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Editorial


It is acknowledged in the Report that while considerable progress has been made over the past decade across all areas of development, the pace of progress observed in previous years is insufficient to fully meet the Sustainable Development Goals (SDGs) and targets by 2030. In relation to some of the key indicators, it is stated that: “While nearly a billion people have escaped extreme poverty since 1999, about 767 million remained destitute in 2013, most of whom live in fragile situations. Despite major advances, alarmingly a high number of children under age 5 are still affected by malnutrition. In 2016, an estimated 155 million children under 5 years of age were stunted (low height for their age). Between 2000 and 2015, the global maternal mortality ratio declined by 37 per cent and the under-5 mortality rate fell by 44 per cent. However, 303,000 women died during pregnancy or childbirth and 5.9 million children under age 5 died worldwide in 2015”.

According to the report, progress has not always been equitable; advancements have been uneven across regions, between the sexes, and among people of different ages, wealth and locales, including urban and rural dwellers. In his Foreword, the UN Secretary-General Antonio Guterres states that “Implementation has begun, but the clock is ticking. This report shows that the rate of progress in many areas is far slower than needed to meet the targets by 2030.”

Earlier reports on progress of the Millennium Development Goals (MDGs) sounded very similar to the above, and that should be a cause of worry to governments and other stakeholders, particularly the people whom the SDGs are meant for. The key principle of the SDGs is “Leave no one behind”. If the present pace of progress to achieve the SDGs is not sufficient, then it is likely that many marginalised groups of people, including persons with disabilities, will be left behind yet again.

It is hoped that the report will act as a spur to governments to increase their efforts
and resources to realise the SDGs. Civil society groups, including organisations representing persons with disabilities, will need to focus on increased efforts to advocate for faster and more effective implementation of the SDGs.

It is 7 years since this journal has been in operation. In 2018 DCID will focus on issues related to its sustainability. Indexing is necessary for academic and technical sustainability, and to make the journal more attractive for authors. All efforts will be made to get the journal indexed by reputed indexing agencies. Management sustainability is another vital issue. Linking the journal with a university or agency involved in promoting disability issues would be of help in maintaining the journal over a longer term and will also help with academic sustainability. The third aspect is financial sustainability. The journal continues to be committed to its mission of being free to readers and authors, and efforts are underway to increase the donor base so that we can maintain this mission.

We welcome suggestions from our readers on the future of the journal.

Maya Thomas
Editor-in-Chief
Disability, CBR and Inclusive Development
Cross-sectional Survey to Assess Prevalence of Disability and Access to Services in Albay Province, The Philippines

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ABSTRACT

Purpose: A cluster randomized cross-sectional survey to assess the prevalence of disability and access to support services was conducted in Albay Province, the Philippines in April 2016.

Method: The population-based survey methodologies developed by the Washington Group of the United Nations Statistical Commission and UNICEF were utilized. A sample of 70 barangays (the 3rd level administrative division in the Philippines) was selected as clusters, with probability proportional to size, and 30 households were selected randomly in each barangay to be surveyed.

Results: The estimated prevalence of disability using the standard criteria of the Washington Group and UNICEF among children (2-17 years old) was 2.0% and for adults (≥18 years old) it was 6.5%. The estimated prevalence of disability was higher in rural than in urban areas. Deficiencies in the performance of existing services were identified; access by children with disabilities to support services was lowest in rural highland and rural plain barangays.

Conclusions: There was a large unmet demand for support services addressing the needs of persons with disabilities in Albay Province, especially in rural highland areas. Persons with disabilities were disadvantaged in access to education and employment; many had not been educated in their basic rights.

Implications: To identify, educate and fully support persons with disabilities, community-based rehabilitation (CBR), health and other rehabilitation services must communicate effectively with each other, their current work should be mapped and analysed, their comparative strengths identified, and their future

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work coordinated. It is a priority to educate persons with disabilities and their families about their rights, and facilitate their access to support services; this requires increased investment in communication targeting persons with disabilities and the communities, especially rural. Providers caring for persons with disabilities need to work in partnership to identify unreached persons with disabilities. Prevalence surveys, with stronger focus on the profiles and performance of CBR and related services, would add to the evidence-base to improve the quality and coverage of services for persons with disabilities.

**Keywords:** Rights, rural, community-based rehabilitation (CBR), inclusion.

**INTRODUCTION**

Under Republic Act (RA) 7277, the Philippine Department of Health (DoH) has set up a national health programme and registry for persons with disabilities and established provincial rehabilitation centres, with the aim of making essential health services available and affordable to them (DoH, 2009 and 2017a). The National Council on Disability Affairs (NCDA) is the government agency mandated to coordinate policies and activities related to disabilities (NCDA, 2017a) and to monitor implementation of RA 7277. The Department of Social Welfare and Development (DSWD) and Local Government Units (LGUs) provide social welfare services for persons with disabilities. The rehabilitation and health services of LGUs are delivered through Barangay Health Centers (at the third level administrative division in the Philippines, below province and city/municipality), Rural Health Units (at municipality level) and hospitals.

The national health programme for persons with disabilities is aligned with the goal and objectives of the World Health Organization (WHO) global disability action plan 2014-2021 (Department of Health, 2017b). WHO’s plan calls for enhanced collection of internationally comparable data on disability and related services; removal of barriers and improved access to health services and programmes; strengthened and extended rehabilitation support services and community-based rehabilitation (CBR) (WHO, 2015).

The Simon of Cyrene Community Rehabilitation and Development Foundation, Inc. (SCCRDFI) is a non-governmental organization (NGO), which supports persons with disabilities, partly through direct service provision, but mainly and increasingly by promoting awareness on rights and service availability through community-based approaches and inter-sectoral action (SCCRDFI, 2017). Working
since 1982, the Foundation has mainly targeted Albay Province, but is expanding to neighbouring provinces in the Bicol Region of southern Luzon. CBR has been the major strategy for the rehabilitation, equalization of opportunities, poverty reduction and social inclusion for persons with disabilities, especially among children and youth 0-25 years old (SCCRDFI, 2017). Its activities have targeted persons with disabilities, their families and communities, with services covering rehabilitation, health, nutrition and education, as well as disability prevention campaigns and livelihood projects.

CBR was progressively expanded to ten of the eighteen municipalities and cities of Albay Province (SCCRDFI, 2017), through partnership between the SCCRDFI, LGUs and disabled people’s organizations (DPOs). From June to August 2016 (after this survey), CBR was introduced to the remaining eight municipalities of Albay. In each barangay, DPOs are expected to identify needs, evaluate services and raise community awareness on disabilities. Recent monitoring and evaluation exercises have highlighted a need for representative data on disability prevalence and service access.

From 1990 to 2010, the primary source of information on disability in the Philippines has been the national census. In 2010, the population of Albay Province was 1,233,695 (Philippine Statistics Authority - PSA, 2010) with about one third living in three cities. The prevalence of disabilities in the province in the household population ≥5 years old was reported to be 1.7% (PSA, 2015), somewhat higher than the national prevalence of 1.57% (PSA, 2013).

Most countries have collected data on disability through censuses (WHO, 2011). Many developing countries have reported disability prevalence rates below those in developed countries, because they have collected data on a narrow set of impairments (WHO, 2011). Compared to a census, sample surveys can include more detailed questions to ensure that more persons with disabilities are identified and so they tend to report higher rates of disability (Mont, 2007). Data on disabilities were not collected in the Philippine 2015 Census of Population (Soriano, 2016), in recognition of the limitations of disability reporting based on census data.

The Washington Group on Disability Statistics (WG) of the United Nations Statistical Commission has worked to develop a short set of questions in six functional domains for use in censuses and surveys consistent with WHO’s International Classification of Functioning, Disability and Health (ICF) (WHO,
The work has aimed to improve international comparability on disabilities (Mont, 2007; WHO, 2011). Prevalence rates using the Washington Group Short Set Questions (WGSSQ) have been generally higher than those from censuses, and ranged from less than 5% to greater than 10% (Loeb, 2014).

Together with the United Nations Children’s Fund (UNICEF), the WG has also developed a Module on Child Functioning and Disability (MCFD) covering children 2-17 years old. Validation of the MCFD began in September 2012 (WG, UNICEF, 2013), and was finalised in 2016, after our survey was implemented (UNICEF, 2016; UNICEF, 2017).

The WG/UNICEF tools assess whether a respondent has a disability based on their responses to questions that determine difficulties in functioning in basic actions (Madans et al., 2011) rather than by asking them to identify whether they have a disability. For all age-groups above two years, the survey tools describe functioning in basic actions on a continuum from ‘no difficulty’ to ‘some difficulty’, ‘a lot of difficulty’ and ‘unable to do it’. If an individual answers ‘a lot of difficulty’ or ‘unable to do it’, s/he is considered as a person with a disability for the purpose of disaggregation of other information, such as access to education and employment (WG, 2017a). Functioning in basic actions forms the building blocks for more complex activities (Madans et al., 2011).

**AIM**

With the purpose of generating representative data for local programme development, we carried out a cross-sectional survey with the WG/UNICEF methodology to examine the prevalence of disabilities, and the accessibility and coverage of relevant services. Our aim is for this information to be used for public policy formulation at all levels, as well as to improve communication and advocacy on disabilities.

**METHOD**

**Study setting and design**

The study was a cluster randomized survey of a sample of households. Barangays were used as clusters and 30 households were selected in each cluster (the number of households that could be interviewed by a team of two surveyors over two days).
Sample size calculation
The sample size of randomly selected clusters, needed to achieve a degree of precision sufficient to determine the overall prevalence of disability in Albay Province, was calculated as:

\[
n = \frac{1.96^2 p(1-p)(DEFF)}{d^2},
\]

where \(p\) is the expected prevalence, \(d\) the desired level of absolute precision and \(DEFF\) the design effect (Bennett et al., 1991; Milligan et al., 2004). The least prevalent functional disability in Albay Province, in the 2007 Census of Population and Housing (PSA, 2015), was difficulty in self-caring, with a reported prevalence of 0.38%. This figure was used as an estimate of the expected prevalence \((p)\). The desired level of absolute precision \((d)\) used was 0.0285, which is a level suitable for less common events (<20%). The design effect in this cluster survey was estimated as:

\[
DEFF = 1 + (b-1) \times roh,
\]

where \(b\) is the average number of responses to the item per cluster/barangay (30) and \(roh\) is the measure of variability between clusters as compared to variation within clusters. Assuming \(roh = 0.1\), \(DEFF\) was 3.9. Thus, a sample size of 70 clusters/barangays was needed with a total of 2,100 households.

Systematic random sampling
Barangays were sampled with probability proportional to size (PPS) (Bennett et al., 1991) and all the 18 municipalities and cities of Albay Province were represented. In each barangay, the 30 households were chosen by systematic random sampling, using a sampling frame of barangay household lists. Staying for two days made it possible for surveyors to return to houses which were closed on the first day. If it was not possible to survey a selected household, the next nearest household was selected. In barangays where a household list was unavailable, the ‘Expanded Programme on Immunization (EPI) method’ (Kok, 1986) was used for household sampling. Barangays were classified according to geography: ‘urban’ barangays were city and town areas with no agriculture, ‘rural coastal’ barangays were fishing areas, ‘rural plain’ barangays had irrigated rice, and ‘rural highland’ barangays were hilly areas with no irrigated rice.
Data collection
Twenty six recent graduates from the College of Social Sciences of Bicol University were recruited as surveyors, and two licensed social workers supervised their work. Surveyors collected data through three questionnaires.

The Household Questionnaire was completed with the household head for all selected households; it included information on environment and socio-economic conditions. If the household head was unavailable, the questionnaire was answered by the spouse of the household head or another responsible adult in the household. Persons with difficulties in functioning in basic actions were identified during enumeration of household members. These children and adults were targeted with two additional questionnaires on levels of functional activity limitation, demography, socio-economic conditions, education, employment and access to services.

For children aged 2-17 years old, the MCFD questions were asked of their parents/caregivers (WG, UNICEF, 2014). These were broader in scope than the WGSSQ and covered basic functional domains (seeing, hearing, walking, understanding/being understood, learning, remembering, self-care) and complex domains (controlling behaviour, playing, worry, completion of tasks, acceptance of change and getting along with other children). Children <2 years old were not included due to the variability of the development process in this age-group (WG, UNICEF, 2013). The questions on adult functioning and disability targeted adults, ≥18 years old or their caregiver. The level of functional limitation present (vision, hearing, mobility, cognition, self-care, and communication) followed the WGSSQ (WG, 2016).

Data analysis
_EpiData Entry_ (www.epidata.dk) was used for data entry and data documentation. Double entry verification was used for error detection and random records were checked for data consistency. Data analyses were performed in _EpiInfo_ 7 (www.cdc.gov/epiinfo). Excel 2016 (http://products.office.com/en-gb/excel) was used for data management, descriptive statistical analyses, and the preparation of charts.

Ethical considerations
Clearance of the survey protocol and questionnaires was obtained from the Department of Health, Region V. Informed consent for data collection was obtained
by the surveyors from the Barangay Captains, staff of the Barangay Health Centres and household heads. Consent was also obtained for all participants in the survey. In cases where it was not possible to obtain direct consent, and for children <18 years old, consent was obtained from parents, caregivers or guardians. To ensure confidentiality, each household and all persons with disabilities were given unique anonymous identification numbers during data management.

RESULTS

2,100 households in 70 barangays were surveyed, with a total household population of 11,104. Eighteen barangays did not have a complete household list and the ‘EPI method’ (Kok, 1986) was used for household selection. It was necessary to replace 1.7% (n=36) of the randomly selected households because no responsible adult was present.

Defining disability as at least one functional domain ‘a lot of difficulty’ or ‘unable to do it’ on the MCFD (children, 2-17 years old) or the WGSSQ (adults, ≥18 years old), 79 children with disabilities and 429 adults with disabilities were identified.

In children (2-17 years old) the estimated prevalence of disability was 2.0% (95% CI 1.6-2.4). The most prevalent functional disabilities were being understood/understanding, playing, worry, and learning (Table 1). Disabilities among children were most commonly reported to be related to complications of pregnancy and inherited conditions 59.5% (n=47), spine and nervous system disorders (8.9%, n=7), accidents and injuries (7.6%, n=6), and difficult birth deliveries (7.6%, n=6).
### Table 1: Percentage of children with disabilities (2-17 years old) where ‘a lot of difficulty’ or ‘unable to do it’ was reported by functional domain

<table>
<thead>
<tr>
<th>Domain type</th>
<th>Age-group</th>
<th>Functional domain</th>
<th>Number of children with disabilities with ‘a lot of difficulty’ or ‘unable to do it’ by functional domain</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Basic functional domains</strong></td>
<td>2-17 (n=79)</td>
<td>Seeing</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hearing</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Walking</td>
<td>16 (2-4 years old – 1; 5-17 years old – 15)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understanding</td>
<td>19 (2-4 years old – 2; 5-17 years old – 17)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Being Understood</td>
<td>23 (2-4 years old – 1; 5-17 years old – 22)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Learning</td>
<td>24 (all ≥4 years old)</td>
</tr>
<tr>
<td></td>
<td>5-17 (n=73)</td>
<td>Remembering</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-care</td>
<td>17</td>
</tr>
<tr>
<td><strong>Complex functional domains</strong></td>
<td>2-4 (n=6)</td>
<td>Playing</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>2-17 (n=79)</td>
<td>Controlling behaviour</td>
<td>13 (all ≥5 years old)</td>
</tr>
<tr>
<td></td>
<td>5-17 (n=73)</td>
<td>Worry</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Completion of tasks</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Acceptance of change</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Getting along with other children</td>
<td>15</td>
</tr>
</tbody>
</table>

NB: Persons with disabilities were classified according their most severe functional limitation.

In adults (≥18 years old), the estimated prevalence of disability was 6.5% (95% CI 5.9-7.1%); functional disability in mobility was most prevalent, followed by vision and cognition (Table 2). Most disabilities were related to accidents (15.6%, n=67), hypertension complicated by cerebrovascular accidents (12.4%, n=53), muscle, back and joint disorders (11.9%, n=51), spine and nervous system disorders (8.6%, n=37) and diabetes (6.3%, n=27).
Table 2: Prevalence of functional disability in Albay Province, persons with disabilities ≥18 years old (survey population ≥18 years old = 6,579)

<table>
<thead>
<tr>
<th>Functional disability</th>
<th>Frequency (n)</th>
<th>Prevalence (%)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty in seeing, even if wearing eyeglasses</td>
<td>111</td>
<td>1.7%</td>
<td>1.3-2.1%</td>
</tr>
<tr>
<td>Difficulty in hearing, even if using a hearing aid</td>
<td>56</td>
<td>0.9%</td>
<td>0.6-1.2%</td>
</tr>
<tr>
<td>Difficulty in walking or climbing stairs</td>
<td>214</td>
<td>3.3%</td>
<td>2.8-3.8%</td>
</tr>
<tr>
<td>Difficulty in cognition</td>
<td>109</td>
<td>1.7%</td>
<td>1.3-2.1%</td>
</tr>
<tr>
<td>Difficulty in self-care</td>
<td>77</td>
<td>1.2%</td>
<td>0.9-1.6%</td>
</tr>
<tr>
<td>Difficulty in communicating</td>
<td>74</td>
<td>1.1%</td>
<td>0.8-1.5%</td>
</tr>
</tbody>
</table>

Pooling of the estimated prevalence results for children and adults gave an estimated prevalence of disability in the population ≥2 years old of 4.9% (95% CI 4.5-5.3).

The mean age at onset of disability among children (2-17 years old) was 2.4 years (SD 3.3 years) and the mean age was 10.2 years (SD 4.0 years). For adults (≥18 years old), the mean age at onset of disability was 40.9 years (SD 27.1 years) and the mean age was 56.0 years (SD 19.1 years). The rate of disabilities increased with age; 59.4% (n=255) of persons with disabilities ≥18 years old were 46-65 years old. Most children with disabilities aged 2-17 years, were male (68.4%, n=54), whereas 52.9% (n=227) of adults with disabilities (≥18 years old) were female.

The estimated prevalence of disability by barangay type/age group was determined by dividing the number of cases of functional disability identified in each barangay type/age category by the total survey household population for the barangay type/age category. The estimated prevalence of disabilities among children (2-17 years old) was higher in rural (2.2%, 95% CI 1.9-2.4%) than in urban barangays (1.7%, 95% CI 1.0-2.5%). The estimated prevalence of disabilities among adults (≥18 years old) was also higher in rural (7.0%, 95% CI: 6.6-7.4%) than in urban barangays (5.5%, CI 4.6-6.4%). The estimated prevalence of disabilities was highest in rural plain and rural highland barangays for both groups (Figure 1).
Among school-aged children with disabilities (4-17 years old, n=75), 32.0% (n=24) had never attended school (Figure 2). Among high school-aged persons with disabilities, 13–17 years old (n=27), 55.6% (n=15) had not studied beyond elementary school. Children from 6 to 12 years old are usually enrolled in elementary school.

The proportion of persons with disabilities, ≥5 years old (n=500), with no school attendance was 11.0% (n=55). Among persons with disabilities ≥18 years old
(n=429), 7.9% (n= 34) had never attended school (Figure 3). Most persons with disabilities ≥18 years of age 56.4% (n=242) had not studied beyond elementary school.

**Figure 3: Highest educational grade of persons with disabilities, ≥18 years old (n=429)**

64.1% (n=91) of working-age males with disabilities (n=142) and 57.5% (n=77) of working-age females with disabilities (n=134), 18-65 years old, reported their work status as unemployed (Figure 4) and health reasons were reported to be the major cause of unemployment. Among women, higher proportions than men reported being self-employed or keeping house. The most common occupations among working-age persons with disabilities were lower-skilled/unskilled jobs: among males, 11.3% (n=16) were farmers, 4.9% (n=7) were artisans/handicraft workers and 4.9% (n=7) were labourers/unskilled workers. Among females, 12.7% (n=17) were service/shop and market sales workers, 3.0% (n=4) were artisans/handicraft workers and 3.0% (n=4) were unskilled workers.
Overall, 34.2% (n=27) of persons with disabilities 2-17 years old and 33.1% (n=142) of persons with disabilities ≥18 years old reported receiving care from a support service. Of persons with disabilities accessing care from a support service, most received care from government services, including government social welfare services (children 70.4%, n=19; adults 52.8%, n=75), Barangay Health Centres (children 55.6%, n=15; adults 36.6%, n=52), Rural Health Units (children 44.4%, n=12; adults 31.0%, n=44) - health facilities providing a wide range of health care services, including a main health centre operated by the municipal-level - and hospitals (children 44.4%, n=12; adults 36.6%%, n=52). NGOs provided support for five children and nineteen adults with disabilities, almost exclusively in areas covered by CBR (two persons with disabilities received care from NGOs in barangays without CBR).

Figure 5 shows that the lowest rates of access to a support service for children with disabilities were in rural highland and rural plain barangays and that the highest rates of access were in rural coastal followed by urban barangays. With this variation in access to services, the odds ratio (OR) was calculated to compare the odds of access to care in urban barangays compared with rural barangays: children with disabilities in urban barangays had greater access to care, although the difference did not reach statistical significance (OR 1.46, 95% CI 0.47-4.23).
Among adult with disabilities, there was only slightly higher (not significant) access to care from a support service in urban barangays compared with rural barangays (OR 1.18, 95% CI 0.76-1.85), and the access was higher in rural plain barangays than in urban barangays (Figure 5).

Figure 5: Percentage of children with disabilities (2-17 years old) and adults with disabilities (≥18 years old) receiving care from a support service by barangay type (n=total number of persons with disabilities in each barangay type)

As shown in Table 3, activity limitation in more than one functional domain was more prevalent among children with disabilities than among adults, including those not receiving care from a support service.

Table 3: Number of functional domains ‘a lot of difficulty’ or ‘unable to do it’ among children with disabilities (2-17 years old) and adults with disabilities (≥18 years old)

<table>
<thead>
<tr>
<th></th>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 domain</td>
<td>&gt;1 domain</td>
</tr>
<tr>
<td>Persons with disabilities not receiving care from a support service</td>
<td>48.0% (n=24)</td>
<td>52.0% (n=26)</td>
</tr>
<tr>
<td>All persons with disabilities</td>
<td>46.8% (n=37)</td>
<td>53.2% (n=42)</td>
</tr>
</tbody>
</table>
Overall, 63.2% (n=50) of persons with disabilities 2-17 years old were not receiving care from a support service; 66.7% (n=286) of persons with disabilities ≥18 years old reported not receiving care. ‘No knowledge of the support services which are available’, was the major reason given for not receiving care from a support service (Figure 6). ‘No contact from a support service’ and support services being ‘too far away’ were the next most common reasons for not accessing care. Only 2.0% (n=1) of the parents/caregivers of children with disabilities not receiving care from a support service and 14.7% (n=42) of adults not receiving care from a support service, reported ‘no need for support services’.

Figure 6: Reported reasons why persons with disabilities do not receive care from a support service - children (2-17 years old) n=50; adults (≥18 years old) n=286

CBR covered all 20 urban barangays and 29 out of 50 rural barangays. Overall, children with disabilities in barangays with CBR had lower access to care from a support service than those in areas without CBR (Table 4), but the difference was not statistically significant (OR 0.85, 95% CI 0.36-2.00). Among adults, the presence of CBR did not appear to be related to the likelihood of access to services (Table 4).
Table 4: Percentage of children with disabilities (2-17 years old) and adults with disabilities (≥18 years old) receiving care from a support service, by barangay type and CBR coverage

<table>
<thead>
<tr>
<th>Barangay type</th>
<th>Persons with disabilities</th>
<th>Percentage receiving care from a support service</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban with CBR (n=20)</td>
<td>Child (n=17)</td>
<td>41.2% (n=7)</td>
<td>18.4-67.1%</td>
</tr>
<tr>
<td></td>
<td>Adult (n=117)</td>
<td>35.9% (n=42)</td>
<td>27.2-45.3%</td>
</tr>
<tr>
<td>Rural with CBR (n=29)</td>
<td>Child (n=43)</td>
<td>27.9% (n=12)</td>
<td>15.3-43.7%</td>
</tr>
<tr>
<td></td>
<td>Adult (n=207)</td>
<td>31.9% (n=66)</td>
<td>25.6-38.7%</td>
</tr>
<tr>
<td>Rural without CBR (n=21)</td>
<td>Child (n=19)</td>
<td>42.1% (n=8)</td>
<td>20.3-66.5%</td>
</tr>
<tr>
<td></td>
<td>Adult (n=105)</td>
<td>32.4% (n=34)</td>
<td>23.6-42.2%</td>
</tr>
</tbody>
</table>

Parents/caregivers of children with disabilities, not receiving care from a support service, reported high rates of ‘no knowledge of the support services which are available’, especially in rural areas (Figure 7). Among adults with disabilities, reports of ‘no knowledge of the support services which are available’ were lower than for children, and highest in rural areas with CBR.

Figure 7: Percentage of children with disabilities (2-17 years old) and adults with disabilities (≥18 years old) not receiving care from a support service with ‘no knowledge of the support services which are available’, by barangay type
DISCUSSION

The estimated prevalence of disability based on the MCFD questions among children 2-17 years old in Albay Province was 2.0%. The primary purpose of the MCFD is to identify children with functional difficulties (UNICEF, 2017) by measuring functioning in a set of relevant domains; the questions would not be expected to identify all children with disabilities. The Global Burden of Disease estimated that 5.1% of children aged 0–14 years globally have “moderate or severe disability” with 0.7% having severe difficulties (WHO, 2008).

The estimated prevalence of disability based on the WGSSQ questions among adults ≥ 18 years old in Albay Province was 6.5%. Globally, based on 2010 population estimates and 2004 disability prevalence estimates from the World Health Survey (WHO, 2017a) and the Global Burden of Disease (WHO, 2008), 15.6% to 19.4% of persons 15 years and older would be “living with disability” (WHO, 2011). Our findings were lower than the global estimates of persons “living with disability”, and this would be expected as the WGSSQ questions only focus on six functional domains. The World Health Survey gave the prevalence of adults with very significant difficulties in functioning at 2.2% (WHO, 2017a), while the Global Burden of Disease data indicated that 3.8% of the adult population were estimated to have “severe disability” – the equivalent of disability inferred for conditions such as quadriplegia, severe depression, or blindness (WHO, 2008).

A cross-sectional population based survey undertaken in Quezon City (Metro Manila) and Ligao City (Albay Province) found the prevalence of disability among adults ≥ 18 years old to be 6.8% and 13.6% respectively (Marella et al., 2016). Persons with disabilities were identified based on their responses to questions on activity limitations using the Rapid Assessment of Disability (RAD) survey. Use of the same tool in Uttarakhand, India found the prevalence of disability among adults to be 6.8% (Grills et al., 2017). Disability prevalence estimates with RAD are comparable to the WGSSQ, however RAD also identifies respondents with psychological distress (Marella et al., 2015) which would be a factor contributing to the lower estimated prevalence of disability found in our survey.

Pooling the data from the MCFD and the WGSSQ, suggests a prevalence of disability in the population ≥2 years old of 4.9%. However, this pooling is questionable, as the MCFD has broader scope (fourteen functional domains) than the WGSSQ (six domains) and would be expected to identify a greater proportion of persons with disabilities.
In children, the major functional disabilities in Albay were in intellectual functioning, behaviour and affect (Table 1). The mean age of onset of disability (or when it was first identified) among children (2-17 years old) was 2.4 years of age. This is consistent with the findings that health conditions such as complications of pregnancy (WHO, 2008), inherited conditions (Vorstman, Ophoff, 2013) and difficult birth deliveries (Gonzales, Miller, 2006) were likely related to many of the disabilities; highlighting a need for improved perinatal care (WHO, 1981). A study of prenatal and perinatal risk factors for disability in rural Nepal has also emphasised the relationship between early marriage, poverty, malnutrition and poor developmental outcomes (Haworth et al., 2017). Disabilities affecting infants and children are major causes of lifelong disability; the greatest impact of disability prevention measures can be expected among children (WHO, 1981).

Functional disabilities in mobility, vision and cognition were most prevalent among adults (Table 2). Accidents and injuries were the health conditions most frequently related to disabilities among adults; road safety and accident prevention programmes, and better care, can help to prevent trauma-related disabilities (WHO, 1981; Peden et al., 2004; Peden, 2008). The mean age at onset of disability among adults (≥18 years old) was 40.9 years and the mean age was 56.0 years, consistent with many disabilities likely being related to degenerative musculoskeletal disorders (Woolf, 2003; Taaffe, Marcus, 2000), and the complications of chronic non-communicable diseases such as diabetes and hypertension (WHO, 2011; Richards et al. 2016). Early detection and treatment of chronic non-communicable diseases can help to prevent disabilities among the elderly (Richards et al., 2016). The higher prevalence of disabilities among the elderly underscores the need to prioritize older adults in reducing disability (Tareque et al., 2017).

Disabilities were more prevalent in rural barangays (Figure 1). Children had lower access to support services in rural highland and rural plain barangays compared with rural coastal and urban barangays (Figure 5). Among adults, the rural-urban divide was less marked, and the lowest access to support services was in rural highland and rural coastal barangays. World Health Survey data for the working-age Filipinos also identified a higher prevalence of disability in rural areas (Mitra et al., 2011). Fewer employment opportunities and migration of able-bodied adults to urban areas for work (Reichert, Myers, 2014; Marella et al., 2016), would contribute to this finding. The higher rate of disability in rural areas might
also be due to poorer living conditions, less education, poverty, fewer health care services and facilities (Tareque et al., 2017).

More than one functional disability was often present in a single individual (Table 3) and these cases may require management by multidisciplinary rehabilitation teams, involving physiotherapists, social workers, speech therapists and others (Short, 1981). Most of these services exist in Albay Province, especially in the three cities, but they are not accessed by most of the rural poor because of ignorance, geographic and financial barriers. Our data indicates that there are presently about 3,400 children and 12,500 adults in the province affected by more than one functional disability (by multiplying the estimated survey prevalence rates of more than one functional disability among children and adults by the total provincial population for these groups), but receiving no specialized care from a support service. Sufficient resources to expand access to services should be allocated and the use of the services should be promoted, especially in rural highland areas.

Extrapolating the study findings on school attendance to Albay Province as a whole, almost 3,000 school-aged persons with disabilities, 4-17 years old, may not have attended school. The proportion of persons with disabilities, ≥5 years old, with no school attendance was 11.0%, compared with 4.0% among the overall household population ≥5 years old in the 2010 census (PSA, 2016); recent studies using the RAD survey found that people with disabilities were significantly less likely to have schooling compared to people without disability (Marella et al., 2016; Grills et al., 2017). We found that most persons with disabilities do not study beyond elementary school (Figures 2 and 3); as of the school year 2012-2013, around 25% of students in the general population did not complete four years of high school (UNESCO, 2015).

Special education (SPED) centres can facilitate school attendance and learning for school-age persons with disabilities (UNESCO, 2009). There are SPED centres in the provincial capital, Legazpi City, and in eight other municipalities and cities of Albay Province. Under the guidelines of the Department of Education (DepEd, 2017), SPED teachers shall also implement integration and inclusion through enrolment of a child with special needs in a regular class with support services. Inclusion is consistent with the rights of children with disabilities and is generally more cost effective than special or separate schools (WHO, UNICEF, 2012). However, additional investments in educational resources are required,
including trained staff, flexible curricula and teaching methods, and accessible facilities (WHO, UNICEF, 2012; UNICEF 2013).

The SCCDRF implements local projects to improve the accessibility of transportation for persons with disabilities (Embassy of Canada, 2016). With limited access to education, persons with disabilities are not supported to become aware of their basic rights (United Nations, 2006), including access to care and most remain unemployed (Figure 4). The unemployment rate among working age persons with disabilities was 60.9%; the comparable rate for the overall Filipino population, was estimated to be 5.7% in April 2017 (PSA 2017). This level of reduced access to work is consistent with the findings of other international studies on employment among persons with disabilities (Grills et al., 2017; WHO, 2011). Employed persons with disabilities generally occupied lower-skilled and unskilled jobs. Limited income compounds the barriers persons with disabilities face in receiving support from health and rehabilitation services (World Bank, 2017).

There were deficiencies in the accessibility of support services for persons with disabilities (Figure 5). Only a small proportion of persons with disabilities not receiving external support, reported ‘no need for care from a support service’ (Figure 6). The CBR strategy intends to address these concerns, by taking rehabilitation services to the barangay-level (Periquet, 1981), where CBR volunteers should identify, educate and support persons with disabilities, to promote their registration and access to care. Registration in the Philippine Registry for Persons with Disabilities provides greater access to services in the public and private sectors, financial help, and educational assistance to pursue study at all levels of the education system (NCDA, 2017b). However, we observed that support services appeared to be more accessible for children with disabilities in rural areas without CBR (Table 4), even though implementation of CBR in Albay Province has concentrated on persons with disabilities 0-25 years old (SCCRDFI, 2017). CBR did not appear to be related to the likelihood of access to services for adults (Table 4).

Although the differences between CBR and non-CBR barangays did not reach statistical significance, they do raise concerns which need further investigation. For example, a contributing factor to explain the apparent deficiencies in the performance of CBR, could be that the programme targets challenging areas with a lower profile of services. It may be that the CBR being implemented is comparable to other services provided in the non-CBR barangays; more detailed
analysis on the targeting and performance of CBR in Albay Province is required. Multiple data collection methods and involvement of all relevant stakeholders would maximise the information gathered (Grandisson, 2014).

Recent studies in the Philippines and India using the RAD survey have shown that people with disabilities had lower access to services compared to people without disability: the barrier most often reported was a lack of information about the services (Marella et al., 2016; Grills et al., 2017). Our study also showed that the most important reason for not accessing support was a lack of knowledge about the availability of services, followed by no contact from support services (Figure 6). In some barangays, CBR has been implemented for decades and the findings reported here do indicate that there is a need to strengthen the communication component of CBR (WHO, UNESCO, 2010; WHO, 2017b) through increased supportive supervision of the CBR volunteers’ work and through more investment in other channels of communication to persons with disabilities and the community (Asian Development Bank, 2005).

CONCLUSION

Our study indicates that disabilities in Albay Province are more prevalent in rural areas. Deficiencies in the accessibility and performance of existing services for persons with disabilities were identified, especially in rural highland and plain areas for children with disabilities and rural highland and coastal areas for adults with disabilities. Persons with disabilities were disadvantaged in access to education and employment and many had not been educated in their basic rights. To identify, educate and fully support all persons with disabilities, CBR and related services must communicate effectively with each other, their current work should be mapped and analysed, their comparative strengths identified, and their future work better coordinated.

Implications

Similar surveys would add to the evidence-base to improve the quality and coverage of services for persons with disabilities, in line with the WHO global disability action plan 2014-2021 (WHO, 2015). These surveys should include the profiles of CBR and related services. It is a priority to educate persons with disabilities and their families about their rights, and facilitate their access to support services; this requires increased investment in channels of communication to persons with disabilities and the community. With the passage and ratification
of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2017a) and the post-2015 Sustainable Development Goals (United Nations, 2017b) there is an obligation to monitor whether those with and without disabilities have equal opportunities to participate in society (WG, 2017b) and this requires identification of all persons with disabilities.

Limitations
In barangays with no current household list, a source of bias may have resulted if households were not selected by strictly applying the ‘EPI method’ (Kok, 1986). Some persons with disabilities in the households may have been missed by the surveyors because of the sensitivity of questions on disability. Furthermore, the WG questions were not designed to identify all persons with disabilities in a population (Mont, 2007). The study would have been strengthened if it had been possible to validate functional limitations with clinical assessments (Mactaggart, 2015). In addition, a more detailed analysis on the delivery of CBR and related services would have strengthened the assessment of service access.

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REFERENCES


Disability Inclusive Development Good Practices: Level of Commitment to Core Concepts of Human Rights

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ABSTRACT

Purpose: Good practices have been documented by International Non-Governmental Organisations (INGOs) to promote disability inclusive development and encourage the replication or scaling up of good practices that use rights based approaches. This study aimed to investigate the extent to which Core Concepts of human rights are illustrated in disability inclusive development good practices related to health.

Method: This study analysed case studies of disability inclusive development good practices focusing on health that are available in the public domain using EquiFrame, an established content analysis framework in benchmarking health and social policies.

Results: A total of 42 health related good practices were identified from 3 different INGOs working in the field of disability inclusive development. The highest occurring human rights Core Concepts were; access 55%, individualised services 48%, capacity building 45% and participation 38%. The Core Concepts with the lowest levels of commitment were; autonomy 3%, cultural responsiveness 3%, accountability 3%, and efficiency 3%. Privacy and autonomy were not mentioned at all. The quality of reporting of the core concepts of human rights was low as they did not state specific programme actions or intentions to monitor Core Concepts.

Conclusion: Level of commitment to Core Concept coverage and quality of reporting was low. EquiFrame was successfully extended to analyse disability inclusive development good practices focusing on health. Its use in further analysis of inclusive good practice is advised.

Implications: These results can be used for advocacy in disability inclusive

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development and to guide programme staff training and documentation of disability inclusive development good practices.

**Keywords:** UN CRPD, advocacy, human rights, inclusive development, good practice, best practice.

## INTRODUCTION

Disability Inclusive Development good practices are examples of programmes implemented successfully which are published to encourage replication or scaling-up (Handicap International, 2009; UN DESA, 2011). International Non-Governmental Organisations (INGOs) working in disability inclusive development express commitments to a rights-based approach to their work (CBM, 2016; Handicap International, 2009; Light for the World, 2016; UN DESA, 2011).

Good practices are case studies focusing on positive elements of programmes that worked with the aim of providing practical, constructive recommendations for decision makers (CBM, 2016; Handicap International, 2009; Light for the World, 2016). The focus of good practice examples is on the positive, or on what innovations, actions or strategies have proved beneficial within programmes. These good practice examples are often snapshots of a development programme and rarely capture all aspects of a programme or the full impact it has had on an individual or community. However it is possible to assess good practices collectively, by analysing performance against a human rights framework as a whole, and identifying common themes.

The distinction between best practice and good practice should be acknowledged. The United Nations published a guide in 2011 titled *Best practices for including persons with disabilities in development efforts* (UN DESA, 2011). Best practice was defined as being based on the United Nations Convention of the Rights of Persons with Disability (UN CRPD) and adopting a right-based approach (UN ENABLE, 2007). This guide to best practice stated that disability inclusive development should demonstrate; non-discrimination, recognition in the interaction between gender and disability, promotion of accessibility, meaningful partnership of people with disabilities, accountability mechanisms, awareness-raising of disability, utilization of effective partnerships, initiatives that are results-based, demonstrate measurable change and are appropriately resourced, replicable and sustainable (UN DESA, 2011). In order to be called a best practice it must fulfill
the above criteria. In order to be called a good practice example it does not have to fulfill set criteria as in the case of best practice.

**Use of EquiFrame for Analysing Good Practices**

Development programmes and policies have the potential to protect or violate human rights through the nature of their design or implementation. Development efforts which help fulfill human rights pay attention to issues which often contribute to the marginalisation of people with disability such as; health, poverty, social disadvantage, vulnerability and discrimination (Braveman & Gruskin, 2003; Mann et al., 1994). Many disability-inclusive development INGOs state that they use a human rights based approach to development, which further supports the use of a human rights framework such as EquiFrame for content analysis.

EquiFrame is an established content analysis framework for benchmarking health and social policies from a human rights perspective (Mannan et al., 2011). It has been used to analyse health, rehabilitation, disability, nutrition, sexual and reproductive health and mental health policies as well as instruments such as the UN CRPD (Andersen & Mannan, 2012; Bedri et al., 2013; Eide, Amin, MacLachlan, Mannan, & Schneider, 2012; Ivanova, Dræbel, & Tellier, 2015; MacLachlan et al., 2012; Mannan et al., 2013; Mannan, McVeigh, et al., 2012; Meral & Turnbull, 2016; O'Dowd, Mannan, & McVeigh, 2013; Schneider, Eide, Amin, MacLachlan, & Mannan, 2013; Van Rooy et al., 2012). Policy analysis using EquiFrame can provide a platform for evaluating policy revision and development, identifying a policy’s strengths and weaknesses in terms of the protection of human rights (MacLachlan et al., 2012). In addition to its use in policy analysis, it has also been put forward that EquiFrame can be applied to other types of guiding and planning documents such as in practice settings. (Mannan et al., 2013).

**AIM AND OBJECTIVES**

The aim of this study was to investigate the extent to which Core Concepts of human rights (Stowe & Turnbull, 2001) are illustrated in disability inclusive development good practices. This study extended the use of EquiFrame, (a content analysis framework) originally developed for benchmarking health and social policies from a human rights perspective, examining the extent to which the Core Concepts are used in practice (Mannan, Amin, MacLachlan, & The EquiTalable Consortium, 2011), thus extending its use from policy to practice examples.
The purpose of this research was not to highlight any one agency with positive or negative findings. It is hoped through highlighting strengths and weaknesses it can lead to increased consideration and reporting of Core Concepts of human rights in disability inclusive development good practices.

The objectives were

1. To establish the extent to which Core Concepts of human rights are illustrated in disability inclusive development good practices.

2. To identify ways to improve documentation of good practices and suggest how can these be addressed.

3. To extend the application of EquiFrame from a content analysis tool of policies ‘on the books’ to policies ‘on the streets’ (i.e. policy in practice).

METHOD

Selection of Good Practice Documents

This study examined good practice documents from INGOs focused on disability inclusive development using a human rights approach. The INGOs selected were the major organisations focusing on disability inclusive development CBM, Light for The World and Handicap International. CBM has been in existence over 100 years and is now working across 63 countries focusing on people affected by extreme poverty and disability with an emphasis on social inclusion and realization of human rights (CBM, 2016). Light for The World has programmes across 15 countries focusing on human rights and disability with an emphasis on eye health, inclusive education and Community Based Rehabilitation (CBR) (Light for the World, 2016). Handicap International was founded in 1982, and is working across 60 countries with vulnerable persons and persons with disabilities aiming to ensure respect for their fundamental rights (Handicap International, 2016). Handicap International set up the “Making it Work” database which pulls together good practice examples which have been successful in implementing the UN CRPD. Examples in this database are from Handicap International and 30 partners including Disabled Persons Organisations (DPOs) over the last 30 years (Handicap International, 2009).

The websites of these three INGOs were searched and all documents and good practice databases available in English were downloaded from the publication
sections on the INGOs websites and scanned for health-related examples of disability inclusive good practice. These included both individual case studies and good practices at the project or programme level. All good practices available online relating to health as of 31st August 2014 were selected. Appendix 1 provides the list of good practice documents identified and chosen for analysis.

**Inclusion Criteria**

All health examples of disability inclusive development good practice were included for analysis. In this analysis, good practices in the field of health were defined as medical, rehabilitation or disability prevention activities. This definition of health is reflected in Article 25 of the UN CRPD and the right to health for people with disabilities (UN ENABLE, 2007).

**Exclusion Criteria**

Case studies capturing aspects of marginalisation and disadvantage for people with disabilities without offering examples of disability inclusive development good practice were not included for analysis. If a good practice was repeated in multiple publications (i.e. more than one occurrence of same case study) the extended and more detailed version of the good practice was chosen for analysis.

**Ethical Considerations**

This study was an analysis of secondary data from documents available publicly on the Internet, which have been put forward as examples of good practice in disability inclusive development. There was no ethical clearance required for completion of this study.

**Analysis of good practices**

The sample of good practices were analysed using EquiFrame. The Core Concepts of human rights in EquiFrame were developed through extensive literature searching. The EquiFrame research identified 37 core concepts, which were further refined through consultations with stakeholder groups to 21 core concepts covering human rights relating to equity in health, delivery health services as a human right and relating to healthcare more generally. Further information is available in Table 1 and in the EquiFrame manual (Mannan et al., 2011).
Table 1. EquiFrame Core Concepts, Key Questions and Key Language adapted from Mannan et al for use in good practice document analysis (Mannan et al., 2011)

<table>
<thead>
<tr>
<th>No.</th>
<th>Core Concept</th>
<th>Key Question</th>
<th>Key Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Non-discrimination</td>
<td>Does the good practice support the rights of vulnerable groups with equal opportunity in receiving health care?</td>
<td>Vulnerable groups are not discriminated against on the basis of their distinguishing characteristics (i.e. Living away from services; Persons with disabilities; Ethnic minority or Aged).</td>
</tr>
<tr>
<td>2.</td>
<td>Individualised services</td>
<td>Does the good practice support the rights of vulnerable groups with individually tailored services to meet their needs and choices?</td>
<td>Vulnerable groups receive appropriate, effective, and understandable services.</td>
</tr>
<tr>
<td>3.</td>
<td>Entitlement</td>
<td>Does the good practice indicate how vulnerable groups may qualify for specific benefits relevant to them?</td>
<td>People with limited resources are entitled to some services free of charge or persons with disabilities may be entitled to respite grant.</td>
</tr>
<tr>
<td>4.</td>
<td>Capability-based services</td>
<td>Does the good practice recognize the capabilities existing within vulnerable groups?</td>
<td>For instance, peer-to-peer support among women headed households or shared cultural values among ethnic minorities.</td>
</tr>
<tr>
<td>5.</td>
<td>Participation</td>
<td>Does the good practice support the right of vulnerable groups to participate in the decisions that affect their lives and enhance their empowerment?</td>
<td>Vulnerable groups can exercise choices and influence decisions affecting their life. Such consultation may include planning, development, implementation, and evaluation.</td>
</tr>
<tr>
<td>6.</td>
<td>Coordination of services</td>
<td>Does the good practice support assistance of vulnerable groups in accessing services from within a single provider system (interagency) or more than one provider system (intra-agency) or more than one sector (intersectoral)?</td>
<td>Vulnerable groups know how services should interact where inter-agency, intra-agency, and intersectoral collaboration is required.</td>
</tr>
<tr>
<td>7.</td>
<td>Protection from harm</td>
<td>Vulnerable groups are protected from harm during their interaction with health and related systems</td>
<td>Vulnerable group are protected from harm during their interaction with health and related systems.</td>
</tr>
<tr>
<td></td>
<td>Liberty</td>
<td>Does the good practice support the right of vulnerable groups to be free from unwarranted physical or other confinement?</td>
<td>Vulnerable groups are protected from unwarranted physical or other confinement while in the custody of the service system/provider.</td>
</tr>
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<td>-------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>9.</td>
<td>Autonomy</td>
<td>Does the good practice support the right of vulnerable groups to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her?</td>
<td>Vulnerable groups can express “independence” or “self-determination”. For instance, person with an intellectual disability will have recourse to an independent third party regarding issues of consent and choice.</td>
</tr>
<tr>
<td>10.</td>
<td>Privacy</td>
<td>Does the good practice address the need for information regarding vulnerable groups to be kept private and confidential?</td>
<td>Information regarding vulnerable groups need not be shared among others.</td>
</tr>
<tr>
<td>11.</td>
<td>Integration</td>
<td>Does the good practice promote the use of mainstream services by vulnerable groups?</td>
<td>Vulnerable group are not barred from participation in services that are provided for general population.</td>
</tr>
<tr>
<td>12.</td>
<td>Contribution</td>
<td>Does the good practice recognize that vulnerable groups can be productive contributors to society?</td>
<td>Vulnerable groups make a meaningful contribution to society.</td>
</tr>
<tr>
<td>13.</td>
<td>Family resource</td>
<td>Does the good practice recognize the value of the family members of vulnerable groups in addressing health needs?</td>
<td>The good practice recognizes the value of family members of vulnerable groups as a resource for addressing health needs.</td>
</tr>
<tr>
<td>14.</td>
<td>Family support</td>
<td>Does the good practice recognize individual members of vulnerable groups may have an impact on the family members requiring additional support from health services?</td>
<td>Persons with chronic illness may have mental health effects on other family members, such that these family members themselves require support.</td>
</tr>
<tr>
<td>15.</td>
<td>Cultural responsiveness</td>
<td>Does the good practice ensure that services respond to the beliefs, values, gender, interpersonal styles, attitudes, cultural, ethnic, or linguistic, aspects of the person?</td>
<td>i) Vulnerable groups are consulted on the acceptability of the service provided  ii) Health facilities, goods and services must be respectful of ethical principles and culturally appropriate, i.e. respectful of the culture of vulnerable groups</td>
</tr>
<tr>
<td>16.</td>
<td>Accountability</td>
<td>Does the good practice specify to whom, and for what, services providers are accountable?</td>
<td>Vulnerable groups have access to internal and independent professional evaluation or procedural safeguard.</td>
</tr>
<tr>
<td>17.</td>
<td>Prevention</td>
<td>Does the good practice support vulnerable groups in seeking primary, secondary, and tertiary prevention of health conditions?</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>Capacity building</td>
<td>Does the good practice support the capacity building of health workers and of the system that they work in addressing health needs of vulnerable groups?</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Access</td>
<td>Does the good practice support vulnerable groups – physical, economic, and information access to health services?</td>
<td>Vulnerable groups have accessible health facilities (i.e., transportation; physical structure of the facilities; affordability and understandable information in appropriate format).</td>
</tr>
<tr>
<td>20.</td>
<td>Quality</td>
<td>Does the good practice support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of vulnerable groups?</td>
<td>Vulnerable groups are assured of the quality of the clinically appropriate services.</td>
</tr>
<tr>
<td>21.</td>
<td>Efficiency</td>
<td>Does the good practice support efficiency by providing a structured way of matching health system resources with service demands in addressing health needs of vulnerable groups?</td>
<td></td>
</tr>
</tbody>
</table>

The documents were analysed under the following according to EquiFrame indices (Mannan et al., 2011).

(i) **Core Concept Coverage** – Whether the concept was mentioned in the document. When one statement met multiple Core Concepts the good practice example was scored as expressing both or more Core Concepts.

(ii) **Core Concept Quality** – Each Core Concept appearing was then scored for the level of commitment to that Core Concept. This was scored from 1-4, with level
indicating that the concept was mentioned, to level 4 where the concept was explained and an intention to monitor expressed. Table 2 provides information on scoring and examples of narrative data extracted. When several references to a particular Core Concept were found the highest score received was recorded for this Core Concept. When the scoring for a particular item was not clear a discussion was held with a second assessor to reach a consensus.

Table 2. Level of Commitment: Scoring and Examples of Narrative Language

<table>
<thead>
<tr>
<th>Level of Commitment</th>
<th>Core Concept</th>
<th>Example from Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1 = concept mentioned</td>
<td>Coordination of services</td>
<td>“The Commission now directs the child and their parents towards the appropriate services in the education, rehabilitation and health areas.”</td>
</tr>
<tr>
<td>Level 2 = concept mentioned and explained</td>
<td>Capability-based services</td>
<td>“Peer support activities implemented by people with disability themselves significantly contributed to raising disability awareness as well as profiling people with disabilities as productive members of society.”</td>
</tr>
<tr>
<td>Level 3 = specific policy actions identified to address concept</td>
<td>Participation</td>
<td>“Outcomes included training programmes for project staff and community health volunteers, with a focus on awareness-raising, addressing stigma, early identification and referral to disability services in the region ...Training cluster programme leaders and appointed disability coordinators from each of the programmes to facilitate, lead and review the implementation of disability-inclusion activities across the 40 health programmes.”</td>
</tr>
<tr>
<td>Level 4 = intention to monitor concept was expressed</td>
<td>Participation</td>
<td>“People with disabilities were also members in Core Coordination Committees (Public Health project planning &amp; monitoring committees at the district level) to plan and implement activities. Being members, they contributed in planning and monitoring, by sharing the issues of persons with disabilities at the village level.”</td>
</tr>
</tbody>
</table>
(iii) **Vulnerable Group Coverage** – The documents were analysed for each of the 12 vulnerable groups mentioned. It has been reported that disability disproportionately affects vulnerable groups, for example the aged, those suffering with chronic illness and women (World Health Organisation & World Bank, 2011). Incorporating the needs of vulnerable groups in programming is an essential part of these groups achieving their human rights and so the inclusion of this in the study was deemed of importance (Amin et al., 2011).

(iv) **Overall Summary Ranking** in terms the level of commitment to Core Concepts being high, moderate or low standing according to the following criteria:

- **High** = if the policy achieved ≥50% on all of the three scores above.
- **Moderate** = if the policy achieved ≥50% on two of the three scores above.
- **Low** = if the policy achieved <50% on two or three of the three scores above.

The number of Core Concepts mentioned out of 21 Core Concepts was calculated for each good practice example. The number of Core Concepts that scored a level of commitment of 3 – 4 was calculated for each good practice example. The averages of these scores were then calculated for all good practices included in the analysis. This ensured that no one single documents or organisations became singled out as the aim was not to highlight any one agency or practice example.

Each good practice example was also given a score out of 12 for the number of Vulnerable Groups documented in the good practice example. When Core Concepts or Vulnerable Groups were negatively expressed, the Core Concept or Vulnerable Group was still scored as appearing in the narrative. When an intention to address a human rights Core Concept or Vulnerable Group was stated, this was also scored as appearing in the narrative.

**Taxonomy of Core Concepts**

The taxonomy of the Core Concepts of human rights found in EquiFrame can be further categorized as being founded in underlying constitutional, ethical or administrative principles or a combination of same (Mannan, MacLachlan, & McVeigh, 2012; Stowe & Turnbull, 2001). The Core Concepts involved have a strong background in national and international legislative documents, providing some Core Concepts with a more constitutional background. Other Core Concepts have a clear ethical grounding in their purpose being to improve quality of life for the person and/or families. Other Core Concepts may be more related to
administrative principles, for example concepts relating to the implementation and action of policies The Core Concepts mentioned in good practice documents were classified according to which principles they represented. This was then compared to the taxonomy of Core Concepts mentioned in policy documents which had been previously been analysed with EquiFrame in order to compare any differences between policy and practice (Andersen & Mannan, 2012; Bedri et al., 2013; Ivanova et al., 2015; Mannan, MacLachlan, et al., 2012; Mannan, McVeigh, et al., 2012; O'Dowd et al., 2013; Van Rooy et al., 2012).

**Adaptations Needed for Use of EquiFrame in Analysing Good Practices**

The wording of Key Questions and Key Language for human rights Core Concepts in the EquiFrame is tailored for policy analysis. For the purpose of this analysis the word ‘policy’ was substituted with ‘good practice’, which included programmes, policies as well as case studies of individuals (Table 1).

For the level of commitment scoring, level 3 was interpreted as specific programme actions identified to address the concept. This could include addressing the Core Concept in programme objectives, programme structure or action plan. For scoring level of commitment 4, 2 and 1, the wording of the criteria did not require adaptation to carry out the analysis.

It was also acknowledged that good practice examples are less detailed than a policy document. Therefore it was acknowledged that while using EquiFrame for analysis not all Core Concepts would be expected to be present in each good practice document. As a consequence the good practice documents were analysed collectively to gain patterns of which Core Concepts were highlighted most frequently and to what extent.

**RESULTS**

A total of 42 disability inclusive good practices in the field of health were identified and included. These examples covered a wide geographical spread including; Bangladesh, Bosnia, Burkina Faso, Cambodia, China, Ethiopia, Haiti, Herzegovina, India, Kenya, Kosovo, Lebanon, Macedonia, Mali, Nigeria, Palestine, Paraguay, Philippines, Serbia, South Africa, Tibet, Uganda, and Vietnam. A range of programme types were covered by these documents from Community-Based Rehabilitation (CBR), to eye health and post-conflict services.
Core Concept Coverage and Quality

Level of commitment to Core Concepts was low at 18% on average across all 42 good practice examples. Level of commitment to Core Concept quality was also low with only 2% on average reporting specific programme objectives, actions or structures or an intention to monitor the Core Concept (a score of 3-4).

Highest occurring Core Concepts included; access 55%, individualized services 48%, capacity building 45%, and participation 38%. Those mentioned in less than 30% of examples included; non-discrimination, integration and entitlement. Core Concepts mentioned in less than 20% included; capacity-based services, family support, prevention, quality, coordination of services and family resource. Those mentioned with less frequency again in less than 10% of examples included; autonomy, cultural responsiveness, accountability, efficiency, protection from harm and contribution. The Core Concepts of liberty and privacy were not mentioned at all. One good practice example did not mention any Core Concepts.

Table 3. Core Concepts Coverage

<table>
<thead>
<tr>
<th>Core Concept Coverage</th>
<th>Core Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentioned most frequently (≥ 25% of examples)</td>
<td>Access</td>
</tr>
<tr>
<td></td>
<td>Individualized services</td>
</tr>
<tr>
<td></td>
<td>Capacity building</td>
</tr>
<tr>
<td></td>
<td>Participation</td>
</tr>
<tr>
<td></td>
<td>Entitlement</td>
</tr>
<tr>
<td>Mentioned with lower frequency (&gt;15% of examples)</td>
<td>Family Resource</td>
</tr>
<tr>
<td></td>
<td>Non-discrimination</td>
</tr>
<tr>
<td></td>
<td>Integration</td>
</tr>
<tr>
<td></td>
<td>Capability-based services</td>
</tr>
<tr>
<td></td>
<td>Coordination of services</td>
</tr>
<tr>
<td>Mentioned with minimal frequency (≤15% of examples)</td>
<td>Family Support</td>
</tr>
<tr>
<td></td>
<td>Prevention</td>
</tr>
<tr>
<td></td>
<td>Quality</td>
</tr>
<tr>
<td></td>
<td>Contribution</td>
</tr>
<tr>
<td></td>
<td>Protection from harm</td>
</tr>
<tr>
<td></td>
<td>Efficiency</td>
</tr>
<tr>
<td></td>
<td>Accountability</td>
</tr>
<tr>
<td></td>
<td>Cultural Responsiveness</td>
</tr>
<tr>
<td></td>
<td>Autonomy</td>
</tr>
<tr>
<td>Not Mentioned</td>
<td>Liberty</td>
</tr>
<tr>
<td></td>
<td>Privacy</td>
</tr>
</tbody>
</table>
Vulnerable Groups Coverage

Unsurprisingly, the highest occurring vulnerable group was persons with a disability mentioned in 100% of examples followed by children with special needs at 31%. All other vulnerable groups were mentioned with low frequency in 3 examples or fewer; women headed households, those with limited resources and living away from services were mentioned in only 8% of examples. The aged, youth and ethnic minorities were mentioned in 5% of examples. Those suffering from chronic illness and mother child mortality were mentioned in only 3% of examples. The Vulnerable Groups of those with increased relative risk for morbidity and displaced populations were not mentioned at all.

All good practice examples were categorized as having low levels of commitment for overall summary ranking. This was as a result of Core Concept quality and vulnerable group coverage being low across all samples.

Table 4. Overall Rankings (Concept Coverage, Quality and Vulnerable Group Coverage)

<table>
<thead>
<tr>
<th>Low Good Practice achieved</th>
<th>Number of Individual Good Practices</th>
<th>Total Number of Individual Good Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 10%</td>
<td>29</td>
<td>42</td>
</tr>
<tr>
<td>11-30%</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>31-50%</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

*Based on Core Concept coverage, Core Concept quality or Vulnerable Group Coverage.

Taxonomy of Core Concepts

When the Core Concepts were categorized by their underlying principles of administrative, constitutional and ethical there was little difference between the three. The findings of previous studies that analysed 17 policy documents with EquiFrame (Andersen & Mannan, 2012; Bedri et al., 2013; Mannan, MacLachlan, et al., 2012; Mannan, McVeigh, et al., 2012; O'Dowd et al., 2013; Van Rooy et al., 2012) were categorized relating to the relevant taxonomies. The Core Concepts relating to administrative were mentioned 72% of the time, ethical 71% of the time and constitutional 68% of the time. Although the Core Concepts were mentioned less often in good practice documents and thus the percentages were lower, a similar trend was seen with administrative mentioned at 20%, ethical at 15% and constitutional at 12% of the time.
Table 5. Taxonomy of Core Concepts – Good Practice Document and Policy Comparison

<table>
<thead>
<tr>
<th></th>
<th>Administrative % Coverage of Core Concepts</th>
<th>Constitutional % Coverage of Core Concepts</th>
<th>Ethical % Coverage of Core Concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good Practice Documents</td>
<td>20%</td>
<td>12%</td>
<td>15%</td>
</tr>
<tr>
<td>Policy Documents</td>
<td>72%</td>
<td>68%</td>
<td>71%</td>
</tr>
</tbody>
</table>

**DISCUSSION**

**Strengths of Good Practices**

The analysis demonstrated that some human rights Core Concepts are better represented in health disability inclusive development good practices than others. This includes; access, individualised services, participation and capacity building. Some of the highest occurring themes reflect findings of a previous study which analysed the UN CRPD using EquiFrame, where access was also the highest occurring theme and where participation and individualised services also scored relatively highly (Mannan, MacLachlan, et al., 2012). The majority of publications included in this analysis were published after the development of the UN CRPD in 2007 and after the United Nations issued the document Best practices for including persons with disabilities in all aspects of development efforts in 2011 which states best practice should be based on the UN CRPD (Handicap International, 2009; UN DESA, 2011; UN ENABLE, 2007). It not surprising therefore that there is considerable overlap between highest occurring human rights Core Concepts in good practice examples and the Core Concepts represented by the guiding principles’ of the UN CRPD. Collectively the good practices analysed in this project covered 84% of all Vulnerable Groups, which is higher than the 75% Vulnerable Group coverage in the CRPD.

The potential influence of the UN CRPD on practice is an important finding. The UNCRPD covers nearly all of the Core Concepts. However, while there is high coverage some Core Concepts are mentioned minimally such as quality, coordination of services, cultural responsiveness and privacy, and for the Core Concept of efficiency not at all. For example the Core Concept of quality was found to be mentioned only once in the UN CRPD in Article 25 exclusively relating to
health and was not mentioned in reference to other sectors such as education and social protection (Mannan, MacLachlan, et al., 2012). The UN CRPD can be seen as an aspirational guide of practice and has been found to be congruent to many Core Concepts also found in both US and Turkish disability policy (Meral & Turnbull, 2016). While the potential influence of the UN CRPD on good practice is a welcome finding, programmes should be mindful that all Core Concepts are considered and given relevant importance to their programming including those less prevalent and not mentioned in the UN CRPD.

Gaps identified
The benefit of analysing good practice examples through a human rights framework lens is that we can identify areas for improvement for future programmes and reporting. There were Core Concepts not mentioned in the sample such as liberty and privacy. Other Core Concepts were mentioned only once in the sample for example autonomy, cultural responsiveness, accountability and efficiency. However, it could be possible that some of the unmentioned Core Concepts were integrated into programme practice but went unreported, for example, the Core Concept of privacy, which includes the rights for an individuals’ information to be kept private. It could be inferred that this was likely happening throughout these good practice programmes however was not documented. It would be beneficial for programmes to report on all Core Concepts in future good practice examples to show the extent to which individuals’ rights were considered. In addition, the level of commitment to quality of reporting of Core Concepts was low with minimal examples demonstrating specific programme actions or intentions to monitor Core Concept elements.

Not all Core Concepts need to be addressed in each good practice document, however if all Core Concepts being practiced are documented it would provide a greater detail to guide others adopting disability inclusive good practice in their specific context. When addressed it needs to be of high quality with a specific programme action and/or monitoring discussed. Overall the good practice examples were of low quality in commitment to reporting the Core Concepts mentioned. Specific programme actions or monitoring were not mentioned in the majority of documents, which makes practice of the Core Concepts difficult to replicate or scale up in other programmes. With replication and scaling up of good practices being the intention of these good practice examples, the lack of reporting of specific programme actions and monitoring can be seen as a major
area for improvement. Future good practice examples need to express the level of commitment to each Core Concept mentioned noting specific programme actions and ideally how it was or will be monitored.

As mentioned it is important to note that it may not be necessary for each good practice example to encompass all the Core Concepts as they may not all be relevant in every case. For example the Core Concept of individualized services may not be as relevant to community wide programmes to address stigma and disability. This was one of the key differences in using EquiFrame for non-policy related analysis as not all Core Concepts were expected to be present in each document as a good practice examples are more of a snapshot than a complete report on a programme. The collective analysis allowed for another application of EquiFrame and for identification of trends of Core Concepts that were present across good practice documentation. However, it would be important to consider each Core Concept of human rights in good practice documentation.

With the exception of persons with disabilities and children with special needs, all other Vulnerable Groups had low coverage in the sample. It was surprising to see that only three good practice examples mentioned women specifically, considering the evidence around the double burden of disability and gender, as well as that the United Nation’s Best practices for including persons with disabilities in development efforts stating that a recognition in the interaction between gender and disability is necessary for disability inclusive development best practice (UN DESA, 2011).

**Criteria for Disability Inclusive Development Good Practice**

There is a great degree of variability in the processes used by INGOs when publishing disability inclusive development good practices, both with regards to their selection criteria and selection process. There was also variability between publications produced by the same agency. While some publications stated their selection processes and criteria for good practices, other publications did not, making it difficult to know how the agency defined good practice in that circumstance.

As well as differences in criteria for disability inclusive development good practices, selection processes varied between publications. For example, some good practices were submitted by project partners following a request from the INGO, while other publications stated disability inclusion trained field workers
were sent to certain programmes to document examples of good practice. Some publications described a multi-stage selection process with good practice examples being reviewed by a district panel, with final selections for publication then being made by a regional committee. Other publications did not state the process of how good practices were gathered or selected. More information on criteria for selection of good practice examples would be of benefit.

The Core Concepts underlying taxonomy regarding principles of administrative, ethical or constitutional were also considered, and while administrative had slightly higher frequency, all scored similar to each other in both policy and practice documents. A similar trend was seen between policy and good practice documents, which was an interesting finding. The influence of policy on practice could be a reason for this and the case is made for more comprehensive policies encompassing the Core Concepts of human rights which may in turn influence the principles in practice.

CONCLUSION

Good practice examples allow programmes to promote and share disability inclusive development for replication and scaling up. The use of a human rights framework EquiFrame for analysis of these examples can ensure they include all the necessary Core Concepts of human rights for each programme – highlighting strengths of programmes and identifying gaps. Knowledge of which Core Concepts and Vulnerable Groups have the lowest levels of commitment from this study can be used for advocacy in disability inclusive development and to guide programme staff training and documentation of good practices, targeting human rights Core Concepts and Vulnerable Groups including those who were not well represented in the analysis of good practices. This can allow for a more comprehensive disability inclusive development practice and full realisation of the rights of persons with disabilities.

Implications

Good practice examples of disability inclusive development put forward should:

(i) Consider all Core Concepts of human rights relevant to their programme
(ii) Consider all Vulnerable Groups relevant to their programme
(iii) Report all Core Concepts and Vulnerable Groups considered within the good practice example
(iv) Increase the quality of reporting by including specific programme actions and intentions to monitor Core Concepts.

EquiFrame has demonstrated the ability to identify strengths and gaps in policy and practice in terms of human rights Core Concepts, level of commitment to Core Concepts and the targeting of Vulnerable Groups. EquiFrame was easily administered in the analysis of health disability inclusive development good practices, requiring only minor adaptations as discussed in the methods section of this report. Further adaptations of Key Questions and Key Language may be useful for administering EquiFrame in guiding documents outside of the health sector.

Limitations

It was not expected that all Core Concepts should be present in each good practice example therefore the examples were analysed collectively. As the documents did not use EquiFrame in guiding reporting of the practice examples the ranking, while demonstrating low reporting of the Core Concepts, does not necessarily mean low commitment in practice. This analysis was limited to good practice examples from the INGO sector. Further study of available good practice examples of disability inclusive development from governmental organisations, in particular UN CRPD country reports, would be of benefit. This study was limited to health examples of disability inclusive development good practices. Analysis of further good practice inclusive development examples for the inclusion of the Core Concepts of human rights in areas not covered in this study, for example education, would be beneficial.

ACKNOWLEDGMENT

The study is based on Professional Practice Unit undertaken by Cheryl Henderson at the Nossal Institute for Global Health.

REFERENCES


Appendix 1

Good Practice Documents Identified


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Online Parent Training: A Pilot Programme for Children with Autism and Neurodevelopmental Disabilities in Bangladesh

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2. Initiative for Non-Communicable Diseases, HSPSD, icddr b, Dhaka, Bangladesh

ABSTRACT

Purpose: This study aimed to assess the implementation of an online parent training programme in Bangladesh, designed to enhance parental knowledge of autism and neurodevelopmental disorders and related interventions. In addition, study participants were expected to become “Master Trainers” with the intention of training other parents in their local communities.

Method: This survey study assessed parental knowledge and programme effectiveness, such as potential online learning barriers, cultural sensitivities, and general course content feedback after each unit.

Results: The programme had an 81% completion rate (with parents completing all but one unit) with an average programme knowledge score of 86%. Parents felt that the course content was moderately difficult, the length of the units was appropriate, and the units were culturally sensitive. They requested more detailed lessons, specific case studies, and adaptation of the curriculum for older children.

Conclusion: The pilot programme merits the next phase of development, which includes local adaptation and translation. However, the findings are limited by the small sample size.

Keywords: Distance learning, disability, community-based training, development.

INTRODUCTION

According to the World Report on Disability (2011), “Across the world, people with disabilities have poorer health outcomes, lower education achievements,
less economic participation and higher rates of poverty than people without disabilities”. This is partly attributed to barriers in accessing services, especially among disadvantaged communities. In 2010, 43.7% of the population in Bangladesh was living in extreme poverty (World Bank, 2016). In a country where nearly half of the population lives on less than $1.90/day (World Bank, 2016), key decision-makers have begun to invest their limited resources in better understanding and evaluating the prevalence of, and need for, related supports and services for individuals with Autism and Neurodevelopmental disabilities (AND) and their families. In recent years, the government of Bangladesh has implemented extensive multisectoral measures for the inclusion of persons with AND. The creation of the National Steering Committee on Autism and Neurodevelopmental Disabilities and the Strategic and Convergent Action Plan on Autism and Neurodevelopment Disabilities has provided a national impetus for developing the services crucial for those who require it and their families.

It is difficult to determine the actual number of individuals with AND in Bangladesh because the country lacks formal data collection processes for monitoring disability prevalence. Small government studies in the country have shown the prevalence of autism to be about .84% percent among children; this information is contradictory to census data (Emdad, 2014). However, going by the global autism prevalence rate of 1% of the population presented by the Center for Disease Control and Prevention (CDC), 15.6 million persons in Bangladesh could be affected. A detailed situational analysis conducted by Emdad in 2014, notes the “critical barrier to improving the quality of life of children and families touched by autism is the paucity of expertise to reliably identify and effectively manage these developmental disabilities”. Thus, more high-quality studies on the prevalence of AND in Bangladesh are needed.

The World Health Organisation (2014) has identified the lack of skilled human resources in low to middle-income countries as a primary barrier to accessing services for children with AND. Successful interventions that are feasible and affordable are often limited in low-income or rural areas. Train-the-trainer programmes aim to combat this lack of expertise by building a community of trainers that can reach both urban and rural communities. Research shows that empowering parents of children with AND not only improves parental self-confidence, but is also an effective method for delivering beneficial interventions (McConachie & Diggle, 2007; Matson et al, 2009; Oono et al, 2013). In addition, train-the-trainer models have demonstrated that parents can effectively act as
skilled trainers in community settings and instigate improvements in behaviour and family dynamics (Reichow et al, 2013).

When designing parent training programmes of this nature, a number of factors must be considered to ensure an effective pilot programme. Parental ability to access, retain and generalise the presented curriculum is a consistent concern (Matson et al, 2009). External factors that may contribute to parental aptitude and correlate to positive outcomes include socioeconomic status, education, previous experience, ability to carry out the training procedures, and the nature and severity of the child’s condition (Matson et al, 2009). Singer et al (2007) add that parental stress is a challenge in parenting children with developmental disabilities, and point to research that shows that access to educational content can improve overall parenting skills and lead to improved results in parent-led training programmes. Though challenges are present, Matson’s review (2009) of parent training programmes demonstrates evidence for positive short and long-term success when parents are empowered, educated and given the resources to serve as the primary educators.

The Bangladeshi Parent Empowerment Programme (BPEP) was a pilot programme designed to provide a cohort of Bangladeshi parents of children with Autism and other related Neurodevelopmental Disabilities (AND), designated as “Master Trainers”, with a tailored, online, evidence-based curriculum aimed at enhancing parental knowledge of AND as well as related interventions. The project objectives were as follows:

- Identify a group of parents of children with AND to serve as “Master Trainers”;
- Develop evidence-based curricula tailored to expand parental understanding of AND, and provide strategies for implementing home and community-based interventions;
- Utilise distance learning tools to share information and exchange knowledge;
- Engage local partners to ensure cultural sensitivity and competence;
- Evaluate the efficacy of distance learning parent training programmes in a developing country;
- Contribute to community engagement and awareness of AND, and provide
families with resources and support to increase their child’s community participation;

- Provide local and national decision-makers with data to support continued focus on AND research.

AIM

The aim of this paper is to review the BPEP pilot programme in Bangladesh, explore lessons learned, and identify the next steps in implementation.

METHOD

The Bangladeshi Parent Empowerment Programme (BPEP) was a pilot study designed to provide parents of children with AND with the knowledge and strategies necessary to implement home and community-based interventions as “Master Trainers” in their local communities. The study also sought to evaluate the efficacy of research instruments (online learning platform, tailored curricula) in a developing country that currently lacks formal programmes serving this target population. The work was accomplished in partnership with the International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,b).

Sampling

Potential study participants were identified by the Ministry of Health and in-country partners, and included individuals who are active in Bangladesh’s Parents Forum, as well as the Kumudini Trust. This resulted in a purposive sample from which eligible participants were selected. Snowball sampling methods were also utilised to recruit additional participants through initial parent volunteers.

Parents were required to meet the following criteria to be eligible for the study:

- Read and write English proficiently;
- Have access to necessary computer technology and supports;
- Commit to the time necessary to complete the training;
- Willingness to train a group of “secondary trainers”.

It is important to note that the BPEP pilot programme targeted participants with the capacity and interest to serve as leaders and train additional parents in their home communities. This resulted in a sample population of individuals whose
baseline knowledge of disability and access to resources may not be representative of the broader population of parents of children with disabilities in Bangladesh. Part of the evaluation of this “Master Trainer” programme was to identify criteria for successful participation in the online training. The research team and in-country partner screened 25 potential candidates for the programme, with a final sample size of 16 parent trainers (n=16). The sample included 12 female participants and 4 male participants. The age of the participants ranged from 35 to 54 years. Their education levels varied from primary level education to Masters’ degrees.

According to the baseline survey that was sent to all participating parents to better understand their needs, the average age of their children with AND was 17.5 years. While the average age may seem high, it is important to note that many of the children have severe autism (or other more severe NDDs) and attend a special school. Additionally, family dynamics and cultural considerations in Bangladesh are such that the children of the parents in this study are not expected to live independently; making the lessons learned through the programme valuable regardless of age. In the survey, parents reported lack of social acceptance and support as the most common barrier they faced on account of their children with disability. They reported feeling frustrated and stressed, but were hopeful.

**Ethical Considerations**
The research team followed the required Institutional Review Board (IRB) procedures according to the University of Massachusetts Boston (UMB), to obtain approval for the study. The research team asked for consent before the initial online survey was completed. If the parent volunteers chose to continue in the online training module, a more detailed consent form was disseminated, signed, and collected before the training began.

**Study Setting**
In collaboration with a local partner in Bangladesh- the ICDDR,b - the study began with a parent focus group session to discuss existing and needed services for children with AND, and to assess the feasibility of implementing an online training programme. Parents then participated, via computer, in the online BPEP training, which included a welcome unit and eight lessons (Table 1). In addition, ICDDR,b conducted telephone and in-person follow-up meetings with participants, to assess progress and any barriers encountered throughout the online training.
Table 1: Outline of the BPEP Programme Curriculum

**Unit 1: Introduction to the Programme and Introduction to Autism**
- Definition of Autism Spectrum Disorder
- Characteristics of ASD
- Prevalence, Diagnosis, and Treatment

**Unit 2: Understanding your child: Social Communication Development**
Introduce the pyramid (interactive and direct teaching)
- Social Communication Overview
- 4 Domains of Social Communication
- Teaching Techniques (Interactive and Direct)
- Social Communication Checklist

**Unit 3: Set Up Your Home for Success: Routines and Structure**
Initiative and Independence
- Setting Up your home
- Predictable Routines
- Defined Space
- Limit Distractions/ Rotate Toys/TEACCH Images?
- Daily Activity Schedule Survey
- ADLs - Common ADLs - Ways to support OT/PT in Home
- Importance of independence for skill acquisition/development

**Unit 4: Interactive Teaching Techniques –**
Follow Your Child’s Lead, Imitation and Animation
- Why play difficult/make play interactive
- Follow Your Child’s Lead
- Imitation
- Animation

**Unit 5: Teach Your Child Language**
Modelling/Expanding, Obstruction, Turn Taking, Communicative Attempts, Review
- Modelling/Expanding Language (Adjust Your Language/Area of Interest/Focus)
- Overview of Language Development/Goal Setting
- Obstruction
- Turn Taking
- Communicative Attempts
- Direct Teaching
- Prompts/ Reinforcement
Unit 6: Sensory Regulation and Activities of Daily Living

- Overview of Sensory Regulation
- Sensory Seeking & Sensory Avoiding
- Methods to increase/decrease sensory arousal
- Intro to Behaviour Management
- Rumbling/ Warning Behaviours
- ABCs

Unit 7: Addressing Problem Behaviours / Direct Teaching and Behaviour Management / Community Outings (Stigma/Awareness/How to Prepare)

- Advance Visits/Community Sensitisation
- Supports (Social Stories/Transition Objects/Routines/Rehearsal/ABC/Picture Schedules) to ensure success
- Community Outing Tips (bring a support person)
- Monitoring the Rumbling/Warning Signs
- Try Again! And Again!
- Safety & Security Issues

Unit 8: Putting It All Together / Creating a community / Teaching others

- How to be a Master Trainer: This programme is a frame for instruction, what to teach is decided by parents
- Creating a supportive parent community
- How to teach others & customisation
- How to find addition resources - special topics
- Special Topics: Lifespan, High Functioning, Puberty, Aggression

Curriculum Design

The curriculum was initially based on Teaching Social Communication to Children with Autism: A Practitioner's Guide to Parent Training (Ingersoll & Dvortcsak, 2010). This decision was based on the success of Project Impact from Michigan State University (Ingersoll & Wainer, 2013) and its approach to easily understandable skill-related development for parents. The initial outline was shared with the in-country partner -ICDDR,b - which received feedback and input from the local participants. A site visit to Bangladesh was conducted to gather further feedback related to content, and the curriculum was tailored accordingly. The outline of the BPEP programme was adapted to the Bangladeshi cultural context and needs (See Figure 1.1).
Distance Learning

Distance or online learning has emerged as a trend in both university and professional development education. A study conducted by Hanover Research (2011) found that “trends in globalisation and the global economy have opened up a new set of potential students who demand access to flexible learning opportunities”. For parents of children with AND in Bangladesh, distance learning provides access to specially tailored content from experts in the field residing across the globe. A study evaluating the efficacy of online distance learning in Africa, found that “ICT can be used to increase access to authentic teaching and learning materials” as well as to act as “a bridge to provide access to education and quality professional preparation” (Wakahiu & Kangethe, 2014). Recognising that internet services and access to technology is possibly limited for the majority of those living in under-resourced and/or rural areas, this study intentionally engaged participants with consistent access to the virtual parent training programme, and provided them with the training and skills necessary to then translate the information into community-based training that does not rely on technology for successful implementation. Curricula were adapted to consider the education levels and resources of both the master trainers in the pilot programme and secondary community participants.

The BPEP research team utilised the online learning platform Moodle. “Moodle is a learning platform designed to provide educators, administrators and learners with a single robust, secure and integrated system to create personalised learning environments” (Moodle, 2015). The course was self-paced and members of the in-country team as well as the research team were available for technical support and content clarification as necessary, thus limiting the impact of “digital potholes” that can deter student satisfaction and retention (Fisher & Baird, 2005). The research team also took steps to ensure that factors that lead to failure as defined by Rovai and Downey (2010), including lack of consideration of design, implementation, evaluation and sustainability were evaluated prior to student enrolment.

In developing and adapting the curricula in an online setting, researchers utilised Universal Design for Learning practices and included multiple methods and media for exchanging information. Researchers took measures to construct each lesson in a standardised, step-by-step format, thereby providing participants with a clear and consistent manner in which to approach the content. A visual
representation of the lessons as they appeared to participants is in Figure 1. Each lesson outlined the goals and learning objectives and core content through a narrated visual presentation (PowerPoint) and included video demonstrations of concepts and strategies along with written materials that could be downloaded and saved for later reference. The lessons concluded with a short assessment of knowledge and a feedback survey on satisfaction with the way in which the information was presented. The online learning platform, Moodle, recorded participant knowledge responses and awarded 1 point for each correct answer, with a total of 5 possible points per unit. Grades were calculated based on the raw scores of the knowledge check, and the mean scores per student, unit, and course were computed. Shaded cells indicated that a participant did not complete that unit’s knowledge check. Units were linear in design and enabled participants to scaffold their learning and build upon previous weeks’ topics, which contributed to overall understanding.

**Figure 1: A Visual Representation of the Lessons as they appear on Screen**

![Image](image.png)

**Research Tools**

Participants were given a baseline parent needs survey aimed at evaluating current levels of understanding around terms and behaviours typically associated with AND. Researchers also utilised this tool to gain insight into cultural intricacies and potential communication barriers with participants. The second survey was a unit feedback survey that each of the participants completed after the end of
each module. This survey gathered information about the time taken to complete the module, the difficulty of the content, and any other feedback the participants wanted to give. Lastly, the researchers created a “knowledge check” or measure for establishing receipt and understanding of the information provided in each lesson. Participants completed this step at the close of each module. A final programme questionnaire was adapted from the Incredible Years® Parent Programme Satisfaction Questionnaire.

RESULTS

Overall, the pilot programme was deemed successful enough for local adaptation and translation. Table 2 shows the completion rate of the participants in the online programme. The majority (n=9) of the participants completed each unit in the online training. Four (n=4) of the participants completed all but 1 unit in the course, and three (n=3) participants completed less than 7 units.

Table 2: Knowledge Check Scores by Unit

<table>
<thead>
<tr>
<th>Participant</th>
<th>Unit 1</th>
<th>Unit 2</th>
<th>Unit 3</th>
<th>Unit 4</th>
<th>Unit 5</th>
<th>Unit 6</th>
<th>Unit 7</th>
<th>Unit 8</th>
<th>Participant Overall Score</th>
<th>Participant Percentage</th>
</tr>
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<td>1</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>5</td>
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<td>92.50%</td>
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<td>5</td>
<td>5</td>
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<td>5</td>
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<td>5</td>
<td>3</td>
<td>5</td>
<td>4.63</td>
<td>92.50%</td>
</tr>
<tr>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>4</td>
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<td>85.71%</td>
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<td>4</td>
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<td>77.50%</td>
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<td>3</td>
<td>4</td>
<td>5</td>
<td>5</td>
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<td>3</td>
<td>5</td>
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<td></td>
<td>5</td>
<td>3.60</td>
<td>72.00%</td>
</tr>
<tr>
<td>16</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unit Mean</td>
<td>3.92</td>
<td>4.33</td>
<td>4.64</td>
<td>4.57</td>
<td>4.20</td>
<td>4.25</td>
<td>3.80</td>
<td>4.73</td>
<td>4.28</td>
<td>85.66%</td>
</tr>
</tbody>
</table>

*shaded cells indicate missing scores
Unit Feedback Survey

According to the unit feedback survey, the participants required 1-2 hours, on average, to complete each unit. They felt that the length of each unit was appropriate for 6 of the 8 units; the other units were rated as “a little short”. Overall, participants felt that the content of all 8 units was moderately difficult. The power-point presentations and videos, which provided the content and examples for each unit, were perceived to be very useful to the parents. On the whole, the participants felt the training courses were culturally sensitive.

Knowledge Checks

Participant scores on knowledge checks ranged from 3.60- 4.88 (77.00%-97.50%) with an average score of 4.28 (85.66%) (Table 1). Any unit or participant who fell one standard deviation ($\sigma_X = 0.42$) below the mean score was examined in more depth to identify potential barriers to participation or misunderstanding of unit content. Three participants (7, 10, and 16) averaged less than 3.86 (77.20%) on their knowledge checks. Two of the participants (7 and 16) did not complete three of the eight units of the online programme. On review of the unit feedback surveys, it was found that participant 10, who also fell below the minimum criteria for accuracy on the knowledge checks, felt all of the units were somewhat hard, had a lower level of education than other participants, and appeared to be less proficient in English language than the rest.

Unit scores ranged from 3.80 - 4.73 (76.00%- 94.67%) with a mean score of 4.31 (82.12%). Any Unit with a participant score one standard deviation ($\sigma_X = 0.34$) below the mean score was examined to identify barriers to participant understanding and to assess the Unit’s content. The scores on Unit 1 and Unit 7 fell below the minimum standard for accuracy at 3.97 (79.4%). Due to initial difficulties in getting accustomed to the online learning platform, all the participants convened for an in-person introductory lesson that included assistance in navigating the BPEP Moodle website. The participants were led through Unit 1 as a group, to demonstrate the proper techniques for navigating each unit. It is hypothesised that many of the participants did not feel the need to complete Unit 1 again or complete the knowledge check for Unit 1 due to this in-person lesson, resulting in a low Unit score.

In addition, participants’ scores fell below the minimum standard of competency for Unit 7, which included content related to addressing problem behaviours, principles of behaviour management, and community outings. Analysis of the
Unit feedback surveys indicated that many participants were confused by the content relating to behaviour management and that the community outing content was not culturally relevant to their setting. In addition, the participants rated the content as somewhat hard and took less than one hour to complete the material.

**DISCUSSION**

This pilot programme provides a context for applying online training for parents in a developing country. First and foremost, the project’s success was dependent on support from in-country partners. The ability to understand specific country needs and the needs of the parents, was critical to the realisation of this pilot programme. The online presentation of information was complex at times. The research team worked closely with a technical team to prepare and design the content, and make it as accessible and as clear as possible. This process of consultation continued throughout the project to ensure that the entire course ran smoothly.

Due to the presentation of the materials online, the research team travelled to Bangladesh to provide orientation before starting the training. The in-country team was then able to assist each master trainer with further orientation to the online modules. Although the technology caused some disruptions, overall the training material was successfully provided to all master trainers.

**Training Content**

The research team requested feedback from the participating parents about the content that was provided in the online modules. Participants desired an increase in the number of videos per lesson, and the inclusion of more practical examples of the concepts being presented, especially in the Bangladeshi context. They also noted that the training was intended to benefit younger children, whereas most of the children of participating parents were teens and adults. Consequently, they felt that many of the strategies were too elementary for their children. However, the research team’s purpose was to create an early intervention programme targeting rural parents with young children, not necessarily to reach the master trainers.

Other anecdotal information from a final survey indicated that participants would have preferred an in-person workshop or Skype sessions and more in-
depth training in order to be better prepared to train other parents. Participants also reported that because autism and neurodevelopmental disabilities are so complex and diverse, it is difficult to create a training programme that targets each child’s individual needs; therefore, more resources and examples are needed. The stated benefits of the programme were: decreasing depression and frustration of parents, support of a parent network, increased knowledge about autism, and a programme that would reach other parents who need assistance.

ICDDR,b also gave the research team feedback about the training process. Although they felt it was effective and timely, they recommended that the training programme be systematised through organisations that could be held accountable for outcomes. This suggestion is imperative for the sustainability of the project in Bangladesh. Furthermore, the training content needs to be translated into Bengali and the videos should be re-made to be culturally appropriate, relevant, and understandable to the local population.

CONCLUSION

Due to the lack of human capital in developing countries, parent training programmes are an effective method for disseminating basic content to enhance parental knowledge of AND, and direct support for children with AND. The findings in this study prove that most parents are able to comprehend basic skills needed for addressing communication and behaviour with such children.

To continue BPEP, ICCDR,b is translating the programme into Bengali and creating videos with local parents and children. These tasks will allow for a second group of parents to be trained by the master parent trainers, using the local language. The desired outcome of the project is that a core group of parent trainers will disseminate the training in rural areas of Bangladesh and support parents who have limited resources. Furthermore, the cohort of parents will provide continuous support for each other, to learn and grow in their knowledge and skills pertaining to AND.

Implications and Limitations

It is important to note that the small sample population for this study does not reflect the typical parent population – rural, low socioeconomic status, limited education levels. The study was designed to follow the training module, on completion of which the pilot study participants, with access to technology, baseline knowledge
of disability and capacity for learning new skills and concepts, would then share their knowledge in a community setting that more closely resembles a “typical” population. This pilot programme created a base of knowledgeable trainers, but the researchers were unable to assess whether the larger population would be able to adequately understand the content of such a programme. Furthermore, not every study participant completed all sections of the programme, which created incomplete data for some surveys and training Units.

While the researchers’ choice of highly educated parents for the training did not represent the majority of Bangladesh’s population, data indicates that a certain level of education and English proficiency were necessary to ensure a thorough understanding of the content. Participant 10, who had a lower education level and limited English proficiency than the others, performed lower on the knowledge checks throughout the course. Ultimately, this trainer may have benefited from receiving the content in Bengali from the “master trainers” in a community-based education setting.

ACKNOWLEDGEMENT

Aliya Naheed conceptualized the research, developed protocol, implemented larger study in Bangladesh as the principal Investigator, and conducted the research reported in the article. Kamrun Nahar Koly developed the protocol, implemented the research and wrote the final report of the project including the part of the larger research reported in the article. We acknowledge the International Centre for Diarrhoeal Disease Research, Bangladesh (icddr, b) who received financial support from Directorate General of Health Services; peoples republic of Bangladesh, and sub contracted the University of Massachusetts Boston for developing the training module as described in the article. The authors would like to express their gratitude to Ms. Saima Hossain, Chairperson of National Advisory Committee on Autism, for her invaluable support of persons with autism and neurodevelopmental disabilities, for technical guidance and to the research participants.

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Is Adaptive Behaviour too Normal to be Normally Distributed?
Scott Spreat*

ABSTRACT

Purpose: This study attempts to ascertain if adaptive behaviour complies with the characteristics of a normal distribution.

Method: Adaptive behaviour data collected from two large state samples of 2900 were reviewed to determine the shape of their distributions. A smaller convenience sample of 37 adults without intellectual disability was similarly reviewed.

Results: Findings suggest that the shape of the distribution of adaptive behaviour increasingly deviates from normal as cognitive abilities increase.

Conclusions/Implications: It does not appear that adaptive behaviour is normally distributed. This will impact the diagnosis of intellectual disability because while IQ scores two standard deviations below the mean reliably cut off about 2% of the population, a similar cut-off cannot be assumed for adaptive behaviour.

Keywords: Adaptive behaviour; normal distribution

INTRODUCTION

The definition of intellectual disability is based on the conjoint assessment of intelligence and adaptive behaviour (Schalock et al, 2010). In order to be classified as having an intellectual disability, a person must have significant deficits in both areas, with the onset of these deficits occurring prior to age 18. Significant deficits are defined in comparison with the general population, such that a significant deficit is approximately two or more standard deviations below the norm of the general population.

This sort of quasi-psychometric definition is quite workable for the assessment of intelligence. Intelligence is widely believed to follow a roughly normal distribution. An IQ score of two standard deviations below the mean reliably cut off
cuts off the bottom 2.28% of the population, based on the known properties of the normal distribution. In a sense, the operational definition of a significant deficit in intelligence is a score that is approximately in the bottom 2% of the general population.

Do the mathematical underpinnings of adaptive behaviour support such an interpretation? It is not clear that the adaptive behaviour of the general adult population follows a normal distribution (Tasse et al., 2012). Most members of the general population are able to score a perfect or near perfect score on any test of adaptive behaviour. At the common level, most of us know people who are exceptionally intelligent. Does anyone know a really super toileter? Are there any genius-level hand-washers out there? Adaptive behaviour reflects skills demonstrated by the overwhelming majority of the general public. It is a series of largely developmental tasks which are completely accomplished by the time most persons enter adulthood. It follows then, that the likely shape of the distribution of adaptive behaviour would seem to approximate only the left half of the normal distribution, sometimes called a triangular distribution. Most people achieve full competence in adaptive behaviour by adulthood, and there really is no provision for super competence in adaptive behaviour. Therefore, there is little reason to anticipate that adaptive behaviour is normally distributed or that the properties of the normal distribution should pertain to adaptive behaviour.

There are implications of the non-normalcy of adaptive behaviour. If the distribution of adaptive behaviour is not normal, then the percentile rankings derived from the properties of the normal curve do not pertain. Two standard deviations below the mean of the general population on adaptive behaviour might not cut off the bottom 2.28%. In fact, if the properties of the normal distribution cannot be applied to adaptive behaviour, it is really not known what percentage of the population is cut off by two standard deviations below the mean. One may recall that McDevitt et al. (1977) expressed similar concerns about the marked skew of the 13 Part II ‘maladaptive behaviour’ domains on the AAMR Adaptive Behaviour Scale. They noted that in some ‘maladaptive behaviour’ domains, a person with no evidence of ‘maladaptive behaviour’ might earn a ranking in the 70th to 80th percentile. Without directly linking their concerns to the issue of normalcy, McDevitt et al. (1977) clearly raised concerns regarding the interpretation of non-normal data.

Distributions closer to normal can be achieved when one limits the sample being studied to persons who have disabilities. Several of the available adaptive
behaviour scales offer norm groups comprised of persons with intellectual disability. The AAMD Adaptive Behaviour Scale (Nihira et al, 1974), for example, offers a norm group comprised of persons living in state institutions at that time. The revision by Nihira et al (1993) also employed a norm group comprised of individuals with “developmental disabilities” living in a variety of sites. The problem is that even if the resultant distributions are normal, how can a condition such as intellectual disability be diagnosed by comparing an individual only with individuals who have that disability? The Vineland Adaptive Behaviour Scale (Sparrow et al, 2005) significantly improved on this issue, employing a norm sample that attempted to replicate the general population rather than some subpopulation of persons with disabilities. Their manual does not really address the issue of normalcy, other than to note that it was necessary to normalise the composite and domain scores. They explained that their use of the term normalise meant ‘to put the scores in the form of a normal curve’.

The two key mathematical determinations of a normal distribution are skew and kurtosis. In a normal distribution, both skew and kurtosis are zero. Skew deals with the length of the distribution tails, while kurtosis deals with the flatness vs. peakedness of the distribution. A distribution may be considered to be non-normal if the skew value exceeds two standard errors of skew, or if the kurtosis value exceeds 2.0 (or effectively, 2.0) standard errors of the kurtosis, the value is outside the 95% confidence interval around the ideal value of zero.

**AIM**

The aim of this study was to investigate the shape of the distribution of adaptive behaviour across two samples - one comprised of individuals with varying degrees of intellectual disability and the other sample from the general public.

**METHOD**

**Study Participants**

There were two groups of participants in this study. Group #1 was comprised of 2900 adults with intellectual disability who lived in a variety of residential settings in Oklahoma. They constituted a subset of all persons receiving residential services from the Oklahoma Department of Mental Retardation, and all were being followed as part of a routine programme evaluation effort. There were 1554 males and 1346 females. The mean age was 41.4 years (SD = 17.94). Group #2
was a sample of convenience, collected from adult colleagues, neighbours, and co-workers of the author. All were employed in or had retired from responsible professional positions. Positions included mechanic, veterinarian, psychologist, farmer, teacher, project planner, bank vice president, and butcher. There were 21 males and 16 females. The mean age was 52.81 years (standard deviation =11.81).

**Instrument**

Adaptive behaviour was assessed using a shortened form of the American Association on Mental Retardation's Adaptive Behaviour Scale (Nihira et al, 1974). This shortened version called the Behaviour Development Survey consists of 32 items, and yields scores that range from 0 - 128, with lower scores indicating lower levels of adaptive behaviour. The scale measures reported current performance in self-care skills, community living skills, and basic socialisation skills. All Behaviour Development Surveys were completed by third- party individuals who were familiar with the individual being assessed. For Group #2, the participants’ adaptive behaviour was assessed by a knowledgeable third party in a manner consistent with described uses of the scale. In-house studies (Devlin, 1989) reveal an inter-rater reliability of .91 for this shortened form of the scale, a figure that is consistent with Isett and Spreat's (1979) report of the longer version of the scale.

**RESULTS**

The first analysis was completed on Group 1. The sample was divided by level of intellectual disability. There were 855 individuals with mild intellectual disability, 574 individuals with moderate intellectual disability, 627 individuals with severe intellectual disability, and 844 individuals with profound intellectual disability. For each of these four groups, the skew and kurtosis for the total adaptive behaviour score were calculated in an effort to assess the extent to which the data conformed to the properties of the normal curve. In a normal distribution, both skew and kurtosis are zero. A distribution may be considered to be significantly non-normal if the skew value exceeds zero plus/minus 2.0 standard errors of the skew or if the kurtosis value exceeds zero plus/minus two standard errors of the kurtosis. In a sense, this is merely stating that a derived value falls within or outside of the 95% confidence interval around the value of zero. For each of the four levels of intellectual disability, both the skew value exceeded 2.0 standard errors as calculated from the sample. Three of the four kurtosis values exceeded
2.0 standard errors of kurtosis as calculated from the sample. These data are presented in Table 1, clearly indicating that within each of these four subsamples, adaptive behaviour is not normally distributed.

Table 1: Distribution of Adaptive Behaviour among Individuals with Intellectual Disability

<table>
<thead>
<tr>
<th>Level of Intellectual Disability</th>
<th>Skew</th>
<th>SE</th>
<th>Kurtosis</th>
<th>SE</th>
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<tbody>
<tr>
<td>Mild</td>
<td>-2.029</td>
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<tr>
<td>Moderate</td>
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<td>.102</td>
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<td>.204</td>
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<tr>
<td>Severe</td>
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<td>-.950</td>
<td>.098</td>
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<tr>
<td>Profound</td>
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<td>.084</td>
<td>-.239</td>
<td>.168</td>
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<tr>
<td>TOTAL</td>
<td>- .248</td>
<td>.040</td>
<td>-1.262</td>
<td>.080</td>
</tr>
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</table>

It is noted that the deviance from normal seems to increase as intellectual capabilities increase. While none of the four subsamples yielded normal adaptive behaviour data, the deviation from normalcy was less in the more challenged groups. Figure 1 illustrates the magnitude of the discrepancy from normal. It was constructed by dividing the determined skew and kurtosis values by the associated values associated with two standard errors. The Figure suggests that the deviation from normalcy increases as intellectual ability increases. Note that in this Figure, a value of zero for both skew and kurtosis would indicate normalcy.

Figure 1: Magnitude of the Discrepancy from Normal
Analysis #2 consisted of calculating skew, kurtosis, and the associated standard errors from a convenience sample of persons without intellectual disability. The mean Behaviour Development Survey score was 127.46 out of a possible 128 points. The standard deviation was 1.48. Note first that 77.8 % of this sample achieved the highest possible scores on the adaptive behaviour Scale. All except one individual achieved scores in excess of 95% of the total possible, and this individual was 85 years of age and in declining health. The primary reasons for lost points were mobility challenges, urinary accidents in an individual who recently underwent prostate surgery, and retirement (which costs the individual one point on the Behaviour Development Survey). Skew and kurtosis, -3.99 and 18.28 respectively, both well exceeded two standard errors of the skew and kurtosis, indicating that the data was not normally distributed. These data reveal that there is very little variance in adaptive behaviour among adults without intellectual disability. It should be noted that while it would certainly be possible to use the standard deviation to establish cut off scores for having an adaptive behaviour challenge, it is not clear that the area of the curve cut off by 2 standard deviations would actually be the same as in the normal curve. It would not necessarily mean the bottom 2%. As an alternative, one could simply say that the bottom 2% equals a disability in adaptive behaviour, and the normal distribution was not pertinent. The Figure below illustrates the shape of the distribution, with a mean of 127.5 and a standard deviation of 1.48.

**Figure 2: Behaviour Development Survey Scores of individuals without Intellectual Disability**
DISCUSSION

It may be noted that a similar argument was forwarded with regard to the “maladaptive behaviour” section (Part II) of the original AAMR Adaptive Behaviour Scale. McDevitt et al (1977) expressed the concern that the marked skew of Part II subscales threatened the interpretation of those subscales, noting that on some scales, any score at all would place an individual in the 70th percentile. They did mention the apparent normalness of the adaptive items, but this is perhaps attributable to the fact that the norm group was a group of persons living in state institutions, and perhaps, a normal distribution was to be expected in this more narrowly defined sample.

The presentation of adaptive behaviour collected from an intellectual disability sample and a convenience sample of adults without disability suggested that perhaps adaptive behaviour is not normally distributed. Data also suggested that the deviance from normalcy may increase as the individual’s intellectual capabilities increase. Early literature on adaptive behaviour addressed the question of whether adaptive behaviour was distinct from IQ. These early studies typically involved correlating IQ and AB scores from various samples. Meyers et al (1979) reported on 25 such studies in which the adaptive behaviour correlation with IQ varied from .09 to .83. They went on to note that the low correlations found in normal children and in adults with mild intellectual disability were probably due, in part, to the ceiling effect of some adaptive behaviour scales. In a sense, the ceiling effect on adaptive behaviour scales can create a restriction of range among members of a more capable sample, such that a strong correlation is not possible. A ceiling effect is indicative of a non-normal distribution of data.

If the distribution of adaptive behaviour is not normal among adults in the general population, it makes little sense to apply a classification rule derived from the properties of the normal distribution. It is not so much that the establishment of a cut-off won’t work, but rather that there is no mathematical surety about the meaning of that cut-off. In a non-normal distribution of data, it is not possible to know that two standard deviations from the mean reliably delineate the upper or lower 2.28% of the population.

A reasonable question might be related to the age of skill acquisition, such as is presented in the Vineland Adaptive Behaviour Scale (Sparrow et al, 2005). It is reasonable to speculate that the acquisition of adaptive behaviour skills might yield a normal distribution with respect to age of acquisition. For example, the act
of learning to tie shoelaces is typically achieved around age 5 or 6. Some children learn it at age 3, and others, like the author, did not learn to tie shoelaces until 8 years of age. If the acquisition of this skill follows a normal distribution with respect to age, it is possible to calculate the mean and standard deviation for age of acquisition, and percentile rankings can be calculated. A significant deficit in adaptive behaviour can be expressed in terms of acquisition age. If an individual has not learned a skill by age \( X \), and 98% of persons of age \( X \) have attained that skill, the person in question has a significant deficit. Of course, the ramifications of this application are that diagnosis could only be done on individuals still in the developmental period. Further complicating this approach would be the incorporation of multiple criteria, each with different developmental profiles.

Greenspan (1999) has written about social intelligence as an important component of adaptive behaviour, suggesting that some of those more subtle deficits, such as credulity and gullibility may be better hallmarks of intellectual disability. It is reasonable to suspect that such traits might more closely approximate a normal distribution than does toileting or other primary activities of daily living. And would not toileting really be a diagnostic criterion only for younger children? If the individual does not have it by age 12, other problems are pretty evident as well.

**CONCLUSION**

The data in these analyses suggest that the distribution of adaptive behaviour increasingly deviates from normal as cognitive abilities rise. It cannot be assumed that two standard deviations below the mean on an adaptive behaviour instrument will reliably delineate the bottom 2% in the distribution. For this reason, the notion of significant deficits in adaptive behaviour needs to be re-conceptualised for use in defining intellectual disability. The re-conceptualisation might include reference to more subtle deficits that might approximate normalcy, or it might include reference to specific criteria.

**REFERENCES**


Development and Standardization of a Test of Motor Proficiency in Children with Intellectual Disabilities in India

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1. University of Jammu, India

ABSTRACT

Purpose: To develop a scale for the assessment of gross and fine motor skills of the children with mild and moderate intellectual disabilities so that their skills could be assessed and accordingly interventions in physical activities could be specifically designed for them.

Method: Thirty-eight items for the Test of Motor Proficiency scale was developed after initial try out, pilot study and final try-out by the researchers. Fifty children with mild intellectual disabilities (n = 26), and moderate intellectual disabilities (n = 24) aged between 6 to 17 years fulfilling inclusion and exclusion criteria were selected from special schools in Jammu district, J&K (India). The Test of Motor Proficiency was administered on the selected sample.

Results: Internal consistency as calculated through Cronbach’s Alpha was .906, indicating very good reliability. There was a highly significant correlation between the two independent assessments in inter-rater reliability r (48) = .95, p< .05 and also within the domains of motor proficiency, Visual-Motor control r (48) = .72, p< .05, Upper limb speed and dexterity r (48) = .98, p< .05, Running speed and agility r (48) = .99, p< .05, Bilateral coordination r (48) = .96, p< .05, Strength r (48) = .98, p< .05, upper limb coordination r (48) = .62, p< .05. Concurrent validity of Test of Motor Proficiency was established against BASIC-MR; the correlation of BASIC-MR (M = 151.92, SD = 18.08, N = 50) and Test of Motor Proficiency (M = 49.22, SD = 12.23, N = 50) was highly significant r (48) = .76, p< .05. The construct validity assessed through test retest was r (48) = .97, p< .05.

Implications: The Scale can be used in the assessment of gross and fine motor skills of children with mild and moderate intellectual disabilities for clinical and research purposes.

Keywords: Motor proficiency, Dexterity, Agility, Bilateral coordination, Visual-Motor, Intellectual disability.

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INTRODUCTION

Intellectual disability is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains (DSM-American Psychiatric Association (2013)). Individuals with intellectual disabilities are physically less active than the general community (Temple and Walkley 2003; Emerson 2005; Stanish, Temple and Frey 2006) due to their low level of motor abilities (Horvat and Franklin, 2001; Seagraves et al, 2004). Insufficient physical activity further limits the person’s autonomy in activities of daily living (Piek, Dawson, Smith and Gasson, 2008) which negatively affects their health (Carbo-Carrete, Guardia-Olmos and Gine 2016). The sedentary lifestyle results in lower balance performance, overall motor functioning (Giagazoglou et al, 2012; Horvat, Ramsey, Amestoy and Croce, 2003; Lin et al, 2010; Yildirim, Erbahceci, Ergun, Pitetti and Beets, 2010), and motor impairments among inactive individuals with intellectual disabilities (Carmeli, Bar-Yossef, Ariav, Levy and Liebermann, 2008). Motor deficits are commonly reported in persons with intellectual disabilities since this condition can affect cognitive and motor functions (Cleaver, Hunter and Ouellette-Kuntz, 2009; Hartman, Houwen, Scherder and Visscher, 2010; Vuijk, Hartman, Scherder and Visscher, 2010). With adequate levels of motor skills training, children with intellectual disabilities can participate and enjoy different physical activities. But adequate testing of the motor skills of these children is a prerequisite before designing any intervention in physical activities to develop their motor skills. Without regular motor testing, the objective to attain physical strength or fitness cannot be achieved (Horvat and Franklin, 2001; Pitetti et al, 2001; Pitetti and Yarmer, 2002). The commonly used scales in different studies are the Bruininks–Oseretsky Test of Motor Proficiency (BOTMP) (Bruininks and Bruininks, 2005), Movement Assessment Battery for Children (M-ABC) (Henderson, Sugden and Barnett, 2007). These scales are costly, time-consuming (Bruininks and Bruininks, 2005), difficult and create a rigid evaluation environment which is difficult for the children with intellectual disabilities. Currently, there is no tool for the assessment of fine and gross motor skills that is standardized on Indian children. Therefore, there was a need to develop a scale that is ecologically valid, sensitive to the child’s level of comfort, less time-consuming, cost-effective and easy to administer and score by staff in Indian special school settings.
AIMS

1. To develop a scale to assess fine and gross motor skills in children with intellectual disabilities.
2. To investigate the reliability and validity of the scale.

METHOD

Design
This research studies the psychometric properties of the Test of Motor Proficiency using the observation method.

Selection and Description of Participants
A total of 50 children with mild (n = 26) and moderate intellectual disabilities (n= 24) participated in this study from special schools in Jammu district J&K (India), with age ranging from 6 to 17 years. The permission from heads of the institutions was granted to conduct research. After explaining the study procedure in detail, consent forms were signed by the legal guardians. Children were selected after fulfilling both inclusion and exclusion criteria.

Inclusion criteria
1. Children of both sexes, aged between 6 to 17 years.
2. Children with mild and moderate intellectual disabilities as identified by an IQ test.

Exclusion criteria
1. Children with severe and profound intellectual disabilities as categorized by I.Q test.
2. Children on anti-depressant or sedative medication.
3. Children showing destructive behaviour or severe behaviour disorders as judged by the care staff.
Procedure
Children with intellectual disabilities diagnosed as per the International Classification of Diseases-10 (WHO, 1992) criteria were selected for the study. Seguin Form Board Intelligence test was administered individually to determine their I.Q. The test assessed visual discrimination, matching, speed, accuracy, eye-hand coordination and visual-motor skills. For standardization of the scale, 26 children with mild intellectual disabilities and 24 children with moderate intellectual disabilities categorized on the basis of I.Q test scores were selected for the study. The age of children with mild intellectual disabilities ranges from 6.33 to 17.00 (M=13.21, SD=3.13) and I.Q ranges from 50.65 to 64.58 (M=57.53, SD =4.10). The age of children with moderate intellectual disabilities ranges from 7.58 to 16.66 (M =11.73, SD =2.57) and I.Q ranges from 35.30 to 46.17 (M = 41.74, SD =3.24). 56% of the sample belonged to rural areas whereas 44% stayed in urban areas.

Ethical considerations
Ethical approval was obtained from the head of to the Department, Department of Education, University of Jammu to conduct the research. Identity and personal information of the participants were kept confidential during reporting of the study. Information form and consent forms were developed in concise and accessible language. The study procedure was explained in detail to the legal guardians who then signed the consent forms. Participants were allowed to voluntarily withdraw from the trial without giving any reason.

Development of the Test of Motor Proficiency
A 69 item scale was initially developed after an exhaustive review of available information on fine and motor skills of children with intellectual disabilities. Different scales such as Development Coordination Disorder Questionnaire (DCDQ; Wilson et al, 2009), Bruininks-Oseretsky Test of Motor Proficiency (BOT-2; Bruininks and Bruininks, 2005), Movement Assessment Battery (MAB; Henderson, Sugden and Barnett, 2007), Behavioural Assessment Scale For Indian Children-MR (BASIC-MR; Peshawaria and Venkatesan, 1992) were reviewed. Children with intellectual disabilities were directly observed for their capability to perform motor skills under different domains in special schools, and the comments from caretakers, teachers, and professionals working with these children were assessed. All the items were written clearly for easy measurement.
after specific observation and recording to avoid any confusion. The children were assessed for their motor skills on the domains of visual-motor control, upper limb speed and dexterity, running speed and agility, balance, bilateral coordination, strength and upper limb coordination. Visual-motor control and upper limb speed and dexterity were grouped as fine motor skills whereas running speed and agility, balance, bilateral coordination, strength and upper limb coordination were grouped as gross motor skills. The items within each domain of fine and gross motor skills were placed in increasing order of difficulty so that maximum number of children with intellectual disabilities would be able to perform the items at the lower end than at the upper end of the scale and complete the test. A glossary was prepared to give clear instructions on the administration of the items wherever the items were clearly explained. A material kit and scoring sheet were prepared to go with the scale. Direct observation technique was used to determine the actual performance of each child. The scale was administered by the researchers with the help of the teacher/caretaker. The materials required for performing the skill was kept ready before starting the assessment. The point score was written on the scoring sheet. Gross and fine motor skills were measured and assigned numerical scores (point score) for each item on the child’s performance on the scale.

Initial try-out of the Test of Motor Proficiency consisting of 69 items was carried out on seven children; three children with mild intellectual disabilities and four children with moderate intellectual disabilities, aged between 6 and 17 years. The results of the scores obtained by these children indicated the practical feasibility of using the Test of Motor Proficiency. Expert opinion and suggestions were sought from professionals working in the field of intellectual disability. They were asked to rate all the items on a point rating scale. By pooling the expert comments, certain items rated as least relevant were eliminated which led to 52 items in all the domains. Content-wise changes in the Test of Motor Proficiency, done after the initial try-out are

Sentence structure: “Climbs down the stairs” changed to “climbs down the stairs using alternate feet”; “Throws ball into a basket” changed to “throws ball into a basket with both hands”; “Throws ball in any direction” changed to “Bouncing a ball and catching it with both hands”.

Change of items: “Puts small objects into the container” changed to “Placing pennies in a box with preferred hand”.

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Sequence arrangement: Sequencing of items 3, 4 and 5 in Visual-Motor control domain was done. Activities were arranged from simple to complex: such as copying of triangle, copying of a circle and then copying of cuboid.

A pilot study of the 52 item scale was carried out on the children with mild intellectual disabilities (n = 13) and children with moderate intellectual disabilities (n = 07). Few items which were non-functional, or difficult to perform were deleted reducing the scale to 40 items.

Final try out of the 40-items of Test of Motor Proficiency was administered on the sample of 50 children with intellectual disabilities (children with mild intellectual disabilities (n = 26) and children with moderate intellectual disabilities (n = 24). Data obtained with the Test of Motor Proficiency was statistically analyzed through Statistical Package for Social Sciences version 16.0 for Windows (SPSS Inc., 2007). Two items with zero variance were removed from the scale during reliability analysis (Cronbach's Alpha) reducing the scale to 38-items. The overall mean baseline scores for gross and fine motor skills and their domain wise distribution of scores is given in Table 1.

Table 1: Domain-wise distribution of scores of Test of Motor Proficiency

<table>
<thead>
<tr>
<th>Domains</th>
<th>No. of test items</th>
<th>Min</th>
<th>Max.</th>
<th>Sum</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fine motor skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A. Visual-Motor control</td>
<td>06</td>
<td>3.00</td>
<td>7.00</td>
<td>236.00</td>
<td>4.72</td>
<td>1.26</td>
</tr>
<tr>
<td>B. Upper limb speed and dexterity</td>
<td>05</td>
<td>6.00</td>
<td>21.00</td>
<td>560.00</td>
<td>11.20</td>
<td>3.57</td>
</tr>
<tr>
<td>2. Gross motor skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. Running speed and agility</td>
<td>01</td>
<td>1.00</td>
<td>5.00</td>
<td>157.00</td>
<td>3.14</td>
<td>1.03</td>
</tr>
<tr>
<td>D. Balance</td>
<td>05</td>
<td>3.00</td>
<td>14.00</td>
<td>423.00</td>
<td>8.46</td>
<td>2.66</td>
</tr>
<tr>
<td>E. Bilateral coordination</td>
<td>04</td>
<td>.00</td>
<td>13.00</td>
<td>142.00</td>
<td>2.84</td>
<td>1.83</td>
</tr>
<tr>
<td>F. Strength</td>
<td>02</td>
<td>2.00</td>
<td>9.00</td>
<td>270.00</td>
<td>5.40</td>
<td>1.48</td>
</tr>
<tr>
<td>G. Upper limb coordination</td>
<td>15</td>
<td>9.00</td>
<td>24.00</td>
<td>718.00</td>
<td>14.36</td>
<td>3.06</td>
</tr>
<tr>
<td>Overall</td>
<td>38</td>
<td>29.00</td>
<td>80.00</td>
<td>2506.00</td>
<td>50.12</td>
<td>11.63</td>
</tr>
</tbody>
</table>
Every item in both gross and fine motor skill is specific and not generalized. The scoring for each item is different because there are variations in performing each item under different domains (Table 2). There is no uniform schema for scoring individual items. The points for scoring individual items vary from 0-4 to 0-8 within as well as across the domains.

Table 2: Scoring of items in the different domains of Test of Motor Proficiency

<table>
<thead>
<tr>
<th>Domains</th>
<th>Items</th>
<th>Scoring of different items</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>1. PS RS &gt; 6</td>
<td>0 6 2-5 1 0 4</td>
</tr>
<tr>
<td></td>
<td>2. PS RS &gt; 6</td>
<td>0 6 2-5 1 0 4</td>
</tr>
<tr>
<td></td>
<td>3 to 5. PS RS TD</td>
<td>0 PP 8-9 VP C I</td>
</tr>
<tr>
<td></td>
<td>6. PS RS &gt; 10</td>
<td>0 10 8-9 3 0-2 4</td>
</tr>
<tr>
<td>B.</td>
<td>7. PS RS 0-5</td>
<td>0 6-10 11-13 14-15 16-17 18-19 20-21</td>
</tr>
<tr>
<td></td>
<td>8. PS RS 0-1</td>
<td>0 2-3 4 5 6 7 8</td>
</tr>
<tr>
<td></td>
<td>9. PS RS 0 0</td>
<td>1-3 4-6 7-9 10-12 13-16 17-20 21-24 25-35</td>
</tr>
<tr>
<td></td>
<td>10. PS RS 0 0</td>
<td>1-10 11-15 16-20 21-25 26-30 31-35 36-40 &gt; 41</td>
</tr>
<tr>
<td></td>
<td>11. PS RS 0 0</td>
<td>1-10 11-15 16-20 21-25 26-30 31-35 36-40 &gt; 41</td>
</tr>
<tr>
<td>C.</td>
<td>12. PS RS &gt; 19</td>
<td>18 17 16 15 14 13 &lt; 12</td>
</tr>
<tr>
<td>D.</td>
<td>13 &amp; 14. PS RS 0 1</td>
<td>1-3 4-5 6-8 9-10</td>
</tr>
<tr>
<td></td>
<td>15. PS RS 0 1</td>
<td>1-3 4-5 6-8 9-10</td>
</tr>
<tr>
<td></td>
<td>16. PS RS TD</td>
<td>0 PP VP C I 4</td>
</tr>
<tr>
<td></td>
<td>17. PS RS 0 1</td>
<td>1-3 4-5 6-8 9-10</td>
</tr>
<tr>
<td>E.</td>
<td>18. PS RS 0 0</td>
<td>1 2 3 4 &gt; 4</td>
</tr>
</tbody>
</table>
|         | 19 to 21. PS RS TD | 0 PP VP C I 4 5 6 7 8
During the administration of the scale, the raw scores were recorded and converted into point scores. These point scores are converted to standard scores which are then interpreted qualitatively as per norms shown in Table 3.

Table 3: Z Scores and qualitative norms for interpretation of different domains of the Test of Motor Proficiency.

<table>
<thead>
<tr>
<th>Domains</th>
<th>Raw scores</th>
<th>Z-scores</th>
<th>Qualitative norms</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Visual-Motor control</td>
<td>20-25</td>
<td>+0.951 to +1.630</td>
<td>Very high</td>
</tr>
<tr>
<td></td>
<td>15-19</td>
<td>+.271 to +.815</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>10-14</td>
<td>-.407 to +.135</td>
<td>Average</td>
</tr>
<tr>
<td></td>
<td>5-9</td>
<td>-1.086 to -.0543</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0-4</td>
<td>-1.222 to below</td>
<td>Very low</td>
</tr>
<tr>
<td>B. Upper limb speed and dexterity</td>
<td>31-38</td>
<td>+1.034 to 1.664</td>
<td>Very high</td>
</tr>
<tr>
<td></td>
<td>23-30</td>
<td>+.314 to +.994</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>15-22</td>
<td>-.404 to +.224</td>
<td>Average</td>
</tr>
<tr>
<td></td>
<td>7-14</td>
<td>-1.124 to -.494</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>0-6</td>
<td>-1.2 to below</td>
<td>Very low</td>
</tr>
<tr>
<td>C. Running speed and agility</td>
<td>7-8</td>
<td>+1.020 to + 1.428</td>
<td>Very high</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>+.612</td>
<td>High</td>
</tr>
<tr>
<td></td>
<td>4-5</td>
<td>-.204 to + .204</td>
<td>Average</td>
</tr>
<tr>
<td></td>
<td>2-3</td>
<td>-1.020 to -.612</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>-1.428</td>
<td>Very low</td>
</tr>
</tbody>
</table>
### RESULTS

Descriptive statistics, Pearson correlation coefficient and reliability analysis (Cronbach's Alpha) were used to analyze the data.

**Reliability:** The measures of reliability were calculated by Cronbach’s Alpha, a measure of internal consistency for the sample (N=50) and 38 items was .906 (Cronbach's Alpha Based on Standardized Items =.903) indicating very good reliability. Items 19 and 20 were removed from scale due to zero variance during the calculation of reliability. Item-total Statistics of Test of Motor Proficiency are given in Table 4.
<table>
<thead>
<tr>
<th>Item no.</th>
<th>Items</th>
<th>Scale Mean if Item Deleted</th>
<th>Scale Variance if Item Deleted</th>
<th>Cronbach's Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td><strong>Visual-Motor control</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Draw a line through a straight path with a preferred hand</td>
<td>46.86</td>
<td>144.69</td>
<td>.90</td>
</tr>
<tr>
<td>2</td>
<td>Drawing a line through a curved path with preferred hand</td>
<td>47.58</td>
<td>148.12</td>
<td>.90</td>
</tr>
<tr>
<td>3</td>
<td>Copying a triangle with preferred hand</td>
<td>48.90</td>
<td>141.80</td>
<td>.90</td>
</tr>
<tr>
<td>4</td>
<td>Copying a circle with preferred hand</td>
<td>48.94</td>
<td>144.71</td>
<td>.90</td>
</tr>
<tr>
<td>5</td>
<td>Copying cuboids with preferred hand</td>
<td>49.16</td>
<td>147.36</td>
<td>.90</td>
</tr>
<tr>
<td>6</td>
<td>Cutting out a circle with preferred hand</td>
<td>49.16</td>
<td>148.58</td>
<td>.90</td>
</tr>
<tr>
<td>B.</td>
<td><strong>Upper limb speed and dexterity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Placing pennies in a box with preferred hand</td>
<td>46.52</td>
<td>135.39</td>
<td>.89</td>
</tr>
<tr>
<td>8</td>
<td>Stringing beads with preferred hand</td>
<td>46.84</td>
<td>137.28</td>
<td>.90</td>
</tr>
<tr>
<td>9</td>
<td>Drawing vertical lines with preferred hand</td>
<td>47.04</td>
<td>131.99</td>
<td>.89</td>
</tr>
<tr>
<td>10</td>
<td>Making dots in the circle with preferred hand</td>
<td>47.32</td>
<td>133.93</td>
<td>.89</td>
</tr>
<tr>
<td>11</td>
<td>Making dots with preferred hand</td>
<td>47.18</td>
<td>134.19</td>
<td>.89</td>
</tr>
<tr>
<td>C.</td>
<td><strong>Running speed and agility</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Running speed and agility</td>
<td>46.08</td>
<td>131.62</td>
<td>.89</td>
</tr>
<tr>
<td>D.</td>
<td><strong>Balance</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>Stand on the preferred leg on the floor</td>
<td>46.92</td>
<td>141.78</td>
<td>.90</td>
</tr>
<tr>
<td>14</td>
<td>Walking forward on walking line</td>
<td>47.08</td>
<td>137.87</td>
<td>.90</td>
</tr>
<tr>
<td>15</td>
<td>Walking forward heel- to- toe on walking line</td>
<td>47.42</td>
<td>137.31</td>
<td>.90</td>
</tr>
<tr>
<td>16</td>
<td>Hops on one foot (preferred foot)</td>
<td>48.60</td>
<td>142.85</td>
<td>.90</td>
</tr>
<tr>
<td>17</td>
<td>Climbs down the stairs using alternate feet</td>
<td>47.62</td>
<td>135.30</td>
<td>.90</td>
</tr>
</tbody>
</table>
### E. Bilateral coordination

<table>
<thead>
<tr>
<th></th>
<th>Activity</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Alternately tapping feet while making circles with fingers</td>
<td>48.94</td>
<td>143.93</td>
<td>.90</td>
</tr>
<tr>
<td>19</td>
<td>Jumping up and clapping hands</td>
<td>48.70</td>
<td>139.92</td>
<td>.90</td>
</tr>
<tr>
<td>20</td>
<td>Jumping up and touching heels with hands</td>
<td>48.78</td>
<td>145.68</td>
<td>.90</td>
</tr>
<tr>
<td>21</td>
<td>Drawing lines and crosses simultaneously</td>
<td>48.52</td>
<td>135.72</td>
<td>.91</td>
</tr>
</tbody>
</table>

### F. Strength

<table>
<thead>
<tr>
<th></th>
<th>Activity</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>Standing broad jumps</td>
<td>46.26</td>
<td>138.11</td>
<td>.90</td>
</tr>
<tr>
<td>23</td>
<td>Sit-ups</td>
<td>46.78</td>
<td>135.84</td>
<td>.90</td>
</tr>
</tbody>
</table>

### G. Upper limb coordination

<table>
<thead>
<tr>
<th></th>
<th>Activity</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>24</td>
<td>Bouncing a ball and catching it with both hands</td>
<td>47.92</td>
<td>142.19</td>
<td>.90</td>
</tr>
<tr>
<td>25</td>
<td>Bouncing a ball and catching it with preferred hand</td>
<td>47.92</td>
<td>142.60</td>
<td>.90</td>
</tr>
<tr>
<td>26</td>
<td>Catching a tossed ball with both hands</td>
<td>48.46</td>
<td>150.78</td>
<td>.90</td>
</tr>
<tr>
<td>27</td>
<td>Catching a tossed ball with preferred hand</td>
<td>48.52</td>
<td>144.09</td>
<td>.90</td>
</tr>
<tr>
<td>28</td>
<td>Throwing a ball at a target with preferred hand</td>
<td>48.76</td>
<td>145.12</td>
<td>.90</td>
</tr>
<tr>
<td>29</td>
<td>Touching nose with index fingers-eyes closed</td>
<td>47.50</td>
<td>141.72</td>
<td>.90</td>
</tr>
<tr>
<td>30</td>
<td>Touching thumb to fingertips-eyes closed</td>
<td>47.64</td>
<td>143.29</td>
<td>.90</td>
</tr>
<tr>
<td>31</td>
<td>Pouring liquid from one glass to another without spilling</td>
<td>47.42</td>
<td>146.49</td>
<td>.90</td>
</tr>
<tr>
<td>32</td>
<td>Turns pages singly from the book</td>
<td>48.84</td>
<td>150.13</td>
<td>.90</td>
</tr>
<tr>
<td>33</td>
<td>Opens the door</td>
<td>48.56</td>
<td>150.78</td>
<td>.90</td>
</tr>
<tr>
<td>34</td>
<td>Folds paper and insert into an envelope</td>
<td>48.40</td>
<td>149.87</td>
<td>.90</td>
</tr>
<tr>
<td>35</td>
<td>Wipes blackboard clean using duster</td>
<td>48.30</td>
<td>149.07</td>
<td>.90</td>
</tr>
<tr>
<td>36</td>
<td>Throws ball into a basket with both hands</td>
<td>48.38</td>
<td>146.60</td>
<td>.90</td>
</tr>
<tr>
<td>37</td>
<td>Tears off a sheet</td>
<td>48.44</td>
<td>146.08</td>
<td>.90</td>
</tr>
<tr>
<td>38</td>
<td>Threads a medium sized needle</td>
<td>48.88</td>
<td>141.86</td>
<td>.90</td>
</tr>
</tbody>
</table>
Cronbach's Alpha if item is deleted as indicated in Table 4 ranges from .89 to .91 which proved very good internal consistency of the items.

**Inter-rater reliability:** The inter-rater reliability for the Test of Motor Proficiency was measured where rater 2 was trained by the researcher who was the caretaker/teacher of the school. The scores for the two assessments were correlated (Table 5). Cronbach’s Alpha for rater 1 was .906 and for rater 2 it was .850.

**Table 5: Correlation in inter-rater reliability**

<table>
<thead>
<tr>
<th>Domains</th>
<th>Rater I&amp;II</th>
<th>Mean (N=50)</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rater 1</td>
<td>4.72</td>
<td>1.26</td>
<td>.72*</td>
</tr>
<tr>
<td>Visual-Motor control (fine motor)</td>
<td>Rater 2</td>
<td>5.36</td>
<td>1.46</td>
<td></td>
</tr>
<tr>
<td>Upper limb speed and dexterity</td>
<td>Rater 1</td>
<td>11.20</td>
<td>3.57</td>
<td>.98*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>11.20</td>
<td>3.57</td>
<td></td>
</tr>
<tr>
<td>Running speed and agility</td>
<td>Rater 1</td>
<td>3.14</td>
<td>1.03</td>
<td>.98*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>3.10</td>
<td>1.09</td>
<td></td>
</tr>
<tr>
<td>Balance</td>
<td>Rater 1</td>
<td>8.46</td>
<td>2.66</td>
<td>.99*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>8.46</td>
<td>2.65</td>
<td></td>
</tr>
<tr>
<td>Bilateral coordination</td>
<td>Rater 1</td>
<td>1.94</td>
<td>2.08</td>
<td>.96*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>2.02</td>
<td>2.08</td>
<td></td>
</tr>
<tr>
<td>Strength</td>
<td>Rater 1</td>
<td>5.40</td>
<td>1.48</td>
<td>.98*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>5.36</td>
<td>1.54</td>
<td></td>
</tr>
<tr>
<td>Upper limb coordination</td>
<td>Rater 1</td>
<td>14.36</td>
<td>3.06</td>
<td>.62*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>16.54</td>
<td>4.50</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>Rater 1</td>
<td>49.22</td>
<td>12.23</td>
<td>.95*</td>
</tr>
<tr>
<td></td>
<td>Rater 2</td>
<td>51.94</td>
<td>12.66</td>
<td></td>
</tr>
</tbody>
</table>

* p<.05

The results in Table 5 indicated a highly significant correlation between the two independent assessments in overall and in all the domains of motor proficiency. The overall correlation was r(48)=.95, p<.05, and within the domains of motor proficiency, Visual-Motor control r (48) =.72, p<.05, Upper limb speed and dexterity r (48) =.98, p<.05, Running speed and agility r (48) =.99, p<.05, Bilateral coordination r (48) =.96, p<.05, Strength r (48) =.98, p<.05, Upper limb coordination r (48) =.62, p<.05.
Validity: Concurrent validity of Test of Motor Proficiency was established against BASIC-MR Behavioural Assessment Scale For Indian Children With Mental Retardation, Part- A (Peshawaria and Venkateshan1992) for the motor domain (M= 151.92, SD = 18.08, N=50). The correlation of BASIC-MR (M = 151.92, SD = 18.08, N=50) and Test of Motor Proficiency (M= 49.22, SD=12.23, N=50) was highly significant r (48) =.76, p<.05.

Construct validity was measured for the differences between the mean scores at test and retest. Children were retested after a time interval of 4 months. Each child with mild and moderate intellectual disabilities was assessed individually. Scores (Mean and Std. Deviation) derived on test-retest were correlated. The reliability by Cronbach’s Alpha was .906 for the test and for the retest it was .861.

Table 6: Test and retest scores of different domains of Test of Motor Proficiency (construct validity).

<table>
<thead>
<tr>
<th>Domains</th>
<th>Mean (N=50)</th>
<th>SD</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual-Motor control</td>
<td>Test</td>
<td>4.720</td>
<td>1.26</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>5.160</td>
<td>1.39</td>
</tr>
<tr>
<td>Upper limb speed and dexterity</td>
<td>Test</td>
<td>11.20</td>
<td>3.57</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>11.26</td>
<td>3.59</td>
</tr>
<tr>
<td>Running speed and agility</td>
<td>Test</td>
<td>3.14</td>
<td>1.03</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>3.12</td>
<td>1.06</td>
</tr>
<tr>
<td>Balance</td>
<td>Test</td>
<td>8.46</td>
<td>2.66</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>8.44</td>
<td>2.68</td>
</tr>
<tr>
<td>Bilateral coordination</td>
<td>Test</td>
<td>1.94</td>
<td>2.08</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>1.94</td>
<td>2.08</td>
</tr>
<tr>
<td>Strength</td>
<td>Test</td>
<td>5.40</td>
<td>1.48</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>5.40</td>
<td>1.48</td>
</tr>
<tr>
<td>Upper limb coordination</td>
<td>Test</td>
<td>14.36</td>
<td>3.06</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>18.16</td>
<td>3.39</td>
</tr>
<tr>
<td>Overall</td>
<td>Test</td>
<td>49.22</td>
<td>12.23</td>
</tr>
<tr>
<td></td>
<td>Retest</td>
<td>53.48</td>
<td>11.36</td>
</tr>
</tbody>
</table>

* p < .05
Table 6 shows a highly significant correlation between the test and retest items scores of different domains of motor proficiency: correlation for Visual-Motor control $r(48) = .79$, $p<.05$, Upper limb speed and dexterity $r(48) = .99$, $p<.05$, Running speed and agility $r(48) = .99$, $p<.05$, Balance $r(48) = .99$, $p<.05$, Bilateral coordination $r(48) = 1.00$, $p<.05$, Strength $r(48) = 1.00$, $p<.05$, Upper limb coordination $r(48) = .67$, $p<.05$. Overall correlation for all the domains was $r(48) = .97$, $p<.05$.

**DISCUSSION**

The aim to develop this scale coincided with the study of Carbo-Carrete, Guardia-Olmos and Gine (2016) that developed and psychometrically assessed an instrument examining the support needs and strategies regarding physical activity by using individuals with intellectual disability, service providers, and family members. The analysis revealed adequate reliability for the developed instrument, with $\alpha$ value between .70 and .80, and good construct validity for the versions of the scale from three information sources. Psychometric properties of a scale assessing motor skills were assessed by Wuang, Lin, Yueh-Hsien, Su and Chwen-Yng (2009) where they assessed the validity in individuals with intellectual disabilities through partial credit Rasch model to examine the measurement properties of the BOT-2 among 446 children and adolescents with intellectual disability aged 4 to 18 years. Items in each composite of the revised BOT-2 showed a good fit to the Rasch model and demonstrated excellent reliability (range .90 to .97). Items from fine manual control and body coordination composites were mostly targeted at the lower levels of ability in these domains. Reliability and validity of the Movement Assessment Battery for Children-2 Checklist (MABC-2), which is similar to our study, was assessed by Schoemaker, Niemeijer, Flapper and Smits-Engelsman (2012). The internal consistency of the 30 items of the Checklist was determined to measure reliability. Discriminative validity was assessed by comparing the scores of children with and without movement difficulties. Construct validity was investigated using factor analysis. Concurrent validity was measured by calculating correlations between the Checklist, Test, and the DCDQ'07. The checklist scores for children with and without motor impairments significantly differed ($p<.001$) and the scores for the Checklist and DCDQ'07 were significantly correlated $r(S) = -.38$ and $p<.001$, and $r(S) = -.36$ and $p<.001$, respectively. Wilson, Crawford, Green, Roberts, Aylott and Kaplan (2009) assessed the Developmental Coordination Disorder Questionnaire on 287 children to identify motor problems in children of 8 to 14.6 years of age. 15 items with the
strongest psychometric properties were selected through internal consistency, factor loading, and qualitative/quantitative feedback from researchers, clinicians, and parents. Concurrent validity was supported through correlations between DCDQ scores and Movement Assessment Battery for Children \((r = .55)\) and Test of Visual-Motor Integration \((r = .42)\) scores. Results indicated internal consistency alpha \(.94\) and construct validity was provided through differences in scores between children with and without DCD \((p< .001)\).

It is concluded that the Test of Motor Proficiency (38 item scale) has high reliability and validity, and could be used in the assessment of gross and fine motor skills of children with mild and moderate intellectual disabilities for clinical and research purposes.

**Limitations and suggestions**
1. The scale has been developed primarily for children with mild and moderate intellectual disabilities aged 6 to 17 years and therefore, it is best suited for this group; but with few modifications, this scale can be adapted for children with severe and profound intellectual disabilities.

2. The reliability and validity analysis of the scale was done on a small sample size.

3. Time to administer the test is 45 minutes; with further simplification, the time period could be reduced for clinical purposes.

4. Face validity and cross-cultural validity will need to be established.

5. Reliability and validity of the scale could be tested on adults with intellectual disabilities.

**Implications**
Gross and fine motor skills of children with mild and moderate intellectual disabilities could be assessed through this scale, and accordingly individualized interventions could be designed to improve their motor skills in special schools. The scale could also be useful in the assessment of intervention programmes intended to improve motor skills of children in institutional settings by researchers, non-government and government organizations. The availability of this scale will be a small step towards more research on children with intellectual disabilities as there is need for evidence-based research in this area.
ACKNOWLEDGMENT

The authors thank the principal, staff, parents and special children for their cooperation during data collection. The authors express sincere thanks to the experts who helped in the validation of the scale.

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Nigerian Teachers’ Understanding of Autism Spectrum Disorder: A Comparative Study of Teachers from Urban and Rural areas of Lagos State

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1. Centre for Education and Research, University of Northampton, UK

ABSTRACT

Purpose: Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterised by difficulties in social interaction and social communication, and restricted and repetitive behaviour (American Psychiatric Association, 2013). Despite its prevalence the world over, there is a paucity of research in some areas such as education, particularly in sub-Saharan Africa. This paper attempts to address the gap by exploring teachers’ understanding of ASD in Nigeria.

Method: Using an adapted version of the Knowledge About Childhood Autism Among Health Workers (KCAHW) questionnaire (Bakare et al, 2008), a survey was conducted among 177 mainstream primary teachers from Lagos State (112 from eleven urban schools and 65 from four rural schools).

Results: The total mean score on the Adapted KCAHW questionnaire among all the participating teachers was 10.81 ± 4.13 out of a possible total of 16. The mean score for urban teachers was 11.21 ± 4.31, while the mean score for rural teachers was 10.11 ± 3.75. In total, 46% of the urban teachers and 31% of the rural teachers demonstrated a generally accurate knowledge of ASD, with 15% (23 urban teachers and 4 rural teachers) of the sample answering all questions correctly. Over 50% of urban teachers and almost 70% of rural teachers surveyed had only a low or moderate understanding of ASD.

Conclusions: This research supports previous studies that identified low professional knowledge and understanding of ASD, and a need for improved professional education and training.

Limitations: The focus was on only one state within Nigeria, and only on mainstream primary schools. Further research is necessary across the educational age range as well as different geographical areas in the country.

Keywords: Education, knowledge.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong developmental condition, characterised by differences and difficulties in social interaction, social communication, restricted and repetitive behaviours, including differences regarding the perception and management of sensory stimuli (American Psychiatric Association, 2013). This condition has a worldwide median prevalence of 62 per 10,000 (Elsabbagh et al, 2012), although identified prevalence varies widely from region to region. In areas where diagnostic services and research into ASD are well established, such as the UK, this figure can rise to about 1 per 100 (Baird et al, 2006). However, in other areas where less research has been undertaken, information regarding ASD can be partial and fragmented. Significant challenges are faced regarding assessment, identification and appropriate treatment across Sub-Saharan Africa in general (Bakare and Munir, 2011a; Ruparelia et al, 2016) and within Nigeria in particular.

ASD and Sub-Saharan Africa

Sub-Saharan Africa comprises the 46 countries south of the Sahara Desert. These are overwhelmingly low-income countries, with a combined population of more than 970 million people, half of whom are below the age of 18 years (UNICEF: Division of Data, Research and Policy, 2014). Due to the prevalence in this region of communicable diseases such as malaria and Human Immunodeficiency Virus (HIV), developmental disorders such as ASD have historically been under-researched. However, medical improvements over recent decades have led to a decline in child mortality (Rajaratnam et al, 2010). As more infants survive into childhood and beyond, there is a corresponding need to meet the needs of children with developmental issues such as ASD (Scherzer et al, 2012). However, there are considerable knowledge gaps in research and practice regarding ASD throughout the region (Franz et al, 2017).

ASD in Nigeria

Nigeria is a federal republic in West Africa comprising 36 states plus the federal capital, with almost 750 local governments (World Education News and Reviews, 2017). With a population of approximately 192 million, it is the most populous country in Sub-Saharan Africa (Worldometers, 2017). ASD was first identified in Nigeria in the 1970s (Franz et al, 2017). Despite this, prevalence rates for the condition remain uncertain (Bakare et al, 2012). A study by Bakare and
Munir (2011b) suggested a prevalence rate of 0.08%, acknowledging that this may be artificially low due to the very limited attendance of children at clinics for childhood developmental disorders. More recently, Lagunju et al (2014) reported a prevalence rate of 2.3%, with five times as many males as females identified, while Chinawa et al (2016) suggested a prevalence rate of 2.9% among schoolchildren in South East Nigeria. Children and young people identified with ASD have been predominantly non-verbal, and co-morbidity with intellectual disability is common as is late identification, often well after age 8 (Bakare and Munir, 2011b; Lagunju et al, 2014).

**Education and Inclusion in Nigeria**

Education within Nigeria is administered by federal, state and local governments. Overall policy formation is the responsibility of the Federal Ministry of Education, which is also involved in the provision of tertiary education. Primary education is largely managed at a local governmental level, while secondary education is mainly provided at a state level (World Education and News Reviews, 2017). The concept of Universal Basic Education (UBE) was introduced to Nigeria in 1988, and strengthened by the UBE Act of 2004 and its accompanying policy guidance (Nigerian Educational Research and Development Council, 2004); this enabled many children – including those with Special Educational Needs (SEN) – to attend primary schools (Imam, 2012). The Nigerian government has adopted the Salamanca Statement regarding the rights of children with SEN to access inclusive education (UNESCO, 1994); nonetheless, significant challenges remain regarding the translation of this principle into practice (Ajuwon, 2008).

**Teachers’ Knowledge regarding ASD**

Research into ASD in Nigeria in particular, and Sub-Saharan Africa in general, has been identified as being limited (Franz et al, 2017), and has largely been undertaken within a medical or healthcare context. Studies have been conducted on how ASD is understood by Nigerian healthcare professionals such as doctors (Eseigbe et al, 2015), nurses (Igwe et al, 2011), healthcare workers (Bakare et al, 2008; Bakare et al, 2009a, 2009b) and medical students (Igwe et al, 2010). All the studies have identified knowledge about ASD to be low and have highlighted a need for education and training.

The typical characteristics of ASD – communication and social difficulties, restricted and repetitive behaviours, and sensory issues – can challenge typical
teaching strategies and approaches (Jones et al, 2008). It has further been shown that individuals with ASD process information and learn differently to typically-developing children (Gunn and Delafield-Butt, 2016). Effectively addressing the needs of those with ASD has implications for all aspects of educational provision: the school and classroom environment, the curriculum, teaching materials and teaching strategies (Barson, 2010). Where teachers lack an accurate understanding of ASD, or hold misconceptions about the condition, it may lead to a mismatch between the educational provision being offered and the child’s abilities, skills and needs, which can have a negative impact on outcomes (Helps et al, 1999). Conversely, it has been shown that where teachers have a firm understanding of ASD, there are benefits for both children and teachers (Syriopulou-Delli et al, 2012; Engstrand and Roll-Pettersson, 2014).

Research in this region concerning educational issues and ASD is limited and fragmented (e.g., Obiyo et al, 2013; Bello-Mojeed et al, 2016). Only two previous studies regarding ASD in Sub-Saharan Africa have been identified which have even tangentially considered teacher’s professional knowledge. Denkyirah and Agbeke (2010) surveyed preschool teachers from Ghana alongside their counterparts from the USA concerning transition strategies for pupils with ASD; this study did not, however, investigate teachers’ knowledge about the condition. Audu and Egbochuko (2011) surveyed 131 primary teachers from Benin City in Edo State, Nigeria, regarding their knowledge about ASD, and found that only 23% of them believed that ASD existed within Edo State, suggesting a low level of awareness.

AIM

This study seeks to fill the gap in research on ASD and education in Nigeria by surveying teachers to understand their levels of knowledge about ASD, and by attempting to identify the factors that may be responsible for more or less knowledge across two groups of teachers (urban and rural) within Lagos State.

METHOD

Setting

This study was carried out within Lagos State, at 11 mainstream primary schools in urban areas and 4 rural primary schools. The average class size in both urban and rural schools was 30 pupils per class, and the children were between 6-11 years of age.
Sample Group
During October 2013, 232 questionnaires were distributed to teachers working in the urban schools. One hundred and twelve were returned (an urban response rate of 48%). During April 2014, 70 questionnaires were distributed to the four rural schools. Sixty-five questionnaires were returned (a rural response rate of 93%). In total, 302 questionnaires were distributed and 177 were returned, with an overall response rate of 59%.

The majority of teachers were female; only 16 urban teachers (14%) and 10 rural teachers (15%) were male. Among the urban teachers 87% held a teaching qualification, whereas in the rural schools only 65% were qualified teachers. Teachers in the rural schools had slightly more experience, with 57% having taught for 16 years or more, and none having less than 5 years’ experience. By contrast, 16% of the urban teachers had taught for less than 5 years, and only 47% had taught for 16 years or more. Rural teachers were also generally older, with only 17% being under 40 years of age, and 35% being 51 years or older. Again, by contrast, 43% of the urban teachers were under 40 years of age, and only 27% were 51 years or older (see Table 1).

Table 1: Socio-demographic Information about Sample

<table>
<thead>
<tr>
<th></th>
<th>Urban teachers (n=112)</th>
<th>Rural teachers (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex: male</td>
<td>16 (14%)</td>
<td>10 (15%)</td>
</tr>
<tr>
<td>Sex: female</td>
<td>96 (86%)</td>
<td>55 (85%)</td>
</tr>
<tr>
<td>Age: 21-30</td>
<td>7 (6%)</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Age: 31-40</td>
<td>41 (37%)</td>
<td>10 (15%)</td>
</tr>
<tr>
<td>Age: 41-50</td>
<td>34 (30%)</td>
<td>31 (48%)</td>
</tr>
<tr>
<td>Age: 51 years and above</td>
<td>30 (27%)</td>
<td>23 (25%)</td>
</tr>
<tr>
<td>Teaching status: qualified</td>
<td>15 (13%)</td>
<td>42 (65%)</td>
</tr>
<tr>
<td>Teaching status: unqualified</td>
<td>97 (87%)</td>
<td>23 (35%)</td>
</tr>
<tr>
<td>Teaching experience: &lt;5 years</td>
<td>18 (16%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Teaching experience: 6-15 years</td>
<td>41 (37%)</td>
<td>28 (43%)</td>
</tr>
<tr>
<td>Teaching experience: 16-25 years</td>
<td>33 (29%)</td>
<td>22 (34%)</td>
</tr>
<tr>
<td>Teaching experience: 26 years and above</td>
<td>20 (18%)</td>
<td>15 (23%)</td>
</tr>
</tbody>
</table>

Survey Instrument
The survey tool used was adapted from the Knowledge About Childhood Autism Among Health Workers (KCAHW) questionnaire developed by Bakare
et al (2008). This tool was designed specifically to identify knowledge about ASD within a Nigerian context. It has been validated and used in multiple studies relating to Nigerian healthcare professionals’ knowledge regarding ASD (Bakare et al, 2008, 2009b; Igwe et al, 2010, 2011). The tool collects data in four domains.

- **Domain 1:** Impairments in social interaction. This domain contains 8 questions addressing problems in social interaction usually found in children with ASD. A maximum score of 8 and minimum score of 0 are possible in this domain.

- **Domain 2:** Impairments in communication. This domain contains 1 item addressing problems regarding communication and language development, as part of the symptoms seen in children with ASD. A maximum score of 1 and minimum score of 0 are possible in this domain.

- **Domain 3:** Obsessive and repetitive behaviours. This domain contains 4 items addressing the restricted and repetitive behaviours found in children with ASD. A maximum score of 4 and minimum score of 0 are possible in this domain.

- **Domain 4:** Other information about ASD. This domain contains 3 items that address knowledge on the nature of ASD, possible co-morbidity with intellectual disability, and educability. A maximum score of 3 and minimum score of 0 are possible in this domain.

The tool was slightly adapted for use with teachers rather than healthcare professionals. Questions within Domains 1 (8 questions), 2 (1 question) and 3 (4 questions) remain unchanged. However, questions in Domain 4 were reduced from 6 to 3 questions, and were amended in order to gain an understanding of educational perspectives on ASD. Questions which had a specific medical focus were removed, while a question regarding the presentation of ASD within a spectrum from severe to mild was added, along with a question – informed by Nigeria’s commitment to educational inclusion – regarding the participation of children with ASD in mainstream educational settings. The tool was field-tested before use, to ensure that the language and terminology used remained appropriate for the Nigerian context.

**Ethical Issues**

Ethical approval for the study was provided by the University of Northampton Research Ethics Committee, which scrutinised all research processes and tools.
All potential participants were provided with information regarding the study, and assured that data would be anonymised. Consent was interpreted by the return of the completed questionnaire. Data was stored securely in compliance with the requirements of the British Educational Research Association (2011) and the institution.

RESULTS

Teachers’ responses to the 16 statements in the Adapted KCAHW are shown in Table 2 below. Results with regard to the overall questionnaire are presented first and then followed by domain results.

Table 2: Responses to Adapted KCAHW

<table>
<thead>
<tr>
<th>Statement</th>
<th>Urban teachers (n=112)</th>
<th>Rural teachers (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marked impairment in use of multiple non-verbal behaviours such as eye-to-eye contact, facial expression, body postures and gestures during social interaction</td>
<td>95 (85%) 54 (83%)</td>
<td></td>
</tr>
<tr>
<td>Failure to develop peer relationship appropriate for developmental age</td>
<td>87 (78%) 39 (60%)</td>
<td></td>
</tr>
<tr>
<td>Lack of spontaneous will to share enjoyment, interest or activities with other people</td>
<td>83 (74%) 38 (58%)</td>
<td></td>
</tr>
<tr>
<td>Lack of social or emotional reciprocity</td>
<td>79 (71%) 42 (65%)</td>
<td></td>
</tr>
<tr>
<td>Staring into open space and not focusing on anything specific</td>
<td>79 (71%) 44 (68%)</td>
<td></td>
</tr>
<tr>
<td>The child can appear as if deaf or dumb</td>
<td>83 (74%) 39 (60%)</td>
<td></td>
</tr>
<tr>
<td>Loss of interest in the environment and surroundings</td>
<td>80 (71%) 29 (45%)</td>
<td></td>
</tr>
<tr>
<td>Social smile is usually absent in a child with autism</td>
<td>73 (65%) 26 (40%)</td>
<td></td>
</tr>
<tr>
<td>Domain 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delay or total lack of development of spoken language</td>
<td>85 (76%) 49 (75%)</td>
<td></td>
</tr>
<tr>
<td>Domain 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stereotyped and repetitive movement (e.g. hand or finger flapping or twisting)</td>
<td>88 (79%) 41 (63%)</td>
<td></td>
</tr>
<tr>
<td>May be associated with abnormal eating habit</td>
<td>85 (76%) 43 (66%)</td>
<td></td>
</tr>
<tr>
<td>Persistent preoccupation with parts of objects</td>
<td>74 (66%) 40 (62%)</td>
<td></td>
</tr>
</tbody>
</table>
Distribution of Scores regarding the Adapted KCAHW

The maximum possible score on the Adapted KCAHW questionnaire is 16 and the minimum score is 0. The questionnaire is divided into 4 domains with maximum possible scores of 8, 1, 4 and 3 respectively; a minimum score of 0 is possible in each domain.

Bakare et al (2008) identify that the mean total score on the KCAHW questionnaire can provide a measure regarding the level of knowledge about ASD among that particular population, while Igwe et al (2011) state that a maximum score on the KCAHW indicates adequate knowledge of the signs and symptoms of ASD. The authors of the current study suggest that a score of 0-6 indicates a low knowledge of ASD on the part of the respondent, a score of 7-12 indicates a moderate knowledge of ASD, while a score of 13 and above indicates a generally accurate knowledge of ASD.

There was wide divergence regarding the teachers’ responses, and there were no questions where consensus was achieved. Only 23 teachers from urban Lagos State (21%) and 4 teachers from rural Lagos State (6%) answered all questions correctly. The mean score for the urban teachers was 11.21 ± 4.31, while the rural teachers had a mean score of 10.11 ± 3.75. Mean total scores in each of the domains is shown in Table 3 below.

Table 3: Distribution of Scores on Adapted KCAHW among Teachers

<table>
<thead>
<tr>
<th>Domain</th>
<th>Maximum possible score</th>
<th>Urban teachers (n=112)</th>
<th>Rural teachers (n=65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1</td>
<td>8</td>
<td>5.71, SD = ± 1.93</td>
<td>4.74, SD = ± 2.18</td>
</tr>
<tr>
<td>Domain 2</td>
<td>1</td>
<td>0.76, SD = ± 0.43</td>
<td>0.75, SD = ± 0.43</td>
</tr>
<tr>
<td>Domain 3</td>
<td>4</td>
<td>2.75, SD = ± 1.23</td>
<td>2.46, SD = ± 1.2</td>
</tr>
<tr>
<td>Domain 4</td>
<td>3</td>
<td>1.99, SD = ± 1.01</td>
<td>2.06, SD = ± 1.0</td>
</tr>
<tr>
<td>Mean score</td>
<td>16</td>
<td>11.21, SD = ± 4.31</td>
<td>10.11, SD = ± 3.75</td>
</tr>
</tbody>
</table>
Domain 1: Impairments in Social Interaction

Questions in Domain 1 concerned the social difficulties in ASD, including problems regarding peer relationships, play, and social reciprocity. Urban teachers scored more highly on average than their rural counterparts, with a mean score of 5.71 ± 1.93, compared to 4.74 ± 2.18. Over 80% of teachers in both groups identified that ASD was characterised by ‘marked impairment in use of multiple non-verbal behaviours such as eye-to-eye contact, facial expression, body postures and gestures during social interaction’. However, there was greater diversity with regard to the statements concerning how this marked impairment might present, with a higher percentage of urban teachers than their rural counterparts identifying ways in which this may occur.

Statistically significant differences were found between the two groups of teachers with regard to 2 questions. These related to interest in the environment and surroundings (chi-square = 7.6614, df=2, significance level = .005641) and absence of social smile (chi-square = 6.6974, df=2, significance level = .009655). In both cases, about two-thirds of urban teachers were aware that these behaviours could be indicative of ASD, compared with less than half of the rural teachers.

Domain 2: Impairments in Communication

This question concerned communicative difficulties in ASD. As in the original KCAHW, this was limited to verbal communication, with non-verbal communication being addressed as part of Domain 1. Urban and rural teachers’ responses were very similar here, with about three-quarters of the participants in each group correctly identifying this communicative impairment.

Domain 3: Obsessive and Repetitive Behaviours

This domain investigated knowledge regarding stereotypical movements such as hand flapping, eating problems, the desire for routines and interest in objects. Urban teachers scored more highly here with a mean score of 2.75 ± 1.23, as compared with the rural teachers’ score of 2.46 ± 1.2. Many teachers were unaware of the preference among children with ASD for routines (n=51, 46% of urban teachers and n=25, 38% of rural teachers). There were no statistically significant differences between the two groups.
Domain 4: Other information about ASD

About two-thirds of teachers in both groups were aware that ASD is a spectrum condition with a range of presentation from mild to severe; and about three-quarters were aware that it can occur alongside intellectual disability. About two-thirds of the teachers also identified that children with ASD can be educated in mainstream schools. Rural teachers scored slightly higher overall (2.06 ± 1.0) than their urban counterparts (1.99 ± 1.01) in this domain. There were no statistically significant differences between the two groups.

Overall Adapted KCAHW Score

The total mean score on the Adapted KCAHW questionnaire among all teachers participating in the study was 10.81 ± 4.13 out of a possible total of 16. Overall, the mean score for the urban teachers was 11.21 ± 4.31, while the mean score for rural teachers was 10.11 ± 3.75. This indicates that urban teachers therefore had an overall higher level of knowledge than their rural counterparts. It was a matter of concern that over 50% of urban teachers and almost 70% of rural teachers surveyed had only a low or moderate understanding of ASD (see Table 4). In total, 46% of the urban teachers and 31% of the rural teachers demonstrated a generally accurate knowledge of ASD, with 15% of the whole sample (23 urban and 4 rural teachers) answering all questions correctly. The differences in accuracy levels between urban and rural teachers do not reach statistically significant levels (chi-square = 3.7336, df = 2, significance level = .154616), and it is acknowledged that there are demographic variables between the two groups (such as the age profile of the teachers) as well as a difference in response rate. Nonetheless the results reflect findings in other settings that suggest that professionals working in urban environments may have greater exposure to pupils with ASD – or to information about the condition in general – and therefore demonstrate a more accurate understanding and provide more appropriate support (Lai et al, 2012; Zhang et al, 2017).

Table 4: Teachers’ level of Knowledge by Location

<table>
<thead>
<tr>
<th>Location</th>
<th>Low accuracy (0-6)</th>
<th>Moderate accuracy (7-12)</th>
<th>Generally accurate (13-16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Urban teachers (N=112)</td>
<td>15</td>
<td>13</td>
<td>46</td>
</tr>
<tr>
<td>Rural teachers (N=65)</td>
<td>11</td>
<td>17</td>
<td>34</td>
</tr>
<tr>
<td>All teachers (N=177)</td>
<td>26</td>
<td>15</td>
<td>80</td>
</tr>
</tbody>
</table>
The potential impact of other variables such as qualification, gender, experience and age were also considered (Table 5). None of these variables achieved statistical significance at <.01, though it should be noted that 56% of teachers under 40 years of age had a generally accurate understanding of ASD, in comparison with just 28% of those over 51 years (Table 6). This result supports other studies suggesting that older professionals may sometimes lack up-to-date knowledge and awareness about ASD (Johnson et al, 2013).

Table 5: Consideration of other variables on Teachers’ Knowledge of ASD

<table>
<thead>
<tr>
<th>Variable</th>
<th>Chi-square</th>
<th>df</th>
<th>Level of significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualification</td>
<td>4.8891</td>
<td>2</td>
<td>.086764</td>
</tr>
<tr>
<td>Gender</td>
<td>5.1589</td>
<td>2</td>
<td>.075816</td>
</tr>
<tr>
<td>Length of experience</td>
<td>5.2569</td>
<td>6</td>
<td>.511314</td>
</tr>
<tr>
<td>Teachers’ age</td>
<td>10.6115</td>
<td>4</td>
<td>.031295</td>
</tr>
</tbody>
</table>

Table 6: Teachers’ level of Knowledge by Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Low accuracy (0-6)</th>
<th>Moderate accuracy (7-12)</th>
<th>Generally accurate (13-16)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Under 40 (n=59)</td>
<td>5</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td>41-50 (n=65)</td>
<td>10</td>
<td>15</td>
<td>32</td>
</tr>
<tr>
<td>51+ (n=53)</td>
<td>11</td>
<td>21</td>
<td>27</td>
</tr>
</tbody>
</table>

**DISCUSSION**

The findings of this study suggest that – as with professionals within the country’s health services and educators in Edo State – school teachers in Lagos State, Nigeria, are generally relatively ignorant about ASD. Over 50% of urban teachers and almost 70% of rural teachers have only a low or moderate understanding of the condition. Furthermore, there is a high degree of divergence both within and across the two groups of teachers with regard to all questions in the Adapted KCAHW. This indicates that behaviours felt to be characteristic of ASD by some teachers were not considered as such by others. It suggests that ASD is conceptualised diversely within this sample.
How professionals conceptualise ASD has been shown to be influenced by many factors. These include previous experience of working with children with ASD, family experience, religious or cultural beliefs, the impact of the media or the wider community, and so on (Mavropoulou and Padeliadu, 2000; Bakare et al, 2009b; Imran et al, 2011; Alqahtani, 2012). ASD is often conceptualised negatively throughout Sub-Saharan Africa, with those affected by the condition frequently being considered as ‘witches’ or ‘possessed’ (Cimpric, 2010). Such views may be held not only by the general population but also by professionals, and can lead to stigmatisation and discrimination (Okey-Martins Nkwolo, 2015). Bakare et al (2009b) reported that 27% of Nigerian nurses included in their study believed ASD to have a supernatural cause, such as cursed ancestral spirits or the action of the devil. Whatever the contributory factors, it is inevitable that inconsistent conceptualisation of ASD, such as that evidenced within this sample of teachers, will lead to inconsistency in how they understand and respond to the educational needs of the children they teach.

Research across a range of disciplines including health (Heidgerken et al, 2005), social work (Preece and Jordan, 2007) and education (Jones et al, 2008) has identified the importance of professionals having a sound understanding of ASD, and the positive impact this can have on the lives of children with ASD and their families (Tilahun et al, 2016). Moreover, accurate knowledge about ASD and the use of ASD-appropriate strategies have been shown to improve teacher self-efficacy and confidence and to reduce likelihood of stress and burnout (Jennett et al, 2003; Ruble et al, 2011). The current study therefore concurs with previous research (Leblanc et al, 2009; Guldberg et al, 2011; Franz et al, 2017) that training with regard both to ASD awareness and appropriate intervention strategies – and evaluation of the impact of such training on professionals’ knowledge, skills and attitudes – is required if children with ASD are to have their needs successfully addressed.

CONCLUSION

ASD is a developing area of research within Sub-Saharan Africa in general and Nigeria in particular, and as such it is relatively unsurprising that this study has identified the level of knowledge among educational professionals within Nigeria to be generally low. This study supports previous research in arguing that there is a need for improved professional education and training regarding the condition.
Limitations
It is acknowledged that this study has focussed only on one state within the country, and only on educators within mainstream primary schools. Further research is necessary, not only across the educational age range but across the different geographical areas of the country.

Implications
There is the need for further research – both within Nigeria and across Sub-Saharan Africa as a whole – which focusses not only on teachers’ knowledge but also on how they are currently teaching children with ASD, what is currently effective and how educational interventions in ASD that are developed within high-income countries can be adapted and utilised within a Nigerian context. Such research – and the practical developments arising from these studies, such as the development of locally-appropriate training and practice – can have a transformative impact on the lives of children with ASD, their families and their teachers within this region.

REFERENCES


Accessibility to Power: Framing of the Disability Rights Movements in India and Nepal
Henrik Schedin*

ABSTRACT

**Purpose:** This paper explores the effect of inherent social inequalities on disability rights movements and their political activities in India and Nepal. The situation for persons with disabilities is similar in both countries. Many social and cultural phenomena coincide, and laws and policies are currently being formulated in line with the human rights agenda. In order to understand the current situation and the envisioned future for persons with disabilities, it is important to probe how, and under what circumstances, the disability issue is framed.

**Method:** Purposive sampling was used to access outspoken activists in Kolkata in India and Kathmandu in Nepal. Semi-structured interviews were conducted, coded according to recurring themes, and analysed with Nancy Fraser’s theory on misrepresentation of social movements along with literature on framing. Though only 7 interviews were conducted (a limitation of the paper), together with informal discussions and previous knowledge they provided a sufficient overview of the social movements in the two countries.

**Results:** This paper increases the knowledge on the two social movements, and provides interesting case studies on how persons with disabilities engage in political activities in the Global South. The rights-based approach has a strong influence within both movements, and appears to be the main strategy adopted by them.

**Conclusions and Implications:** The Indian and Nepalese disability rights movements are affected by social inequalities. It seems as though the urban middle-class and their needs colour the movements and its framing. Further research is needed to probe what implications these inequalities have for the situation of persons with disabilities.

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Keywords: disability, social movements, rights-based approach, misrepresentation, inequalities, India, Nepal.

INTRODUCTION

Participation in political activities is important since it is a strategy to gain and exert influence in society. However, persons with disabilities in the Global South usually have little access to political activities, since living with a disability in the Global South is often linked to low literacy and poverty (Opokua et al, 2016). In this context, most persons with disabilities have few resources to articulate their needs and claim their rights and entitlements. The same scenario is found in India and Nepal, where political participation is generally limited to advocating for their rights within the countries’ disability rights movements. Nonetheless, civil society groups are a vital part of political life in India and Nepal, and the disability rights movements are actively striving for the implementation of their rights.

The situation of persons with disabilities in India and Nepal is strikingly similar. Both countries have ratified the United Nation’s Convention on the Rights of Persons with Disabilities - CRPD (UN, 2016). In line with the CRPD, the Indian Parliament passed a new Disability Rights Law in December 2016, and a similar Act is pending in the Nepalese Parliament. Even though persons with disabilities still face discrimination in their everyday life, improvements are being made at a policy level. These changes are an effect of tenacious advocacy work and pressure from the disability rights movements. They signal that there is a will to change the situation among government authorities and politicians, and these policy changes are to be seen as a sign of partial success.

The disability rights movements of India and Nepal are not based on open protest and social disruption, often defined as contentious politics (Tarrow, 2011). Instead, the movements make use of awareness-raising and advocacy work among the public and government authorities. The intention of these strategies is to change the understanding of persons with disabilities and their capabilities among decision- and policy-makers. However, much like contentious politics, the advocacy work of the two movements needs to be seen as a dynamic process that intersects with various social and political mechanisms (McAdam et al, 2001).

It is also important to keep in mind that divisions occur within social movements even though they often claim to be unified (ibid, 127).
of the disability movements in India and Nepal have various socio-cultural backgrounds, opinions and needs. Ingstad (2007) points out that there is a risk of elite-capture in the implementation of human rights for persons with disabilities in the Global South. In other words, the urban-based elite, who are well-connected with international and national organisations and institutions, set the agenda for the movement. This is not unique for the disability rights movement but a common phenomenon among civil society groups in South Asia (cfr. Bhatta, 2012; Robins, 2012).

It is important to keep in mind that social inequalities based on caste, religious belonging, and gender are common in India and Nepal, and poverty is a major social issue in both countries. This is also the case for persons with disabilities. They experience discrimination to a large extent, and poverty is common within the group due to lack of access to education and employment (Lamichhane and Okubo, 2014; Ghosh, 2016). There are tremendous social differences and inequalities between urban and rural areas due to the unequal access to education and employment opportunities, and cultural inequalities. In India, healthcare and education opportunities for persons with disabilities are mostly concentrated in the metropolitan areas, and in Nepal the same opportunities are largely found in the Kathmandu Valley. Due to poor infrastructure and inaccessible public transport in rural areas, the mobility of persons with disabilities creates further marginalisation and isolation there. These are systems and structures that increase the inequalities and strengthen the existing social relations between urban and rural populations. Since there are enough similarities between the Indian and Nepali movements, the author has treated them as analogous throughout this analysis. However, each of the two movements is, in reality, unique.

AIM

There is little knowledge regarding the disability rights movements in India and Nepal. It is important to understand the current situation for persons with disability in these countries, see how the current rights struggle reflects the envisioned future, and shed light on issues that need further inquiry. Therefore, this article aims to explore how the disability rights movements in India and Nepal are influenced by inherent social inequalities.
METHOD

Approach
The article is based on 7 semi-structured interviews - 4 with disability rights activists in Kolkata, and 3 in Kathmandu. Semi-structured interviews were suitable since it gave an opportunity to obtain in-depth information in a short time (Blee and Taylor, 2002), and the informants were an integral part of the study’s development and construction. During the interviews, the author was critical of his own assumptions and open to unexpected insights (Brinkmann and Kvale, 2007); this allowed the informants to speak freely about predefined themes and to describe phenomena that mattered to them.

Sampling
Purposive sampling was used to access outspoken and prominent members of the movements in the two cities. All the interviews were conducted with well-educated urban-based activists, belonging to the middle-class. The interviews are obviously biased towards a specific group. However the selection is representative of active leaders in the disability rights movements in India and Nepal, and the interviews illustrate how the movements were formed, the main issues that are being pursued by them, and what social realities are constructed.

Analysis
Data was concurrently analysed during the fieldwork to ensure that the interview questions were relevant and appropriate. Additionally, preliminary findings were discussed with Indian scholars while the author was in Kolkata, to gain further insight on the data.

The interviews were transcribed and coded according to themes identified to be salient and relevant. The coded transcripts were continuously reviewed together with the author’s field notes in order to make a thorough analysis of the interviews. Throughout the data collection process and analysis, a constructivist approach was applied. This has allowed for the informants’ experiences to be interpreted within the social and cultural context, and this has led the analysis (Kitzinger, 2004). However, so as not to base the analysis solely on the informants’ socio-cultural background, the data has been approached with an intersectional stance, and has been viewed as constituted of complex identifications (Christensen and Jensen, 2012).
Theoretical Framework of Framing and Misframing

An important function of social movements is to formulate grievances (Tarrow, 2011). Through these grievances meaning is created for the movement to frame its goals and visions. Snow and Benford (2000) write that: “Collective action frames are constructed in part as movement adherents negotiate a shared understanding of some problematic condition or situation they define as in need of change, make attributions regarding who or what is to blame, articulate an alternative set of arrangements, and urge others to act in concert to affect change”.

By framing goals, the movement can effectively communicate people’s desires and more people can be mobilised. It is a political instrument that evokes emotions, provokes action, and sets the agenda of the movement. However, framing is a selective process, and cultural and power aspects of this process need to be taken into consideration. Those who frame the movement are responsible for setting the agenda and create imagined realities that the movement strives for and, if successful, the Indian and Nepali society will in the future be shaped by the agenda (della Porta and Diani, 2006).

Social movements that strive for justice have often been faced with what Nancy Fraser (1995) calls “the redistribution-recognition dilemma”, the dilemma of whether to demand economic redistribution or cultural recognition. The first case applies to an economically marginalised group, and needs to claim the same economic rights as other groups. The latter, applies to a group that faces cultural discrimination, and needs to claim their specificity as a way to be subjected to affirmative action. However, political economy and culture are often intertwined, and many marginalised groups cannot make this distinction. Persons with disabilities in India and Nepal need to strive for a situation where they are not treated in a different way economically, at the same time as they are recognised as having different cultural and physical needs. To paraphrase Fraser (1995), how can persons with disabilities fight simultaneously to abolish disability differentiation and to valorise disability specificity?

Fraser (2008) has further developed these ideas and added a third dimension to her theory on justice claims, namely representation. The author claims that one needs to consider who is striving for change and not only what social movements are struggling for. Within social struggle there is a risk of exclusion of the people who are to be represented, and this leads to what Fraser (2008) calls “misrepresentation” and further to “misframing”. In other words, the ones who
are to be represented within a social movement lose their voice and their right to frame the agenda. This phenomenon occurs in social movements that are unequal in their structure. Fraser gives the example of transnational movements where Northern elite often monopolise the movement’s framing. However, the author of the current study argues that these theories are also applicable to the national disability movements in India and Nepal, since there exist great inequalities within the movements. This leaves three dimensions of justice claims: economic, cultural and representational. These need to be addressed simultaneously, otherwise there is a risk that one dimension has a negative effect on the others (Mladenov, 2016).

RESULTS

The most commonly used frame of the Indian and Nepali disability movements is the human rights agenda. Both the countries’ movements have adopted the rights-based approach, and the movements are coloured by the language and scheme of the CRPD. After many years of struggle, first for each government to ratify the CRPD and then advocating for a domestication of the Convention, the rights-based approach has left a mark on the two movements. Now that the Indian government has approved the new Disability Rights Act and the Nepali Parliament is in the last stage of approving an equivalent law, the strategy has yielded positive effects.

In line with Benford and Snow (2000), the collective action frame of the human rights agenda recognises a problem and suggests a solution, namely that the welfare approach, the previous normative approach, is patronising and that it is vital to grant persons with disabilities rights instead of welfare. The welfare approach focusses on structural support through economic handouts and redistribution of assistive devices, and is often talked of as charity. In the Global South the welfare approach has often led to a dependence on family members, other informal relations, non-government organisations and charities, due to the lack of governmental resources and support. The rights-based approach suggests that the attitude towards persons with disabilities needs to change and it is vital to create possibilities for them in order to change their own situation; it thus focusses on empowering the individual. This is an approach which advocates that persons with disabilities need to strive for a more individualistic lifestyle and become economically independent in order to prove that they can contribute to society and therefore are entitled to rights. The embracing
of the rights-based approach is driven by the movements’ leaders, and they are making efforts to redirect the mindset of the actors within the movement towards this approach.

Examples of the main themes that are evoked during advocacy are: provisions within higher education and governmental employment opportunities, as well as universal design. These issues are of course very important but, for persons with disabilities living under poverty and in rural areas, these issues are generally not relevant in their everyday life. Among the population that lives under poverty, informal economic activities are most common and education and formal employment are far from possible. Even though the concept of universal design encompasses accessible public spaces, the infrastructure in rural areas is so deficient that the forms of accessibility that need to be addressed there are very different from the urban areas. The rights-based approach is directed towards the right to be fully part of society, by having access to activities that will empower the individual to take care of oneself. The strategy adopted by the movements places them in the recognition side of Fraser’s (1995) above-mentioned dilemma, and focuses less on redistribution of resources. The movements struggle to be recognised as a marginalised group that need certain provisions to be able to participate in societal activities, and the individual’s right is the focus of their struggle instead of purely economic issues. A main strategy among many organisations in the two countries is to educate members regarding their rights, and to raise awareness of the rights of persons with disabilities among other groups and authorities. The understanding of rights varies, but in India and Nepal the CRPD is used as a reference.

There is frustration among urban-based activists that persons with disabilities across the countries do not fully embrace the rights-based approach. A Nepali activist told the author:

“People don’t know what rights are, they cannot read, they don’t understand the international scenario, and human rights principles. They always believe that they should be asking for the disability allowance, and not asking for the rights to livelihood. Getting money without working is not good”.

There is evidently a divide between the leaders’ visions and the grassroots’ acts. The inequalities within the movements are evident and are presented in its framing. This phenomenon is also common within other civil society groups in South Asia (cfr. Robins, 2012).
As an explanation for the misrepresentation of the less privileged population in the advocacy work, one of the interviewed activists identified the involvement of international organisations as a reason and said:

“Another reason why they get so cut off from the grassroots is probably because [the international organisations] are up there and [the urban-based organisations] are somewhere in the middle. [...] You are not looking at exactly what the grassroots are thinking”.

Collaborating with external organisations comes with benefits, such as resources and knowledge exchange. However, it often means that the cooperation is based on terms set up by the international organisation. Due to North-South relationships and neo-liberal development schemes, the Western notions of disability and the CRPD have become hegemonic around the world (Soldatic and Grech, 2014). However, in the process of rights implementation, it is vital to consider the cultural context of the countries and remember that the majority of persons with disabilities in India and Nepal live in a vulnerable economic situation.

While there is no question that all persons with disabilities need rights, a major part of the group still struggle to manage daily expenses and would benefit from economic support together with cultural recognition and political representation. However, many of the movements’ leaders consider that economic redistribution reinforces the notion that persons with disabilities are incapable of taking care of themselves. While discussing this dilemma, an Indian activist who is critical of the rights-based approach said:

“I think grassroots-people are much more practical. They say that they want jobs. If there is no job, then they want money from the government”.

Another issue that comes with the rights-based approach is that it is based on individuality. India and Nepal have strong family-based cultures where the community is in focus and not the individual. This means that the approach conflicts with the lived reality of many persons with disability. Additionally, persons with disabilities are more likely to be dependent on family members to care for them, due to lack of social security systems and discrimination in the labour market. Persons with disabilities in India and Nepal are therefore often dependent on family and community support one way or the other, and will most likely find it hard to have a more individualistic lifestyle.
The Indian and Nepali societies are changing, and individualism is growing along with modernity and urbanisation. However, outside the metropolitan areas informal community care is still a strong institution, and often the only social security system that exists. One of the objectives of the rights-based approach is of course to change this scenario, to overcome discriminating barriers to create independence. In the meantime, people's needs must be catered for, and not only their rights. Additionally, activists in India have witnessed that the Indian government has pushed for individualisation of society in modernisation campaigns, but has tended to shift towards a more community-based stance when the resources run out. The government makes promises, but in the end the responsibility of care is again handed over to the informal systems. This dilemma further complicates the implementation of disability rights in countries with inherent inequality, and needs to be taken into consideration when discussing disability rights in India and Nepal.

**DISCUSSION**

The human rights agenda is a hegemonic frame within both the Indian and Nepali movements, where the agenda clearly dominates the efforts to improve the situation for persons with disabilities. The agenda is a global discourse that is articulated and translated into the Indian and Nepali context by civil society groups and the elite. In both countries, there is a clear divide between the needs of the urban and the rural populations, and those who live under poverty and those who do not. All the activists that the author interacted with were aware of this fact, and were making efforts to change the situation. However, the advocacy strategies and the majority of the addressed issues are based on urban needs from a middle-class perspective. When framing the movement, the leaders set the agenda of what to strive for and an idea of what the future of persons with disabilities is likely to be. It is a powerful act that will shape social and political realities to come (della Porta and Diani, 2006). The urban-based activists clearly frame the issue from their perspective. Even though they have the best interests of all persons with disabilities in mind, there is a clear divide between the educated and articulate activists and the persons with disabilities who struggle to survive from day to day. In Fraser’s (2008) words, there is a misrepresentation of the group of persons with disabilities as a whole. Great divides in needs exist within the group, and urban middle-class activists are dominating the discussion about what to strive for and how policies are to be written.
The advocacy strategies and discussions regarding rights of persons with disabilities need to consider the social context of India and Nepal. There are many persons with disabilities who live in poverty and need support to cover their most basic needs, which in many cases means dependence on family members or other well-wishers. Even though the Indian and Nepali societies are moving towards a more individualistic social structure, persons with disabilities will find it increasingly hard to follow this societal development. When interdependency on family members is a cultural and economic element of life and survival, it is problematic that leaders of the disability movement push for legislation that is based on individuality. The differences and inequalities within the group are evident when those advocating for the more individualistic rights-based approach are those who are not vulnerable to these changes.

To be able to communicate and cooperate with international organisations, the activists need to be sufficiently articulate. This implies a certain amount of education and the ability to work full- or part-time with advocacy. Resources and specific language skills are needed to be able to perform advocacy work that is taken seriously. It is necessary to make time to visit governmental offices repeatedly and formal language and “development lingo” are needed for communication. In other words, advocacy work is dependent on human and economic resources, which are not a given among the members of the disability movements in India and Nepal. This means that in many cases people at grassroots level cannot speak for themselves. The inequalities within the movement may create a situation where the advocacy-elite capture the issue and are disconnected from the grassroots and those who have more urgent needs.

CONCLUSION

In this article, inequalities and conflicting interests within the Indian and Nepali disability movements have been highlighted. These are inequalities that reflect social injustices at the societal level and are not unique to the disability rights movements of the two countries. Nonetheless, certain issues have been brought to light that arguably are important to consider when advocating and writing policies for the rights of persons with disabilities.

It is clearly the urban middle-class population that frames the disability rights issues. Thus there is a risk that the already existing inequalities are deepened and can become entrenched if the current activities mostly benefit the urban middle-class population. Leaders are frustrated that the rights-based approach is not
embraced by all within the movement. At the same time, paternalistic attitudes towards the rural and poor population have been found among leaders. This is a sensitive issue for a group which is struggling to overcome the very same issue on a societal level. Throughout history, persons with disabilities have been infantilised in the same way and considered unable to voice and frame their own problems.

It is obvious that many difficulties emerge when advocating for rights in countries with repressive cultural understandings of disability and when striving to maintain an active movement in countries with vast social inequalities. India has, and Nepal soon will have, laws that have a rights-based approach, and the disability rights movements in the two countries must deal with this political context. This is not necessarily wrong, but it is important to keep in mind that this is a complex scenario where the voices of those who have the most needs also need to be heard. It is vital for the disability rights movements to create a political environment where perspectives and voices from all social categories are brought forward.

These issues need to be further researched in order to fully understand the implications and effects that these tendencies have. How can needs be met in a socio-political context that is so riddled with inequalities, and when the needs differ to such a large extent? How can an inclusive and more dynamic disability rights movement be developed? If social inclusion of persons with disabilities is to be realised, all persons with disabilities need to be heard, including those who struggle to articulate their needs.

ACKNOWLEDGEMENT

The author would like to thank the informants who spared their valuable time to answer questions. He is also grateful to Abby Peterson, Nandini Ghosh, and the review board for their insightful comments.

REFERENCES


Academic Challenges of Students with Hearing Impairment (SHIs) in Ghana

Efua Esaaba Mantey Agyire-Tettey, Marigold Cobbina, Emma Seyram Hemanoo

ABSTRACT

Purpose: Several researches have showed that the average academic performances of students with hearing impairment (SHIs) are below that of hearing students. This research sought to elucidate challenges that prevent SHIs from high academic achievements, using the case of students in Tetteh Ocloc State School for the Deaf in the Greater Accra Region of Ghana.

Method: A qualitative research design was used for data collection through in-depth interviews, analysis and the interpretation of the responses of thirty participants (12 Students with hearing impairments, 11 parents and 7 special educators).

Results: Findings showed that challenges which hinder SHIs academic performance emanate from different systems and actors including SHIs themselves, their parents and other institutional barriers that exist in deaf education. The findings also indicated that parents influenced the academic performance of their children with hearing impairment (CHI) through their responsibilities, expectations and the learning assistance they gave to their wards at home. Results also established that institutional barriers such as effective instructional procedures adopted in deaf education, availability of facilities, teaching, reading learning materials, and curricular contents posed challenges to the academic performance of students with hearing impairment.

Conclusion: The identified challenges which prevent SHIs from higher academic performance are from different systems of SHIs’ environment and the interplay between them. The study recommends that interventions must be directed at the different systems within their environment.

Keywords: Disability; academic performance; education.

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INTRODUCTION

All over the world, people living with disabilities are recognized as a group of vulnerable people. Disability is described as impairment in the human body structure or function, activity limitations, and participation restrictions (WHO & World Bank, 2011). A significant 15% of the world's population lives with various forms of disability, out of which 360 million persons have hearing impairment of all kinds with a ratio of 91% adults and 9% children (WHO & World Bank, 2011). Persons with hearing impairment are mostly categorised as deaf of hard of hearing (D/HH) based on the severity of their hearing loss which might be permanent or fluctuating and may range from mild hearing loss to profound deafness (Shemesh, 2010). Hearing loss is however, the loss in the ability to hear only 25 or less decibels of sound (Duthey 2013; Alberta Education, 2004; Shemesh, 2010). According to the 2010 Housing and population census in Ghana, persons with hearing loss are about 211,712 out of a total population of 678,877 persons living with disabilities in Ghana (Nyarko, 2013). Forty-two population-based studies worldwide estimate that hearing loss among children is greater in Sub-Saharan Africa as compared to other parts of the world (WHO 2012). There are special programmes and welfare services such as healthcare and education offered to enhance the social functioning of children with hearing impairment (CHI) in societies all over the world (DADHC, 2001). These services are enshrined in various international conventions and national laws such as: the United Nations Convention on the rights of PWDs, the Ghanaian PWD Act 2006 (Act 715) and the Ghanaian Children’s Act 1998 (Act 560).

The provision of education as a social welfare service serves as an effort to ensure that the hearing impaired do not feel limited in terms of privileges and opportunities to become productive, employable and have successful and independent future. Kyere (2009) states that education is a tool to empower the hearing impaired to lead an independent life. Empowerment through education begins at the basic level where skills and essential knowledge are acquired through taught programs in aid of preparing students for a higher level of education (Oduro, 2000). Progress from one level of education to another is dependent on the student's academic performance. As a result, there is a greater need to emphasize the academic performance of all students, including SHIs.

In line with Kyere (2009), Aidoo (2011) found that, there are more than two thousand students enrolled in various deaf schools in Ghana. Institutionally, there are ten basic and two Senior High Schools dedicated to the education of Students...
with Hearing impairment (SHIs) in Ghana. Students with hearing impairment (SHIs) which is used interchangeably with deaf or hard of hearing (D/HH) in this study are described as students within an educational setting who have been diagnosed with hearing loss. In Ghana, the academic performance of SHIs at the basic level of education is tested through teacher/continuous assessment and external examinations such as Basic Education Certificate Examination (BECE) (Hayford, 2007). The results from these assessments are used to promote SHIs to the next level of their education. Results from such assessment tests have been analyzed in several researches to come up with conclusions about the general academic performance of SHIs. Aidoo (2011) found out that in the 2006/2007 academic year, only a small number of SHIs in Ghanaian deaf schools were able to pass BECE well enough to gain admission into senior high school. Five consecutive BECE results of Tetteh Ocloo State School for the Deaf (TOSSD) show unsatisfactory results even though they presented only 135 candidates from 2009-2015. From five (5) TOSSD Ghana Education Service (GES) Analysis Forms, only 5.93% and 6.67% students from the school graduated with Aggregates 13-16 and 17-19 respectively. Majority of the students, thus 9.63% and 77.78% attained Aggregates 20-24 and 25+ respectively (TOSSD GES Analysis Form, 2009; 2011; 2012; 2013; 2014; 2015). This poor performance of the students provides evidence of challenges preventing them from obtaining good results in their BECE. These challenges, which serve as access barriers to good academic performance, may come from the students themselves, their parents, society, and the school in which their education occur (Marschark et al 2001; Szymanski et al, 2013). Consequently, because of the small number of SHIs climbing the educational ladder, there is a general misconception among some teachers, parents and lay persons that hearing loss is interrelated to lack of intelligence which prevents them from higher academic achievement (Vernon, 2005).

Vernon (2005) asserted that in total, there are about 50 comparative researches on the knowledge of SHIs. Results from these researches show that the academic performance of SHIs is below satisfactory levels (Qi & Mitchell, 2012). It is also evident that the SHIs in Ghana and across Africa have low academic performance, (Dogoe-Torsu, 2011; Ikonta and Maduekwe, 2005).

Studies in Western English speaking countries have shown poor academic performance of SHIs in subjects such as English and Mathematics assessment tests (Trybus and Karchemer 1977 Powers, 2003; Qi & Mitchell, 2012). Also, most SHIs in African countries such as Kenya, Tanzania, Zambia, Uganda, Malawi,
Namibia and Democratic Republic of Congo and Ghana leave “school around the 10th grade (EQUIP3 / Youth Trust, 2006: 2). Studies conducted in Nigeria further highlights the fact that there is poor academic performance among the deaf or hard of hearing (D/HH) especially in English language as compared to their hearing mates (Ikonta and Maduekwe, 2005). Poor performance in English Language is likely to affect their performance in other core subject such as Science, Social Studies and also Mathematics since these subjects are taught, written and read in English.

The poor academic performance of SHIs can be attributed to the challenges which they face in their education. A number of studies have proven that without the consideration of language as test base or the existence of multiple handicaps, there is no distinct dissimilarity between the intelligence of SHIs and that of their hearing mates; yet, SHIs perform poorer than their hearing mates in assessment tests (Drever & Collins, 1926; Vernon, 2005). Such distinct challenges of SHIs are caused by both direct and indirect factors. The low academic achievement of D/HH students is, therefore, associated with a complex group of factors which relate to the students themselves, their families, and various educational institutions (Melander, 2008; Aidoo, 2011; Obosu et al, 2013; Marschark et al, 2015).

Since there is limited literature and research on the challenges of the academic performance of SHIs in Ghana especially at the basic level of education, this research sought to contribute to the body of knowledge by investigating the various challenges affecting the academic performance of SHIs in order to help various stakeholders come up with effective strategies to improve their performance in assessment tests.

The study thus aimed at identifying the major challenges hindering the academic achievement of D/HH students in the Tetteh Ocloo State School for the deaf (TOSSD). Specifically, the study focused on the personal characteristics of SHIs which affect their own academic performance, parental influence on the academic performance of their D/HH child and institutional barriers to the academic performance of SHIs. Students with hearing impairment (SHIs) which is used interchangeably with deaf or hard of hearing (D/HH) in this study are described as students within an educational setting who have been diagnosed with hearing loss.

Theoretical Framework

This research adopted the ecological systems theory propounded by Urie Bronfenbrenner (1917-2005). The ecological/bio-ecological theory was used to
guide the study as well as the basis for the interpretation of data as it categorised the factors and explained how the challenges from these factors affect the academic achievement of SHIs.

According to the theory, children develop within multiple social systems that influence every aspect of their lives including education. Elements within the various systems potentially influence the self-efficacy and educational outcomes of children with disabilities. Bronfenbrenner argues that various immediate and distant forces affect an individual’s development. He classified these systems into five; namely, the **microsystems, mesosystems, exosystems, macrosystems, and chronosystems** in which the first four interact with or are linked together in a system of nested, interdependent and dynamic structures ranging from the proximal, consisting of immediate face-to-face settings, to the most distal, comprising broader social contexts such as classes and culture (Bronfenbrenner 1993). He believes that development involves a reciprocal and dynamic relationship between all these five systems, in which each developing person is significantly affected by interactions between numbers of overlapping systems.

The microsystem consists of interpersonal relationships and pattern of activities as experienced by an individual in a given society of specific physical and material features (Bronfenbrenner, 1995). This layer has direct contact with the individual as it contains structures, relationships and interactions within the person’s immediate environment (such as family, school and neighbourhood) and therefore has the most influence on the individual (Berk 2000; Paquette & Ryan 2001).

The mesosystem directly affects the child and is within the child’s immediate environment characterised by direct relationships and interactions. For instance, the teacher in the classroom plays a very important role in the school system since he/she is one of the key persons who can help SHIs. Allodi (2000) noted this when he studied the interaction between psychosocial aspects and teachers’ attitudes. The study showed that the teacher’s attitude has an effect on the climate in the classroom with respect to pupils learning. Again, it came out that children achieve more in an academic environment where they feel happy since the classroom environment is controlled directly by the teacher. More so, the teacher is seen as a role model upholding the values and standards of education hence children modeling his/her behaviour. In addition, the teacher takes the central role in the management and support of the education of children with disabilities.
Further, according to Donald et al (2001), what happens at home and amongst the peers can influence the learner’s reactions in school. These interactions have a notable influence on adopted teaching practices. Berk (2001) also stated that in the case of children with disabilities, their self-efficacy and educational outcomes are in the first instance influenced by the family in the home setting as beliefs and practices of these primary people in the child’s life have a direct bearing on the child’s development.

Beyond the micro and mesosystem, is the exosystem. Bronfenbrenner explains it to be consisting of the settings or events that do not directly involve the child but still influence the people the child has proximal relationships with in the microsystems. That is, the indirect effect impacts the child through the other people in the child’s life. For example, if there is financial crisis in a country, it affects the child’s parents who may not be able to meet the needs of the family. There will be stress on the family due to financial insecurity. Within this study, these settings or events can be identified as school policies, interactions between the school, community and other stakeholders such as the parents, counselors and other professionals. Even though there is no direct involvement of the child and teacher in these interactions or decision making processes, it has impact on them because as noted by Bronfenbrenner (1995), it could affect children’s academic performance due to its direct contact with the component of their microsystem.

The macrosystem refers to the layer which comprises of political, social, economic and cultural patterns which has great influence throughout the interactions of all other layers. It may be thought of as a societal blueprint for a particular culture, or a broader social context. For example, the constitution of Ghana serves as a blueprint and makes provision for operations of all educational institutions in Ghana. The constitution guarantees equal access to and a non-discriminatory attitude towards education for all learners. Thus from the ecological perspective, the constitution of Ghana influences the operations of all the other systems within the ecosystem (microsystem, exosystem, meosystem and the macrosystem). This suggests that a broader policy change in the educational system affects other layers in the ecosystem and the application of policies developed has an influence on the practice and management of inclusive education. The macrosystem is out of reach of the children but has an influence on them (Paquette & Ryan, 2001). It looks at policy makers, educational policies, beliefs and perceptions of persons with disabilities by community members. These inclinations set the context for the kind of education they receive which could affect the academic performance...
of SHIs. For instance, according to Melander (2008), “The negative stereotypes and attitudes the majority of hearing people in Ghana have towards deaf people produce inequalities in education that contribute to lower school performance levels” (p.2).

The last system is the chronosystem, which describes the time frame of development. Swart and Pettipher (2005) describe it as a developmental time frame that crosses through and affects interaction between systems and in turn, their influences on individual development. It is through the interaction among any of the above levels that barriers or support may be present at any time. They further suggested that a change in any part of the system affects other systems and individuals and at a later time could be seen as a cause for change. Elements within this system can be either external, such as the timing of a parent’s death; or internal, such as the physiological changes that occur with the ageing of a child…” (Paquette & Ryan, 2001). This means that the age of onset and detection of hearing loss and even the time made available for studies (which constitute the chronosystem of SHIs) can influence their academic performance.

It is worth noting that all these different layers or systems are highly dynamic and interactive. To understand the activities of a school, one needs to get insight into and knowledge of the interactions that occur amongst the different systems. This is important especially when one is trying to understand an educational system. This means that when a change occurs in one part of the system, it affects the entire system and thereby impacts educational practice. For example, when there is a change in the school management system, it affects all those that interact within it. Bronfenbrenner believes that development is reciprocal and has dynamic relationships between the five systems. Likewise, individual development is affected by interaction between a number of overlapping systems thus describing the complexity of the influences, interactions and interrelations between a learner and all the systems in which the learner functions.

AIMS AND OBJECTIVES

The study aimed at identifying the major challenges hindering the academic achievement of D/HH students in the Tetteh Ocloo State School for the deaf (TOSSD). Specifically, the study focused on

- the personal characteristics of SHIs which affect their own academic performance
• parental influence on the academic performance of their D/HH child and
• institutional barriers to the academic performance of SHIs.

METHOD

A qualitative research design was adopted because it helped to provide a rich description of the phenomenon under study. Also, the study focused on interpreting phenomenon in their natural setting to bring meaning in their own uniqueness (Boateng, 2014). Moreover, qualitative design is more appropriate for this research than quantitative design because attitudes and perceptions cannot be quantified (Mazooue, 2011). This study aims to explore the challenges that prevent high academic performance among SHIs.

The study was carried out at Tetteh Ocloo State School for the Deaf (TOSSD) in Adjei Kojo; a suburb of Greater Accra Region. TOSSD was selected for the study because every student in the school has some form of hearing loss and thus, were either Deaf or Hard of Hearing (D/HH). This made it an ideal location to select participants for the study. Again, it is the only basic school for SHIs in Greater Accra region which is mandated to partake in the Basic Education Certificate Examination (BECE). The study population was Junior High SHI, teachers and parents of SHIs from the Tetteh Ocloo State School for the Deaf.

The study adopted purposive sampling approach in selecting the participants. Using purposive sampling, JHS students who had low, average and high academic performance were all purposively selected from each JHS class. Purposive sampling was also used in selecting (four) 4 core subject teachers in the JHS (Mathematics, Integrated Science, English language and Social Studies). These teachers were chosen because the scores of the subjects they are teaching are among the subjects used to determine the grading of BECE results. Apart from the core teachers, the headmistress, Basic Design Technology and ICT teachers were also included.

A total of thirty participants were selected for the study. The participants included 12 SHIs, 7 special educators and 11 parents. One of the special educators selected was a guardian to one of the student participants. As a result, there were 11 parents instead of the intended 12 parents.

Prior to the gathering of information, verbal consent was sought from each participant and this was followed by written consent. Informed consent was
obtained from the parents on behalf of their children and the children also accepted to be part of the study. A face to face in-depth interview approach was utilized for the data collection. A sign language interpreter was used throughout the interview sessions with SHIs due to the researchers’ limited skills in sign language. All interviews with parents and teachers were held in English and Twi. Twi is the dominant Ghanaian local language and it was used when necessary because not all hearing participants were fluent in English. The questions that directed the interviews were open-ended questions which allowed participants and the researcher to discuss their experiences freely and in detail. Interviews with hearing participants lasted approximately 30 minutes. However, sessions held with participants with hearing loss lasted between 35 and 50 minutes due to the interpretations. An audio recorder was used throughout the interview sessions with permission from participants.

Data collected was analysed thematically. It began with the transcription of collected data. All the transcribed data were read through thoroughly to identify the flow of information and themes that emerged. Since this study had different categories of research participants, all transcripts were carefully read and the information extracted from each was categorised under broad themes based on the objectives of the research. The analysis was guided by both the analytical tool and the theoretical framework underpinning the study. It involved interpreting and making meaning of the data collected. The six steps proposed in Creswell (2009) were adopted in the data analysis. Firstly, data collected in notes and through recordings were transcribed into word documents. Pseudonyms were given to all respondents instead of their real names during transcription. This was followed by data familiarization by thorough reading of the data collected over and over. Codes were then generated and given to similar responses from which themes were developed afterwards.

RESULTS AND DISCUSSION

This part is made up of four sections. The first section describes the demographic characteristics of each group of participants (parents, SHIs and teachers). In the second section, the themes that were discovered from the responses have been presented with supporting quotes from participants. The third section includes the discussions of the findings relating it to the literature reviewed and the theory used to explain the study while the fourth section concludes the paper.
Demographic Characteristics of Participants

The study included students with hearing impairments, teachers and parents. The ages of students ranges from 15-25 years. Out of the 12 SHIs participants, only 5 students lived with both parents, 6 lived with one parent and one lived alone under the guardianship of a teacher. The majority of SHIs interviewed were deaf with only 2 being hard of hearing.

The ages of the parents range from 35-61 years. Of the 11 parents interviewed, 6 were single parents. Also, all parents except one had no hearing loss. Their educational level ranged from primary to tertiary. Two had no form of education, 5 had primary education; one had completed senior High school while 2 had tertiary education. Three parents were unemployed and 5 had a low and insecure source of income. The ages of special educators who were interviewed range from 28-58 years with the majority being between 41-58 years. Four teachers had first degree in special education; two had master’s degree and only one had diploma certificate in education. Their years of teaching experience in deaf education ranges from 1-17 years. 42.86% had 1-3 years of experience while the rest have 8-17 years of working experience.

Themes identified

Nine themes were generated from the responses and analyzed (Table 1) based on the broad research objectives of the study:

- the personal characteristics of SHIs which affect their own academic performance
- parental influence on the academic performance of their D/HH child and
- institutional barriers to the academic performance of SHIs.

The themes generated from the first objective include “health issues”, “reading skills and habits” and “expectations of SHIs in education”. The second research objective: Parental Influence on the Academic Performance of Their SHI, sought to find out the extent of parental influence on the academic performance of their D/HH child(ren). Three themes were generated: parental responsibilities, parents’ expectations and learning assistance made available at home. Objective three of the paper explored the institutional challenges and the themes that emerged. Three were carefully selected: effectiveness of instructional procedures adopted in deaf education; issues relating to the availability of facilities and teaching
This research was conducted to identify the major challenges that hinder the academic achievement of SHIs in Tetteh Ocloo State School for the deaf (TOSSD). Similar to Szymanski et al’s (2013) findings, this study identified several challenges which are influenced by multiple factors that prevented SHIs from excellent academic performance. From the findings, students who are hearing impaired were seen as having certain personal characteristics (health issues reading skills and habits and their own expectations in education) which contribute to some of the challenges they encounter in their education.

The health of the students was seen as one of the major factors contributing to their poor performance. Some of the students had other disabilities which made their educational problems more complex since their educational needs were not met. These health issues affected the way they learnt, their attention during class lessons, attendance in school and their ability to fully participate in or write assessment tests. As a result, they receive very low grades.

Consistent with the findings of Furth (1966), Baker (1972), and Gaustad and Kelly (2004), SHIs in TOSSD face serious challenges when it came to reading educational materials and understanding exam questions because of their poor reading skills, limited vocabulary and their inability to comprehend complex sentences and grammar. As a result of this, most SHIs were not interested in reading textbooks and other reading materials. They consider reading boring and exhaustive since they are often confused about the meaning of words and sentences in these materials. Engin-Demir (2009) and Adane (2013) found out in their study that the time students spend learning on their own has been attributed to high academic achievements; therefore, SHIs in TOSSD not being able to do this contributed to their low academic achievement. Moreover, their inability to read examination questions in order to understand the demands of each question affected the kind of scores they receive in their assessment tests.

Similar to the findings of Johnson (1989), students in TOSSD also expressed poor expectations to climb higher on the educational ladder. Most SHIs did not want to continue school after JHS or SHS mostly because they were more interested in learning a trade than continuing their education to a higher level.

Regarding parental influence, the findings of the research showed that parents have some level of influence on the academic performance of their wards in
### Table 1. Themes identified

<table>
<thead>
<tr>
<th>PERSONAL CHARACTERISTICS OF SHIs AFFECTING THEIR ACADEMIC PERFORMANCE</th>
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<tr>
<td><strong>THEMES</strong></td>
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<tr>
<td>Health</td>
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<td>Reading skills and habits</td>
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<td>Reading Skills and Habits</td>
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</table>
Expectations of SHIs in Education  | Special Educator 3 | Only a few have high expectations. Most of them do not care. After JHS they do not want to continue. They like to learn a trade than to climb the academic ladder. Only a few care and are interested in school.

Expectations of SHIs in Education  | Student 7 | I want to make aggregate 49 in BECE and I do not have any idea of what educational level I want to reach but I want to be a hairdresser when I finish JHS. So I do not think I will continue from here.

Expectations of SHIs in Education  | Student 10 | I cannot tell which grades I want to make in the BECE because I do not know if I want to work after JHS. I will make more money working than going to school so I do not want to go to SHS.

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**PARENTAL INFLUENCE ON THE ACADEMIC PERFORMANCE OF THEIR SHI**

<table>
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<tr>
<th>THEMES</th>
<th>RESPONDENTS</th>
<th>RESPONSES</th>
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<tbody>
<tr>
<td>Problems of parental responsibilities</td>
<td>Special Educator 5</td>
<td>…the problem is textbooks they will use in school. Parents do not buy the necessary textbooks…with a child who doesn’t have exercise books in the class, when you ask they will tell you their parents refused to buy the books for them. So this person will never do any whether the child understood what was taught assignments, and this affects the children in a way when the teacher wants to assess</td>
</tr>
<tr>
<td>Problems of parental responsibilities</td>
<td>Parent 5</td>
<td>One of her sisters is in SHS but their father doesn’t help me so I do everything all by myself, I try to help her in her education. Sometimes when I am unable to provide for her education, I try to sit her down and explain everything to her. Hmm, you see when I have money problems, it sometimes doesn’t let me perform some of the responsibilities I am supposed to very well</td>
</tr>
<tr>
<td>Learning Assistance at Home</td>
<td>Parent 5</td>
<td>…because I couldn’t continue school, I cannot teach her or assist her learning. Her sister could have helped however she is unable to assist her well because she cannot also sign very well. But what she does is that she writes the answers of the homework so that she copies without any explanation</td>
</tr>
<tr>
<td>Learning Assistance at Home</td>
<td>Student 11</td>
<td>I am unable to do my homework at home because I am not taught by anyone. Sometimes, the work is too difficult so I copy from my friends at school… no one in my family can sign so they talk and because my mother did not go to school, she cannot read to help me with my homework.</td>
</tr>
<tr>
<td>Learning Assistance at Home</td>
<td>Special Educator 6</td>
<td>Everything they learn is from the classroom without any additional help from home. Whatever the teachers teach, it ends when they leave the school to the house… To get somebody to assist them at home is very difficult. Most of the people at home are not conversant with the sign language so it becomes a problem to help even if they can.</td>
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<tr>
<td>Parental Expectations of their SHIs.</td>
<td>Parent 4</td>
<td>…comparing the salary I receive and the expenses I make on her, it is just by God’s grace. Her father is not around so everything is on me. Therefore, I will not get the money all the time for her to continue her education… I have a machine at home and she likes sewing, and she also like hair dressing. So after school she will choose one of them.</td>
</tr>
<tr>
<td>Parental Expectations of their SHIs.</td>
<td>Parent 3</td>
<td>Personally I do not think my child can go to the secondary school because of the condition in which she finds herself. Also, she is not doing too well in school. Mostly, she comes almost last in class.</td>
</tr>
<tr>
<td>Parental Expectations of their SHIs.</td>
<td>Special Educator 2</td>
<td>some of the parents with other children without disabilities, see their education as more important than the hearing impaired child because they do not think or have hope in their children with hearing impairment. Due to that, most parents shift their attention to their children without disability and divert most of their resources in educating them to the highest level.</td>
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**INSTITUTIONAL BARRIERS IN DEAF EDUCATION.**

<table>
<thead>
<tr>
<th>THEMES</th>
<th>RESPONDENTS</th>
<th>RESPONSES</th>
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<tbody>
<tr>
<td>Effectiveness of Instructional Procedures</td>
<td>Special Educator 3</td>
<td>…because the person can’t hear what you tell him/her, and you know in sign language we do not have signs for individual words, about 10 words will have one sign, so it is difficult to explain some concepts to them. And because</td>
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</tbody>
</table>
we also went to school and learnt the language, we are not perfect so we find it very difficult to explain to the person to get it very well in order to understand and answer whenever you ask a question.

<table>
<thead>
<tr>
<th>Effectiveness of Instructional Procedures</th>
<th>Special Educator 5</th>
<th>… if you have a fewer number, you will be able to take care of them. For example, if you have 8 students you will use some time to guide them and to explain the topic and use another time to go around and see what they are doing. But if they are 30, by the time I finish and I start teaching them the time is already up. So if the class is small it will help them.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness of Instructional Procedures</td>
<td>Student 8</td>
<td>The teachers normally use difficult words that do not make me understand and that worries me… for instance, we were taught in class but we all did not understand it so the whole class had it wrong. The teacher used speech, she concentrated on the speech more than the signing since she is not really good at signing and we are deaf so we didn’t get what she was saying as we did not get the explanation.</td>
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<tr>
<td>Availability of Facilities and Teaching Materials</td>
<td>Student 9</td>
<td>…if we have a well-furnished library and if I stay in school and the teacher stays in school, I will be able to go to a teacher for better explanation and to understand the concept more. In all, I want to say we need a teacher’s bungalow and a boarding facility. Because if we go home, we are unable to learn because we are too tired to and there is hardly anyone to help.</td>
</tr>
<tr>
<td>Availability of Facilities and Teaching Materials</td>
<td>Parent 1</td>
<td>…They need a boarding house because my children are always complaining about how tired they are and therefore can’t learn when I tell them to. My house and the school is a long distance. They have to wake up early in the morning mostly feeling sleepy and have to prepare for school only to come home very tired.</td>
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<tr>
<td>Availability of Facilities and Teaching Materials</td>
<td>Special Educator 7</td>
<td>Where teachers need the Teaching and Learning Material and it is not available, they then teach in abstract, and the children find it difficult to understand lessons that way…The funds from the government are not regular.</td>
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</tbody>
</table>
and are inadequate too. As I am talking to you, we are in the 7th week and the funding is not in, it’s only the donations made by philanthropists that we depend on for the materials.

| Contents of Curricula and Reading Materials | Special Educator 1 | ...for a topic, you have to break it into smaller units for them. So now, the maximum topics can be 2 or 3 topic in a term instead of 5 or 6. Let’s say if he takes one topic, I can break it into three topics throughout the term… the syllabus itself and the topics are many, the syllabus has three objectives per term, but for them, I can only set one objective for them so they are unable to complete it before BECE |
| Contents of Curricula and Reading Materials | Student 1 | Lessons are confusing and sometimes we get confused with some of the topics. I do not understand the wording. Literature, for example, is for the hearing not the deaf. Because of this, I do not understand the questions or know the answers to them … Also I am unable to read often because it is boring. The words in the books are difficult when you want to learn on your own. |
| Contents of Curricula and Reading Materials | Special Educator 3 | ...because the person can’t hear what you tell him, and you know in sign language we do not have signs for individual words, about 10 words will have one sign, so it is difficult to explain some concepts to them. In our training, instructors use more of normal way of teaching than the sign language, so we graduate with less skills in the sign language and mostly no special teaching method for the deaf. |
| Contents of Curricula and Reading Materials | Student 2 | The reading material is inadequate, we have to share text books and at times it is difficult to concentrate if you we share because we end up chatting with another. By the time the teacher finishes teaching, we have learnt nothing |
| Contents of Curricula and Reading Materials | Parent 2 | I realized that the curricula do not meet the needs of my child because it is like using the curricula for the children who can hear and my child tells me often he does not understand when he uses the text book |
TOSSD. This supports research works of Cohen (1997) Luckner and Muir (2001) Reed (2008) Adane (2013) who also found a significant relationship between parents and the academic performance of their wards. The involvement of most parents in the education of their wards in TOSSD was relatively low; this was as a result of their inability to perform their responsibilities adequately. That is, the limited learning assistance they made available to their wards and the low expectations they had regarding the education of their children in TOSSD.

The inability of some parents to perform certain parental responsibilities towards their wards’ education seems to be one of the challenges that hinder the academic performance of SHIs in TOSSD. Parents with low income jobs posited their inability to pay for exams fees, buy educational materials (books, and pens, mathematical set) and other required items needed. Some SHIs confirmed that their parents’ inability to provide their educational needs did not help them perform well in various tests. However, these parents, especially the single mothers, stated that their inability to provide such needs is because of their low income and the financial burden they carry. From the ecological theory, using the concept of the exosystem, though actors from SHIs microsystem (parents) were experiencing financial burden, it still affected SHIs academics. The inability of such parents to provide the required materials for their wards prevented these students from improving their academic performance. The children are not able to partake in class exercises and homework as well as get access to the reading materials they need in school. Again, participant responses revealed that SHIs had limited learning assistance when they got home after school. Similar to the findings of Reed et al (2008), this research also indicated that one challenge causing the poor academic performance of SHIs was parents’ inability to assist them in doing homework and studying. The main reason for this was because of the low educational level of most parents and the communication barriers between them and their wards in the school. As supported by the findings of Cohen (1997) and Thou (2014), some parents are not able to assist their wards because they have low level of education and do not have the knowledge about school work and could therefore be of no assistance to their children. However, in situations where SHIs were helped with their homework, there were no explanations to it due to the parents’ inability to sign. This communication barrier rendered parents who could have assisted their wards in their studies, incapable of doing so. Zwiebel (1987) and Calderon’s (2003) findings support this research and noted that the signing skills of parents do have a part to play in their wards’ academic performance. Apart from the SHIs with deaf parents, all students in TOSSD faced this challenge at
home and because the number of SHIs with deaf parents is small, it is expected that majority of SHIs would have no form of learning assistance and this hinders their academic performance (Marschark et al, 2015; Mitchelle and Karchmer, 2004). 

Besides, parents of SHIs do not want their wards to continue education due to their low expectations for them to move further in education. Congruent with the ecological theory, the macrosystem of SHIs, which comprises the beliefs and expectation of parents, has negative implications on SHIs academic performance. According to Reed (2008), one variable that facilitates the academic success of SHIs is parental expectation of their CHIs. However, this important ingredient in facilitating academic achievement was missing in the responses given by participants. Even though some parents had hearing children in secondary schools and tertiary institutions, they wanted their hearing impaired children to learn a vocation, trade or sports right after JHS. Parents with such expectations are reluctant and have less determination to perform roles which will help increase the academic achievement of their wards. This neither motivated nor encouraged high expectations in SHI themselves. Consistent with the ecological theory, as explained by Berk (2000) and Paquette & Ryan (2001) because parents are one of the actors of SHIs’ microsystem, the challenges which emanate from them have great impact or influence on their wards’ academic performance in TOSSD. Therefore, a strong relationship exists between the expectations of parents and how well their wards perform and how far their CHIs can climb the academic ladder. Consequently, parental motivation is very critical in the academic progress of their wards.

Evidence also showed that the school (TOSSD) and other institutions involved in the education of the D/HH have contributed to the challenges facing SHIs in their academic performance. Some of the institutional barriers barring SHIs from higher academic performance were identified as: ineffective instructional procedures adopted in deaf education, challenging syllabi and reading materials and lastly, inadequate materials and facilities in the school. The findings of this study are in agreement with Woolsey et al’s (2004) as it also identified that due to the ineffectiveness of institutional methods adopted by special educators, most students complained of not understanding lessons taught in class. Teachers in TOSSD confessed that the large numbers of students in the classroom did not permit them to pay attention to each individual student’s SEN adequately. According to Powers (2003), the ideal number of D/HH students in a class is 10;
however, the numbers of SHIs in most of TOSSD classrooms ranges from 20 to 30. Limited lesson time is identified as a cause for the inability to attend to each individual student in such a large class. As a result, students especially those with severe additional disabilities are not given any special attention because of the number of students per teacher. Also, teachers are unable to attend to each student’s educational needs after the class. Hence, majority of the students are unable to benefit from lessons taught. Again, consistent with the observation made by Melander (2008) in some deaf schools, most special educators in TOSSD were also not fluent in sign language because they learnt the sign language at the tertiary level of their education. Even though all the teachers in TOSSD are qualified special educators and knowledgeable in the subjects they teach, they are unable to express themselves well in sign language for students to understand.

Further, the contents of syllabi and reading materials used in the school did not help meet the special education needs of students thereby creating a challenge for students to excel in assessment tests. Curricula contents and textbooks used in deaf education are the same as those used in the regular schools and therefore does not consider the needs of SHIs (Aidoo, 2011; Kyere, 2009). SHIs do not learn at the same pace as their hearing colleagues according to most participants; TOSSD, therefore, has an additional level in the JHS department (JHS4) to enable teachers to complete the syllabi before presenting candidates for BECE. The curricula are bulky and most teachers are unable to cover every topic in them before BECE. Also, SHIs are unable to make sense out of the contents of textbooks used in their school; this finding is consistent with that of Aidoo (2011). The textbooks used by SHIs contain complex sentences and words which students in TOSSD find difficult to understand or read. The authors of such textbooks do not take into consideration the learning needs of SHIs. Some topics in subjects such as English language and Science are too complex for SHIs to relate with or conceptualize, therefore impairing their performance in these subjects.

Inadequate facilities such as boarding houses to accommodate students living far was one of the major barriers which hindered the academic performance of students in the school. TOSSD is the only deaf school in the whole of Greater Accra region. As a result, SHIs come from all over the region to attend the school. From the ecological theory, the mesosystem, which in this case is the distance between their homes and the school, affects their academic performance in that the boarding facilities which could have curtailed the problem of distance are not in existence. The lack of these facilities affects their learning and prevents them
from getting extra help from teachers as other SHIs from several residential deaf schools. The absence of facilities such as a scientific laboratory and a working vocational workshop for practical Science and Basic Design and technology (BDT) lessons contributed to the inability of students to perform well in science and BDT. From several literatures and responses, SHIs benefit more from visual and practical lessons in their education (Kyere, 2009). The unavailability of these facilities and Teaching and Learning Materials (TLM) made students in TOSSD learn in abstract. This, therefore, did not help them to fully understand and retain lessons taught in class in order to reproduce the right answers during assessment tests.

Relating to the findings of inadequate facilities and institutional barrier to the ecological theory, it can be said that the exosystem of the ecological theory influenced the academic performance of the SHIs. Even though certain institutions within deaf education had no direct contact with SHIs, because of their contact with the school, they indirectly created barriers to their academic performance. For example, irregular funding from government to purchase TLMs and their inability to build the needed facilities within the school does not foster effective teaching and learning; thereby posing a challenge to the academic performance of SHIs. Within the macrosystem, policies guiding instructional methods and curricula used in deaf education were discovered to be inadequate. Just as opined by Nortey (2009) and Obosu et al (2013), policies used in deaf education are inadequate to ensure that the D/HH student benefited from their education.

CONCLUSION AND RECOMMENDATIONS

Evidently, the long standing assertion about SHIs having low academic performance as reflected in their examination results remained important to this research. From the responses given by participants, it was discovered that challenges which affect SHIs’ academic performance are neither from one source nor do they exist in isolation. They rather emanate from different systems and actors which includes SHIs themselves, their parents and institutional barriers that exist in deaf education. An aspect of SHIs which was identified as contributing negatively to their academic performance included their health issues such as their hearing loss and other forms of impairments; their reading and learning habits; and their expectations in excelling in education. Also, parental involvement in their children’s education was low due to their low expectation of their children’s education. In addition, some institutional barriers such as ineffective instructional
methods, inadequate reading and teaching materials, facilities and rigid syllabi contents did not enable SHIs to excel in their academics.

Any intervention towards tackling the various challenges has to be directed at the different systems within SHIs’ environment. For instance, the use of more effective instructional methods which may include special educators putting greater emphasis on visual and practical lessons that involve more demonstrations and pictorial materials. Government must provide teaching and learning materials and the necessary facilities such as workshops and laboratories to make practical and visual learning possible in deaf schools. In addition, early interventions to enhance SHIs’ academic capabilities must be adopted at an early school age in order to enhance their effectiveness. Early enrollment of SHIs into deaf schools or an educational setting created to meet the special education needs of SHIs will help improve their reading, vocabulary, reasoning ability and skills which will positively affect their academic achievements as they progress.

Finally, to create effective educational policies for deaf education, GES and the Ministry of education must collaborate with experienced special educators to create a comprehensive educational policy specially made to cater for the learning needs of SHIs. The policies must seek to provide the appropriate approach to teaching SHIs in various school settings which will see to a uniform communication mode. This should also create an effective approach that will help meet the special education needs of SHIs through reviewing and changing the syllabi and providing a standardized testing procedures and reading materials to meet the special needs of SHIs.

REFERENCES


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.

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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.

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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.

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