). Accessibility refers to the ease of access to the location of service provisions, taking into consideration other logistics factors such as distance, transportation resources and travel time (Penchansky and Thomas, 1981).
Within the public sector, rehabilitation services such as physiotherapy or occupational therapy are mainly available at state and national hospitals, and at certain district hospitals. Although not all hospitals have rehabilitation wards, they would have rehabilitation units providing outpatient services. CBR centres have been set up nationwide as a ‘one-stop’ generalist centre for persons with disabilities. The services provided include diagnosis, rehabilitation, treatment, special education and vocational training. However, the available services vary from centre to centre, depending on the availability of funding and trained staff or therapists. In fact, many centres were underperforming due to the lack of skilled manpower supply (Balakrishnan and Kumaresan, 2014).

Most private hospitals do offer various rehabilitation services, depending on the size and structure of the healthcare facilities. As for the NGOs, many centres are set up with the aim of providing early intervention, learning, training programmes and rehabilitation services for persons with disabilities, inclusive of children. However, the services offered lay emphasis on early intervention and education training, with less physical rehabilitation services. The actual number of services is not available as there is still a lack of integration between relevant stakeholders (Amar, 2008; Balakrishnan and Kumaresan, 2014).

The improvement in the Malaysian healthcare sector has led to a decline in the mortality rate. Advances in technology and medical services have resulted in individuals surviving from severe injuries, unlike before. However, these survivors are left with more severe and complex disabilities. Consequently, the demand for rehabilitation has increased (Ministry of Health, 2010a). There is a considerable lack of physiotherapists and occupational therapists (Ministry of Health, 2010b, 2017a) due to the low intake of trainees for training (Ministry of Health, 2010a). In addition, training is long and once training is completed the lure of the private sector is stronger. This has further contributed to the imbalanced distribution of manpower (Ministry of Health, 2010b). The high demand, coupled with the continual migration of clinicians from the public to the private sector, has resulted in a heavier workload for an already stressed public sector which currently caters to 60% of the population. Consequently, public healthcare is struggling to ensure sufficient contact time with clients (Ministry of Health, 2010b).

It is estimated that approximately 80% of people with disabilities worldwide live in low- and middle-income countries, with only 2% having access to rehabilitation services (Puvanachandra and Hyder, 2009). In addition, the geographical dispersion of population, especially in rural areas and in developing countries,
poses another important logistics problem in accessing healthcare services. Allied health professionals including physical therapists are generally available at urban centres (Barnes, 2001; World Health Organisation, 2011). Lack of transportation is another common barrier in accessing healthcare, and the impact of transportation barriers may be higher among persons with physical disability and impaired mobility. The limited access to healthcare services outside of urban areas makes it costly and impractical for rural communities (Bury, 2005; World Health Organisation, 2011). In Malaysia, about 32% of the total population lives outside major cities, hence the lower levels of accessibility to healthcare services (Ministry of Health, 2010a).

The inadequate services, lack of professionals and resources, and the physical and communication barriers, coupled with the high demand for rehabilitation services, have compromised the ability of current healthcare service providers to deliver optimum rehabilitation. Improvement, expansion and diversification of the current healthcare system are necessary to ensure improved accessibility to healthcare services and to ensure its effectiveness (Ministry of Health, 2010b). Therefore, proper planning, design and implementation of a healthcare system are fundamental to maximise its potential.

**Objective**

This project aimed to review the provision of physical rehabilitation services for children with brain injury so that the information gained could contribute to better rehabilitation planning by the relevant stakeholders.

**METHOD**

**Setting**

The survey was carried out from January to April 2014, within the state of Selangor and Federal Territories of Kuala Lumpur and Putrajaya (SFT) in Malaysia.

**Design**

It was designed to gather information regarding the provision of physical rehabilitation services within SFT. A list of organisations that provide services for children with neurological injuries was compiled. Multiple means were employed to identify and list the service-providers through researchers’ knowledge, internet
searches and the snowball sampling method. The organisations were categorised as hospital, government, or non-governmental centres.

Procedure
The researchers decided on a list of questions for the survey (see Appendix). The questions included some basic organisational details, to identify target group(s) and services offered, funding sources, and human resources information if available. The same document was used as a template to record the information gathered throughout the survey.

Inclusion criteria:
(i) Public/private hospitals which provide medical services including rehabilitation;
(ii) Rehabilitation centres;
(iii) Non-governmental organisations involved in rehabilitation;
(iv) Organisations based within SFT.

Exclusion criteria:
(i) Specialty hospitals, e.g., maternity hospitals and dialysis centres;
(ii) Non-governmental organisations which provide care and services solely for orphans, underprivileged individuals, and/or old folks;
(iii) Organisations based outside SFT.

A list of service-providers was compiled before executing the survey. Information related to services provided by hospitals and CBR centres were obtained from the respective websites. On the assumption that hospitals and CBR centres under the public sector are genuine establishments, the researchers attempted to verify information related to non-governmental agencies only. Thus, the researchers started by contacting the centres for an appointment to visit the facility whenever possible. If visiting was not possible, attempts were made to obtain information via telephone or email communication.

Data Analysis
All information gathered through the survey was tabulated in Microsoft Excel. Frequency analysis was conducted to obtain an overview of data collected.
Since this survey included all types of rehabilitation services for children with neurological disabilities, the data relevant to physical rehabilitation was extracted subsequently. Further analysis was conducted to examine the distribution of services within SFT, using the estimated incidence of children with brain injury (Tay et al, 2016) and the reported population density per district (Department of Statistics, 2015) as reference points.

RESULTS

The researchers attempted to verify all the NGOs (N=205) within the survey period. The 50 establishments that were already known to the researchers were not contacted. The remaining 151 establishments were contacted either via telephone or by email, and subsequently 59 of them were visited. The services of some centres were not verified as they were not cooperative or were unwilling to share information with the researcher. Despite their best efforts, the team was not able to verify 35 (17%) non-governmental organisations or associations identified (Figure 1).

Figure 1: Progress of Survey – Flowchart depicting Number of Centres verified or not verified
Table 1 shows the public and private hospitals and non-governmental centres that are providing rehabilitation services for children with brain injury, and their financial set-up according to districts. There are 40 hospitals and 17 service providers offering acute and / or chronic physical rehabilitation services for individuals of all ages, including children within SFT. Of the 17 NGOs, only three centres were not-for-profit centres. The Federal Territory of Kuala Lumpur and Petaling district have the highest number of services. Despite the number of services, the majority were from fee-for-service providers. Furthermore, there were no rehabilitation services in the Kuala Selangor district and Sabak Bernam district.

### Table 1: Rehabilitation Services and Financial Set-Up

<table>
<thead>
<tr>
<th></th>
<th>Public hospital</th>
<th>Private hospital</th>
<th>Non-governmental centre/association</th>
<th>Total (%)</th>
<th>Ratio Centre: Client</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not FP*</td>
<td>FP</td>
<td>Not FP</td>
<td>FP</td>
<td></td>
</tr>
<tr>
<td>Kuala Lumpur</td>
<td>2</td>
<td>14</td>
<td>1</td>
<td>5</td>
<td>22 (38.6%)</td>
</tr>
<tr>
<td>Petaling</td>
<td>9</td>
<td>2</td>
<td>7</td>
<td></td>
<td>18 (31.6%)</td>
</tr>
<tr>
<td>Hulu Langat</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
<td>6 (10.5%)</td>
</tr>
<tr>
<td>Klang</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td>4 (7.0%)</td>
</tr>
<tr>
<td>Gombak</td>
<td>1</td>
<td></td>
<td>1</td>
<td></td>
<td>2 (3.5%)</td>
</tr>
<tr>
<td>Kuala Langat</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>1 (1.8%)</td>
</tr>
<tr>
<td>Kuala Selangor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Sepang†</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
<td>3 (5.3%)</td>
</tr>
<tr>
<td>Hulu Selangor</td>
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<td></td>
<td></td>
<td></td>
<td>1 (1.8%)</td>
</tr>
<tr>
<td>Sabak Bernam</td>
<td></td>
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<td></td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Total (FP)</td>
<td>29</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Not FP)</td>
<td>11</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*FP = For profit.

†Hospital Putrajaya is included based on the geographical location.
Figure 2 shows the distribution of rehabilitation services with Kuala Lumpur set as the centre for reference. Approximately 83% of these hospitals and centres are located within a 20 kilometre (km) radius from Kuala Lumpur and 97% are located within a 40 km radius from Kuala Lumpur (Figure 2). There are only two district hospitals (3%) that provide rehabilitation services that are located more than 40 km away from the city centre. This implied that service provisions were not evenly distributed or easily accessible.

**Figure 2: Distribution of Rehabilitation Services**

The unshaded area represents the state of Selangor and the Federal Territories of Kuala Lumpur and Putrajaya. The blue circle indicates a 20 kilometres radius and the orange circle indicates a 40 kilometres radius from Kuala Lumpur city centre.

Despite the concentration of service providers in districts with high population density and higher incidence, such as Petaling, Klang, Gombak and the Federal Territory of Kuala Lumpur, the number of clients per centre demonstrates the unequal distributions of services, with centre to incidence ratio ranging from 1:2 to 1:9 (Table 1). The centre to client ratio of 1:2 in the Federal Territory of Kuala Lumpur and Petaling districts suggests that these two districts have relatively
more rehabilitation centres, even with their higher incidence rates, as compared to other districts. In contrast, other districts with high population density such as Klang and Gombak had the ratio of 1:6 and 1:9, implying the rehabilitation service centres in these two districts cater for 3 to 5 times more clients than in the Federal Territory of Kuala Lumpur and Petaling districts.

**DISCUSSION and IMPLICATIONS**

This survey highlighted the unequal distribution of rehabilitation services within SFT. These services were not widely dispersed across the states, and most of them were located within a 20 km radius from the city centre. Subsequently, this might negatively affect the availability of and accessibility to these services for the population in need of rehabilitation.

The study found that rehabilitation services were generally available in hospitals and health centres that were situated relatively close to the city centre, while there is limited provision in the suburban or rural areas, leading to unequal distribution of services. The situation is often exacerbated by skills shortages. It was beyond the scope of the research team to obtain further information on the therapist to client ratio in these identified centres and hospitals. However, according to Malaysia’s Health Human Resources report, there were only 4.5 and 3.4 physiotherapists and occupational therapists respectively per 100,000 population in 2014 (Pathmanathan, 2015). This ratio was way below other countries such as Singapore, with a ratio of 30 per 100,000 population (Ministry of Health Singapore, 2017), and Australia, with a ratio of 121 per 100,000 population (Physiotherapy Board of Australia, 2017). The under-provision will be more glaring if one compares the health expenditure as a percentage of gross domestic product (GDP) (World Health Organisation, 2017b). Total health expenditure of GDP was 9.4% in Australia, yet understaffing of allied health professionals was still evident (Adams et al, 2015). In comparison, Malaysia had a total health expenditure of GDP of 4.2%, thus understaffing was expected to be more prominent.

Accessibility barriers due to travel distance were observed in this study. In cases where individuals live at a distance from the urban centre, the travel distance to the service providers can be as much as 60 - 100 km or more, depending on the route taken. Although the national average travel distance from a rural household to the nearest healthcare facilities was estimated to be about 11.2 km, these rural healthcare facilities usually focus on primary care such as maternal and child
health, immunisation, nutrition, dental health, treatment of common illnesses, etc., (Ariff and Teng, 2002). Specialised healthcare services such as physiotherapy and occupational therapy are not available; hence individuals requiring such services will have to travel further, as reflected in the study. Moreover, transportation is another common barrier in accessing healthcare services, but that topic is beyond the scope of this discussion.

Findings from this survey revealed that the distribution of service provision and demand was not matched to population. The number of applicable services was highest in the 2 most developed districts, while the number decreased significantly in other urban, suburban, or rural districts. Extrapolating from current findings, it is anticipated that the disparity and inadequacy of service provisions will be greater, if not similar, in other less-developed states or regions of Malaysia. This postulation is based on two indicators, namely, the number of hospitals per population (Sivasampu et al, 2015) and population density in all states within Malaysia (Department of Statistics, 2015; Sivasampu et al, 2015). Besides the state of Penang, Selangor has the highest number of hospitals per 100,000 population. Despite these numbers, the under-provision of applicable services has been demonstrated by this survey. Consequently, this situation is expected to be worse in other states with a lower number of hospitals per 100,000 population or with a wider dispersion of population, notwithstanding other confounding factors.

The unequal distribution of rehabilitation service provision by districts has been highlighted in this study. In order to increase the availability of and accessibility to services, the solution is to build and set up more rehabilitation centres or hospitals that provide such services in rural areas. However, this may not be a cost-effective solution as the number of brain injury clients is relatively lower in rural areas. A proposed solution is to provide a remote-monitoring virtual rehabilitation programme. With proper planning and implementation, a remote virtual rehabilitation programme may be a better approach to reach out to the wider community and to deliver the intervention at a lower cost.

One of the ways to overcome these issues is through the use of technology. In Malaysia, there is a growing trend towards telehealth (teleconsultation), by utilising information and communication technology initiatives within the healthcare services (Ministry of Health, 2010b). Healthcare service providers are encouraged to maximise the use of information and communication technology initiatives in their operations as a means of enhancing efficiency, accessibility
and productivity (Ministry of Health, 2010b). Although this comes with a cost in training, maintenance of the system and infrastructure redesign, the direct benefits of utilising information and communication technology in healthcare services can be observed in an improved healthcare delivery system (Ministry of Health, 2010b).

**CONCLUSION**

A survey was conducted to understand the state of physical rehabilitation services for children with brain injury in Malaysia. The findings showed that the provision of rehabilitation services was highly concentrated in the urban areas, while the availability of services decreased by more than half in the other suburban or rural areas. From the map view, it is apparent that the majority of the services are situated close to the city centre and in the areas with larger population size. This implies the unequal distribution of services, and hence raises the issues of availability and accessibility especially to those who live some distance away from the city. Additionally, it was found that besides public hospitals, a majority of the services identified were fee-for-service. Consequently, this raises the issue of affordability among the public.

Putting together these findings, the need to increase the availability of and to improve access to rehabilitation services is important. Setting up new healthcare facilities is one of the solutions but this may incur high costs in terms of development, construction, and manpower. An alternative solution proposed in this research is the use of a home-based virtual rehabilitation programme. It is envisaged that the benefits of this solution will be multifold. The rehabilitation intervention can be delivered remotely, individuals can receive a higher amount of intervention without travelling out from home or adding to the workload of therapists, and the use of virtual reality or video games can enhance one’s experience and engagement in interventions. Tele-rehabilitation is not only low cost but can also reach out to the urban poor community or rural populations without excessive financial burden.

**ACKNOWLEDGEMENT**

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REFERENCES


## APPENDIX

Survey Notes

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Contact</th>
<th>Website</th>
<th>PIC</th>
<th>Email</th>
<th>Hour</th>
<th>Status</th>
<th>Funding</th>
<th>Services</th>
<th>Target Group</th>
<th>Number</th>
<th>Staffing</th>
<th>Vacancy / Waiting List</th>
<th>Others</th>
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Effect of Abacus Training on Numerical Ability of Students with Hearing Loss

Atul Kaluram Jadhav¹*, Varsha Shrikant Gathoo¹

ABSTRACT

Purpose: The study focussed on the effect of Abacus training on numerical ability (comprising of counting and mathematical operations) of children with hearing loss.

Method: 90 students with hearing loss were sampled from 6 special schools in Mumbai, India. A quasi-experimental study was employed using two group pre-test and post-test design. Data were collected using the Numerical Ability Test (NAT) as an instrument. Six null hypotheses based on the objectives were formulated and tested at 0.05 level of significance using t-Test - Assuming Equal Variances.

Results: The findings revealed that the experimental group which was instructed through Abacus showed higher proficiency in numerical ability as compared to the control group instructed through the conventional method. Gender as a variable seems to influence the mean achievement of numerical ability of students with hearing loss. While girls and boys did not differ in simple tasks such as counting, boys were found to be better in mathematical operations and overall numerical ability.

Conclusions: The Abacus teaching method results in higher mathematical achievements among students with hearing loss. Gender also plays an important role in mathematical learning, as evidenced by boys demonstrating more numerical ability than girls in the study sample.

Key words: Abacus, numerical ability, counting ability, mathematical operations, students with hearing loss

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INTRODUCTION

Mathematics has an enormous applicability and is an essential language and framework for all sciences (Puebla, 2015). It lays a robust foundation not only for school subjects, but also for undertaking daily-life skills. Mastery over numeracy or numerical ability in children is fundamental to achieving mathematical literacy, as 'what spelling is to writing', 'numbers is to maths'. Teachers of the deaf have always been striving hard to develop numeracy for these children as they lag behind their hearing peers both in numerical ability and mathematical skills (Traxler, 2000). One reason for this is because deafness restricts acquisition of language, and language is important for allowing access to mathematical information. Zarfaty et al (2004), Pagliaro and Kritzer (2012), and Edwards et al (2013) also reiterate that historically children who are deaf and hard-of-hearing scored less in mathematics and other academic subjects as compared to hearing peers in the same age group. Studies from both deaf and hearing populations typically show a strong association between language and mathematical abilities (e.g., Kelly & Mousley, 2001; Hyde et al, 2003), with some researchers arguing that language is the key barrier to success, particularly in mathematics word problems (Marschark & Hauser, 2008).

Research has also shown that the process of cognitive development required for developing numerical ability and later mathematical skills seems to be closely connected with the development of verbal language. Estimation skills, a strong facilitator of mathematical learning, is found to be lacking in individuals with hearing loss. These skills have been characterised as part of number sense. Kritzer (2008) argued that because of their hearing loss and frequently impoverished language environments, some deaf children lack access to incidental learning opportunities that limit their exposure to early developing numerical concepts. This has been supported by Gregory (cited in Bull et al, 2011). As a result, they often lack the building blocks required for formal mathematics encountered during the later school years (Bull et al, 2011).

Mathematical Instructions for Children with Hearing Loss

Children with hearing loss learn mathematics at a delayed pace as compared to their hearing peers (Wood et al, 1983; Traxler, 2000). Various aspects to this are cited in the reviewed literature.

Many years ago Fridrikksson and Stewart (1988) had suggested reasons for maths
instructions receiving little attention in Teacher education programmes for deaf students. They observed that in the first place, training programmes to develop teachers for the deaf tend to emphasise speech and language skills, and the trainees are not provided with an adequate foundation in mathematics teaching. Secondly, mathematics in the classroom is often only pencil-and-paper learning, with little hands-on experimentation or computer use. Thirdly, mathematics is not seen as important, and progress in mathematical understanding is not stressed.

Along similar lines, Pagliaro (1998) also pointed out that if there is to be any hope of improving the mathematical performance of deaf and hard of hearing students, the mathematics competency of their teachers must be improved. The study highlighted that improvements in the mathematics preparation of teachers has direct relation to better instruction. This in turn would affect student learning and increase achievement. It has been further stressed that the society and economy of the 21st century will depend on mathematics-competent workers. Hence, the teacher competency has to be improved in order to prepare children with hearing loss to be effective persons of tomorrow. Towards this end the pedagogical practices in maths need attention.

According to Louie et al (2008), multiple approaches to teaching math concepts are needed, to help students with disabilities reach a deeper understanding of the subject. According to Pau (1995) and Nunes and Moreno (2002) evidence shows that principles and elements of Balanced Mathematics Instructions (BMI) are beneficial to students with hearing loss. This has been supported by Stewart and Kluwin (2001) and Pagliaro (cited in Tanridiler et al, 2015). BMI is remarkable as it consists of strong features of both direct instruction and constructivism. BMI defends the balance in determining whether there is a need for direct instruction or an indirect support depending on the preliminary knowledge of a student. It adopts the principles stated in the Primary Education Mathematics Teaching Programme (1998), which are as follows:

1. Teaching should start with concrete experiences.
2. Meaningful learning should be targeted.
3. Students should communicate with their mathematics teaching.
4. Association should be given importance.
5. Student motivation should be considered.
(6) Technology should be used effectively.

(7) Cooperation-based learning should be given importance.

(8) Lessons should be organised by appropriate teaching stages.

The National Council of Teachers of Mathematics, Inc. (2004), lays emphasis on adaptation of instructional strategies for math teaching. It suggests that to make learning mathematics more accessible and rewarding for students with special needs, the students require instructional modifications and accommodations along with use of appropriate learning materials.

Role of Manipulative Material for Learning Mathematics

Mathematc learning is all about doing and practicing through use of objects generally referred to as manipulatives. Cope (2015) defines Physical Manipulative as an object which is designed for free manual movement for developing motor skills or understanding abstractions. Manipulatives are generally three-dimensional and range from simple everyday items, such as buttons, paper clips, toothpicks, etc., to more complex and discipline-specific items, such as calculators, two-colour counters, algebra tiles, and pantomimes (Bellonio, cited in Cope, 2015) and Abacus slates.

The history of the use of manipulatives for teaching mathematics is at least 200 years old and it has been stressed by Friedrich Froebel (1782 -1852), Maria Montessori (1870-1952), Jean Piaget (1896-1980), Zoltan Dienes (1916-2014) and Jerome Bruner (1915-2016) (Moore, 2014). Each of them has emphasised the use of experience through concrete tools for development of understanding. The National Council of Supervisors of Mathematics - NCSM (2013), in its position paper, suggests that for developing students’ mathematical proficiency, leaders and teachers must systematically integrate the use of concrete and virtual manipulatives into classroom instruction at all grade levels. Manipulatives usually have moving parts that learners use to illustrate the math process concept. While providing guidelines for the use of manipulatives, Cope (2015) suggests that learners need explicit instructions on how to use manipulatives and each learner should individually get the opportunity to explore and investigate problems using manipulatives.
Abacus - a Manipulative Tool for Mathematics

Abacus is a classic tool consisting of a simple wooden frame with beads, making it portable and flexible in usage. It is used worldwide for teaching basic arithmetic in elementary classrooms. Abacus is useful because it helps to develop speed and accuracy of calculations (Stigler et al, 1986). It can be used to provide a sound basis for mathematical calculations like addition, subtraction, multiplication, and division. It can also be used to carry out calculations involving fractions and decimals, as well as an aid in completing arithmetic operations included in higher level mathematics (Research and Development Institute, Inc., 2006). According to Tanaka et al (2012), research has shown that skilled Abacus users are able to perform quick and accurate mental calculations using visual imaging of the manipulatives. Several studies have reported improvements in the numerical ability of subjects trained to use an Abacus. For instance, Hatano and Osawa (1983) reported that elementary school children trained to use an Abacus, performed significantly better on tests of calculation speed and accuracy compared with those who were not so trained. The numerical ability of Abacus users has inherently been better, as children tend to benefit from Abacus training. In addition, it was found to boost confidence in children and consequently increase their interest in maths (Foong, 1998; Shwalb et al, cited in Freeman, 2014).

Rationale for the Study

Several studies on the use of Abacus for children with visual and intellectual disabilities have been conducted (Beal & Shaw, 2009; Vita & Kataoka, 2014; Wanjiru et al, 2014; Matías-Guiu et al, 2016). Shen (2006) found that the use of Abacus facilitates basic mathematical concepts and understanding in children who are cognitively challenged. According to the Research and Development Institute, Inc. (2006) Abacus is one of the most effective calculation tools for blind children, when used in conjunction with other devices. However it is not sufficiently documented whether or not it is beneficial to children with hearing loss. In the Indian context, a survey documenting the use of Abacus, by Jadhav and Gathoo (2017), concluded that the special teachers had a lower level of functional and overall awareness about Abacus, as compared to the mainstream school teachers. One of the reasons cited was lack of documentary evidence on the benefits of Abacus. In the Indian state of Maharashtra where the present study has been conducted, many special schools for children with hearing loss opt for lower level maths or choose an optional subject instead of math. This is
because many students with hearing loss find math to be a difficult subject (Nair & Ramaa, 2015). Since a baseline study undertaken for the present study found that majority of special schools only use the conventional method, an experimental study about the use of Abacus training was conceptualised.

Gender as a variable is also studied, as the outcomes of many studies reveal that boys tend to perform better than girls, especially in numerical problems, while girls perform better than boys in verbal tasks (Maitland, & Goldman, 1974; Arigbabu & Mji, 2004; Bassey et al, 2004; Kolawole, 2007). In the Indian context, gender as a variable has not been sufficiently documented with respect to mathematical achievement of children with disabilities and hearing loss in particular.

**Objective**
The main aim was to study the effect of Abacus training on numerical ability, comprising of counting and mathematical operations, in children with hearing loss. The gain in the numerical ability if any, in the experimental group, was also designed to be studied for gender as a variable. Based on the objectives, six null hypotheses were formulated and tested at 0.05 level of significance using t-Test - Assuming Equal Variances.

**METHOD**

**Study Design**
A quasi-experimental two group pre-test and post-test experimental design was employed, with the purpose of determining the effect of Abacus training on numerical ability of children with hearing loss.

**Sampling**
A list of the primary level special schools in Mumbai and sub-urban areas was obtained from the Social Welfare Department of the Government of Maharashtra. Of these, 12 special schools were shortlisted on the basis of having sufficient number of students in III and IV grades. From the 12 shortlisted schools, 6 special schools were then randomly selected. A sample of 90 students was finalised for the study. Treatment was randomly allocated to the students from special schools, thus dividing them into experimental and control groups. The distribution of the sample in experimental and control groups is shown in Table 1.
Table 1: Sample Distribution

<table>
<thead>
<tr>
<th>Groups</th>
<th>Sample</th>
<th>Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Experimental</td>
<td>17</td>
<td>18</td>
<td>35</td>
</tr>
<tr>
<td>Control</td>
<td>25</td>
<td>30</td>
<td>55</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>48</td>
<td>90</td>
</tr>
</tbody>
</table>

Research Instrument

The Numerical Ability Test (NAT) developed by Khire et al (2013) was used for data collection. The tool has four sub-tests and their respective reliability and validity is as shown in Table 2.

Table 2: Reliability and Validity of NAT

<table>
<thead>
<tr>
<th>Sr. No.</th>
<th>Test No.</th>
<th>Reliability Coefficient</th>
<th>Validity Loading Obtained</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Test 1</td>
<td>0.70</td>
<td>0.56</td>
</tr>
<tr>
<td>2</td>
<td>Test 2</td>
<td>0.83+</td>
<td>0.55</td>
</tr>
<tr>
<td>3</td>
<td>Test 3</td>
<td>0.77+</td>
<td>0.62</td>
</tr>
<tr>
<td>4</td>
<td>Test 4</td>
<td>0.81</td>
<td>0.32</td>
</tr>
</tbody>
</table>

NAT is designed to assess three aspects, namely, understanding of basic numerical concepts, simple numerical computations, and numerical reasoning. The first aspect refers to understanding of numbers and related concepts like odd, even, squares, etc. The second aspect refers to ability to add, subtract, multiply and divide quickly and accurately, and the third aspect refers to ability to use numbers in a logical and rational way. NAT had four sub-tests, namely (i) Cognition of Symbolic Systems (CSS), (ii) Convergent Production of Symbolic Units (NSU), (iii) Convergent Production of Symbolic Systems (NSS), and (iv) Evaluation of Symbolic Relations (ESR).

For the present study a theoretical model was developed, depicting the skills and abilities drawn from various sub-tests of NAT. It is diagrammatically represented below in Figure 1.
Figure 1: Baseline Theoretical Model of Numerical Ability

![Baseline Theoretical Model of Numerical Ability](image)

Table 3: Items on Numerical Ability Test

<table>
<thead>
<tr>
<th>Test No.</th>
<th>Test Name</th>
<th>Categories clubbed for present research</th>
<th>No. of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>CSS</td>
<td>Counting Ability items</td>
<td>10 + 9 = 19</td>
</tr>
<tr>
<td>2</td>
<td>NSU</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>NSS</td>
<td>Mathematical Operations items</td>
<td>10 + 12 = 22</td>
</tr>
<tr>
<td>4</td>
<td>ESR</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Procedure**

NAT was administered as a pre-test to both the Control group (CG) and Experimental group (EG) to measure the levels of numerical performance. The Experimental group received instructions through Abacus for a duration of 8 months and the Control group received instructions through the conventional...
method from the researcher. A time schedule was maintained and balanced so that both the groups were instructed in the morning as well as in the afternoon. NAT was administered as post-test to both the groups to compare their achievement in numerical ability.

RESULTS and DISCUSSION

Table 4: The Overall Gain in Numerical Ability of Experimental and Control Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group</th>
<th>N</th>
<th>Mean Gain</th>
<th>Standard Deviation</th>
<th>‘t’ value</th>
<th>Level of Significance at .05</th>
<th>Null Hypothesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counting ability</td>
<td>EG</td>
<td>35</td>
<td>2.06</td>
<td>1.08</td>
<td>5.88</td>
<td>Significant</td>
<td>Rejected</td>
</tr>
<tr>
<td></td>
<td>CG</td>
<td>55</td>
<td>0.85</td>
<td>0.92</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mathematical operations</td>
<td>EG</td>
<td>35</td>
<td>2.71</td>
<td>1.1</td>
<td>10.29</td>
<td>Significant</td>
<td>Rejected</td>
</tr>
<tr>
<td></td>
<td>CG</td>
<td>55</td>
<td>0.62</td>
<td>0.82</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numerical ability</td>
<td>EG</td>
<td>35</td>
<td>4.78</td>
<td>1.37</td>
<td>13.04</td>
<td>Significant</td>
<td>Rejected</td>
</tr>
<tr>
<td></td>
<td>CG</td>
<td>55</td>
<td>1.45</td>
<td>1.03</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

EG = Experimental Group and CG = Control Group

From the findings reported in Table 4, it can be concluded that the use of Abacus has resulted in significant positive differences between the achievements of numerical ability in the experimental group as compared to the control group. The experimental group has scored significantly higher in all the dependent variables. This could be attributed to the activity-based learning fostered by Abacus. Abacus is a slate with beads, and children learn visually through moving and manipulating the beads in rows and columns. The procedure of Abacus instructions has features of all the five approaches for developing numerical ability mentioned above. The Abacus training instructor first demonstrates the ways of counting and calculating to the students, and the students later practice on their individualised slates. The instructor also scaffolds wherever required. These are the features of the 'Demonstration approach' wherein students learn by observation and practice. Abacus instructions also incorporate the features of 'Inquiry-based approach' as it is student-centred. Children often work in pairs and groups undertake role reversals as instructors, so it is collaborative and based on the constructivist theories for development of higher-order reasoning.
Abacus is a 'Practice work approach' as the learners manipulate concrete objects, i.e., the beads, and/or perform activities to arrive at a conceptual understanding of phenomena, a situation, or a concept such as doing addition, subtraction or multiplication to quickly arrive at a solution. Since the instructor guides the students through the basics of counting and on to higher order abilities - such as place and face values, or how many more vs. how many less to reach a number - it follows the principles of 'Discovery approach' too. In the present study, Abacus training ranged from 'guided discovery' to 'free discovery' and the focus was on the procedure, i.e., how to learn. Children in the experimental group worked in small intense groups to solve a task such as depicting units, tens and hundreds, or the ascending vs. descending orders, so it covered the features of the 'Mathematics Laboratory Approach'.

Mathematics is generally considered a difficult and abstract subject where most of the students struggle to understand the basic concepts. Teaching and learning mathematics through an activity such as Abacus makes use of multiple senses (visual, auditory and kinaesthetic). Abacus training leads to forming mental imagery over time, as children imagine moving the beads and think logically, thus fostering mental maths. By performing mental math repeatedly, the ability to apply logic in other day-to-day life scenarios is built up as well. Hence, along with improving their counting ability, the experimental group might have fared better on the word problems. In contrast, when the conventional teaching method is employed, students are forced to learn mathematics through the lecture cum demonstration method, using only their auditory and/ or visual sense to solve problems on the board. Since no kinaesthetic sense is used, students may not be able to retain and apply their knowledge when it comes to word problems. Findings of the present study are in congruence with similar studies undertaken by Hatano and Osawa (1983) and Irwing et al (2008). Shen (2006) also found that ‘Soroban’ (a type of Abacus) facilitates understanding of basic mathematical concepts in children who are cognitively challenged.

Since the experimental group gained in the study, the next objective was to study whether the boys and the girls benefitted equally in their numerical ability by use of Abacus instructions.
Table 5: Overall Gain in Numerical Ability of Gender in the Experimental Group

<table>
<thead>
<tr>
<th>Variable</th>
<th>Group</th>
<th>Gender</th>
<th>N</th>
<th>Mean Gain</th>
<th>Standard Deviation</th>
<th>‘t’ value</th>
<th>Level of Significance at .05</th>
<th>Null Hypothesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counting ability</td>
<td>E G</td>
<td>Boys</td>
<td>17</td>
<td>2.35</td>
<td>1.22</td>
<td>1.61</td>
<td>2.03</td>
<td>Not Significant</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Girls</td>
<td>18</td>
<td>1.78</td>
<td>0.88</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mathematical operations</td>
<td>E G</td>
<td>Boys</td>
<td>17</td>
<td>3.24</td>
<td>0.9</td>
<td>3.03</td>
<td>2.03</td>
<td>Significant</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Girls</td>
<td>18</td>
<td>2.22</td>
<td>1.06</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Numerical ability</td>
<td>E G</td>
<td>Boys</td>
<td>17</td>
<td>5.59</td>
<td>1.12</td>
<td>4.16</td>
<td>2.03</td>
<td>Significant</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Girls</td>
<td>18</td>
<td>4</td>
<td>1.14</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

EG = Experimental Group

From the findings reported in Table 5, it is concluded that though girls and boys in the experimental group do not differ significantly in counting ability, boys perform better in mathematical operations and the overall numerical ability as compared to girls with hearing loss. This might be because the functions like simple counting are taught and reinforced both at home and at school at an early age, so that both boys and girls acquire those skills. Boys however outperformed the girls in other aspects of numerical abilities, i.e., mathematical operations. This is attributed to Indian culture whereby boys are assigned more outdoor tasks than girls and hence, over time, make faster word calculations. Research on the neural make up of boys and girls have proved that boys have faster and greater problem-solving ability. This result is supported by the study done by Casey et al (cited in Vani, 2014), wherein the researchers conclude that boys display greater confidence in their math skills, which is a strong predictor of math performance. The result of the present study is also in congruence with a study done by Bassey et al (2004) and work by other researchers such as Alio and Habor-Peters (2000), Raimi and Adeoye (2002), Ojo (2004), Odili and Maduabum (2007), Olowojaie(cited in Akinsola & Odeyemi, 2014), and Onabanjo(cited in Adeyemi, & Adaramola, 2014), which concluded that boys performed better than girls in numerical and mathematical achievements. In the present research, the pre-existing superior abilities of the boys on word problems may have been enhanced due to the Abacus instructions and may have resulted in the overall gain.
for boys in the experimental group. Hence, gender may have had a significant effect on students’ achievements in numerical ability.

CONCLUSION

- The use of Abacus results in higher achievements in numerical ability as compared to the conventional mathematics teaching method.
- Gender plays an important role in mathematical learning among students with hearing loss. While abilities of girls and boys do not differ in simple tasks such as counting, gender is found to favour boys in mathematical operations and overall numerical ability.

Recommendations

Based on the results of the current study, it is recommended that teachers need to use manipulatives like Abacus for teaching math to language-deficit children like those with hearing loss. Such aids are especially beneficial for kinaesthetic learners, inclusive of children with hearing loss.

Incidentally it was observed that students of the study’s experimental group seemed to be highly motivated about the sessions. Their class teacher would receive enquiries regarding the next session of Abacus. Since the class teacher and school Principal requested that the Abacus instructions be continued, it is assumed that the children with hearing loss were well-disposed towards Abacus learning. Against this backdrop it is recommended that a unit in pedagogical practices, using manipulative materials such as Abacus, be included in the teacher training curriculum of special education. Alternately, the short-term training programmes conducted by the Rehabilitation Council of India (RCI) could list this as a topic for teachers’ continuing education programmes.

ACKNOWLEDGEMENT

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REFERENCES


Cross-Cultural Adaptation and Evaluation of Psychometric Properties of Persian Version of Supports Intensity Scale among Adults with Intellectual and Developmental Disabilities

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Clinical Psychology Department at Azad University of Sari, Khouzestan Association for Autism, Ahvaz, Iran.

ABSTRACT

Purpose: This study was designed to translate and assess the psychometric properties of Supports Intensity Scale among adults with intellectual and developmental disability in Ahvaz and Tehran, Iran.

Method: The cross-sectional study was carried out in two stages. The first stage consisted of the forward-backward translation of Supports Intensity Scale - Adult Version) SIS-A). In the second stage, 197 people with intellectual and developmental disabilities were recruited in order to assess the internal consistency and test-retest reliability, concurrent and content validity of SIS-A. The confirmatory factor analysis (CFA) was performed to approve the seven-factor model of the instrument.

Results: The intra-class correlation coefficient values varied between 0.85 and 0.99 (very good to excellent). All subscales of the SIS-A showed Cronbach’s alpha above 0.70. Correlation coefficient between SIS-A and Barthel index was about -0.65, which shows excellent concurrent validity of SIS-A. The findings showed SIS-A had high ability to discriminate between groups with different IQ (p<0.05). There was no significant correlation between SIS-A and the age of participants (p>0.05). The result of CFA confirmed that the seven-factor model of SIS-A is the fittest pattern for SIS-A.

Conclusion: The results indicated that the Persian version of SIS-A is a valid and reliable instrument to assess function and disability among people with intellectual and developmental disability.

Keywords: Intellectual and developmental disability, SIS-A, Barthel

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INTRODUCTION

Assessing and measuring the support that people with intellectual and developmental disabilities need is very important since this type of disability affects many different aspects of life and increases the responsibilities of families and the economic burden for societies (Thompson, 2008; Schalock et al, 2010). The American Association on Intellectual and Developmental Disabilities (AAIDD) designed and introduced the Supports Intensity Scale - Adult Version™ (SIS-A™) over a 5-year period to address the problems of individuals with these disabilities. The purpose of designing and presenting this Scale was to have a valid and reliable tool to determine the support and service levels required for people with intellectual and developmental disabilities. Unlike other support measurement tools, SIS-A is a practical tool that evaluates the support needs on 57 domains of important life activities. Health policy-makers and planners can also use this tool to organise facilities and improve the process of fair allocation of resources. Another advantage is that this Scale helps in prioritising the amount and type of support needed, creating opportunities to empower individuals, helping them adapt their abilities and skills with their tasks, and helping to improve the decision-making process at the national level (Luckasson, 2002; Buntinx & Schalock, 2010; Watson et al, 2011; AAIDD 2017 (online)).

SIS-A assesses and evaluates three important aspects of life including specialised medical and behavioural support needs, the support needs index, and litigation activities among people aged 16 and above (AAIDD 2014). The results of recent studies have shown that SIS-A has a high degree of intraclass reliability, and that the internal consistency of the tool is higher than the minimum acceptable value. In a study by Verdugo et al (2010), carried out with the aim of validating the Spanish version of this tool, the results indicated that the construct validity of the Scale was perfect and all aspects of this Scale had a Cronbach’s alpha higher than 0.9, indicating the high internal consistency of SIS-A. This scientific tool has been translated into English, French, Japanese, Chinese, Hebrew, Catalan and seven other languages and its psychometric properties have been tested (Verdugo et al, 2010).

Objective

The aim of this study was to first translate the English version of SIS-A into the language and culture of the Iranian people, and then measure its psychometric properties among individuals with intellectual and developmental disabilities so that the tool could be used to measure the level of the needed support.
METHOD

Study Sample
The available sampling method and the Cochran formula were used to select 197 adults with developmental and mental disabilities, living in the two metropolises of Ahwaz and Tehran. The number of Support Scale questions was also kept in mind.

Inclusion criteria were:

• Onset of the disability before the age of 18, with confirmation by a psychologist or a physician that this disability would result in a limitation in the physical and mental performance or both (according to the definition of developmental and mental disability).

• Being literate and able to read and write in Persian (the person himself/herself or, if necessary, family members or caregivers who had been continuously interacting with the person for at least 6 months).

Exclusion criteria:

• If the individual’s IQ score was not recorded in his/her portfolio.

• If the individual or his/her family was not willing to continue participating.

Before commencing the study, all participants (parents of persons with intellectual and developmental disability) signed an informed consent form which had been approved by the local ethics committee. Data on the demographic characteristics of the subjects such as language, gender, IQ, ethnicity, the type of disability, the status of residence, the place of residence, education level, and employment status were collected. This data was then recorded in the form of the Support Scale.

Measures
The Support Intensity Scale -This Scale was designed by Thompson et al (2008) to measure and assess the support level needed by individuals, 16 years of age and above, with intellectual and developmental disabilities, in order to enable them to effectively participate in most social life situations and activities. It includes the following three important domains of life:

1) Supporting specialised medical and behavioural needs (32 questions);
2) Support index - the first aspect: in-house activities with 8 questions; the second aspect: activities related to community life with 8 questions; the third aspect: continuous learning activities with 9 questions; the fourth aspect: job-related activities with 8 questions; the fifth aspect: health and safety activities with 8 questions; and the sixth aspect: social activities with 8 questions; and,

3) On litigation and support activities (8 questions).

The duration of the interview to complete this Scale is about 2 hours. To manage and complete the Scale and obtain the raw score for each question, the interviewer must first determine the type of support needed (0 = no support, 4 = needs full physical assistance), the frequency of support required (0 = none or fewer than once a month, 4 = support needed every hour or more), and the duration of daily support (0 = none, 4 = four hours or more), and then add up the obtained score for each of these three parts so that the raw score for each question and aspect is calculated (Thompson et al.,).

**Barthel Index** - The Barthel questionnaire contains 11 questions, of which the question on "the degree of activeness" or "wheelchair access" is filled for each person. In case a person gets a zero score on the "the degree of activeness" question, "wheelchair access" is considered as an alternative question. In this questionnaire, depending on the subject’s condition and the nature of the question, a score between 0 and 15 is allocated. To "moving from chair to bed and vice versa" and "activeness" questions, each a maximum of 15 points; to "going up and down the stairs", "using of the toilet", "faeces control", "urine control", "eating food", and "dressing" questions, each a maximum of 10 points; and to "using the wheelchairs", "bathing" and "personal hygiene" questions, each a maximum of 5 points are allocated. The first option in each question is “inability” and the fifth option is “complete independence”.

In sum, this tool determines the ability of a person in different aspects of daily performance on a scale of 0 - 100, with higher scores indicating a better situation. Scores 20 - 60 indicate strong dependence, scores 61 - 90 intermediate dependence, scores 91 - 99 partial dependence, and score 100 indicates complete independence (Tagharrobi et al.,2011).

**Translation and Modifications implemented in the Persian version of SIS-A**

Through searches on scientific sites and databases such as Science Direct and Pub Med, it was determined that no studies had been conducted to measure the
psychometric properties of the Persian version of the Support Scale. Therefore, the translation process was carried out according to the IQOLa protocol after obtaining permission from AAIDD to translate and assess the validity and reliability of the Scale (Bullinger et al, 1998).

In step 1 (primary translation), the original version of the Support Scale was translated into Persian by two Farsi speakers who were very proficient in the English language. In step 2 (analysis), the research team (physiotherapy, occupational therapy, and rehabilitation management groups), together with the translators, discussed the primary versions of the translation. Their discussion resulted in a single tentative translation. In step 3 (reviewing the quality of translation), another translator was employed (an expert with proficiency in Persian and English texts and literature). Translation quality aims to ensure the appropriateness of phrases and sentences in terms of clarity, use of common language, and the uniformity of concepts. At this step, a series of modifications was carried out on the Scale; thus, the questions regarding the original language, the ethnicity and race of the respondents were changed according to the Iranian culture, and it was decided to prevent the negative charge for each by assigning two choices: for the original language - Persian and other languages, for ethnicity - Persian and other ethnicities, and for race - Iranian and non-Iranian, respectively. In step 4 (back translation), the translation obtained in the previous step was translated into English by an English-speaking translator, living in Iran, who had mastery over the Persian language. The purpose of this step was to see whether the content of the questions in the translated version (back translation) reflected the same questions in the original version (SIS-A). In step 5 (experts committee), the translated version along with all the reports, was finally evaluated by individuals with experience in the field of research, at a joint session of the translation. Before proceeding further, the English translation team sent the translated version of the Support Scale to the chief director of AAIDD in order to be consistent with the original version and to examine its semantic and conceptual equivalence. All these steps eventually led to a Persian version of high translation quality. In step 6 (field test), the Persian version of the SIS-A was tested on 20 parents of persons with intellectual and developmental disabilities, to identify and resolve potential problems and deficiencies (such as inappropriate phraseology, inappropriateness of some of the terms from the standpoint of culture, vague and unclear understanding of vocabulary, difficulty understanding the content of questions). The results
showed that they did not have any problem in understanding the concepts of the Persian version of SIS-A.

**Measurement of Psychometric Properties**

Given that the results of K-S test showed that data distribution was not normal, nonparametric tests were used in this study.

**Validity**

**Concurrent validity:** Concurrent validity is evaluated in order to determine how much a tool can correlate with similar concepts in other tools. In this study, to assess the concurrent validity of the Persian version of SIS-A, Spearman Correlation Coefficient between the Barthel index and SIS-A was used. If the correlation coefficient between the two tools was higher than 0.6, the concurrent validity would be considered as excellent, and if the correlation coefficient was 0.6 - 0.2 and less than 0.2, it would be reported as good and weak, respectively (Roos et al, 1998).

**Content validity:** In this study, the content validity of the Persian version of SIS-A has been evaluated with the “ceiling and floor effects” method of analysis, with a cutting point of 20%. This means that if the value of these effects is less than 20% for the entire tool, the tool has acceptable content validity (Bennett et al, 2002).

**Construct validity:** Two methods were used to assess the construct validity of the Persian version of SIS-A. It was hypothesised that if a tool could measure a structure or a concept, statistically there should be a correlation between its aspects. In this study, the construct validity was evaluated by calculating the Spearman Correlation Coefficient among the aspects of the Persian version of SIS-A. Confirmatory factor analysis (CFA) is another technique that can be used to analyse the construct of a tool. In this study, the seven-factor model of the Persian version of SIS-A has been used. If the RMSEA value is equal to or less than 0.06 and the SRMR value is less than 0.08 and also the CFI is greater than 0.9, then the given model is well-fitted (Negahban et al, 2013).

**Discriminative validity:** Discriminative validity is used to show to what extent a Scale can theoretically differentiate between different groups. In this study, it was hypothesised that people with different IQs needed different support; for example, subjects with an IQ lower than 50 would need more support than subjects with an IQ between 50 and 70. To test this hypothesis, Kruskal Wallis H test was used (Garin et al, 2010).
Reliability

Reliability can measure the error rate when evaluating a result and shows how error-free a tool is. In this research, two types of the most common methods of measuring reliability, i.e., internal consistency and test-retest reliability were used.

Internal consistency, one of the important methods to measure relative repeatability, shows to what extent the questions of a Scale or a questionnaire are conceptually consistent with each other. In this study, Cronbach's alpha coefficient was used to calculate the internal consistency. If the Cronbach's alpha value is more than 0.9, the internal consistency is considered to be excellent; between 0.89 and 0.89, 0.7 / 0 are considered good and acceptable, respectively.

Test-retest evaluates the stability of a tool at different times; that is, a researcher first gives a test to a particular group of participants in the study, and then, after a certain period of time, repeats the same test for the same group. If the results of the two tests do not differ, or differ slightly, it indicates the high stability of the tool at the time of the test. In this study, intraclass correlation coefficient (ICC) was used to calculate the repeatability of test-retest with 95% confidence interval. The second interview was carried out 10 days after the first interview (Silveira et al, 2013).

SPSS16 software and LISREL8.8 software were used for the analysis and evaluation of the seven-factor model of the Persian version of SIS-A.

RESULTS

Demographic Characteristics of the Participants

Among the 197 participants, 111 (56.3%) were male and 86 (43.7%) were female. The average age of the participants was 25 years. Approximately 20% had an IQ higher than 70. There were 122 people with intellectual disabilities, and 14 people were high school graduates. More than half of the participants lived in families with around 7 members. About 15.83% of the participants were city-dwellers. Table 1 shows the demographic characteristics of the participants.
Table 1: Demographic Features of Participants

<table>
<thead>
<tr>
<th>Domains</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENDER</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>111(56.3%)</td>
</tr>
<tr>
<td>Female</td>
<td>86(43.7%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>(SD=9) 25 Age</td>
</tr>
<tr>
<td><strong>LANGUAGE (Please Select One)</strong></td>
<td></td>
</tr>
<tr>
<td>Persian</td>
<td>107(54.3%)</td>
</tr>
<tr>
<td>Other</td>
<td>90(45.7%)</td>
</tr>
<tr>
<td><strong>CURRENT OCCUPATION (Select any which apply)</strong></td>
<td></td>
</tr>
<tr>
<td>Sustained occupations</td>
<td>3(1.5%)</td>
</tr>
<tr>
<td>Supported occupations</td>
<td>93(47.2%)</td>
</tr>
<tr>
<td>Voluntary occupations</td>
<td>11(5.6%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>90(45.7%)</td>
</tr>
<tr>
<td><strong>IQ</strong></td>
<td></td>
</tr>
<tr>
<td>Above 70</td>
<td>39(19.8%)</td>
</tr>
<tr>
<td>Between 51 to 70</td>
<td>101(51.3%)</td>
</tr>
<tr>
<td>Less than 50</td>
<td>57(28.9%)</td>
</tr>
<tr>
<td><strong>ETHNIC GROUP</strong></td>
<td></td>
</tr>
<tr>
<td>Persian</td>
<td>107(54.3%)</td>
</tr>
<tr>
<td>Non-Persian (Please Specify)</td>
<td>90(45.7%)</td>
</tr>
<tr>
<td><strong>DISABILITIES</strong></td>
<td></td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>122(62%)</td>
</tr>
<tr>
<td>Autistic Range of disability</td>
<td>15(7.5%)</td>
</tr>
<tr>
<td>Physical or sexual dysfunction</td>
<td>28(14.2%)</td>
</tr>
<tr>
<td>Blind/vision impaired</td>
<td>11(5.6%)</td>
</tr>
<tr>
<td>Deaf/hearing impaired</td>
<td>21(10.7%)</td>
</tr>
<tr>
<td><strong>RESIDENCE (Select only one)</strong></td>
<td></td>
</tr>
<tr>
<td>I live in my own house</td>
<td>3(1.5%)</td>
</tr>
<tr>
<td>I live with Relatives</td>
<td>9(4.6%)</td>
</tr>
<tr>
<td>I have a small family (less than seven household members)</td>
<td>56(28.4%)</td>
</tr>
<tr>
<td>I have an average family (between seven to fifteen household members)</td>
<td>129(25.5%)</td>
</tr>
<tr>
<td><strong>AREA OF RESIDENCE (Select only one)</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>164(83.2%)</td>
</tr>
<tr>
<td>Sub-Urban</td>
<td>19(9.6%)</td>
</tr>
<tr>
<td>Country-side</td>
<td>14(7.1%)</td>
</tr>
<tr>
<td><strong>LEVEL OF EDUCATION</strong></td>
<td></td>
</tr>
<tr>
<td>High school education</td>
<td>183(92.9%)</td>
</tr>
<tr>
<td>High School Graduate (Diploma)</td>
<td>14(7.1%)</td>
</tr>
</tbody>
</table>
Evaluation of the Validity and Reliability of the Persian version of SIS-A

Validity
In this study, the “ceiling and floor effects” method was used to determine the content validity of the Scale. As seen in Table 2, the percentage of participants who scored the minimum and maximum grades in SIS-A was 20% lower than the cutting point. "Health and safety activities” had the highest ceiling effect (only 4.5%) among the aspects of the SIS-A. In general, the results of the study showed that the ceiling and floor effects on the whole Persian version of SIS-A was 0.5% and 4.5% of the participants respectively, which was lower than the cutting point of 20%.

Table 2: Mean, Standard Deviation, Content Validity, ICC and Internal Consistency

<table>
<thead>
<tr>
<th>Domains</th>
<th>Number Questions</th>
<th>Mean</th>
<th>SD</th>
<th>Floor effect</th>
<th>Ceiling effect</th>
<th>ICC N=40</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section 1</td>
<td>32</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exceptional Medical Support Needs</td>
<td>19</td>
<td>3.6</td>
<td>1.8</td>
<td>3.2</td>
<td>0.5</td>
<td>0.85</td>
<td>0.76</td>
</tr>
<tr>
<td>Exceptional Behavioural Support Needed</td>
<td>13</td>
<td>4.8</td>
<td>3.5</td>
<td>2.5</td>
<td>1.7</td>
<td>0.91</td>
<td>0.92</td>
</tr>
<tr>
<td>Section 2</td>
<td>49</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life Long Learning Activities</td>
<td>8</td>
<td>51.2</td>
<td>24</td>
<td>1.5</td>
<td>1</td>
<td>0.98</td>
<td>0.91</td>
</tr>
<tr>
<td>Community Living Activities</td>
<td>8</td>
<td>69</td>
<td>20.2</td>
<td>1</td>
<td>0.5</td>
<td>0.94</td>
<td>0.87</td>
</tr>
<tr>
<td>Life Long Learning Activities</td>
<td>9</td>
<td>75.9</td>
<td>13.7</td>
<td>2.5</td>
<td>0.7</td>
<td>0.92</td>
<td>0.82</td>
</tr>
<tr>
<td>Employment Activities</td>
<td>8</td>
<td>68.1</td>
<td>18.7</td>
<td>3.7</td>
<td>0.8</td>
<td>0.95</td>
<td>0.80</td>
</tr>
<tr>
<td>Health and Safety Activities</td>
<td>8</td>
<td>59.4</td>
<td>19.1</td>
<td>4.5</td>
<td>1</td>
<td>0.88</td>
<td>0.85</td>
</tr>
<tr>
<td>Social Activities</td>
<td>8</td>
<td>69.5</td>
<td>18.8</td>
<td>3</td>
<td>1.5</td>
<td>0.97</td>
<td>0.93</td>
</tr>
<tr>
<td>Section 3</td>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advocacy Scale and Supplemental Protection</td>
<td>8</td>
<td>65.8</td>
<td>20.5</td>
<td>3.6</td>
<td>0.7</td>
<td>0.99</td>
<td>0.94</td>
</tr>
<tr>
<td>Total Persian SIS-A</td>
<td>89</td>
<td>50.9</td>
<td>12.5</td>
<td>4.5</td>
<td>0.5</td>
<td>0.98</td>
<td>0.96</td>
</tr>
</tbody>
</table>
Concerning the concurrent validity, the results of the correlation analysis showed that the SIS-A had a perfect, significant and inverse correlation with the Barthel questionnaire (0.65). Furthermore, all aspects of the SIS-A (with the exception of the need for support and activities related to work and employment) displayed a correlation higher than 0.48 with the total score of the Barthel questionnaire. In the aspects of SIS-A, medical support and social activities had the highest correlation (-0.84 and -0.56 respectively) with the Barthel score of adults with intellectual and developmental disabilities. Table 3 shows the results of concurrent validity.

Table 3: Correlation between SIS-A and Bartel Index

<table>
<thead>
<tr>
<th>Bartel Domains</th>
<th>Advocacy Scale and Supplemental Protection</th>
<th>Social Activities</th>
<th>Health and Safety Activities</th>
<th>Employment Activities</th>
<th>Life Long Learning Activities</th>
<th>Community Living Activities</th>
<th>Life Long Learning Activities</th>
<th>Exceptional Behavioral Support Needed</th>
<th>Total Persian SIS-A</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman's correlation coefficient</td>
<td>-0.51</td>
<td>-0.56</td>
<td>-0.48</td>
<td>-0.039</td>
<td>-0.49</td>
<td>-0.45</td>
<td>-0.523</td>
<td>-0.013</td>
<td>-0.84</td>
</tr>
<tr>
<td>p-value</td>
<td>0.004</td>
<td>0.001</td>
<td>0.01</td>
<td>0.84</td>
<td>0.009</td>
<td>0.001</td>
<td>0.004</td>
<td>0.35</td>
<td>0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman's correlation coefficient</td>
</tr>
<tr>
<td>p-value</td>
</tr>
</tbody>
</table>

The results of the study showed that SIS-A aspects had a correlation coefficient between 0.3 - 0.86, and the highest correlation was between two aspects of health and safety activities, with a total Scale score of 0.86. Also, CFA was used to evaluate the construct validity of the Scale. The results of the study showed that the seven-factor model was confirmed in the present study; RMSEA indices with a value of 0.66 and CFI with a value of 0.92 showed that this seven-factor model had an acceptable agreement with the original seven-factor model and was fully fitted. Also, all questions in the questionnaire had a factor load higher than 0.4. Figure 1 shows the seven-factor SIS-A model.
In this study, the results of Kruskal-Wallis H test showed that there was statistically a significant difference between the three groups (people with different IQ) in need of support (p <0.05). Table 4 shows that individuals with an IQ lower than 50 need more support than those with an IQ in the range of 51 - 70 and over 70.

Table 4: Discriminative Validity

<table>
<thead>
<tr>
<th>Domains</th>
<th>70&lt;IQ</th>
<th>IQ=51-70</th>
<th>IQ&lt;50</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exceptional Medical Support Needs</td>
<td>1.6</td>
<td>1.9</td>
<td>2.1</td>
<td>0.017</td>
</tr>
<tr>
<td>Exceptional Behavioural Support Needed</td>
<td>3.1</td>
<td>4</td>
<td>5.4</td>
<td>0.001</td>
</tr>
<tr>
<td>Section 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life Long Learning Activities</td>
<td>23.7</td>
<td>37</td>
<td>65</td>
<td>0.001</td>
</tr>
<tr>
<td>Community Living Activities</td>
<td>56.2</td>
<td>64.9</td>
<td>80</td>
<td>0.001</td>
</tr>
</tbody>
</table>
According to the results of this study, Cronbach's alpha coefficients showed the highest internal consistency for all aspects of SIS-A in the range of 0.83 to 0.93, as well as the aspects of social activities and in-house activities. Concerning the repeatability of the test-retest, the results of the research showed that in-house activities and social activities, with values of 0.98 and 0.97 respectively, had the highest stability among the aspects of the Scale. The ICC was calculated to be 0.98 for the whole Scale. Table 2 shows the results of internal consistency and reliability.

DISCUSSION

Validity
Concerning the “ceiling and floor effects”, the results of the research showed that all aspects of SIS-A had floor effects of lower than 20% cutting points, indicating that this Scale had good content validity. Verdugo et al (2010) used an agreed-upon chart and the analysis of the Cohen and Krippendorff correlation coefficients to examine the content validity of SIS-A. The results of the study indicated that the Spanish version of SIS-A had an acceptable degree of agreement. In another study by Thompson et al 2014, it was shown that the original version of the Scale had excellent content validity, which was consistent with the results of the current study. The results of this study showed that there was significant and moderate correlation coefficient between the aspects of in-house activities, intra-community activities, continuous learning activities, health and safety activities, social activities, and litigation and support activities with the total score of Barthel's questionnaire. There was also a significant, excellent and negative
correlation between the total scores of Barthel and SIS-A. The result of a study by Smit et al (2011) on people with physical disabilities showed that the aspect of in-house activities had the highest correlation coefficient with the total score of the Barthel questionnaire (-0.78), which was consistent with the results of this study. Also, there was no significant relationship between specific support needs (r = -0.03) and Barthel’s questionnaire, which is in line with the results of the current research. Another aspect in the study by Smit et al (2011) that had a significant correlation with the Barthel questionnaire though its correlation coefficient was low, was the aspect of social activities (r = -0.2), which in the current study had an excellent and significant correlation with Barthel’s questionnaire. The reason for this might be the number of samples. In the study by Smit et al (2011), only 65 subjects were used to measure psychometric properties, accounting for about one-third of this study’s sample. Another study by Chou et al (2013) in Taiwan showed that most of the aspects of SIS-A had a significant, strong, and inverse correlation with Barthel’s total score, which was consistent with the results of the present study.

In this study, it was demonstrated that the aspects of the SIS-A scale had a correlation coefficient between 0.3 - 0.86 with each other and with the total score. Chou et al (2013), in their study on 139 individuals with intellectual disabilities, concluded that there was a positive and significant correlation between the aspects of SIS-A with 0.93 - 0.99 range. Their research showed that the highest correlation coefficient belonged to the relation between the aspects of health and safety activities with the total score of SIS-A (r = 0.93). These results were consistent with the findings of the present study, in which the highest correlation coefficient belonged to the aspect of health and safety activities with the total score of SIS-A (r = 0.85) (Chou et al, 2013). In another study by Buntinx 2008 to assess the psychometric properties of the Dutch version of SIS-A on 15224 people with intellectual disability, the results showed that the aspects of health and safety activities and continuous learning activities had the highest correlation coefficients. The correlation coefficients between the SIS-A aspects were in the range of 0.71- 0.94. The results of the present study were relatively consistent with the results of this study. Viriyangkura conducted a study (2013) on 1,036 subjects with intellectual disability living in the United States. Viriyangkura’s aim was to evaluate the factor structure of SIS-A using a confirmatory factor analysis. The results of his research showed that the seven-factor model was the best model for the SIS-A structure. Both RMSEA and S-RMR indicators ranged between 0.06 and 0.08, indicating the acceptable status of these indicators and also showing that the
model was fitted to an acceptable and satisfactory level. The study found that the CFI was reported as approximately 0.98. This index shows that the hypothesised seven-factor model of this study was in full agreement with the original seven-factor model. The results of the Viriyangkura study (2013) were consistent with the findings of this study.

The results of a study by Verdugo et al (2016) on 814 subjects with intellectual and developmental disabilities in Spain showed that RMSEA indices with a value of 0.9, CFI with a value of approximately 0.99, and S-RMR with a value of 0.33 could support the hypothesis that the seven-factor model was the best and most suitable model for the SIS-A. In this seven-factor model, the factor load between the aspects and the total score of the SIS-A index was between 0.88 - 0.98 which indicates a strong correlation between the aspects and the total score of SIS-A. In the present study, the results showed that the values of RMSEA, CFI and S-RMR indices were largely consistent with the Verdugo study. Also, the factor loads between the aspects and the total score of SIS-A score were reported to be 0.75 - 0.95, which was consistent with the results of the Verdugo study (2016). In general, the results of the study showed that the Persian version of SIS-A had excellent construct validity.

Research by Buntinx et al (2008) showed that people with different levels of intellectual disability (in terms of IQ) had different needs. In Buntinx’s study, the result of the analysis of ANOVA test showed that people with slightly lower IQ needed less support while those with IQ lower than 20 needed more support. Buntinx also noted in his research (2008) that there was a significant difference between the overall SIS-A score for people with mild intellectual disabilities and those with severe intellectual disabilities. In the present study, it became clear that the need for support in people with IQ above 70 and between 70 - 50 differed from the people with the IQ below 50, and those with the IQ above 70 had less need for support. In general, the results of the Kruskal-Wallis H test showed that SIS-A has a high differential capability.

Reliability

The results of this study showed that the Persian version of SIS-A has excellent psychometric properties. Cronbach’s alpha coefficient was used to assess the internal consistency of the scale. The results indicated that all aspects of SIS-A had a Cronbach alpha coefficient higher than 0.7. In the meantime, social activity showed the highest (0.93) and occupational activity the lowest (0.8) internal
consistency. Also, the calculated Cronbach's alpha coefficient for the whole SIS-A was 0.85, indicating an excellent degree of internal consistency. In their study, Morin et al stated that all aspects of the French version of SIS-A had the Cronbach's alpha coefficient of close to 0.9. In a study by Buntinx et al 2008 on 192 people with mental disorders (major depression, bipolar depression, schizophrenia), the results showed that all aspects of SIS-A had Cronbach's alpha coefficient of higher than 0.8. Also, Cronbach's alpha coefficient for the whole SIS-A was 0.87, which was consistent with the results of this study (Buntinx et al, 2008). In another study by Thompson et al 2014 on 140,000 people with intellectual and developmental disabilities, it was found that all aspects of the SIS-A had an internal consistency coefficient higher than 0.9. This value was calculated to be 0.98 for the whole SIS-A, which, in comparison, has better internal consistency than the results of the present study (Claes et al, 2009). The reason for this might be the high number of samples (140,000) in the Thompson study.

Regarding the reliability of the retest test, which was obtained by calculating the intra-category correlation coefficient, the results of the study showed that the intraclass correlation coefficient of SIS-A was 0.96, indicating high repeatability of this scale in the number of tests. Meanwhile, health and safety activities had the lowest (0.88) and home life activities the highest (0.98) repeatability. A study by Lamoureux-Hébert and Morin (2009) on 245 adults with intellectual and developmental disabilities showed that the French version of the SIS-A had an ICC value of 0.84 and social activity had the highest (0.93) ICC, which was partly consistent with the results of the present study. Morin, in her study of 72 people with developmental disabilities, concluded that the ICC of all aspects of the support scale was between 0/68 and 0.86. The results of the current study were better than the results in the study by Morin and Cobigo (2009). The reason for this might be the duration of the retest; in the study of Morin and Cobigo it was 3 weeks but in the recent study it was 10 days. In another study, conducted by Verdugo 2010 on 885 adult subjects with intellectual and developmental disabilities, the retest was carried out on 143 people three weeks later. In the Spanish version of SIS-A, the lowest repeatability was reported at 0.84 and the highest at 0.93. In this study, it was found that the Spanish version of SIS-A had high repeatability which was consistent with the result of the present study (Verdugo et al, 2010).
CONCLUSION

The authors suggest that the responsiveness of this Scale should be measured in future research. Also, the support level could be reviewed and reported for different groups with intellectual and developmental disabilities. Overall, it is concluded that the Support Level Scale is a valid and reliable tool and is in accordance with Iranian cultures, races, ethnicities, and languages to measure the support level for adults with intellectual and developmental disabilities.

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ABSTRACT

The promotion of the socioeconomic participation of persons with disabilities is an important concept of developmental social work in community-based rehabilitation (CBR). This approach can be used to tackle poverty and inequalities, and to foster inclusion and empowerment. However, since discussions in the literature on common frameworks for developmental social workers in CBR appear inadequate, this review article aims to develop a practical framework that promotes the socioeconomic participation of persons with disabilities by applying the capability approach. First, the concept of socioeconomic participation and some of its dimensions are discussed and analytically framed using the capability approach. Following this, the practical framework for developmental social work is laid out. It is suggested that developmental social workers consider the complex dynamics between capabilities, functionings, resources, conversion factors, and other factors, with an emphasis on the social dimensions of practice. Thereafter, some theoretical and practical challenges and recommendations are identified.

Key words: capabilities, human development, developmental social work, social investment, community-based rehabilitation

INTRODUCTION

As shown in the Preamble of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol (United Nations, 2006), the promotion of the full participation of persons with disabilities is a key item on the agenda of disability-inclusive development around the globe. Scholars and social workers have paid much attention to the possible contribution from promoting the socioeconomic participation of persons with disabilities in tackling poverty
and socioeconomic inequalities (Knapp & Midgley, 2010; Jones & Truell, 2012; International Federation of Social Workers, 2014; Lombard, 2015; Veal et al, 2016). However, practical frameworks of developmental social work practice, particularly in disability issues and community-based rehabilitation (CBR), appear to be underdeveloped (Lightfoot, 2004; Mousavi, 2015; Van Breda, 2015; Higashida, 2017; Persson, 2017). The author of the current article argues that the perspectives of Amartya Sen’s capability approach (1992, 1999, 2005) and Mitra’s (2017) human development model of disability, health, and wellbeing (based on the capability approach) are useful in developing the practical framework of developmental social work in CBR.

Although it involves different discourses, CBR as ‘a strategy within general community development’ (ILO et al, 2004; WHO et al, 2010) emphasises the importance of poverty reduction and equalisation of opportunities, as well as inclusion and empowerment. The CBR prototype in the 1970s and 1980s placed a great deal of weight on ‘rehabilitation’ in the narrow sense (i.e., physical rehabilitation) for persons with disabilities at the individual level. This rehabilitation was to be partly provided by caregivers and volunteers who received training through CBR programmes (e.g., Helander et al, 1983). Since ‘concern with the use of the word “rehabilitation”’ was expressed in the International Consultation to Review Community-Based Rehabilitation (WHO, 2003), it remains controversial whether ‘rehabilitation’ in the narrow sense is prioritised in CBR. Nevertheless, international actors such as WHO et al (2010) have placed CBR in the general community and social development sphere, where it is a strategy to address disability-related inequalities and poverty, and to promote the empowerment and inclusion of persons with disabilities. Given that WHO et al (2010) have introduced community-based inclusive development as the overall goal of CBR, it is necessary to further develop comprehensive and practical frameworks for promoting the socioeconomic participation of persons with disabilities.

The literature in social work also suggests the necessity of emphasising the social and developmental aspects of their practice. After all, the term ‘social work’ literally includes the word ‘social’ (Veal et al, 2016). The global definition of social work put forward by the International Federation of Social Workers (IFSW) and the global agenda for social work and social development (Jones & Truell, 2012; Lombard, 2015) have suggested that social workers pursue ‘social change, social development, social cohesion, and the empowerment and liberation of
people’ based on human rights, social justice, and diversity (IFSW, 2014). These principles include indigenous and social developmental practices by social workers in cooperation with local stakeholders. In terms of developmental social work in disability and development issues, the literature suggests promoting socioeconomic participation and leadership development for persons with disabilities, rather than solely providing remedial intervention at the micro level (Knapp & Midgley, 2010).

This paper temporarily uses the term ‘(developmental) social worker(s)’ to refer to human resources who perform the substantive functions of social workers in social development in the broad sense (Akimoto, 2017). In fact, despite lacking professional qualifications, there are many social workers who tackle social and developmental issues in developing countries. This is partly because educational systems for social workers are often undeveloped and unorganised, adding to the argument that the status of social workers should be improved (Midgley, 2017a).

The simultaneous presence of medical and social perspectives in CBR creates a somewhat controversial situation. It is therefore significant to discuss social work frameworks that shed light on socioeconomic aspects in order to prescribe the practice of CBR (Veal et al, 2016). Yet discussions on the approach of developmental social work in CBR towards addressing disability-related poverty and socioeconomic inequalities have been insufficient. Hence, a practical framework that is applicable to the promotion of socioeconomic participation at the community level should be developed (Midgley & Conley, 2010; Higashida, 2017). This article thus focusses on the social dimension of person-centred social work in sustainable development (Veal et al, 2016) by integrating social and economic aspects in policy and practice (Myradal, 1970; Midgley, 1995, 2017b).

The aim of this theory review article is to develop the practical framework of developmental social work in CBR for the promotion of socioeconomic participation by persons with disabilities. It argues that the capability approach is appropriate for developing the practical frameworks in the field.

This paper can be considered a type of theory/model review since it attempts to develop a practical framework (Noguchi, 2006). Purposive sampling was applied to this review in order to develop the practical framework. Relevant literature was collected using Scopus, EBSCO host, and PubMed, supplemented by Google Scholar in January 2018. The sample included papers that discuss the
socioeconomic participation of persons with disabilities, the capability approach in disability issues and social work, and developmental social work. First, this paper discusses the concept of socioeconomic participation and some of its dimensions before analytically framing it using the capability approach. Second, this paper develops the practical framework for developmental social work for promoting the socioeconomic participation of persons with disabilities.

SOCIOECONOMIC PARTICIPATION OF PERSONS WITH DISABILITIES
This section takes a general view of the socioeconomic participation of persons with disabilities, defining the concept with reference to international classifications and common models of disability. It discusses not only the contents of participation but also its goals, decisions, and levels, given that the concept has multiple and complex aspects.

Definition and Concept
While the term and concept of ‘participation’ has been used as an alternative to a top-down approach in social development circles, the range of its use appears to be broad and occasionally vague (Midgley et al, 1986; Cornwall & Brock, 2005; Cornwall, 2008). After reviewing international discussions on the participation of persons with disabilities, this section defines socioeconomic participation and discusses its multifaceted aspects.

Participation is a key term in disability issues and is often used as a human rights slogan. Indeed, the concepts of participation, inclusion, and empowerment of persons with disabilities have appeared in international discussions and documents, exemplified by the CRPD (United Nations, 2006), CBR guidelines (WHO et al, 2010), and Sustainable Development Goals (United Nations, 2015). As a result, participation has various meanings and implications. For example, the International Year of Disabled Persons held in 1981 defined ‘full participation and equality’ as:

‘the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens, and have an equal share in improved conditions resulting from socio-economic development’ (United Nations, 2004).

As Kuno (2012) has argued, this definition situates participation as both a process and a result, while simultaneously implicating empowerment and inclusion.
Participation of persons with disabilities is well discussed within debates about models of disability, including medical and social models, although the literature suggests a need to transcend such models and form an alternative way (Beaudry, 2016; Levitt, 2017). The International Classification of Functioning, Disability and Health (ICF) has integrated the medical and social models of disability (WHO, 2001), whereas the previous classification, namely the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980) was considered the medical model. The ICF (WHO, 2001, 2013) has suggested that activities and participation are influenced by their interaction with personal and environmental factors. It has also provided the perspective of ‘performance’, which refers to ‘what a person does in their actual environment’, and ‘capacity’, which is ‘what a person does...in a standardized evaluation setting’ (WHO, 2013). The ICF lists nine domains in activities and participation that can be either restricted or promoted by environmental and personal factors (Schneidert et al, 2003; WHO, 2001, 2013). These nine domains are: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social, and civic life (WHO, 2001).

In the context of poverty and socioeconomic inequalities, researchers have emphasised the importance of comprehensive perspectives that include economic and non-economic aspects (Myrdal, 1970; Midgley, 1995, 2017b). With regard to the community-level socioeconomic participation of persons with disabilities who are at a productive age, this concept would be interchangeable to some extent with the terms ‘community participation’ and ‘social participation’ due to potentially overlapping activities. Measurement tools for the community participation of persons with disabilities have been proposed by researchers, some of which include socioeconomic domains (e.g., Perenboom & Chorus, 2003; Verdonschot et al, 2009a, 2009b; Chang et al, 2013). These tools imply that a sole indicator is not suitable for measuring socioeconomic participation that has multiple domains, and perhaps multiple dimensions are more appropriate, as discussed in the following section. In order to show the range of discussions about the concept within developmental social work in disability issues, this section adapts the definition of Chang et al (2013) about community participation to broadly define the socioeconomic participation of those who are at a productive age as ‘active involvement in activities that are intrinsically socioeconomic and either occur outside the home or as part of a non-domestic role’.
Multiple Aspects of Socioeconomic Participation

The multiple dimensions of socioeconomic participation of persons with disabilities are discussed from the viewpoint of possibility in the real world, namely, ends and means, the subject, contents, and levels. These four dimensions may overlap.

The first aspect of socioeconomic participation is the ends and means dimension, which has implications for philosophical arguments about the concept. The participation of persons with disabilities is described as a target to be achieved since its restrictions due to social and environmental barriers are observed internationally and domestically (Oliver & Barnes, 1998; Klasing, 2007; Knapp & Midgley, 2010). The literature classifies various types of participation of persons with disabilities. Kuno (2012) has summarised participation into three types: as a name, as means for other ends, and as a goal of empowerment and inclusion. Some developmental programmes may use the term participation without substantial promotion (i.e., as a name), while some stakeholders may encourage persons with disabilities to participate in their programmes to improve their appearance and obtain external funds from donors (i.e., as means for other ends). Finally, other actors, including social workers and persons with disabilities themselves, promote socioeconomic empowerment and participation in both the processes and results of grassroots activities (i.e., as a goal of empowerment and inclusion).

The second aspect of socioeconomic participation is the subject of participation itself, including autonomy, determination, and ownership. Global discourses that are represented in disability issues, such as the CRPD (United Nations, 2006), the independent living movement (e.g., DeJong, 1979), and disability studies (e.g., Carney, 2014; Lashewicz et al, 2014), have argued that the maximum degree of self-determination and decision-making of persons with disabilities should be respected and promoted, together with consideration of the social context (Veal et al, 2016). With respect to participation in real-life settings, the decision-making of persons with severe cognitive impairments would be supported by caregivers and professionals, although paternalistic decisions may be made without attaining adequate informed consent of persons with disabilities in some undesirable cases (Coulter, 1999).

In addition, this aspect includes ownership of socioeconomic activities. There are many possible options for ownership. They are exemplified by persons with disabilities who commence and manage self-employment, disabled people’s
organisations, general companies hiring persons with disabilities, and community professionals and workers who promote disability-inclusive socioeconomic activities (Knapp & Midgley, 2010).

The third aspect includes the contents of socioeconomic participation opportunities. Some researchers have suggested an integrated perspective on economic and social activities at the community level (Myrdal, 1970; Midgley, 1995, 2017b); for instance, workers in community development ‘uniquely integrate economic and social objectives’ (Midgley, 2017b). As shown in the previous section, there are lists that involve socioeconomic activities and participation, such as the ICF (WHO, 2001, 2013) and measurements proposed by researchers (e.g., Perenboom & Chorus, 2003; Verdonschot et al, 2009a, 2009b; Chang et al, 2013). The CBR Matrix also includes ‘livelihood’ and ‘social’ components, while placing the ‘empowerment’ component at its centre (WHO et al, 2010). It is, however, controversial whether listing is suitable or not for this socio-cultural and personal context-dependent concept. The next section touches upon a similar issue regarding the list of capabilities.

The fourth aspect of socioeconomic participation is its multiple levels, ranging from the individual to the social and macro levels (Veal et al, 2016). From a social work perspective (e.g., Friedman & Allen, 2011), participation is analysed at the micro, meso (mezzo), and macro levels. It includes, for instance, socioeconomic participation at the individual and household levels (e.g., self-employment), at the community level (e.g., CBR group activities and collective income-generating programmes), and at the provincial, national, and international levels (e.g., involvement in the process of policy-making). Likewise, socioeconomic participation could be classified using individual participation and collective participation from the traditional social psychological scheme, although even individual behaviours are social because of direct and indirect interactions with others and the social environment (Turner et al, 1994).

These four aspects will be referred to during the discussion of the theoretical frameworks of socioeconomic participation in the next section. In addition to the four aspects, it is also necessary to consider the complex dynamics among the various factors that depend on the socio-cultural context. For example, socioeconomic factors would impact socioeconomic participation, and vice versa.
THEORETICAL FRAMEWORK: THE CAPABILITY APPROACH

This section examines the application of the capability approach and the human development model to the socioeconomic participation of persons with disabilities. It argues that the capability approach is useful for framing the multiple aspects of socioeconomic participation.

Applicability of the Capability Approach to Disability Issues

Amartya Sen’s capability approach (1992, 1999, 2005) has been applied to many academic fields, including healthcare studies (e.g., Mitchell et al, 2017) and disability issues (Terzi, 2005; Mitra, 2006, 2017; Saleeby, 2007; Dubois & Trani, 2009; Trani et al, 2011; Kuno, 2012; Brunner, 2015; Mousavi, 2015). The human development model of disability, health, and wellbeing has been proposed based on the capability approach (Mitra, 2017). Given that disability is frequently discussed within the following models of disability, namely the moral model, the tragedy and charity model, the medical model, and the social model (e.g., Marks, 1997; Mitra, 2006, 2017; Dubois & Trani, 2009; Knapp & Midgley, 2010; Kuno, 2012), the application of the capability approach and the human development model are offered as alternatives to these models (Mitra, 2006, 2017). The background of the capability approach is different from other models of disability because it was not introduced directly as a model of disability but rather stemmed from welfare and development economics, which involves discussions about poverty and inequalities. The interpretation of disability varies in each of the models listed above, while the capability approach enables the comprehensive analysis of the various factors that cause deprivations (Mitra, 2006, 2017).

Key concepts in the capability approach are functionings, capabilities, resources, conversion factors, choice, agency, and human diversity. Functionings refer to ‘the various things a person may value doing and being’ and ‘what a person is actually able to do’, and capabilities refer to ‘the substantive freedom to achieve alternative functioning combinations’ and ‘real opportunities’ (Sen, 1999). Nussbaum (2001) has proposed a list of ‘central human capabilities’, yet that has been widely debated, with some researchers arguing that capabilities should be determined through democratic processes amongst stakeholders (Robeyns, 2005; Mitra, 2006, 2017; Morris, 2009).

Even if a person has access to resources and commodities such as services, goods, and information, the ability to transform them into capabilities and functionings depends on conversion factors (Robeyns, 2005; Mitra, 2006, 2017; Morris, 2009;
Kuno, 2012). Robeyns (2005) has clarified three main conversion factors: personal conversion factors (e.g., psychological and physical characteristics), social conversion factors (e.g., policies and socio-cultural norms), and environmental conversion factors (e.g., geographical features and infrastructures). Impairments can be placed within personal characteristics (Burchardt, 2004; Mitra, 2006), although the human development model places it in health deprivations (Mitra, 2017).

In addition, a person’s choices and values are fundamental to achieving the functionings that lead to his or her wellbeing (Sen, 1992, 1999), reflecting human diversity and freedom. Choices are influenced by multiple conversion factors, including the person’s preferences. Choices may be a result of adapting to a disadvantaged environment, including extreme poverty, indicating that understanding capabilities is also essential (Sen, 1992, 1999). Even if resources and commodities are available to a person, both the capability set and choices based on his or her values would be converted by personal, social, and environmental factors (Robeyns, 2005).

The concept of agency is also crucial in the capability approach, which has various implications for disability issues (Mitra, 2017). A person with agency is described ‘as someone who acts and brings about change, and whose achievements can be judged in terms of her own values and objectives’ (Sen, 1999). A person’s agency achievement is described as ‘the realization of goals and values she has reasons to pursue, whether or not they are connected with her own well-being’ (Sen, 1992). It is thus possible to consider a distinction between wellbeing and choices: someone might undertake actions for others regardless of his/her own wellbeing in the narrow sense. Further, agency is not limited to the individual level but can be expanded to collective agency, which is defined as ‘a group of individuals acting as agents not only to improve their own living conditions but also to bring about changes in their societies’ (Pelenc et al, 2013).

From the viewpoint of the capability approach and the human development model, disability is regarded as deprived capabilities and functionings among persons with health deprivations, interacting with multiple factors (Terzi, 2005; Mitra, 2006, 2017). As Sen (1992, 1999) has also described poverty as deprivations of capabilities, disability-poverty linkages are well-documented (Mitra, 2017).

The present article analyses socioeconomic participation by drawing on the capability approach, but without forcefully integrating it with the ICF. There are
debates about whether the capability approach complements the ICF (Saleeby et al, 2007; Morris, 2009) or whether it should distinguish itself from the ICF entirely (Mitra, 2014). The ICF uses terms similar to the capability approach, such as capacity and functioning, but the meanings are different. For instance, the meaning of functioning in the ICF is human experience related to the interaction among factors, namely body functions and structures, activities, participation, personal factors, environmental factors, and health status. The meaning and implications of functionings in the capability approach are broader than those of the ICF (Mitra, 2006). In addition, the capability approach acknowledges human diversity, freedom to achieve, and agency, thereby considering multiple conversion factors and capabilities that the ICF does not include (Morris, 2009; Mitra, 2014, 2017). Indeed, the ‘ICF conceptualises functioning and disability in the context of health, and therefore does not cover circumstances that are brought about solely by socioeconomic or cultural factors’ (WHO, 2013). With regard to participation, the ICF lists cover broad domains of activities and participation, but the distinction between them is unclear and discussions on social participation seem to be inadequate (Eyssen et al, 2011). Hence, this article uses the capability approach to discuss socioeconomic participation.

Socioeconomic Participation from the Perspective of the Capability Approach

This section argues that the capability approach provides comprehensive and holistic views on the socioeconomic participation of persons with disabilities. It goes on to discuss the relationship of the perspective of the capability approach with the four aspects explained in the previous section.

The literature considers disability issues, including the participation of persons with disabilities, by applying the capability approach. As Morris (2009) has indicated, the participation of a person is considered in terms of functionings (in particular, ‘doings’), whereas potential opportunities and freedom to participate are considered capabilities. A person’s experiences, such as subjective experiences regarding participation, are to be included as ‘beings’ of functionings. In real life, these beings and doings are mixed at the individual level. In addition, it is possible to grasp influences on achieved participation (functionings) and potential opportunities for participation (capabilities) through personal, social, and environmental factors, together with a consideration of available resources and commodities (Sen, 1992, 1999; Robeyns, 2005). It is therefore fundamental to acknowledge the choices of a person with disabilities to participate or not participate in any opportunities.
The following is an example of the socioeconomic participation of persons with disabilities to explain the above concepts with reference to Sen’s (1992) example on starving. Even if a young woman does not participate in any social and economic activities on a regular basis (as functionings), the key point is whether she has possible opportunities for such participation or not (as capabilities). The available resources and commodities (e.g., services, assistive devices, and income for transportation expenses) are converted into possible participation opportunities (capabilities) and achieved participation (functionings) by various factors. These factors include personal (e.g., gender, age, and impairments), social (e.g., prejudice, discrimination, and information accessibility), and environmental factors (e.g., mountainous and remote areas or urban areas). Hence, the case that a person with disabilities could not achieve participation due to a lack of available opportunities is entirely different from the case that she decides not to do so (as choices) because of her preference, even though she has such opportunities. In other cases, persons with disabilities and their caregivers might give up such participation because of self-stigmatisation and just accept the situation (adaptation).

The capability approach covers all of the four aspects of the socioeconomic participation of persons with disabilities—ends and means, the subject, contents, and levels. In a situation where a person has the fundamental freedom to participate in social and economic activities, achieved socioeconomic participation depends on his or her choice of whether or not to participate. If there is freedom to choose to participate, this could enable a process of empowerment through self-determination of the person with disability. In another situation where the person does not have any opportunity for socioeconomic participation because of a lack of assistance (e.g., for body motion, or income for transportation), this could be seen as deprivations of capabilities and functionings. If a person who has actual opportunities for participation has difficulty deciding whether or not to participate in any activities because of cognitive impairments, the line between supported decision-making and paternalistic interventions would be a context-dependent issue.

Like capabilities, the contents and levels of socioeconomic participation also depend on various factors, particularly the socio-cultural context. Opportunities for achievable participation are likely influenced by personal, social, and environmental factors as well as resources and commodities. As Trani et al (2011) have indicated, it is essential for stakeholders to collect information on the
values (i.e., what opportunities for participation should be included, and what social barriers to participation should be addressed) expressed by persons with disabilities and community members through dialogue and assessment. Since this point is associated with practice, it will be discussed in the next section.

PRACTICAL FRAMEWORK

This section develops the practical framework of developmental social work for promoting the socioeconomic participation of persons with disabilities from the perspective of the capability approach. It argues that the role of developmental social work includes establishing available resources and changing conversion factors in society in order to enhance a person’s capability set, while identifying his or her needs and deprived capabilities. It also suggests that developmental social workers could provide support for the decision-making of persons with disabilities who have difficulties and could coordinate available resources with them. That said, social workers need to reflect on some potential issues in social casework such as paternalism and power relationships. This article concludes that this framework provides useful guidance to improve the wellbeing and enhance the agency of persons with disabilities.

Developmental Social Work with the Capability Approach

Developmental social work is a holistic and pragmatic social work approach based on the principles of human rights and social justice that addresses poverty and socioeconomic inequalities at the individual, household, community, and policy levels (Elliott & Mayadas, 2001; Midgley, 2010; Knapp & Midgley, 2010). In addition to leading scholar James Midgley, researchers and professionals from the Global South, such as Africa, have developed its practical approaches (e.g., Patel, 2005; Gray, 2006; Patel & Hochfeld, 2013; Van Breda, 2015). Developmental social work utilises multiple approaches and skills, in particular social investment, community building, capacity development, and the integration of micro-macro practice (Midgley, 2010; Van Breda, 2015). Social investment is the distinctive approach in developmental social work and is defined as ‘allocations to social programmes that produce returns and promote future social well-being’ (Midgley, 2017b). Social investment includes the aim to ‘mobilize human and social capital, facilitate employment and self-employment, promote asset accumulation, and in other ways bring about significant improvements in the material welfare of individuals, families, and communities’ (Midgley, 2010).
The integration of developmental social work with disability issues and CBR has been examined by researchers, albeit in a small body of literature. Developmental social work addresses poverty and inequalities that persons with disabilities face, while promoting socioeconomic participation, developing leadership for persons with disabilities, and realising inclusion and empowerment (Knapp & Midgley, 2010; Higashida, 2017). The practical framework of developmental social work, however, appears to be underdeveloped (Van Breda, 2015). Promoting socioeconomic participation, for example, is one possible entry point, but its systematic and practical frameworks need to be further developed. This section suggests that the application of the capability approach to developmental social work provides practical perspectives to address poverty and socioeconomic inequalities.

The application of the capability approach to social work and social welfare, including developmental social work, has been examined by several researchers (Saleeby, 2007; Braber, 2013; Veal et al, 2016). For example, Midgley (2017b) has argued ‘the need for new policies and programmes that invest in human capabilities rather than transferring resources to passive welfare recipients’, while also referring to Sen’s capability approach in his other papers on developmental social work (e.g., Midgley, 2010). However, the relationship between developmental social work and the capability approach does not appear to have been discussed in detail in the literature. Possible reasons for this absence are that each has a different focus, even though both developmental social work and the capability approach address poverty and inequalities. Developmental social work tends to focus on the improvement of material wellbeing for persons and communities (Midgley, 2010), whereas the capability approach tends to focus on potential opportunities and achieved functionings that lead to the wellbeing of a person (Robeyns, 2005). With respect to its nature, developmental social work emphasises practice, whereas the capability approach emphasises analysis. The present article argues that the application of the capability approach to developmental social work in disability issues is both possible and helpful for understanding the socioeconomic participation of persons with disabilities.

Through its micro, meso and macro practice, developmental social work could address the deprivations of capabilities and functionings that persons with disabilities face in their life. In other words, developmental social work responds to ‘the constraints that the environment adds to a person’s impairment in order to expand their capability set and to allow them to live a life which they value’
As well as development, developmental social work would have the process of expanding the freedom of people with disabilities (Sen, 1999; Mitra, 2017). The application of the capability approach suggests that social work includes practices to develop resources and improve social structures and physical environments (Saleeby, 2007; Mitra, 2017). Developmental social work could also include direct care to improve a person’s central human capabilities (Nussbaum, 2001; Mousavi, 2015; Van Breda, 2015), yet careful consideration is necessary because it might simply encourage individual interventions based on the medical model of disability (Kuno, 2012). Thus, it is worth clarifying that poverty and the socioeconomic inequalities facing persons with disabilities are addressed by expanding the actual opportunities for them in developmental social work practice.

The concepts of choices and agency also have implications for developmental social work. Developmental social workers need to respect self-determination by persons with disabilities, while supporting their decision-making if necessary. In some cases, reflection on the social workers’ practice and relationship with persons with disabilities, including potential paternalistic interventions, is required (Higashida, 2017). In addition, the concept of agency emphasises the importance of human rights as well as the importance of choices for persons with disabilities. Persons with disabilities promote their human rights and empowerment through political participation, advocacy, and collective movement, and their claims may include criticism of professionals, including in the social work practice (Oliver & Barnes, 1998; Knapp & Midgley, 2010). This might pose a difficult dilemma for social workers between prioritising a person’s agency or wellbeing. There is no one-size-fits-all answer to this issue, but developmental social workers can find reasonable practice with persons with disabilities and other stakeholders through substantial dialogue.

**Developmental Social Work for Promoting Socioeconomic Participation: The Capability Approach**

This section proposes the practical framework of developmental social work in disability issues and CBR by applying the capability approach. The ultimate values of developmental social work in CBR involve human rights, social justice, and socioeconomic equality (Elliott & Mayadas, 2001; Higashida, 2017). The targets of developmental social work practice emphasise the importance of promoting socioeconomic participation of persons with disabilities, although it is not limited...
to participation in specific domains (Midgley, 2010, 2017b). Developmental social work tackles the constraints faced by persons with disabilities because of multiple factors in society, in order to expand their actual opportunities and allow them to choose those which they value (Mitra, 2006, 2017; Saleeby, 2007; Dubois & Trani, 2009).

In line with this framework of developmental social work in disability issues, its practice expands socioeconomic participation opportunities through engagements with health deprivations, resource shortages, and structural barriers in society, all while considering human diversities (Mitra, 2017). Developmental social work therefore covers a range from practice in the community to social change and policy making (Elliott & Mayadas, 2001; Midgley, 2010; Higashida, 2017). Since one of the distinctive approaches of developmental social work is social investment, which addresses poverty and socioeconomic inequalities (Midgley, 2010, 2017b), it is the preferred practice to expand actual opportunities for persons with disabilities to enjoy socioeconomic participation.

Referring to the literature (Saleeby, 2007; Midgley, 2010; Knapp & Midgley, 2010; Van Breda, 2015; Higashida, 2017), this paper summarises dimensions of developmental social work for the promotion of socioeconomic participation based on the application of the capability approach (Sen, 1992, 1999; Robeyns, 2005; Morris, 2009; Kuno, 2012). Figure 1 illustrates the conceptual framework that integrates the micro, meso and macro practices of developmental social work. Five squares in the figure indicate key components of the capability approach: commodities/resources, conversion factors, capability set (freedom to participate), choice, and achieved functionings (participation). The black arrows represent potential interactions between these components, whereas blue arrows indicate the entry points of developmental social work practice. Blue arrows also imply the bi-directional relationships: the influence of developmental social work practice on each component and the feedback of each component on developmental social work practice. Although Van Breda (2015) has described six stages of developmental social casework at the individual level (engagement, assessment, planning, implementation, evaluation, and termination), this article proposes some entry points and a non-linear process so as to respond to the personal and local context and micro-macro dynamic practices, to be explained below.
Figure 1: Conceptual Framework of the Capability Approach applied to Developmental Social Work for Promoting a Person’s Participation

First, social workers, in corporation with other stakeholders including persons with disabilities, develop available resources that can be converted into the foundation for a person’s capability set and opportunities for socioeconomic participation. Resources include not only income and physical objects (e.g., mobility allowance, and assistive devices) and the personal support that are necessary for them to participate, but also self-help groups, microfinance, income-generating activities, vocational training, and inclusive workshops that are potential means to participate at the community level (Knapp & Midgley, 2010). After identifying the community needs and necessary resources for marginalised persons with disabilities, these resources can be developed by mobilising social capital and building networks at the community level, while promoting social investment and funding by government, non-government, and private sectors. Developmental social work therefore facilitates creating available resources in collaboration with persons with disabilities and local stakeholders by using the social investment strategy and workers’ own knowledge and skills.

Second, by utilising existing and alternative local resources, developmental social work improves the social environment and promotes social change in partnership with persons with disabilities and other stakeholders. This is an engagement tool to tackle negative conversion factors in society for mitigating the impacts on the potential opportunities of persons with disabilities (Saleeby,
There are many options, ranging from personal support and coordination, such as individual placement and support (IPS) and care management, to more socially dynamic actions, such as lobbying for the improvement of employment policies and raising awareness of discrimination against persons with disabilities (Knapp & Midgley, 2010; Higashida, 2017). Such multi-dimensional and multi-sectoral practice can expand the range of potential functionings or the actual participation opportunities of persons with disabilities (Saleeby, 2007; Veal et al, 2016).

Third, if persons with disabilities have any difficulties with choosing which participation opportunities they value, due to any impairments, developmental social workers can provide support for decision-making at the micro level. They can also identify what the person would value and coordinate relationships and resources with stakeholders such as family members of the person with disabilities (Higashida, 2017). In other words, supportive practice for promoting choice and expanding a person with disabilities’ capability set may be conducted simultaneously. Developmental social workers also consider basic principles such as social justice, human rights, and the strength perspective during such coordination, avoiding prioritising other stakeholders’ interests (Midgley, 2010; Knapp & Midgley, 2010; Higashida, 2017).

Finally, the perspective of agency is emphasised at the stage of achieved participation, including capacity development for leaders who have disabilities and community mobilisation through socioeconomic activities. This stage includes leadership training programmes, capacity development of disability-inclusive committees, and the facilitation of collective and sustainable activities (Knapp & Midgley, 2010). These practices by developmental social workers would facilitate the individual and collective agency of persons with disabilities and would be additional resources that could be converted into a person’s capability set (Veal et al, 2016).

As indicated in Figure 1, the above activities in developmental social work would be influenced by feedback from persons with disabilities and other stakeholders. For instance, the constructed local resources could be utilised for expanding the range of participation opportunities for persons with disabilities. This means that persons with disabilities have additional potential functionings or options for their choices, while developmental social workers obtain additional options to promote the participation of persons with disabilities. A similar relationship can be seen between conversion factors and developmental social work practices.
The developmental social work practices attempt to change conversion factors, in particular to remove social and physical barriers, and such changed factors would influence their practice. For example, practical targets and collaborators for developmental social workers could vary flexibly in accordance with the needs and current situation of persons with disabilities in society. Furthermore, promoting self-determination by developmental social workers is not necessarily a one-time result but a dynamic process. Therefore, the practices of developmental social workers would also vary depending on the decisions and wishes of persons with disabilities in the process.

Limitations

There are some theoretical and practical limitations to this review. Some limitations are related to the theoretical assumption of the capability approach. Researchers have argued that the capability approach is too individualistic and that it is therefore necessary to consider the collective aspects in each concept of the approach (Dubois & Trani, 2009; Trani et al, 2011). While this article touched upon the collective aspects of some concepts, the focus on collectivity would need to be further examined (Veal et al, 2016). In addition, because the capability approach is less likely to provide adequate information on the causes behind each factor, other models—in particular, the social model of disability—could strengthen the framework for practice to address social issues (Kuno, 2012).

Next, there are some limitations related to the perspective of developmental social work. For instance, one of the roles of developmental social workers is to improve capabilities for persons with disabilities, including opportunities for socioeconomic participation. However, the real needs and choices of persons with disabilities are diverse. This means that emphasising a specific approach, such as social investment, might not be suitable for some persons in the community. Hence, developmental social workers need to consider how reasonable the adaptation of persons with disabilities to such participation opportunities is and the power relationship(s) involved.

Finally, the feasibility and usefulness of the application of the capability approach depend on future work. The capability approach uses some terms and concepts that include unique meanings and implications. It is likely to be difficult for strangers to this academic circle to understand the perspective, which might cause some misunderstanding (Kuno, 2012). Therefore, frameworks that are easier for practitioners to understand are required. In addition, the range that the
proposed framework of developmental social work practice covers is likely to be broad because the capabilities and functionings relate to various areas. Hence, from the perspective of feasibility and practicality, this framework needs to be more developed in terms of the skills, processes, and activities of developmental social workers (Van Breda, 2015). Moreover, this article did not discuss in detail the evidence-based practice and education system of developmental social work that should be developed (Midgley, 2010).

CONCLUSION

This review article aimed to develop the practical framework that is applicable to developmental social work in CBR for addressing disability-related inequalities and poverty by using the capability approach. It identified aspects of the socioeconomic participation of persons with disabilities to which developmental social work could contribute. In reaction to insufficient discussions on the framework of developmental social work in CBR, this article enables developmental social workers and other stakeholders to consider the complex social dynamics amongst capabilities, functionings, resources, conversion factors, and other factors, together with an emphasis on the social dimensions of its practice. CBR practitioners, including social workers, develop indigenous practice while gaining experience through practice and the sharing of knowledge with stakeholders in line with the local socio-cultural context. These practitioners could utilise the proposed framework, which has space for diverse practices at the grassroots level. This paper recommends that future practice develop the framework further. In addition, it is possible to discuss other issues that this paper has not included, such as the relationship of practice to innovation and technology, developmental social work education, and public policies in developing countries. In this way, this paper also suggests further discussion of CBR practice based on a broad and comprehensive understanding.

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ABSTRACT

Purpose: To study the difficulties (if any) faced in the admission process of Children With Special Needs (CWSN) and the reason for these difficulties (if any) and also to suggest possible solutions for overcoming the difficulties.

Methods: The data was collected from 16 resource teachers working in Delhi. The anecdotal narratives provided by resource teachers were qualitatively analyzed via content shifting.

Results: Majority (more than 80%) of the resource teachers faced lot of difficulties while acting as facilitator for admission of CWSN.

Conclusion: Existing lack of awareness about the zero rejection policy by the school authorities (principal/head teacher), fear of accidents in the school, bullying of CWSN by non-CWSN, non-availability of resource teacher and the required support, were found to be the main challenges in implementation of zero rejection policy in admission of CWSN. The possible solution lies in preparing the regular teachers for addressing the needs of CWSN in the inclusive classroom and in turn making them responsible and accountable for teaching learning of CWSN, just like they are for children without special needs.

Key Words: CWSN admission, inclusive school, admission policy

INTRODUCTION

The Right to Education (RTE) for every child up to 14 years of age, without discrimination, is enshrined in the Constitution of India (Government of India, 1948). The RTE Act (Government of India, 2009) defines many aspects of education such as the role of the teacher, pupil-teacher ratio, school and its infrastructure, etc., apart from making free and compulsory education the right...
of every child. Indian Government’s commitment to educate Children With Special Needs (CWSN) is also evident from schemes like Inclusive Education for Disabled at Secondary Stage (IEDSS) and Sarva Shiksha Abhiyaan (SSA) and also being signatory to United Nations Conventions on the Rights of Persons with Disabilities (UNCPRPD).

**Policy Directives, Provisions and Schemes regarding Issue of Admission to Children with Special Needs**

In India, the Persons with Disabilities Act (Government of India, 1995), section 26, advises local authorities and appropriate governments to ensure that every child with disability has access to free education in an appropriate environment till the age of eighteen years. Section 30 of the same Act advocates provision for removal of architectural barriers from school/college, supply of books, uniforms and other essentials, scholarships to children with special needs, and restructuring of curriculum for these children. More than a decade later, RTE Act 2009, made free education a legal right for all children without any discrimination. The Persons with Disabilities Act was revised in 2016.

Sarva Shiksha Abhiyaan (SSA), a pan India scheme initiated in 2000 for universalisation of elementary education, adopted a zero rejection policy in education. Various states in India had formulated their own admission guidelines under SSA. Guidelines formulated in Haryana suggest that every identified child with special needs, in the age group of 6 - 18 years, shall be enrolled in the neighbourhood schools without any discrimination. Every child with special needs shall be enrolled in classes according to their age. No child shall be denied admission in school due to the absence of required documents. They shall be enrolled throughout the academic year (Guidelines Haryana, 2015). Madhya Pradesh initiated ICT- based tracking of assistance, provided to CWSN, to ensure personalised follow up (Madhya Pradesh Education Portal, n.d.). Office of the SSA Karnataka had drafted a policy on education of CWSN in the year 2013, ensuring no discrimination in admission for CWSN and other children belonging to Scheduled Castes (SC), Scheduled Tribes (ST), minorities, girls and other disadvantaged conditions (Draft policy, Education of CWSN, Karnataka, 2013).

The Delhi High Court in its landmark judgment directed the state government to develop an admission and reporting mechanism for admission of CWSN at entry level in schools. The admissions were to be routed through a single window clearance centre, without any need to run from pillar to post (Order Hon’ble High
Court, 2014). Following directives of the Delhi High Court, the Delhi Government made provision for CWSN to seek admission in any five schools of their choice, by filling up a common admission form available on the website of the Directorate of Education. The filled in application forms were to be later transferred online to the private schools that had been applied to, and to the nodal officer. The school, after taking the necessary steps, need to convey the result to both the parent and the Directorate. Non-compliance would lead to stringent action (Sharma, 2015).

In 2009, the Central Board of Secondary Education (CBSE) issued a circular to its affiliated schools to ensure that no child with special needs is denied admission in the regular schools. In addition, the schools were advised to allow parents, when they make a request, to provide an aide so that individual attention is possible for the child and the student is enabled to grow and learn along with other peers in the class. The schools were cautioned that failing to provide attention to a child with special needs or denying admission to CWSN due to their disability, will be liable to stringent action, even to the extent of disaffiliation (Government of India, 2009).

The Indian Government’s commitment to educate children with special needs is also evident from schemes like Inclusive Education for Disabled at Secondary Stage (IEDSS), and by virtue of being a signatory to United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD).

Rationale for Present Study

The SSA enrolment data indicates encouraging trends regarding enrolment of CWSN in regular schools. The enrolment of CWSN has gone up from 1.17 million in 2003-04 to 2.35 million (86.45% of identified CWSN) in 2013-14. In addition, 33,900 CWSN were enrolled in school readiness programmes and 206,000 children were provided home-based education. The total coverage of CWSN is 2.6 million, which is 95.3% of the total number of identified CWSN (EFA, NUEPA, MHRD, 2014).

The Census 2011 reveals that the percentage of persons with disabilities increased from 2.13 % in 2001 to 2.21% in 2011. Of this 2.21% population of persons with disabilities, 1.14% was in the age group 0 - 4 years (early years), 1.54% in the age group 5 - 9 years (primary school age) and 1.82 % in the age group 10 - 19 years (Census, 2011).

SSA school statistics show that the joint efforts made by SSA and RTE Act 2009 towards universalization of elementary education have been a success. However,
the researcher worked as teacher educator and resource teacher for in-service teacher training programmes under SSA and found through experience that the situation was quite different. The number of CWSN enrolled in the schools is still below the national average of this population of children.

The aim of the present study therefore was to discover the difficulties (if any) faced by resource/special teachers in the admission process of CWSN and the reason for these difficulties (if any), as well as suggest possible solutions to overcome them. This could improve the admission scenario for CWSN in regular schools.

**METHOD**

**Design**
The survey mode, with open ended items, was used to gather data.

**Sample**
Data was collected from 16 resource teachers working under the Sarva Shiksha Abhiyaan (SSA) scheme in Delhi. The anecdotal narratives provided by these teachers was qualitatively analysed via content shifting.

| Narrative received from special educators | = | 16 |
| CWSN mentioned in narratives              | = | 26 |
| Principals in the narratives              | = | 22 |

**Table 1: Nature of Children with Special Needs, as mentioned in narratives**

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Special Needs due to</th>
<th>Number of CWSN</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Mental Illness</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Intellectual disability</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Visual Impairments</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>Autism</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>Multiple Disabilities</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>Physical Handicap</td>
<td>2</td>
</tr>
<tr>
<td>7</td>
<td>Others</td>
<td>9</td>
</tr>
</tbody>
</table>

**Data Analysis and Inferences**
The narratives of the special teachers were qualitatively analysed and content was sifted in terms of: identifying the school principal’s initial reaction when parents, with the support of special teachers, approached the school for admission of children with special needs; reasons for refusal given by principals; counselling of parents; nature of undertaking; pressure strategies adopted by special teachers; and, the supportive principals. The paragraphs and Tables below present the inferences drawn on each theme.

Table 2: Initial Reaction of School Principals, as mentioned in narratives

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Reaction of School Principal</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Refusal</td>
<td>17 (77%)</td>
</tr>
<tr>
<td>2</td>
<td>Yes</td>
<td>5 (22%)</td>
</tr>
<tr>
<td>3</td>
<td>Foul Language</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>4</td>
<td>Anger</td>
<td>2 (9.1%)</td>
</tr>
</tbody>
</table>

According to the narratives of the special educators, refusal of admission was the initial reaction of majority (77%) of the school principals, 22% said ‘yes’ to admission, around 9% used foul language and 9% expressed anger at the special teacher who was supporting admission of children with special needs in regular schools and helping parents in the process. The reaction of majority of the principals was not in harmony with the policies, acts and provisions provided by the Government. This was also contrary to the CBSE admission guidelines and zero rejection policy adopted in the SSA.

Table 3: Reasons for Refusal given by Principals, as mentioned in narratives

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Reason for Refusal given by Principal</th>
<th>Frequency (percentage calculated from 17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lack of Special Teacher</td>
<td>8 (47%)</td>
</tr>
<tr>
<td>2</td>
<td>Who will take responsibility?</td>
<td>5 (29.4%)</td>
</tr>
<tr>
<td>3</td>
<td>CWSN will be bullied by other kids</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>4</td>
<td>Non-availability of disability certificate</td>
<td>3 (17.6%)</td>
</tr>
<tr>
<td>5</td>
<td>Busy in other work, come tomorrow</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>6</td>
<td>Age more than 5 years</td>
<td>1 (5.8%)</td>
</tr>
<tr>
<td>7</td>
<td>Last date of admission is over</td>
<td>1 (5.8%)</td>
</tr>
<tr>
<td></td>
<td>Reason</td>
<td>Count</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>8</td>
<td>CWSN roam around in the school</td>
<td>1(5.8%)</td>
</tr>
<tr>
<td>9</td>
<td>Lack skilled resources to teach CWSN</td>
<td>1(5.8%)</td>
</tr>
<tr>
<td>10</td>
<td>Admission in-charge not available</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>Negative attitude of other teachers</td>
<td>1</td>
</tr>
<tr>
<td>12</td>
<td>No seat available</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>Registration now, admission later</td>
<td>1</td>
</tr>
<tr>
<td>14</td>
<td>Cannot shift respective classroom from upper floor to ground</td>
<td>1</td>
</tr>
<tr>
<td>15</td>
<td>File is sent for approval</td>
<td>1</td>
</tr>
<tr>
<td>16</td>
<td>Get admission to special school</td>
<td>1</td>
</tr>
</tbody>
</table>

The Table above lists the reasons stated by the school principals, as mentioned in the narratives, for denying admission to CWSN in their schools. Lack of special teachers was the main reason for denying admission to CWSN, as reported by majority (47%) of the school principals. Some of the other reasons given by principals for denying admission were: Who will take responsibility? (29.4%), CWSN will be bullied by other children (17.6%), and lack of disability certificate (17.6%).

**Counselling of Parents**

A few school principals also attempted to discuss the issue with the parents, in the hope of convincing them not to admit their children with special needs in the school. The interaction between the principals and the parents revolved around the following themes, as culled from the narratives:

- The children without disability studying in the school will hit your child, we will not be able to provide due care, due to other work.
- Please give in writing that you do not want your child to be admitted here.
- This is requested for your own good and benefit to your child.
- If your child doesn’t understand what is being taught or done in the school, then his/her time spent in the school would be wasted.
- If it were our own child, we would get him/her admitted in a special school.
- Why do you keep coming to school and waste both your time and ours?
- What if the child is physically abused?
When authority- in this case, the school principal - clearly advises against admission, the economically backward and illiterate parents are hardly in a position to object. However, thanks to persistent efforts of some special teachers, a few school principals agreed to give admission, with an undertaking from the parents.

Table 4: Nature of Undertaking from the Parents

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Nature of Undertaking</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>In case of any accidents or unfortunate event, school will not be held responsible</td>
<td>8</td>
</tr>
<tr>
<td>2</td>
<td>One of the parents will have to accompany the child to school</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Child will not be sent to school till appointment of special educator</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>Special teacher will be completely responsible for all issues</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>School will not be responsible for difficulty faced by the child in school</td>
<td>1</td>
</tr>
</tbody>
</table>

The undertaking, regarding any unfortunate event or accidents, given by the parents indicates the assumption by the school authorities that CWSN are more prone to accidents and injuries as compared to their peers without disabilities. The same kind of undertaking is rarely requested from the parents of children without special needs. This is against the spirit of the Constitution of India (Government of India, 1948) ensuring no discrimination via Article 15 which prohibits discrimination on any grounds. Article 15(1) enjoins on the Government not to discriminate against any citizen on the grounds of religion, race, caste, sex or place of birth.

By asking parents of CWSN to accompany their child to school, the principals are not only discriminating between children on the basis of disability (violation of Constitution Article 15) but have also found a polite way to refuse them admission, as most of the parents who send their children to state-run schools belong to the lower rung of the socio-economic ladder and have minimal or no knowledge of their rights or legal provisions. The family’s difficulties will be compounded further if one of the parents is forced to accompany the child to school and spends a lot of time trying to get the child admitted, thereby losing out on a working day’s wages and halving the family’s income.
Pressure Strategies adopted by Special Teachers

In the narratives, the special teachers have mentioned that more than often they have to draw support from the policy, provisions and Acts, various circulars issued by the state SSA offices, or bring the matter to the notice of higher authorities, in order to succeed.

Table 5: Strategies adopted by Special Teachers

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Strategy adopted by Special Teacher</th>
<th>Frequency (out of 16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Involved higher officials like DDE, BRCC, etc.</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>Quoted/showed RTE Act</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Written complaint with parents support</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>Examples from neighbouring schools</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Referred to SSA circulars</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Threatened to file written complaint</td>
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</table>

Not every special teacher voluntarily adopted these pressure tactics. During the household survey, many parents refused to give the name of their child as they had been through bad experiences earlier. They felt this was only eyewash, one of the routine tasks to be completed by the education system, without actually having any will to admit the CWSN in the schools. This was also mentioned in one of the narratives.

When the system is not geared to provide support and the policy or practice implementation is imposed from above, without proper checks and balances in place, the implementing officer may become frustrated. This is the situation in the SSA. The state offices initiate the admission drive for CWSN and involve the special educators. However, the intermediate authorities, namely the school principals, attempt to find a way out of implementing the initiatives, and the special educators end up frustrated.

The Other Side of the Coin: The Supportive Principals

A few school principals not only welcomed the parents and the CWSN, but had also extended cooperation to parents and special teachers. These school principals had expressed readiness to accommodate more CWSN in their institutions. They
also shared their knowledge about the provisions for CWSN under SSA and RTE, with the parents.

Ironically, one school principal who also happened to be a person with disability was mentioned as one of the non-cooperative principals in the narratives.

RESULTS and DISCUSSION

The data analysis indicated that majority (more than 80%) of the special teachers faced lot of difficulties while acting as facilitator for admission of CWSN.

Suggestions

The possible solution lies in preparing the regular teachers to address the needs of these children in the inclusive classroom, and in making them responsible and accountable for the progress of CWSN, as they are for children without special needs.

- There should be a mechanism to address the grievances of special teachers and the parents.
- The procedures for obtaining the disability certificate should be simplified.
- Dedicated programmes targeting awareness-building and skills enhancement for parents.
- Dedicated programmes aiming to enhance sensitivity, leadership and knowledge for principals and other educational administrators.
- Situation-based, focussed attempts to build positive attitudes among teachers, educational administrators and peers of CWSN.
- Attempt should be made to reestablish the faith of parents in the system.
- The field functionaries like special teachers should be provided hand-holding and a support mechanism to perform their expected duties without fear, anxiety and frustration.
- The skills of regular teachers should be enhanced to address the teaching-learning needs of all, including CWSN in inclusive settings.
- The prime responsibility for teaching-learning of CWSN should devolve on the regular teachers, and they should be accountable just like they are for teaching-learning of children without disabilities.
- Roles and responsibilities of regular and special teachers should be clearly spelt out and conveyed to them.
CONCLUSION

At present, the educational administrators like the principals of regular schools, require sensitisation and awareness-training to facilitate admission of CWSN in neighbourhood schools. The objections raised resulted from lack of awareness by the school authorities (principal/head teacher) about the zero rejection policy, fear of accidents in the school, bullying of children with special needs by their peers, non-availability of resource teachers and the required support, etc. The regular teachers should be empowered to address the learning needs of CWSN in inclusive settings, and should be made accountable and responsible for their progress.

REFERENCES


Ujamaa and Universal Design: Developing Sustainable Tactile Curricular Materials in Rural Tanzania

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ABSTRACT

Purpose: This article illustrates the power of collaboration in the spirit of Ujamaa to build curricular materials that can engage and support the learning of a diverse group of students in under-resourced environments. The authors reflect on their personal experience overseeing collaborative service learning projects with Tanzanian partners through a study abroad programme.

Method: The service learning project took place in a rural primary school in northern Tanzania, characterised by large class sizes and the unavailability of teaching and learning materials. Tactile curricular materials were collaboratively developed by Tanzanian student teachers, practising teachers, and American undergraduate students. Locally available and recyclable materials were used, such as plastic water bottles, tubing, plastic bags and cardboard boxes.

Results: Examples of curricular materials that were developed are presented, and lessons learned through the experience are shared.

Conclusion: The use of locally available, recyclable materials enhanced sustainability. Having sustainable curricular materials that are accessible to a diverse range of students in under-resourced educational settings has the potential to foster learning for all. The underlying cultural concept of interconnectedness or Ujamaa strengthened the collaborative relationship between participating teachers and students, and can be drawn upon to enhance future service learning and international development efforts in education.

Key words: universal design, sustainable development, service learning, Tanzania
INTRODUCTION

Universal Design for Learning (UDL) is an approach to curriculum and instruction designed to enhance access to education and multiple pathways to learning for diverse students. Initially construed as a philosophical and technological approach to teaching via multiple means of representation, response, and engagement that best align with students’ learning styles (Rose & Meyer, 2002), UDL was primarily proposed as a means for including students with disabilities in general education classrooms. Now, the utility of UDL has expanded to a more general framework that can improve educational outcomes for all learners by making the curriculum more universally accessible to students with and without disabilities alike. For example, UDL would promote the use of tactile three-dimensional curricular materials that would jointly support kinesthetic learners who learn best by active touch and doing, as well as learners with a visual impairment who primarily learn through their sense of touch.

This article presents and reflects on 2 case examples of curricular materials that were collaboratively constructed by Tanzanian primary school teachers and American undergraduate students during a study abroad community engagement experience in rural Tanzania. Although the teachers and students did not intentionally operate from a technical UDL framework, UDL principles were organically applied during the creation process by innovatively using sustainable materials to build the curricular materials. The curricular material creation process highlights the humanistic approach that builds upon collaborative relationships (i.e., the Ujamaa principle), providing examples of teaching and development practices based on a human-centred approach. Ujamaa is a sociopolitical concept that emerged from President Julius Nyerere’s (1968) development plan, the Arusha Declaration, and is translated to mean ‘family-hood’. Nyerere thought of Africa as one family and the whole world as an extended family, and today many Africans still think of themselves in the context of this extended relationship with the world (Gathogo, 2008). It is hoped that the lessons learned from this experience can be incorporated into broader UDL and inclusionary educational reforms and practices in developing contexts.

Tanzanian Context

Tanzania is the largest and most populous East African country, with a land mass of 947,300 sq km and a population of nearly 54 million people (Central Intelligence Agency, 2018). Most of the land is used for agriculture and the majority of the
population lives in rural areas. The study abroad community engagement experience that is the basis of this article took place in a village primary school, characterised by large class sizes and the unavailability of teaching and learning materials (Wadsworth, 2015). Accordingly, students and the practicing teachers collaboratively designed and created curricular materials with locally available and recyclable materials such as plastic water bottles, tubing, plastic bags and cardboard boxes. In this way, if the curricular materials broke through use over time, the teachers could easily and affordably repair them.

METHOD

The examples presented below are based on the authors’ personal experience overseeing collaborative service learning projects with Tanzanian partners through a 6-week summer study abroad programme that took place in a Maasai village in Northern Tanzania. The goal of the programme was to provide the students with classroom and experiential opportunities to learn about education and development in Tanzania. To help meet the needs of the local community, a collective decision was made with Tanzanian partners to create curricular materials that teachers could use in their under-resourced classrooms. Tanzanian student teachers worked with the primary school teachers and the American study abroad students to build curricular materials by hand, using locally available and recyclable resources.

Curricular Material Case Examples

Example 1

The first example of an accessible, sustainable curricular material that was made by our students, Tanzanian student teachers, and primary school teachers is a tactile urinary system poster.
As can be seen in the in-progress photograph (see Figure 1) and finished product photograph (see Figure 2), the poster was constructed using cardboard, manila paper, tape, tubing, and plastic water bottles. The various parts of the urinary system were created using these locally available materials and were then labelled in Kiswahili (the primary local language) with coloured markers. Due to the tactile nature of this poster - with the three-dimensional tubing and bottles fixed onto the two-dimensional poster surface - students with visual impairments and kinesthetic learners could use their sense of touch to physically feel the different parts of the urinary system, thereby aiding in their learning of the science curriculum content.

Figure 3: Respiratory System curricular material
Example 2
The second example is a respiratory system demonstration device.

As can be seen in Figure 3, this was made using a large plastic water bottle, tubing, balloons, plastic bag, and rubber bands. A science teacher could demonstrate how lungs expand and contract during breathing by pulling the bottom of the plastic bag up and down. As the teacher demonstrates and explains the process of the respiratory system, students can watch the balloons (i.e., lungs) fill and empty with air. Using this curricular material could help support the learning of hearing impaired and visual learners, allowing them to physically see how the respiratory system functions.

RESULTS and DISCUSSION

Reflecting on the experience, the authors identified 5 key challenges and areas for improvement related to collaboration, teacher buy-in, teacher capacity, language barriers, and the availability of resources. The lessons learned are summarised below.

Collaboration

An important lesson that became apparent even before the programme came to an end was that teaching and learning is a collaborative activity. Working collaboratively had personal and professional benefits for everyone involved (i.e., the Tanzanian partners, the undergraduate students, and the authors themselves). The decision to work solely with teachers for the service learning component of the study abroad programme was initially made from logistical concerns. When the programme began in Tanzania, the school year had just ended and it would have been logistically difficult to ask the students to come back to school. Brunner (1985) posits that collaborative learning environments have better student outcomes. Therefore, involving students in this manner would have been useful in motivating students who were already experiencing insurmountable difficulties in school. While working in partnership with the primary school teachers provided the opportunity to collaboratively create sustainable curricular materials that could be used in their classrooms, there is the feeling that also involving students in the creation of the materials would have been even more beneficial.
Teacher Buy-In
One of the challenges was to convince teachers that this exercise was a worthwhile endeavour. The primary school teachers with whom the authors interacted felt overworked and under-appreciated. They faced numerous daily challenges such as large class sizes, extremely difficult working conditions, lack of resources, and low pay. Such challenges are compounded by time constraints that demoralise teachers and inhibit creativity. Additionally, due to pressures of annual high-stakes standardised testing, the teachers were reluctant to take on additional tasks that they were unsure would translate into positive academic outcomes for their students. Thankfully, over time the authors were able to overcome these challenges and convince teachers that the sustainable tactile curricular materials would be invaluable for their instructional practices and student learning. If the teachers had not been convinced, the authors acknowledge that their efforts would have had far less impact.

Teacher Capacity
Related to the initial reluctance displayed by teachers, it was found that teachers were not sure how to effectively use the curricular materials that they developed to accomplish learning goals. In a context where professional development is limited (particularly for educating students with disabilities) and teaching is heavily focused on preparing students for standardised tests, it was not surprising that the teachers lacked confidence in their ability to develop relevant curricular material that would help improve student learning. To respond to this need, the authors’ role evolved to help the teachers see the pedagogical connections between the curriculum, learning objectives, and instructional materials. Furthermore, explanations were made about how the tactile and visual elements of the materials would enhance the accessibility of the academic lessons for a diverse range of students. It was also sought to equip teachers with the skills and knowledge to generalise the work, so as to be able to create additional curricular material, using a similar approach, in the future. Building teacher capacity is imperative in the quest to develop curricular materials that can effectively support student learning.

Language Barriers
Another limitation was the language barrier between the American undergraduate students and the Tanzanian counterparts. A number of the collaborating teachers
spoke limited English, while some of the American students barely spoke the local language, Swahili. This resulted in communication problems, which sometimes impacted the ability to work together cohesively. This experience demonstrated the importance of addressing language barriers for effective collaboration and professional development.

**Availability of Resources**

Finally, while developing curricular materials using locally available recyclable materials is a worthwhile cause, in poor rural communities that lack resources this can be extremely challenging. It was very difficult to find recyclable material, given that many people do not have the financial means to purchase resources that end up as recyclable material. While it is felt that this approach of using locally available recyclable material is more sustainable than bringing foreign curricular materials from the U.S. that cannot be locally repaired or replaced, it is acknowledged that the availability of all resources (recyclable or not) is limited in poverty-stricken environments.

**CONCLUSION**

Reflecting on the lessons learned during this collaborative service learning experience, the authors would like to offer some concluding thoughts about the value of this type of work and how it relates to the broader themes of UDL and Ujamaa. First, it is felt that the collaborative nature and use of locally available, recyclable materials enhanced the sustainability of these efforts; those factors enabled the Tanzanian student teachers and primary school teachers with whom the students collaborated to continue to work together to develop new curricular materials after the authors left, and repair those that were made together. It is too often the case that international development projects and initiatives end abruptly when the outside partners leave (Hodgson, 2004; Rich, 2007).

Additionally, there is great value in the engaging and UDL nature of the curricular materials that were developed, particularly in resource-stricken educational contexts in developing countries like Tanzania. By incorporating multiple modes of learning (i.e., visual and kinesthetic), the curricular materials make the academic content more accessible to students with and without disabilities alike. Having these sorts of sustainable curricular materials that are accessible to a diverse range of students in under-resourced educational settings has the potential to...
foster learning for all, which is aligned with the current global policy initiatives of inclusive education and the United Nations (2015) sustainable development goal of quality education for all children.

Lastly, these case examples illustrate the power of collaboration in the spirit of Ujamaa to build curricular materials that can engage and support the learning of a diverse group of students. The authors feel that this underlying cultural concept of interconnectedness and unity strengthened the collaborative relationships between the Tanzanian student teachers, primary school teachers, and the participating students, and encouraged the creation of accessible curricular materials. It is hoped that the spirit of Ujamaa can be drawn upon to enhance future service learning and international development efforts to support the education of all the world’s children.

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**Netherlands Leprosy Relief (NLR)** 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.

Netherlands Leprosy Relief 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.

**CBM** is an international Christian disability and development organisation whose primary purpose is to improve the quality of life of the world’s poorest persons with disabilities and those at risk of disability.

**Light for the World** stands up for equal rights of persons with disabilities in developing countries. Their support focuses on three domains:

1. Special services for people with a disability, such as eye care and rehabilitation services through financial support and capacity building of local NGOs and governments.

2. Promoting inclusive development by building the capacity of organisations and institutes to give better access to persons with a disability to their services (leading to increased access to health, education and the labour market).

3. Support to Disabled People's Organisations to help them advocate for their rights and to increase their self-sufficiency.

**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.