Disability, CBR and Inclusive Development
Formerly Asia Pacific Disability Rehabilitation Journal

Volume 29 ▇ No. 1 ▇ 2018

Contents

EDITORIAL

Maya Thomas .................................................................................................................. 3

ORIGINAL RESEARCH

Anticipated Barriers to Implementation of Community-Based Rehabilitation in Ribeirão Preto, Brazil
Regina Celia Fiorati, Regina Y Dakuzaku Carretta, Karine Pereira Joaquim,
Aline Ferreira Placeres, Tiago Silva Jesus ........................................................................... 5

Parental Perceptions, Attitudes and Involvement in Interventions for Autism Spectrum Disorders in Sarawak, Malaysia
Jing Xin Teo, Bee Theng Lau ............................................................................................. 26

Utilisation and Satisfaction with Health Services among Persons with Disabilities in Accra, Ghana
Annang Yemosen Abraham, Peter Agyei-Baffour, Cosmos Yarfi ........................................ 47

BRIEF REPORTS

Predictors in the Selection of an AAC system: An Evidence-based Report on Overcoming Challenges
Sita Sreekumar, Suja K Kunnullath, Vineetha Sara Philip ................................................. 60

Negotiating Future Uncertainty: Concerns of Mothers of Children with Down Syndrome in Kashmir, India
Bilal Ahmad Khan, Wakar Amin Zargar, Shabir Ahmad Najar ........................................... 67

Competencies of Students with Visual Impairment in using the White Cane in their Learning Environment: a Case Study at Wenchi Senior High in Ghana
Frank Twum, Wisdom Kwadwo Mpah, Anthony Kwaku Edusei, Joseph Ampratwum,
Isaac Adu Gyamfi ............................................................................................................. 78

Teacher Trainees’ Perceptions of Inclusion of and its Challenges
Krishna Duhan, Chandrika Devarakonda .............................................................................. 93

LETTER TO THE EDITOR

Concern about citation and misrepresentation of our work in recent publication
Paula Jacobs ................................................................................................................... 104
Disability, CBR and Inclusive Development
Formerly Asia Pacific Disability Rehabilitation Journal

CONTENTS

EDITORIAL

Maya Thomas ................................................................................................................................. 3

ORIGINAL RESEARCH

Anticipated Barriers to Implementation of Community-Based Rehabilitation in Ribeirão Preto, Brazil
Regina Celia Fiorati, Regina Y Dakuzaku Carretta, Karine Pereira Joaquim,
Aline Ferreira Placeres, Tiago Silva Jesus ...................................................................................... 5

Parental Perceptions, Attitudes and Involvement in Interventions for Autism Spectrum Disorders in Sarawak, Malaysia
Jing Xin Teo, Bee Theng Lau .......................................................................................................... 26

Utilisation and Satisfaction with Health Services among Persons with Disabilities in Accra, Ghana
Annang Yemoson Abraham, Peter Agyei-Baffour, Cosmos Yarfi .............................................. 47
BRIEF REPORTS

Predictors in the Selection of an AAC system: An Evidence-based Report on Overcoming Challenges
Sita Sreekumar, Suja K Kunnath, Vineetha Sara Philip ..................................................... 60

Negotiating Future Uncertainty: Concerns of Mothers of Children with Down Syndrome in Kashmir, India
Bilal Ahmad Khan, Wakar Amin Zargar, Shabir Ahmad Najar ........................................ 67

Competencies of Students with Visual Impairment in using the White Cane in their Learning Environment: a Case Study at Wenchi Senior High in Ghana
Frank Twum, Wisdom Kwadwo Mprah, Anthony Kwaku Edusei, Joseph Ampratwum, Isaac Adu Gyamfi ................................................................. 78

Teacher Trainees’ Perceptions of Inclusion of and its Challenges
Krishna Duhan, Chandrika Devarakonda ................................................................. 93

LETTER TO THE EDITOR

Concern about citation and misrepresentation of our work in recent publication
Paula Jacobs ............................................................................................................... 104
The Global Disability Action Plan (2014-2021) of World Health Organisation calls for the strengthening of community-based rehabilitation (CBR) through monitoring and evaluation. The subject of CBR evaluation has been under discussion and debate since the early 1990s and the need for indicators to measure the effectiveness of CBR programmes has been well documented since then. In the last few years, interest in CBR evaluation and indicators gained fresh impetus with the publication of the CBR Guidelines.

One of the difficulties with CBR evaluation is the development of indicators that are applicable and acceptable to the wide range of stakeholders involved in implementation in various countries, who may have differing programme philosophies and aims, along with different structure and organization of activities. In the early years, CBR tended to be poorly defined, leading to widely varying understanding and interpretation of its aims and activities. Much of the early efforts on monitoring and evaluation also tended to be based on individual donor priorities. Health programmes like malaria or TB control that are implemented in the same way in different parts of the world can use the same set of indicators in evaluation, enabling comparison between programmes. In the case of CBR however, this may not be easily achieved because CBR is multi-dimensional, multi-sectoral, culture-dependent and involves multiple stakeholders.

The CBR Guidelines have helped substantially to move towards a more unified understanding of CBR concepts and practice, guided by the principles of the UN CRPD. CBR has ‘come of age’ now, and with this, there are calls for more ‘standardised’ ways of evaluating CBR in order to prove its effectiveness, improve implementation on the ground and convince policy makers and donors about the need for continued support for such programmes.

Over the last 2-3 years, different groups have come out with frameworks for monitoring and evaluation of CBR, based on the framework of the CBR Matrix.

The Monitoring Manual and Menu (MM&M) from the University of Sydney, Australia, provide information on how to develop or improve monitoring. The Menu contains information items organised into four broad groups: Person - personal profile and history, functioning and disability, environmental factors, and outcomes; Organisation - purpose, structure and strategy, resources, environment, and outcomes; Activities - what is done, and outcomes; and Workforce - personal profile of staff, knowledge and skills, responsibilities and

Participatory Inclusion Evaluation (PIE) is developed by the Institute for Global Health, University College London; Enablement, Netherlands; and KIT Royal Tropical Institute, Netherlands, as a new participatory approach for evaluating outcomes and impact of CBR. PIE provides a ‘structured but flexible’ approach for collecting and analysing information about the changes that CBR has made on the lives of people with disabilities. The toolkit includes a range of tools: supports the whole evaluation process from planning; data collection to data analysis, validation and report writing. The PIE approach defines individuals and groups of players that are to be included in the impact evaluation: the CBR core team, (the team of people directly involved with the CBR programme); people with disabilities and their families/carers; and the network of strategic partners who are service providers or other organisations and groups working closely with the CBR Core team or other key community stakeholders. (www.ucl.ac.uk/igh/research/a-z/related-docs-images/pie/handbook)

The WHO CBR Indicators manual contains outcome indicators to capture the situation of people with disability who live in a community where CBR is implemented. It provides a simple guide to selecting appropriate indicators and collecting the relevant data. Additional information is also provided on how to manage this data, including calculating percentages, displaying results and generating meaningful conclusions. This manual is meant to standardize the monitoring of the situation of people with disability and their families, making it possible to track change over time and compare the difference CBR makes across areas and countries. (www.who.int/disabilities/cbr/cbr_indicators_manual/en/)

From programme implementers’ point of view, today there is a range of options available to guide monitoring and evaluation, including lists of indicators and toolkits. While this is advantageous in many ways, it can also lead some confusion on what option to choose. For implementers, it is important to consider that monitoring and evaluation need to be related to the aims of their programme and be able to measure the change brought about by their work. From the available frameworks, tools and indicators, implementers need to choose options that are most relevant and applicable to their own programme aims and activities.

**Maya Thomas**
Editor-in-Chief
Disability, CBR and Inclusive Development

www.dcidj.org  Vol. 29, No.1, 2018; doi 10.5463/DCID.v29i1.747
Anticipated Barriers to Implementation of Community-Based Rehabilitation in Ribeirão Preto, Brazil

Regina Celia Fiorati¹, Regina Y Dakuzaku Carretta¹, Karine Pereira Joaquim¹, Aline Ferreira Placeres², Tiago Silva Jesus³*

1. Medical School of Ribeirão Preto, University of Sao Paulo, Brazil
2. Ribeirão School of Nursing, University of Sao Paulo, Brazil
3. Institute of Hygiene and Tropical Medicine, NOVA University of Lisbon, Lisbon, Portugal

ABSTRACT

**Purpose:** Disability is a global health and a global development concern. To address both issues, a community-based rehabilitation (CBR) approach is increasingly recommended to meet a spectrum of needs, especially for people with disabilities. It is first necessary to understand the perceptions of local, frontline providers, in order to design effective measures for implementing CBR programmes. This paper aimed to understand the conceptions of Primary Healthcare Providers (PHPs) - serving a sub-urban, socially-vulnerable territory in Brazil - about: 1) disability, 2) rehabilitation, and 3) the possible local implementation of a CBR strategy, including any anticipated barriers.

**Method:** Cross-sectional, exploratory qualitative research was based on focus groups conducted between 2013 and 2016. It involved a total of 78 PHPs serving the western region of the Ribeirão Preto municipality in São Paulo, Brazil. Data analysis was based on Habermas’ critical hermeneutics approach.

**Results:** PHPs understood disability mostly within the biomedical paradigm. Similarly, the predominant conception of rehabilitation was focused on enabling individuals’ capacity, more than their environment. For local CBR implementation, the barriers that were anticipated were: 1) difficulties in managing and running action across sectors, and 2) the broader socio-political environment that hardly empowers civil society and is affected by power differentials.

**Conclusion and Implications:** While local PHPs identified important CBR implementation barriers which are contextual in nature, the predominant
conceptions of disability and rehabilitation (i.e., biomedical, impairments-based) also act as a barrier. Contextual and cognitive barriers must both be addressed when envisioning a local CBR implementation.

**Key words:** People with disabilities; rehabilitation; CBR; primary healthcare

**INTRODUCTION**

The number of people with a permanent disability is estimated as 1 billion or 15% of the world’s population (World Health Organisation and World Bank, 2011). Furthermore, prevalence has been increasing over time. For example, using data from the Global Burden of Disease Study, the World Health Organisation (WHO) reported a 23% increase in the global prevalence of health conditions associated with severe disability from 2005 to 2015 (World Health Organisation, 2017), while most of the disability “burden” is carried by middle- and low-income countries (World Health Organisation and World Bank, 2011).

In contrast with this epidemiological trend, most health systems are insufficiently equipped to respond to the needs of people with disabilities (Chatterji et al, 2015; Prince et al, 2015). In many lower-income territories, physical rehabilitation services are in short supply (Bunning et al, 2014; Wylie et al, 2016; Agho & John, 2017; Jesus et al, 2017; Krug & Cieza, 2017). Besides, in those areas, people with disabilities typically experience more financial, transportation or attitudinal barriers to access needed healthcare than people without disabilities (Mlenzana et al, 2013; Abdi et al, 2015; Neille & Penn, 2015; van Hees et al, 2015; Ganle et al, 2016; Munthali et al, 2017; Visagie et al, 2017; Vergunst et al, 2017), even though people with disabilities usually have higher health needs, higher risks of chronic and secondary health conditions, higher cost of living, and finally, lower earnings and lower employment rates (Mitra et al, 2009; Rimmer et al, 2011; World Health Organisation and World Bank, 2011; Gudlavalleti et al, 2014; Mitra et al, 2017).

Apart from health issues and determinants, people with disabilities often struggle to perform everyday activities or desired social roles due to a restricting environment (e.g., social stigma, non-inclusive legislation, inaccessible services), which prevents them from participating in society on an equal basis with others (World Health Organisation, 2001; Skempes et al, 2015). Concretely, people with disabilities often experience restrained access to education, employment, livelihood, to empowered civil society participation, as well as to a myriad of public or private services or goods, especially those not universally designed
or not designed to accommodate the special needs of people with disabilities (MacLachlan, 2009; World Health Organisation, 2010; Visagie et al, 2017).

In that context, the United Nations Convention on the Rights of Persons with Disabilities, launched in 2006, has brought the issue of the human rights of people with disabilities into international law (Durham et al, 2014; Skempes et al, 2015). Even global development policies such as the Sustainable Development Goals, are now disability-inclusive (United Nations, online) in contrast with the earlier Millennium Development Goals.

In short, beyond a global public health issue, disability is increasingly a global development concern - with equity, human rights and social justice issues.

Consideration of community-based initiatives is required to address all these issues and to meet the health, rehabilitation and societal needs of people with disabilities, especially in lower income, socially-vulnerable territories (Bunning et al, 2014; Gilmore et al, 2017).

Community-Based Rehabilitation (CBR) is a multisectoral approach working to equalise opportunities and include people with disability in all aspects of community life. It is globally recommended as a strategy for community-based inclusive development – i.e., one that empowers and actively engages people with disabilities and their families, and addresses health, education, livelihood, and empowerment issues towards ensuring an effective inclusion in society (World Health Organisation, 2010).

As of 2010, the WHO reported that CBR was implemented in over 90 countries (World Health Organisation, 2010). Besides, a recent scoping review also found that a large pool of literature on CBR was published from 2003 to 2012, with a focus on 26 countries; however, those studies were published only in the English language and, perhaps for that reason, only 1 came from the Americas (Cleaver & Nixon, 2014).

On effectiveness, a systematic review found that CBR for people with disabilities in low- and middle-income countries may be effective in improving health-based outcomes; however, the heterogeneity of the interventions and the scarcity of good-quality evidence mean that findings should be interpreted with caution, while non-health outcomes remain understudied (Patel et al, 2013; Iemmi et al, 2015).

The evaluation of CBR approaches comes with challenges. A literature review published by Lukersmith et al (2013) found a dearth of common, standardised
procedures or tools for monitoring and evaluating CBR programmes. Fortunately, there have been systematic advances since then (Grandisson et al, 2014; Grandisson et al, 2016a; Grandisson et al, 2017), which complement the WHO-launched CBR guidelines (World Health Organisation, 2010) and the recent standardised CBR outcome indicators (Mason et al, 2017). In sum, there are now important tools enabling the proper implementation and evaluations of CBR approaches.

Nonetheless, implementation barriers and functioning challenges remain all too often. That includes a "disconnect" between acute and community-based rehabilitation (Khan et al, 2015) and overall lack of coordination between all stakeholders and sectors involved (McVeigh et al, 2016). Furthermore, lack of stakeholders’ awareness and understanding of CBR remains among the most significant implementation barriers (Dennis et al, 2016). Once again, that international CBR knowledge comes mostly from the Asia-Pacific region and from Africa (Cleaver & Nixon, 2014; Dennis et al, 2016), while socio-cultural variables, including those typical of Latin America (Andrade et al, 2015), may play an important role.

In Brazil, a large middle-income American country in which social, territorial and health inequalities are common (Szwarcwald et al, 2011; Andrade et al, 2015), laws and policies exist for meeting the whole spectrum of needs of (the most vulnerable) people with disabilities (Almeida & Campos, 2002; Leão, 2011). Since 1988, the Federal Constitution enacts the need to meet and protect the human rights of people with disabilities, including the need to offer them healthcare and social protection under the public service provision (e.g., the national health system). Finally, legislation also calls for the needed articulation among entities at the primary, secondary and tertiary healthcare levels, as well as across societal sectors (Health Ministry, Brazil, 2010; Rocha et al, 2011).

However in Brazil, as in many other countries, people with disabilities - especially those living in lower-income, socially-vulnerable territories of the country - experience a myriad of disparities in the access to health and education as well as in moving around or performing active social participation roles (Othero & Aires, 2012; Souza, 2012; Aoki & Oliver, 2013; Fiorati & Elui, 2015).

In this context, Brazilian primary healthcare providers (PHPs) have mandates for the promotion of health, prevention of diseases and early identification of people with disabilities in need of care within their territories, as well for the provision
of rehabilitation services within the context of intersectoral collaboration, for an integrated care to people with disabilities, including at the community level (Junior et al, 2012). However, those mandates which align with CBR principles have not been fully operationalised into multisectoral CBR practices all across the Brazilian context (Oliver & Carvalho, 2007; Aoki & Oliver, 2013).

To understand the root causes of this sub-optimal implementation of CBR approaches in socially-vulnerable Brazilian contexts, and hence to inform further implementation measures, it is important to first understand the actual conceptions of disability, rehabilitation and of the CBR approach among Brazilian PHPs (Othero & Dalmaso, 2009). That includes any readiness to engage with the CBR approach as well as the anticipation of any factors that may affect its functioning and effective implementation into practice.

**Objective**

As such, with the focus on a socially vulnerable, sub-urban Brazilian territory, this study aims to understand how local, frontline PHPs perceive: 1) disability, 2) rehabilitation, and 3) CBR; including whether PHPs perceive CBR as a viable model to be implemented in their territory, and which factors they anticipate could affect such implementation.

**METHOD**

**Study Design**

This cross-sectional qualitative exploratory study, using focus groups of PHPs, was conducted between 2013 and 2016. The study was approved by the Ethics Committee of the School Health Centre of the Ribeirão Preto Medical School, University of São Paulo.

**Setting**

The focus groups were conducted in 6 sub-urban primary healthcare units, specifically in 6 sub-units of Family Health Centres (FHCs) serving the socially-economic deprived west region of the Ribeirão Preto municipality. Shanty towns or squatter areas (“favelas” in the Brazilian terminology) exist in plenty there, and a significant number of the inhabitants, including people with disabilities, have lower income, experience social iniquities and are in a more socially vulnerable
position when compared with inhabitants of other regions of the Ribeirão Preto municipality.

The studied Family Health Centres (FHC1, FHC2, FHC3, FHC4, FHC5 and FHC6) are all located in that sub-urban territory but centrally coordinated by the Ribeirão Preto Medical School, being part of a broader health system that also contains hospitals, a rehabilitation centre and other rehabilitation units.

In these 6 centres, in addition to the activities performed by permanent staff, there are clinical training or supervised practices for undergraduate programmes (Medicine, Occupational Therapy, Physiotherapy, Speech Therapy and Nutrition) and graduate programmes of the Ribeirão Preto Medical School (Residency Programme in Community and Family Medicine and the Multi-Professional Residency in Integrated Health Care), as well as other programmes of the University of São Paulo at Ribeirão Preto, such as those of Pharmacy, Nursing, Dentistry and Psychology.

Participants
The participants were healthcare workers from the FHC (i.e. permanent staff), as well as university-affiliated clinical professors, undergraduate students, and medical or multi-professional residents studying or providing service in those centres at that time.

A total of 78 individuals (i.e., all participating in the different activities of the included FHCs) were part of the study: 17 from FHC 1; 9 from FHC 2; 14 from FHC 3; 15 from FHC 4; 12 from FHC 5, and 11 from FHC 6. The total number of participants is stratified by profession as follows: 7 physicians, 2 Family Health Centre coordinators, 5 nurses, 9 auxiliary nurses, and 30 community health agents. In addition to the permanent staff, there were 9 medical residents, 12 multi-professional residents, 1 undergraduate student, 1 clinical professor of dentistry and 2 dentistry residents.

Informed consent was obtained from all participants.

Procedure
Six focus groups, one for each unit included in the study, were conducted by the main investigator (RCF) with help from a graduate Occupational Therapy student (KPJ) who is also one of the authors. The focus group meetings were between 60 - 90 minutes in duration. All focus groups started with a brief contextualisation
of the research, followed by the outline of the procedures as well as the questions to be debated: 1) What is disability? 2) What is rehabilitation? 3) Whether a CBR programme would be valid and feasible in their own territory, and which factors could affect its functioning and implementation?

**Data Analysis**

The group sessions were audio-recorded, and all content transcribed verbatim in Portuguese. The raw data was de-identified and only supplied with the professional identification of who said what and when, as these were important elements for the analysis. That de-identified raw data is available from the first author upon request.

Data was analysed according to Jürgen Habermas' (1988) theoretical framework of Critical Hermeneutics, based on his Theory of Communicative Action and the concepts of mutual understanding, and finally using the respective methodological guidelines.

This approach was deemed ideal for the study as it promotes elements for the interpretation and understanding of the expressed group conceptions for a given phenomenon. For this study, the main phenomenon (i.e., CBR) is essentially intersectoral, interdisciplinary and requires cooperation; therefore, the data analysis was based on a collaborative context of inter-subjectivity, as the researcher conversed with the study participants to understand their ‘collective’ messages through a method which has an interpretative-reconstructive nature (McIntosh, 1994).

Following this interpretative-reconstructive approach, data analysis was interactive, shared with members of the research team (RCF, RYD, KPJ, AFP), while the coordinator (RCF) made a final review, in interaction with the senior author (TJ). The process consisted of the following stages:

1. Sorting data by reading and re-reading the information contained in the transcripts of the discussions, towards identifying themes that emerged in each focus group and relating them to the other groups. The objective was to identify a thematic body that either converged or diverged among the different focus groups and their participants.

2. Developing thematic axes that emerged from the discussion, which outlined the symbolic shared universe - what Habermas calls propositional truth (Habermas, 1988).
3. Establishing relationships between statements and contextual elements, such as cultural, political, economic, historical and social contexts.

4. Analysing the reports according to intention of validity and veracity, supported by the subjective authenticity of the statements in accordance with their positions of reciprocity or putative coercion in the argumentative process. The presence of hierarchical relationships among the members was therefore considered.

5. Interpreting reports based on the study’s objective and the tenets of the analytical approach, which was intended to re-constructively unravel the reasons that led the participants to deliver such reports in a particular time, space and context.

Participants’ quotations have been reported, without identifying the exact participants or services. Only the professions are disclosed to point at hierarchical issues or those related to power differentials, as this is relevant for the methodology. Table 1 unravels the acronyms/codes used in the results to identify each profession. Finally, quotations and their themes are reported in supportive Tables, while leaving the text focussed on the interpretative-reconstructive nature of the method and its findings.

**Table 1: Acronyms / Codes by which each Professional Category is reported**

<table>
<thead>
<tr>
<th>Professional Category</th>
<th>Acronym / Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician</td>
<td>P</td>
</tr>
<tr>
<td>Nurse</td>
<td>N</td>
</tr>
<tr>
<td>Community Health Agent</td>
<td>CHA</td>
</tr>
<tr>
<td>Medical Resident</td>
<td>MR</td>
</tr>
<tr>
<td>Multi-Professional in Health Resident</td>
<td>MHR</td>
</tr>
<tr>
<td>Occupational Therapy Student</td>
<td>OTS</td>
</tr>
<tr>
<td>Physiotherapy Student</td>
<td>PHYSIO</td>
</tr>
<tr>
<td>Psychology Student</td>
<td>PSYS</td>
</tr>
<tr>
<td>Speech Therapy Student</td>
<td>STS</td>
</tr>
<tr>
<td>Dentistry Student</td>
<td>DS</td>
</tr>
<tr>
<td>Nutrition Student</td>
<td>NTS</td>
</tr>
<tr>
<td>Nursing Student</td>
<td>NSS</td>
</tr>
<tr>
<td>Dentistry Teaching Staff</td>
<td>DTS</td>
</tr>
</tbody>
</table>
RESULTS
The results are organised according to the focus group questions, and presented in light of the theoretical analytical framework.

1. “What is disability?”
In most focus groups, the first reports were made by the physician, then by the nurses, followed by the community health agents and, in some groups, by medical residents. The students had limited participation in the discussions.

Regarding the content of the reports, the initial responses reflected, in general, organic conceptions of disability, such as reflecting an injury or morphoanatomical issue. Initial responses also were focussed on deficits of functional capacity and the individual who has a dysfunction, with standards of ‘normal’ capacity as the backdrop.

Only when the moderator asked a question to encourage discussion - “Do you think disability can be socially or culturally determined?” - did the participants provide reports that nonetheless were dynamically balanced between the merely organic view of disability and one that incorporated social determinants and consequences of disability. Even in this new context some participants, usually with a biomedical background, reiterated a purely organic conception of disability - debating, disagreeing and counter-arguing on any social perspective of disability proposed by some of the other participants. Excerpts of the reports and conceptions are presented in Table 2.

Table 2: Conception of Disability expressed by the Reports

<table>
<thead>
<tr>
<th>Conception of Disability</th>
<th>Reports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reports that reveal an organic conception of disability</td>
<td>“It is a limitation of a given capacity, be it mental, physical or sensorial, which leads to some functional impairment for a person.” (P1)</td>
</tr>
<tr>
<td>Conceptions that balance between organic and social conceptions</td>
<td>“Society is organised for... for daily activities considering a standard of normality, the functionality of individuals. When someone, as we say, falls, that is... presents a greater difficulty in a given aspect, they... They can’t adapt to what society expects them to be able to do in their day-to-day routine. So, it is also a difficulty of society; we are not prepared to embrace all types of people, we are not prepared to accept these differences people...”</td>
</tr>
</tbody>
</table>
have. Society is adapted to a standard, the normal human being, who can do everything that is expected from us, but if a person fails to meet these expectations, they are excluded from society.” (CHA1)

Reports that discuss a social perspective of disability, reiterating the organic conception

“In fact, it was not the society that established this standard; all children are born with four limbs, so if a child is born with one limb less, you know, physically, she has, she has a different anatomy, just as being born without an eye, being born with the heart over there and not over here, so, as such, it is a morbidity, the same as a hypertensive or diabetic person, it’s... and within what society... physically there are some adaptations; she doesn’t have the conditions or is not prepared or it is not common, people would die before using a wheelchair, like, you know?” (P3)

2. “What is rehabilitation?”

The professionals outlined two main conceptions. Initially, and more strongly, professionals, mostly driven by medical doctors’ viewpoints, presented a conception of rehabilitation as a process in which an individual with disability regains capacity and (re-)acquires skills, as a process focussed on the ability of the individuals, not so much on their environment. Only later, and not so strongly, did other participants present a conception of rehabilitation, not only focussed on individuals (within an idealisation of normality) but also considering the social dimension of disability as well as the modification of the environment and of social relationships as possible interventions. Examples of these conceptions and respective reports are presented in Table 3.

Table 3: Examples of Conceptions concerning the Rehabilitation of a Person with Disability

<table>
<thead>
<tr>
<th>Conception concerning Rehabilitation</th>
<th>Reports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional conception of rehabilitation – centred on the individual capacities and normality standards</td>
<td>“…we want to recover an ability. I think that’s it... And in the context of disability, I think that it is an attempt to re-establish lost efficiency, unachieved efficiency.” (MR1)</td>
</tr>
<tr>
<td>The few conceptions recognising the need to change the environment</td>
<td>“In fact, I think that’s the problem with rehabilitation, because we focus, not only us, but society as a whole, on the individual, you don’t have a capacity, so you have to adapt to everything, because the world is like this...” (MHR1)</td>
</tr>
</tbody>
</table>
“It’s no use taking a disabled person, someone with a physical disability, a paraplegic, for example, there is no way I can transform that paraplegic into an able person, making him autonomous or independent, if I don’t build ramps, if I don’t create the means, elevators, accessibility for that person. But nobody does this, not the government, not society and not even health services. Do you think a wheelchair user can get in and move around, even here?” (N4)

3. CBR: “What are the potential benefits and difficulties you may find for implementing CBR in your territory?”

Most of the participants were receptive to the need for and viability of implementing a CBR programme in their territories. Even though they were not against the general idea (examples are presented in Table 4), participants often raised important contextual difficulties (examples are presented in Table 5).

Table 4: Examples of Conceptions regarding the Potential Benefits and Difficulties in the Implementation of a CBR Programme

<table>
<thead>
<tr>
<th>Conception on the Implementation of a CBR Programme</th>
<th>Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive conceptions concerning the implementation of a Community-Based Rehabilitation programme</td>
<td>“I think it’s super important... I think that we have to believe in this type of thing. I think the question of viability has to pass through credibility and willpower too. I think that it is viable, I think that we have to try and encourage it, but I think that it is a long-term process, for many reasons, especially because of many of the things that were said here.” (N4)</td>
</tr>
</tbody>
</table>

“Let’s suppose, if I had a programme of this kind for the six FHCs, if they rotated, among the six, I think it would be very interesting, because then we would have support in the visits, would have to tell, right? Attend closer, because for some people have difficulty doing, let’s assume, physical therapy at the specialised rehabilitation centre, for them is
very complicated because they don’t have adequate transportation, even access difficulty. If it had something closer to their house it would be very interesting.” (CHA6)

Conceptions showing difficulties concerning the implementation of a Community-Based Rehabilitation programme

“I was thinking about this, about these three partners that are directly involved, but they need to approximate... Because today, we can achieve some things, but the difficulty in dialoguing, it has to be everyone really together, everyone with the same objective, with the same purpose... So, I think that there is work to be done, but there should be the moment to discuss and to make it viable.” (N5)

“I think that there is a lack of central planning, there has to be a municipal policy establishing what the services are supposed to do, sharing everything, meeting periodically and regularly to develop that policy, that programme, together.” (P6)

Table 5: Examples of Challenges for the implementation of Community-based Rehabilitation programmes pointed out by Participants

<table>
<thead>
<tr>
<th>Challenges pointed out by Participants</th>
<th>Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordinating action across sectors</td>
<td>“Is more than a lack of communication, lacking a culture to work in intersectorality. People generally remain in their own squares and cannot share actions and strategies. They send the problem to the other sector and forget that problem exists, as if becoming a problem of the other, it is no longer their problems.” (P1)</td>
</tr>
<tr>
<td></td>
<td>“I think people need to be trained to work in an intersectoral way, because they think that intersectorality is to work forwarding problems to others, picking up the phone and passing the case to the other.” (N3)</td>
</tr>
<tr>
<td>The Brazilian political context</td>
<td>“Do you believe that governments are concerned about improving the lives of the population? Do you believe that they are concerned about a person with a disability? If</td>
</tr>
</tbody>
</table>
that person votes, she/he will win a wheelchair at the time of the election. If she/he does not vote, she/he will neither be seen nor listened.” (N5)

“Politicians are worried about re-election and will not invest in programmes that require the hiring of several professionals from different areas of activity and they are only interested in assistance and punctual actions that give them credit to the media.” (P1)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Within a more interpretive-reconstructive stance conferred by the analytical method, the anticipated barriers reported by the participants can be categorised and interpreted as related to: 1) the challenges of coordinating action across sectors, and 2) the Brazilian political context. Indeed, one of the reported concerns was the inherent difficulty of managing an intersectoral programme with the characteristics of a CBR programme, such as difficulties in terms of interaction and coordination of objectives, plans and actions. Participants pointed out the anticipated difficulties in the articulation of all agents involved, and finally the lack of managerial vision for creating intersectoral forums and running decentralised agencies or units accountable for the local and regional management of cross-sectoral CBR action. These considerations would thus emerge as important challenges to the effective implementation and functioning of a CBR programme. Another pointed concern was the Brazilian macro-political context. According to the participants, policy-makers are mainly focussed on their own interests and on actions that have the potential to promote their image in an electoral cycle, rather than in promoting the public interest. This macro-political context is seen as broadly reflected in the way social policies are (not) made and (not) implemented in the country. It was commonly understood that the broader socio-political environment barely empowers the civil society, little addresses its concerns and is rather affected by power differentials. Professionals often spoke about the underlying motivations for the policy-making process that typically were, according to them, more often related to lobbies and particular interests of those in positions of power, and less so on the common good and on the needs of the most vulnerable, including people with disabilities.</td>
</tr>
</tbody>
</table>
Overall, it was a common understanding that well-intended but broadly-defined policies for serving the needs of people with disabilities often remain only as good intentions, which somehow get lost when it comes to being translated into practice. That issue seemed prevalent in the participants’ reasoning about the minimal penetration of full CBR approaches in the Brazilian context – and it therefore remains as an anticipated challenge.

**DISCUSSION**

The biomedical and impairments-based model of disability and rehabilitation were predominant among participants’ viewpoints. That might reflect the culture of their training as well as it seems aligned with the predominant biomedical model of providing care to people with disabilities in Brazil (Bampi et al, 2010). This biomedical ideology in the Brazilian health system apparently overcomes an interdisciplinary, holistic and intersectoral one (Conill, 2008; Müller & Artman, 2012; Andrade et al, 2015). However, that scenario does not seem exclusive to the Brazilian context. For example, Community Health Workers in an established Mongolian CBR programme found difficulties in shifting from a medical approach to disability and rehabilitation (Como & Batdulan, 2012). So, it seems that either in anticipation of or for an established CBR programme, the biomedical view of disability and rehabilitation can be problematic for optimal CBR functioning and/or its effective implementation.

The predominance of the biomedical and impairments-based reasoning in this study can also reflect the predominance of the viewpoints of medical doctors observed in the focus groups, which seemed to reflect a professional hierarchy determining the focus, scope and paradigm of the services provided, and thus the ‘collective’ perspectives taken. While medical doctors typically spoke first, followed by the nurses, the perspectives of other professionals either did not emerge or were not totally free of coercion. It is likely that the implicit use of power positions had inhibited the opportunity for reciprocal dialogue and arguments (e.g., from the frontline community health workers), which is far removed from the ideal dialogue and a truly collective perspective-building idealised by Habermas (1988). Similarly, a recent review of ethical issues around CBR programmes found that key topic areas are: partnerships among stakeholders, respect for culture and local experience, empowerment, accountability, and fairness in programme design. Authors also claim that all those involved in CBR projects should pay close
attention to the development of partnerships that, despite asymmetries among stakeholders, are respectful and effective (Clarke et al, 2016). This can currently be hard to achieve in the studied scenario, given the observed imbalances of power in the perspectives. With a strong biomedical view of disability and rehabilitation, it is not easy for primary healthcare services to be prolifically extended to actively incorporate CBR principles in its full spectrum.

PHPs explicitly anticipated difficulties in coordinating action across sectors in their territory. The difficulty in cross-sectoral coordination seems to resonate with the CBR literature around the globe (McVeigh et al, 2016). In the case of Brazil and the broader Latin America, studies have also pointed to similar challenges in developing, managing and running programmes across sectors, which might relate with the way strong silos are nationally, regionally and locally established and maintained; obviously, that complicates the share and delegation of roles and accountability for those closer to the frontline (Conill, 2008; Müller & Artman, 2012; García-Ramírez & Vélez-Álvarez, 2013). Again, it seems there is sometimes a political discomfort (e.g., a need to retain power positions) and/or organisational difficulties in decentralising operations and deliberative capacity to intersectoral forums. These latter have, nonetheless, potential benefits for implementing a cross-sectoral programme (Conill, 2008; Müller & Artman, 2012; García-Ramírez & Vélez-Álvarez, 2013; Andrade et al, 2015).

Policy options to delegate decision and management capacity to decentralised stakeholders exist, and particularly for the scope of CBR (McVeigh et al, 2016). These options can emerge from the civil society itself and can actively include people with disabilities, while empowering them in doing so. For instance, engaged stakeholders might actively contribute towards the planning and management of the CBR services across sectors, and even towards planning and doing research for its support. Most notably, in a low-income country, a Community Action Research on Disability, nurturing participation and collaboration between all stakeholders, has been established to drive research agendas that likely are translated into practice – as the ultimate knowledge-users and beneficiaries are involved in the agenda-setting process (Hartley et al, 2017). That type of collective involvement and leadership can reverse the power differentials pointed out by the participants, but that involvement was far from achieved in the context of the current study. Nonetheless, this solution may well apply and help overcome most anticipated challenges.
CONCLUSION and IMPLICATIONS

PHPs in an economically and socially deprived sub-urban region of Ribeirão-Preto, Brazil, anticipated important CBR implementation and functioning barriers which could be addressed. Options may include the decentralisation and re-balance of the management and decision-making power, creation of decentralised entities to manage action across sectors and, finally, the empowerment of the civil society and of people with disabilities in doing so. However, it is important that PHPs’ predominant conceptions (i.e., biomedical, impairments-based) of disability, rehabilitation and CBR are addressed, even before the actual implementation of a CBR programme. Otherwise, a narrow view of disability and rehabilitation can be reflected into a narrow contribution of PHPs for a multisectoral CBR programme.

Limitations

The study was focussed on a specific context and territory, so the results cannot be generalised for others, even though many issues resemble aspects addressed by related literature in Brazil (for programmes across sectors) and challenges in implementing CBR programmes in other parts of the globe. Another major limitation is that the challenges for the implementation and functioning of a CBR programme are merely anticipated, and are not the result of a lived experience. Nonetheless, local professionals might be knowledgeable about the very local factors that may be expected to influence the implementation of a multisectoral programme in their own territory. Different professional categories of PHPs were purposively brought together at the same focus group discussions to identity: 1) ‘collective’ perspectives of those in the same service unit, and 2) how ‘dominant’ professional-group perspectives affected those ‘collective’ thoughts. These are useful findings for the context of this study as they reveal that future implementation endeavours need to address current dominant-group perspectives first, if they want to succeed. On the other hand, that pragmatic option impeded the more active and free participation of lower-level providers, whose ‘real’ perspectives might not be reflected in the study’s results. Finally, the study considered the perspectives of PHPs but not those of other stakeholders such as people with disabilities, their families or their representatives. That could be an important avenue for further research.
REFERENCES


Parental Perceptions, Attitudes and Involvement in Interventions for Autism Spectrum Disorders in Sarawak, Malaysia

Jing Xin Teo*, Bee Theng Lau
1. Swinburne University of Technology, Sarawak Campus, Malaysia

ABSTRACT

Purpose: This study explores and compares perspectives of educators and parents regarding interventions used in managing Autism Spectrum Disorder (ASD) in Sarawak, Malaysia. Information on parental desires and limitations when selecting and maintaining management will aid in the development of strategies for ASD educators to work effectively with parents and caregivers, and vice versa.

Method: This qualitative research employed traditional question and answer interviews with 7 ASD educators and 30 parents. Interviews were semi-structured and questions were open-ended to allow for additional details to be relayed within the scope of the subject matter. Thematic analysis revealed overarching perceptions concerning parental attitudes towards involvement in their children’s interventions, and implications of cultural context.

Results: Perspectives were similar regarding the importance of confidentiality from educators and cultural factors playing a major role in content of intervention chosen by parents. Perspectives differed across four themes. Of significance was the way in which both samples viewed parental self-reliance in supplementing interventions and parental attitudes in effort and perseverance.

Conclusion: Parental resources and culture influence ability and attitudes towards involvement. While educators may not agree on certain aspects, mutual appreciation of differing perspectives would benefit the children.

Limitations: Due to the lack of ASD service providers in the region as well as cultural reservations, sample size of educators and parents was small. The sample of parents is not typical of parents coping with ASD in the region.

* Corresponding Author: Jing Xin Teo, PhD Candidate, Faculty of Engineering, Computing and Science, Swinburne University of Technology, Sarawak Campus, Malaysia. Email: jxteo@swinburne.edu.my
**Key words:** Special education, disability service development, South East Asia, Asian culture, Autism support, developing nations

**INTRODUCTION**

Awareness and understanding of ASD is lacking in developing countries (Al-Sharbati et al, 2013; Low & Zailan, 2016). This may be due to the poor infrastructure, dearth of practitioners, overall lower education levels, stigma associated with disability, traditional parental roles in child rearing, underlying cultural elements, and competition for resources in national spending (Rahbar et al, 2010; Wang et al, 2013; Tait et al, 2015; Heys et al, 2016; Blake et al, 2017). Faced with these hurdles, parents find it challenging to obtain resources, support, and maintain motivation throughout the long years of educating a child with ASD. For educators working in ASD amelioration, these factors can have a major impact on proper intervention application and success.

**Need for the Study in Sarawak, Malaysia**

Sarawak is the fourth most populous state in Malaysia with 2.65 million inhabitants, 58% of whom reside in urban areas (JPM - Jabatan Perangkaan Malaysia, 2015). There are only 7 known intervention centres for children with ASD in Sarawak, and these are located in the main cities. It was found that admission ranged from 20 to 150 students per establishment. With ASD incidence being as high as 1 in every 68 children (Christensen, 2016), there is an immense gap between available services and need. Despite conducting a rigorous academic database search, the researchers were unable to find any published studies originating from Malaysia which investigate educators’ or parents’ perceptions of ASD interventions.

**Objective**

To facilitate effective cooperation in running ASD interventions and programmes, educators and parents need to find some common ground. The main aims of this study were therefore to:

1. Investigate educators’ perspectives of parental attitudes towards ASD intervention.
2. Investigate parental attitudes towards ASD intervention from their own perspectives.
3. Compare similarities and differences in perspectives in order to detect gaps.
METHOD

Research Design
The study employed a qualitative research design, with a semi-structured, topic-centred interview approach.

Participants
The 37 study participants consisted of educators working with ASD, and parents of children with ASD. Educators were approached by contacting ASD intervention centres, and 7 of them were interviewed. Parents were recruited through an advertisement for participation in a project involving creative-based intervention for children with ASD, which was a larger mid-term experiment the researchers were concurrently working on. The multilingual advertisement was sent to ASD education centres in a major city in Sarawak. If both parents showed up at the interviews, they were regarded as one parental unit. Thirty parental units or “parents” agreed to be interviewed.

Inclusion Criteria
Educators had to be from an institution licensed by the state government to carry out special needs services. Also, educators had to be in charge of the day-to-day running of their respective centres.

Parents had to be the parent or primary caregiver of a child between the ages of 5 and 12 who had been officially diagnosed with ASD.

Informed Consent
Participation was voluntary and uncompensated. Informed consent was recorded before starting the interviews. Participants were told that no personal or place names would be referred to, should any data be used in published materials. No identifiers pointing to the children, their parents, the educators, or place of work would be used as well. Participants had the right to stop the interview at any time and withdraw consent should they wish to do so.

Ethical clearance was obtained by Swinburne University, Sarawak Campus, and Swinburne University, Melbourne (2017/012).
Data Collection
Data collection took place by means of face-to-face interviews in a private room. Approximately 30 minutes were allocated for each interview. Participants were asked 10 open-ended questions to probe personal and perceived feelings of others. They were free to elaborate on their answers. This helped to reveal community attitudes and societal values at large regarding ASD. Questions were aimed at discovering what parents found most challenging about their situation with their child with ASD, the most pressing matters they were working towards improving, and what they wished to achieve through participating in the creative intervention project. Finally, if they wished to, parents were invited to share more about their child as an individual.

Due to sensitivities in this region regarding the subject matter and personal privacy, no demographic information was collected as regards participant ethnicity, religion, education level, marital status, or income.

Data Analysis
Thematic analysis as described by Thomas and Harden (2008) was used to synthesise and analyse the data. This consisted of three stages:

Stage 1
Interviews were typed out on word documents, then imported into QDA Miner Lite, a computer-assisted qualitative text analysis software.

Stage 2
Researchers determined and defined topics and sub-topics, then went through the text and dragged and dropped text segments into these headings, organising them according to meaning and content. This facilitated the emergence of major and recurring themes. Codes were reviewed and refined. Flexibility was employed by allowing new themes to naturally occur (Braun & Clarke, 2006). When codes at times overlapped topics, the researchers merged themes to improve strength of analysis by focussing on main ideas and concepts (Javadi & Zarea, 2016).

Stage 3
Once the researchers arrived at a consensus on the most important descriptive themes, the information making up the themes was used to resolve the objectives.
RESULTS
Explicit themes emerged from the codes – four of them reflected differing perspectives between samples and two reflected similar perspectives.

Table 1: Differing Perspectives between Educators and Parents

<table>
<thead>
<tr>
<th>THEME DEVELOPED</th>
<th>Time spent actively involved in child’s ASD interventions</th>
<th>Financial burden of ASD interventions</th>
<th>The necessity of self-reliance in developing/under-resourced countries</th>
<th>Parental attitudes are the single most influential factor in intervention success</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educators’ perspectives of parental attitudes towards ASD intervention</td>
<td>Parents need to spend more time actively involved in their children’s daily intervention and overall educational programmes, although the majority does not.</td>
<td>Parents face a significant financial burden in attempting to provide basic intervention for their children.</td>
<td>Parents need to be self-reliant in terms of supplementing basic and limited intervention that educators can offer.</td>
<td>There is an element of learned helplessness seen in most parents.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parents should learn and administer intervention to manage costs.</td>
<td></td>
<td>Many believe that there is little they, the educators, or interventions can do for their children.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>This attitude results in self-fulfilling prophecy.</td>
</tr>
<tr>
<td>Parents’ attitudes towards ASD intervention from their own perspectives</td>
<td>Parents would like to spend more time actively involved in their children’s daily intervention and overall educational programme.</td>
<td>Parents face a significant financial burden in attempting to provide beyond basic interventions for their children.</td>
<td>Parents are highly self-reliant in terms of supplementing basic and limited intervention that educators can offer.</td>
<td>Parents are driven and determined to strive towards their child’s improvement.</td>
</tr>
<tr>
<td></td>
<td>Most are unable to do so due to time constraints such as work, childcare, and other responsibilities.</td>
<td>Nevertheless, parents are willing to pay to try novel or multiple interventions.</td>
<td>Own online research acts as a major source of knowledge and learning in terms of existing interventions and their applications.</td>
<td>Parental involvement in intervention is very important and prominent.</td>
</tr>
</tbody>
</table>

Summary of comparisons between samples

<table>
<thead>
<tr>
<th>Comparison of perspectives</th>
<th>Educators understand the burden and lack of these resources, but feel strongly that most parents do not put in enough time in their child’s intervention.</th>
<th>Opinions of educators and parents are on opposite ends regarding parental effort and persistence.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parents make a clear distinction between willingness versus the ability to do so.</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Similar Perspectives between Educators and Parents

<table>
<thead>
<tr>
<th>OBJECTIVES</th>
<th>THEME DEVELOPED</th>
<th>Cultural factors determine what aspects are most valued in ASD interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educators’ perspectives of parental attitudes towards ASD intervention</td>
<td>Protection of privacy and confidentiality surrounding ASD</td>
<td>Chinese parents place emphasis on academic learning above all else.</td>
</tr>
<tr>
<td></td>
<td>• ‘Special needs’, in general, is a very sensitive subject due to negative public perceptions and potential embarrassment.</td>
<td>• The demand for intervention to focus on this aspect is apparent.</td>
</tr>
<tr>
<td></td>
<td>• Most parents avoid photography and videos of their child during sessions/classes.</td>
<td></td>
</tr>
<tr>
<td>Parents’ attitudes towards ASD intervention from their own perspectives</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Confidentiality is extremely important when considering programmes and educators.</td>
<td>• Parents place major emphasis on academic learning, and their child’s happiness.</td>
</tr>
<tr>
<td></td>
<td>• Parents believe that negative public perceptions may result in their child being treated poorly.</td>
<td>• Non-academic or creative interventions are valuable if they can encourage academic focus.</td>
</tr>
<tr>
<td></td>
<td>• Parents avoid photography and videos of their child with ASD during sessions/classes.</td>
<td></td>
</tr>
</tbody>
</table>

Summary of comparisons between samples

| Comparison of perspectives | Educators have a clear understanding of parental perceptions involving the need for privacy. | Both perspectives strongly suggest that improving academic ability is the single most important goal of intervention for parents. |

Time Spent on Active Involvement in Children’s ASD Interventions

All educators and parents agreed that being short on time is the typical parental experience. This makes it difficult to get actively involved in their child’s intervention sessions.

Educator: “We can’t expect so much. They are always busy - working, other children…a parent who is coming here is already committed.”

Educator: “If you want them to do (extra) work at home and spend time with their children, then it is very hard. They have a lot of things - work, other siblings.”

Among the parents, 90% noted that their jobs and other children were the main reasons, and 74% of them reported feeling guilty that they were unable to be more involved.

Parent: “We both work, so we really need to organise between ourselves exactly how we are going to send Alex (name changed) to his classes here and there.”
Parent: “I work a lot, weekends as well… my wife works too…she has to take a lot of work home. Somemore (additionally), she’s also always busy with our other two. I wish I could spend more time with Jimmy (name changed), teaching him, helping him learn. I feel really guilty that I can’t.”

It would seem that packed schedules are the norm, as children are involved in a multitude of after-school activities throughout the week. 97% of parents reported extra-curricular activities outside of school and primary intervention. This ranged from other therapies to academic tuitions (after-school extra classes to help in exams), to music and sports.

Parent: “Saturday is scouts, then swimming and speech in the afternoon. Sunday is piano and after that, drums. He has 2 hours free on Sunday after that, so we can only take part if it is on Sunday.”

Educator: “I have parents that go to play group, speech therapy, Sunday school, swimming, tuition and so on, so forth. So, I would say taking part in 3 afternoons (of intervention) is already considered very committed.”

Five of the seven educators shared the opinion that a means of managing the severe lack of time to facilitate intervention involvement was for one parent to stay at home, at least temporarily.

Educator: “We need to educate the parents that you need to put down your job and concentrate on the children. But most people here are working class…they don’t have the time…”

**Financial Burden of ASD Interventions**

The financial burden of ASD interventions was mentioned as a major issue by 97% of parents and 86% of educators.

Educator: “Not many parents come from rich backgrounds…some are so hard up that we even have to try our best to help, which is tough for us as a non-profit. We can’t afford to keep paying fees for everybody.”

While educators found that even basic intervention was often unaffordable for many parents, the interviewed parents established that finances would still take a noticeable blow, even for those considered affluent. Two parents demonstrated how their financial means determined the type, quality, and setting of intervention chosen:
Parent: “Not including the private school...just the ABA, speech, OT (occupational therapy), music therapy, art therapy - I will try whatever there is if it might help – Aiyoh (expression of difficulty or pain), I think I spend at least 3800 to 5000 a month! For some people, that’s maybe five months gaji (salary)!”

Parent: “We go to Singapore a lot for ABA. If I’m in England or Australia, David (name changed) does a lot of sessions there too. But it’s so expensive! So, not realistic.”

While all educators advocated getting involved in intervention, more than half (57%) noted that there were financial benefits in doing so.

Educator: “EIP (Early Intervention Programme) is expensive. Parents should learn interventions to cut costs, but only a very small percentage is motivated to work with their children at home.”

Necessity of Self-reliance in Supplementing Intervention

All educators stressed that children would eventually need to leave the centres, either due to age or sufficient progress. As such, they tried to push parents towards self-reliance in working towards closing the gap of service.

Educator: “We want to work harder and get more from parents and their partnership, and we know we can only be there for a few years. After that, they are very much on their own.”

Educator: “Those children who are OK enough to go with their parents, then we don’t allow them to come already... because if they have a place to go they won’t do anything themselves.”

Some educators sensed hesitation in trying new interventions, ASD management techniques, or accepting new information.

Educator: “We really try hard to discover new ways to help the autistic children. If there is new thing and we tell some parents, they just smile at me and are not interested. They say they don’t dare to try.”

Two educators explained that this hesitation or fear might be explained by the difference in mentality between people in smaller towns and those in bigger cities. Both mentioned Kuala Lumpur (the Malaysian capital city) to illustrate this contrast while describing Sarawakian culture as “kampung” (rural or small village).
Educator: “In West Malaysia, I was surprised that so many parents dare to speak out. In Sarawak, we don’t discuss issues. Parents don’t have enough awareness. They don’t realise how much they can learn for their children. We have kampung mentality.”

Educator: “The KL side - they are more open. They will try new things. Research. Discover. Here in Sarawak we are still in a sort of kampung culture.”

A majority of the parents interviewed (83%) however, expressed considerable interest in learning about ASD interventions and new or significant studies released by the media concerning the condition. All pointed to the Internet as their main source of ASD research.

Parent: “I research a lot on the Internet… all the types of ways we can try to cure or reverse autism…we do the bio-organic diet, gluten-free, we cut out sugar.”

Parent: “I googled how to deal with her tantrums, her meltdowns - how to stop her from banging her head first, so she doesn’t hurt herself, and then giving her time to calm down by herself.”

Unfortunately, this did not always have favourable consequences, as one father recounted:

Parent: “I found this exercise and relaxation programme online, by an Australian company. Supposed to be really good for autism. It cost us something like 20,000, but we found that it seems not suitable for Ryan (name changed). And they say they support you, but how to support from so far? In the end we don’t use it.”

**Parental Attitudes are the Single Most Influential Factor in Intervention Success**

All educators agreed that while perseverance and positivity were minimal, those parents who did have these attitudes were rewarded with noticeable progress.

Educator: “When parents are very involved we can see very fast progress. Unfortunately, majority of parents play the role of driver and sit in the car checking their handphones (mobile phones).”

Educator: “A minority will do a little bit at home. Not many. But in these we see the difference, you can see improvement so much faster. The hardworking ones - the kids are so much better.”

In contrast, lack of cooperation with educators meant that children would miss out on other often free or low-cost extra interventions.
Educator: “I certainly cannot say all the parents will cooperate. Even though we ask them to come to the centre, they won’t bother. They just promise and say, ‘I will come’, then don’t come. That’s one of the sad things about the parents here.”

Educator: “When they come to interview we tell them the things they must do and to cooperate with teachers. ‘Oh, yes, yes, yes’. But the minute the child is admitted to the school, it stops.”

At times, this would jeopardise existing intervention programmes.

Educator: “Simple things like toilet training you need cooperation from the parents. You can’t wear diapers at home and then don’t wear diapers at school. So sometimes toilet training programme is not successful because for the child it’s very confusing.”

Two educators explained that this negative attitude might come from a sense of division of labour.

Educator: “They just leave it to the school – ‘my child comes to study, so that’s your job’. Do whatever you want to do.”

Educator: “I already paid. I already sent my kid. I already did a lot. You go train them.”

All educators also recognised that a sense of learned helplessness could often lead to parents “giving-up” on their child and experiencing feelings of defeat and failure. This could be disastrous for chances of success at intervention.

Educator: “Once you have an autistic child, the progress or improvement is very dim. That’s the general perception, this feeling of ‘lost cause’.”

Educator: “A lot of teachers in this field are not well trained so when there is no progress they blame the children. As a result parents also have low expectations…the outcome is they do not want to do much more because there’s no point – ‘I’m wasting my time’.”

Educator: “‘Never mind’, just, ‘tak apalah’ (it doesn’t matter)”, ‘nantilah’ (later). They don’t see the point anymore and we can’t force them.”

Almost all parents interviewed (93%) expressed a determination and persistence which, although very different from the educators’ typical experience, was similar to parents in the minority “hard-working” category, previously mentioned.

Parent: “We do intervention with him every single day. We take turns. That way, he can have full-time ABA and some sort like play therapy.”
Parent: “I stopped working so I can spend whole day with Evan (name changed)… My husband also, never-give-up type. Any therapy, he also want to learn! We actually speaking Chinese, but because all the ABA is English, so we learn English and speak English at home, don’t care.”

Parent: “We did flash cards… when you believe in it faithfully, every night, you come home, no matter how tired, and you work at it for days, weeks, months, years… You really have to stay focussed and dedicate that kind of time to him and don’t allow anything to disturb it.”

Five educators touched upon ways to instil and encourage the correct attitude in parents. The consensus was to make it a point to educate parents, then show them the fruits of their labour.

Educator: “If you want to see progress, you need to help parents engage and let them see that with their input, you can see your children grow and thrive.”

Protection of Privacy and Confidentiality surrounding ASD
All parents expressed the desire that educators should respect the privacy of their child and ensure confidentiality. Educators understood this concern and while some said that lack of awareness of ASD and traditional societal mindset may be why privacy is so important, none would go against parents’ wishes in this case.

Educator: “Majority, if not all, want privacy. Confidentiality. Especially the older ones are more private. This is across the board. All parents here.”

Some educators believed this stemmed from previous experiences of how socially frowned upon behaviours are viewed.

Educator: “Even if we do counselling or family meetings or even let parents communicate amongst themselves to share feelings… I think they’re very ashamed to speak about their children. Society makes them feel malu (ashamed).”

Educator: “Sarawakian culture can be very gossipy. When I tell you my problem, you gossip to others.”

As a result, throughout the course of intervention or even for research and service improvement purposes, recording images or videos of children for any reason were not condoned.

Educator: “If we have visitors come and want to take photos, most Chinese and Iban will say ‘no’. Maybe it’s our upbringing. Maybe the public will think that ASD is very strange.”
Educator: “Very few allow pictures. Usually no one allows video. And even if they do allow, they will ask you if you are using their children to do advertisement and make money for fundraising. They are very sensitive.”

On probing, parents admitted that public opinion was a factor, although it was the judgment of their own family and peers that carried the most weight in influencing this behaviour.

Parent: “I don’t like to post photos on Facebook. So, I don’t like to join the classes that take a lot of photos and post everywhere, because none of my friends know.”

Parent: “Until now my mother doesn’t know. You know old people - she would say it’s my fault.”

A real fear was that being too open about the condition would result in their children being ostracised. Again, culture was thought to play a role in this.

Educator: “‘Why your children like that?’ Maybe my father or grandfather did something bad and now it comes back. Chinese and Iban believe this. ‘Or you were pregnant and something happened?’ Old people say things like this.”

Parent: “Sometimes other children in school, you know kids - they will tease or laugh at him. Maybe their parents also don’t understand. It’s better if we don’t say too much.”

Cultural Factors determine what is Most Valued in ASD Interventions

Both educators and parents agreed that culture determined the most desired areas to be concentrated on during intervention. An overwhelming number of educator responses seemed to link Chinese culture with the need for academic learning and improvement, even if it meant neglecting other important areas.

Educator: “That’s the problem with Asian families, they like it to be academic, particularly Chinese. ‘How come my child still cannot do ABC?’ ‘How come my child still cannot read?’ For them, that’s the important thing even if we say your child can do independent self-care already. For other races, this may not be so.”

This observation was substantiated by parental responses on the matter.

Parent: “Eye contact is not so important for the moment. But he is starting primary one (First Grade/ Standard 1) next year and still doesn’t know his alphabet. This is our biggest concern.”

Parent: “All the tests that come back, five marks, ten marks, zero marks - he needs to learn
to sit still and focus on his studies, otherwise what will happen in the future?”

Chinese culture was also felt to be the reason why creative interventions may not be very popular with parents.

Educator: “We only focus on ABA. We don’t go to creative interventions because otherwise parents will say ‘aiyoh, I pay so much and then they do only running around!’”

Educator: “Our culture as Chinese…creative curriculum - singing, art, craft, music and movement has never been very emphasised. Even though I know children and adults would enjoy this.”

When parents were asked what they might be expecting from creative interventions however, a small majority (53%) had the idea that these interventions could be useful in improving focus in school or for homework.

Parent (mother): “After exercising for around an hour, he can really sit down and pay attention in class. So, I thought something like dancing or sports would be really good for him.”

More parents (60%) were hoping that creative interventions might bring happiness and fun to their children’s routines.

Parent: “We brought her to a ballet class but…everybody kept looking…we didn’t feel nice, like we were disturbing them. Because they would be all doing the same thing and then Sharon would be happily doing her own thing. A bit…paisih (feeling of embarrassment). We didn’t bring her back. But she was so happy so we kept looking.”

DISCUSSION

Results show that overlaps exist across themes and perspectives. The researchers made every effort to be inclusive and attempted to obtain random samples of parents. Despite not collecting demographic data, it was observed that most respondents in both samples seemed to be Chinese. It is not known whether this was due to more diagnoses of ASD occurring within this ethnicity, more practitioners working in the field, strong assistance-seeking behaviours for the well-being of their children as cultural traits, or the propensity for other cultures to be more accepting of ASD or disability. This could in part explain why responses pointed predominantly towards Chinese culture.
ASD Interventions within the Constraints of Time and Money

Time and money are universal worries in the realm of ASD amelioration (Sawyer et al, 2009; Frye, 2016; Burrell et al, 2017), more so in situations where there is no funding and user pays (Krakovich et al, 2016). As voiced by some parents, the need for time to create money in order to pay for intervention, results in not having time to spend with children during intervention. This vicious cycle also has repercussions for family time, which is thought to be highly beneficial for children with ASD (Kapp & Brown, 2011; Ferraioli et al, 2012; Amet, 2013). While some educators suggest giving up one job in exchange for home parenting, a loss of one income for a family struggling with the effects of ASD can be debilitating (Cidav et al, 2012). Rising costs of living in Malaysia mean more dual career families are emerging in order to make ends meet, even without the presence of disability (Bakar & Abdullah, 2013; Zaimah et al, 2013).

During the interviews, two respondents revealed that they were single parents. For them and others in similar situations, the constraints of time and money would be unmistakable (Jurado, 2005; Varin-Mignano, 2013; Dyches et al, 2015; Thakur & Varmani, 2015; Seepersad, 2016; Stebbins, 2016). Researchers and professionals need to focus on the development of intervention(s) of low or reasonable cost so that fewer sacrifices need to be made by other siblings, dependents and parents themselves. This in turn may cut down the need to exchange time for money. Initial studies, including those in rural areas and with travelling military families, have shown great promise of parent-as-interventionist models (Loughrey et al, 2014; Hampshire et al, 2015; Klin et al, 2015; Blake et al, 2017), while emerging research involving the use of telepractice to train or self-train parents in this regard contain compelling cost-saving elements which should be considered (Meadan, 2016; Neely et al, 2016).

Designing Interventions within a Cultural Context

Privacy and confidentiality about children and their families was an issue on which both parties saw eye-to-eye. Being stigmatised by the community is common in settings with low awareness, and results in anxiety regarding private details being leaked (Davidson & Henderson, 2010; Grinker et al, 2012; Kinnear et al, 2015; Tilahun et al, 2016). The parents’ and educators’ responses are illustrative of those from enmeshed cultures, often seen in the East. To avoid causing offence or strain in the extended family or peer group, the opinions of others are often taken on board or family members may not be told of the diagnosis (Wang et al,
Confucian emphasis on saving face and respect for the older generation also means that many parents of children with ASD still need to comply with their own parents’ points of view, even if they realise that they may be doing so at the expense of better alternatives (Yi & Lin, 2009; Nelson et al, 2012). Such frustrations can weigh heavily on the well-being of families.

While results showed that creative interventions were not considered as valuable as interventions such as ABA which were believed to be more academic, all but one of the parents reported that they had put their children into extra-curricular activities outside of school and interventions. Researchers in East Asian cultures explain this as parents’ aspirations to achieve in competitive environments and accumulate cultural capital (Wu, 2011; Lu, 2014; Cheng & Kaplowitz, 2016). A point for researchers to consider would be the incorporation of academic learning and traditionally approved pursuits, such as music and sports, within ASD intervention in order to make them more attractive to parents.

Privacy is of utmost importance when developing any form of intervention. This translates to educators needing to employ sensitivity and prudence when it comes to public outings, play dates, and the way information is managed. While this is a far cry from the current movement of “owning” the condition as seen in developed nations (Cascio, 2012; Owren & Stenhammer, 2013; Powell & Acker, 2015), compliance by educators is crucial in order to cultivate trust. Re-educating parents about the merits of acceptance and tolerance needed for holistic intervention is a long journey in many Eastern cultures, as old ideas seep into and shape current ones. Although recent studies suggest that there is evidence that societal understanding is slowly emerging in developing countries (Wallace et al, 2012; Malcolm-Smith et al, 2013; Taha & Hussein, 2014), for now, one might surmise that going against the grain could do the children more harm than good.

Creating a Norm in Parental Attitudes towards ASD and its Amelioration

As regards parental attitudes and self-reliance, there was a noticeable gap between what educators observed and what parents reported. The presence of ASD in families can be extremely stressful and it is imperative to find ways to close the gap and achieve congruence between educators and parents for the child’s progress, mental well-being of parents and therefore of the entire family.

Due to the nature of the sample selection process, it is assumed that parents who applied would have been self-motivated enough to do so. In this sense, there is
much to learn from them as they would most likely have comprised the successful examples of intervention mentioned by the educators. ASD literature upholds the finding that parental attitude is a robust predictor of outcome - above type of intervention, duration, and intensity - relative to the severity of the condition (Moore & Symons, 2011; Karst & Van Hecke, 2012; Narzisi et al, 2015; Pickles et al, 2016). The failure to follow through with programmes, frustration, and episodes of helplessness are not uncommon experiences for parents managing ASD (Moore & Symons, 2011; Weitlauf et al, 2012; McStay et al, 2013). It can be due to numerous and differing reasons, so each experience is unique and needs to be tackled individually until norms in parental attitudes are established in Sarawak. Creating and nurturing a culture of acknowledging the condition and its trials and tribulations, at least within the community of parents, will go a long way in providing empathy, support, and eventually the demand for associated services.

For now, the onus is on educators to continuously remind parents that effort equals results. Having said that, research does advise that due to etymological reasons, some interventions work exceedingly well for some children while some are found to have hardly any effect, and vice versa (Dempsey & Foreman, 2001; Vivanti et al, 2014). It can be recommended therefore that allowing a wider range of intervention options might bring more success and thus motivation to soldier on.

CONCLUSION

Results of the study suggest that educators in this field are well aware of the difficulties that parents face but are often unable to assist beyond the limitations of their role and available resources. The parent sample indicates that awareness of ASD and attitudes towards interventions are however changing established beliefs and the mentality of whole populations, whether they be ethnic, geographical or cultural, but it can take years. Time is always of the essence in ASD amelioration, hence educators and parents cannot and should not wait. ASD professionals and service providers working in these regions need to continue exploring reasons for resistance, in order to develop and share knowledge about culturally accepted interventions which can be applied swiftly for the benefit of the children.

Limitations

Due to the lack of ASD service providers and difficulty in accessing personal opinions and information from parents, both samples are very small and therefore
only able to relate a narrow viewpoint. Additionally, because the parent sample was obtained through a call for research, there is a disproportionate number of actively involved parents. To construct a more realistic picture of the situation at hand, the researchers would recommend developing means to gather further information from average parents who have children with ASD.

REFERENCES


Kinnear SH, Link BG, Ballan MS, Fischbach RL (2015). Understanding the experience of


Utilisation and Satisfaction with Health Services among Persons with Disabilities in Accra, Ghana

Anang Yemoson Abraham¹, Peter Agyei-Baffour², Cosmos Yarfi³*

1. Assistant Director, Education of the Hearing Impaired, Special Education Division, Ghana Education Service, Ghana
2. Senior Lecturer, Department of Occupational and Environmental Health, Kwame Nkrumah University of Science and Technology, Ghana
3. Assistant Lecturer, Department of Physiotherapy and Rehabilitation Sciences, University of Health and Allied Sciences, Ghana

ABSTRACT

目的: 健康保健，是人类的基本需求之一，但残疾人却常常因为生理和社会的限制而被排斥和歧视，在发展中国家尤其如此。由于健康相关的可持续发展目标（SDGs）旨在改善健康与福祉以及减少社会不平等，因此作者认为有必要通过研究确定残疾人群体利用医疗服务的水平及满意度，并提出改进建议以改善该国的现状。

方法: 本研究采用非干预期、描述性横断面研究方法，采取定量数据收集方式。使用结构化的问卷调查，既包含开放性问题也包含封闭性问题。总共涉及363名受访者，其中360名为残疾人群体，3人为关键信息提供者。

结果: 共有66.9%的残疾人群体表示受到健康专业人员的热切欢迎，23.1%的人群表示受到冷淡的态度，5.6%的人群表示受到鄙视。只有20.5%的残疾人群体频繁访问健康设施，42.8%的人群不频繁访问健康设施，36.4%的人群很少访问健康设施。此外，76.4%的受访者表示他们因身体不适而频繁就医。

结论: 虽然健康设施的使用率较低，但大多数受访者表示他们受到了良好的接待。

* Corresponding Author: Cosmos Yarfi, Assistant Lecturer, Department of Physiotherapy and Rehabilitation Sciences, University of Health and Allied Sciences, Ghana. Email: cyarfi@uhas.edu.gh
there and as such would visit health facilities for all their medical needs.

**Implications:** Persons with disabilities should be included in all areas of society by spreading awareness about their abilities. Partnerships between persons with disabilities and the government and other non-governmental organization’s should be established, to mainstream health services to meet their general and specific needs. It is increasingly important that persons with disabilities play an active role in managing their healthcare needs.

**Key words:** Utilisation, satisfaction, health service, person with disability

**INTRODUCTION**

Healthcare is one of mankind’s basic needs since everyone is prone to sickness. In Ghana, the first point of call for persons with disabilities is the traditional medicine practitioner, and not a healthcare facility, due to the high doctor–patient ratio and the many barriers they face in accessing healthcare (Antwi-Baffour et al, 2014). Persons with disability face many barriers relating to physical accessibility to healthcare facilities and these vary to different degrees depending on the kind of disability experienced by the individual (Aderemi, 2011). People with disabilities often are more susceptible to preventable health problems that decrease their overall health and quality of life. Health disparities and secondary conditions can be the result of inaccessible healthcare facilities and equipment, lack of knowledge among health professionals about specific differences among persons with disabilities, transportation difficulties, and higher poverty rates among people with disabilities (Hansen et al, 2008). Health professionals are also often not aware of how to effectively communicate with clients who have a range of disabilities, including people who are deaf or hard of hearing, or who have a speech, vision, or intellectual disability (Dora et al, 2015). Persons with disabilities may have a range of impairments, from those who are fully self-sufficient at home and in the workplace, to those who are entirely dependent on others for custodial care and decisions about their healthcare.

Access to healthcare is very important to all people, but persons with disability face many barriers including physical barriers, cost of accessing healthcare, inadequate equipment and skills of healthcare providers, negative experiences with healthcare personnel, and direct exclusion since they are generally relegated to the background in society. This inequity in accessing healthcare will lead to deteriorating health of persons with disabilities and consequently impede their
efforts at working, improving productivity, income generation, poverty reduction and the realisation of the Sustainable Development Goals. Therefore, there is the need to investigate the extent of utilisation and satisfaction with health services among persons with disabilities.

The health-related Sustainable Development Goals (SDGs) talk about good health and well-being and reducing inequality in societies, but people with varying disabilities in developing countries are marginalised and society does not incorporate their needs in the design and building of health services, leading to under-utilisation. It is therefore important to look at the factors affecting utilisation of health services by persons with disabilities in developing countries (Slikker, 2009).

In South Africa and Ghana, constitutional provisions and policies have been made for inclusion and for reducing inequality of persons with disabilities, though implementation is in its infancy. The 1992 Constitution of the Republic of Ghana and the Persons with Disability Law (Asante and Sasu, 2015) seek to lay much emphasis on the provision of health services for persons with disabilities to utilise and achieve optimum health, in order to increase productivity, generate income and reduce poverty.

Aim

The aim of this study is to determine the level of utilisation and satisfaction with health services among persons with disabilities, and to recommend strategies to improve the current situation.

Specific Objectives

1. To determine the demographic information of persons with disabilities in Accra;

2. To determine the proportion of persons with disabilities utilising health facilities in Accra;

3. To determine the predisposing factors influencing the use of health services among persons with disabilities.
METHOD

Study Design
This is a cross-sectional non-interventional study, descriptive in nature, involving people with varying forms of disabilities in the Accra metropolitan area. This study design was chosen because it dealt with the issues and contention behind the investigation.

Study Area
The study was conducted in Accra, the capital of Ghana. The Greater Accra Region is the smallest of the 10 administrative regions in terms of area, occupying a total land surface of 3,245 square kilometres or 1.4% of the total land area of Ghana. However, it is the second most populated region, after the Ashanti Region, with a population of 4,010,054 in the 2010 census, accounting for 16.3% of Ghana’s total population (Linard et al, 2012).

The urban metropolis of Accra is the most densely populated part of the region with a total population of 1,848,61 people, which is 46.1% of the population of the Greater Accra Region from the 2010 population census (Linard et al, 2012). It is divided into 6 sub-metros, namely Ablekuma, Ashiedu-Keteke, Ayawaso, La, Okaikoi, and Osu-Clottey. Each of the sub-metros is served by a government hospital / polyclinic. In addition, there are several small government clinics, numerous private clinics and several quasi-government hospitals.

Study Population
The study population included persons with disabilities, between 18 - 60 years of age, living in the Accra metropolis. They had various forms of disabilities - developmental, intellectual or physical disabilities, and associated communication and hearing disorders – and were members and non-members of the Ghana Blind Union, Ghana Association of the Deaf, Ghana Association of the Physically Challenged and the Ghana Federation of the Disabled. Students with intellectual disability from 2 special schools were also included. They were all within the La and Osu-Clottey sub-metros of the Accra metropolis.

Sampling Method
Multi-stage sampling technique was used at different phases of the study. The
Greater Accra Region was purposively selected since it is densely populated, is home to many persons with disabilities, and houses the head office of the Ghana Federation of the Disabled (GFD). Due to the presence of the Federation’s head office, it is believed that persons with disabilities are sensitised about their health needs and rights, and will utilise health services well.

**Sample Size**

A total of 360 persons with disability and 3 key informants were involved in the study. This figure was arrived at by using the formula below (Charan and Biswas, 2013).

\[
n = \frac{z^2pq}{d^2}
\]

\[
(1.96)^2 (0.5) (0.5)
\]

\[
0.9604
\]

\[
0.0025
\]

n=360

Where \( n \) = sample size

\( p \) = the proportion of persons with disability in the population who have access to health service, estimated to be 50%

\( q \) = proportion of population of persons with disability not having access to health service (\( q=1-p \))

\( z \) = 95% confidence interval

\( d \) = the allowable margin of error
Data Collection
A quantitative data collection method was used. Structured questionnaires made up of closed-ended questions measured the level of satisfaction with utilisation of health services by persons with disability. Respondents were approached at their association meetings, the study was explained to them and they answered the questionnaire after giving their consent.

The 3 key informants were leaders of DPOs. They were interviewed by the investigators, using an interview guide. The general purpose of the research was explained to them and their responses were recorded and analysed thematically and manually.

Data Management and Analysis
The data was entered into an Excel spreadsheet and analysed using Statistical Package of Social Science (SPSS) version 16.0. Tables and percentages were used for the analysis. Recorded interviews were transcribed and content was analysed to ascertain the variables of interest. Relevant text-specific statements were used to triangulate the findings.

Ethical Considerations
Ethical clearance was obtained from the Ethics Committee of the KATH/KNUST, School of Medical Sciences, through the Department of Community Health. The regional leaders of the Disabled Peoples’ Organisations were contacted to provide administrative clearance for the research. Informed consent was also sought from the participants. The relevance of the study was explained to them and they were assured that information would be kept confidential.

RESULTS
Demographic Information of Respondents
The data collected showed that 360 persons with disabilities responded to the structured questionnaire, and 3 key informants, who were leaders of DPOs, were interviewed.

Among the persons with disabilities, there were 217 male respondents, representing 60.3% of the total sample, while there were 143 female respondents, representing 39.7% of the sample. The highest percentage of respondents (39.7%)
was in the 25-36 year age group, while 3.3% were 56 years of age. Two of the respondents did not disclose their age on the questionnaire.

The highest percentage of respondents or 52.5% had hearing impairment, and the lowest percentage or 0.6% were those with speech impairment.

The educational levels of persons with disabilities was quite impressive - 19.4% with tertiary education, 29.7% with senior high education, 23.6% with junior high education, and 12.5% with primary education. A total of 13.3% had informal education.

Among the 3 key informants, the types of disability were mobility, visual and hearing impairments. Two of them were male while one was a female. They were between 30 – 60 years of age. Two were employed and one was unemployed. Two had tertiary qualifications, with one having post-secondary vocational qualification as shown in Table 1.

**Table 1: Demographic Characteristics of Respondents (Persons with Disabilities)**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency n=360</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex of Respondents</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>217</td>
<td>60.3</td>
</tr>
<tr>
<td>Female</td>
<td>143</td>
<td>39.7</td>
</tr>
<tr>
<td><strong>Age of Respondents</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-25</td>
<td>96</td>
<td>26.7</td>
</tr>
<tr>
<td>26-35</td>
<td>143</td>
<td>39.7</td>
</tr>
<tr>
<td>36-45</td>
<td>78</td>
<td>21.7</td>
</tr>
<tr>
<td>46-55</td>
<td>29</td>
<td>8.0</td>
</tr>
<tr>
<td>56 and above</td>
<td>12</td>
<td>3.3</td>
</tr>
<tr>
<td>Rather not say</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Type of Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td>86</td>
<td>23.9</td>
</tr>
<tr>
<td>Hearing</td>
<td>189</td>
<td>52.5</td>
</tr>
<tr>
<td>Sight</td>
<td>43</td>
<td>11.9</td>
</tr>
<tr>
<td>Mental</td>
<td>37</td>
<td>10.3</td>
</tr>
<tr>
<td>Speech</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Religion of Respondents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>---</td>
<td>------</td>
</tr>
<tr>
<td>Christian</td>
<td>305</td>
<td>84.7</td>
</tr>
<tr>
<td>Muslim</td>
<td>47</td>
<td>13.1</td>
</tr>
<tr>
<td>Traditional</td>
<td>2</td>
<td>0.6</td>
</tr>
<tr>
<td>None</td>
<td>6</td>
<td>1.7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest level of Education</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>45</td>
<td>12.5</td>
</tr>
<tr>
<td>Junior High</td>
<td>85</td>
<td>23.6</td>
</tr>
<tr>
<td>Senior High</td>
<td>107</td>
<td>29.7</td>
</tr>
<tr>
<td>Tertiary</td>
<td>70</td>
<td>19.4</td>
</tr>
<tr>
<td>Others</td>
<td>48</td>
<td>13.3</td>
</tr>
<tr>
<td>Rather not say</td>
<td>5</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Proportion of Persons with Disabilities who utilise Health Services

According to the respondents, only 20.5% visited health services frequently, while 36.4% rarely visited health services as shown in Table 2.

**Table 2: Utilisation of Health Services**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utilisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequent</td>
<td>74</td>
<td>20.5</td>
</tr>
<tr>
<td>Not frequent</td>
<td>154</td>
<td>42.8</td>
</tr>
<tr>
<td>Rarely</td>
<td>131</td>
<td>36.4</td>
</tr>
<tr>
<td>Rather not say</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Total</td>
<td>360</td>
<td>100.0</td>
</tr>
</tbody>
</table>

From the responses, the study established that 80% of persons with disability felt that health services were available for their use while 20% reported that health services were not available, as shown in Table 3. A total of 60.6% of persons with disability reported that they had access to the services at health facilities while 38.6% reported that the services rendered at health facilities were not accessible.
Table 3: Availability of Health Services to Persons with Disability

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availability of Health Services to Persons with Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>240</td>
<td>80.0</td>
</tr>
<tr>
<td>No</td>
<td>60</td>
<td>20.0</td>
</tr>
<tr>
<td>Total</td>
<td>300</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Affordability of Healthcare to Persons with Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>148</td>
<td>41.1</td>
</tr>
<tr>
<td>No</td>
<td>199</td>
<td>55.3</td>
</tr>
<tr>
<td>Rather not say</td>
<td>13</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>360</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>Accessibility of Health Services to Persons with Disability</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>218</td>
<td>60.6</td>
</tr>
<tr>
<td>No</td>
<td>139</td>
<td>38.6</td>
</tr>
<tr>
<td>Rather not say</td>
<td>3</td>
<td>0.8</td>
</tr>
<tr>
<td>Total</td>
<td>360</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Reception of Persons with Disability by Health Professionals

While 66.9% of persons with disability reported that they were given a warm reception at health services, 23.1% reported that they got a cold reception. Negligence and cultural beliefs greatly hinder the spread of knowledge about disabilities and accessing healthcare for specific infirmities. About 76.4% of the respondents said they would take all types of cases to the health facility, 16.7% said they would take only severe cases, and only 1.1% said they would take mild cases to the health centre.

The 3 key informants agreed that all health conditions should be sent to health facilities for treatment. They also said that health personnel receive them warmly when they visit health centres. The challenges they encountered in accessing health services included high cost of transportation, accessing the built environment, financial constraints, and lack of information about the severity of their conditions.
Table 4: How Persons with Disability are received by Health Professionals

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency n=360</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impression of Persons with Disability about reception by Health Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warm</td>
<td>241</td>
<td>66.9</td>
</tr>
<tr>
<td>Cold</td>
<td>83</td>
<td>23.1</td>
</tr>
<tr>
<td>Scorned</td>
<td>20</td>
<td>5.6</td>
</tr>
<tr>
<td>Rather not say</td>
<td>15</td>
<td>4.2</td>
</tr>
<tr>
<td>Others</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Cases that Persons with Disability will take to Health Facilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All cases</td>
<td>275</td>
<td>76.4</td>
</tr>
<tr>
<td>Severe cases</td>
<td>60</td>
<td>16.7</td>
</tr>
<tr>
<td>Mild cases</td>
<td>4</td>
<td>1.1</td>
</tr>
<tr>
<td>Rather not say</td>
<td>9</td>
<td>2.5</td>
</tr>
<tr>
<td>Others</td>
<td>12</td>
<td>3.3</td>
</tr>
</tbody>
</table>

**DISCUSSION**

The study aimed to determine the level of satisfaction with utilisation of health services by persons with disabilities and to recommend strategies to improve the current situation. The idea was also to obtain the demographic information of persons with disability in Accra, the proportion of those utilising health facilities in Accra, and the predominant factors influencing the use of health services by persons with disability.

The number of male respondents was far higher than that of females. This was not surprising since in many developing countries males with disabilities have more opportunities than their female counterparts.

Most of the respondents were between 26 - 35 years of age; this can be attributed to the fact that about 80% of youths with disabilities live in developing countries (Gregorius, 2016). These people also participate actively in the activities of the disability organisations. The hearing impaired population recorded the highest proportion of respondents by type of disability. The hearing impaired association also happens to be more organised, the members are mobile and often consider themselves a closely-knit and interconnected group as compared to other associations of persons with disability (Ladd, 2003; Reynolds, 2010).
The educational levels of persons with disability were quite encouraging, with majority of them having some form of formal education. This contradicts a study by Avoke (2001) that majority of people with disability are not educated. The results of this study may be as it is because the study was situated in an urban city in Ghana where most people are enlightened about the abilities of persons with disabilities.

The study respondents confirmed that they did not often go to health facilities to access care; only one-fifth utilised health facilities frequently while one-third reported visiting health facilities. They rarely reported for health services because of lack of funds, ignorance about their condition, poverty, distance of the health facility from home, embarrassment on the part of accompanying family members, stigmatisation from health personnel, and resorting to traditional and other non-orthodox forms of treatment. This was found to be consistent with studies by Pal et al (2000) and Crisp et al (2000).

A number of people with disability (80.3%) reported that they were received cheerfully by health professionals whereas 10.7% reported the contrary. This may be attributed to the creation of awareness about disability issues and the rights of people with disability, with the coming into force of the Ghanaian Disability Law (Asante and Sesu, 2015). This supports a study by Mlenzana et al (2013) that health professionals exchanged information during consultation and care of people with disability.

Only one-fifth of the respondents reported that they had utilised health facilities. The reason for not patronising health services was affordability, as most of the time they require rehabilitation services which are not covered by the National Health Insurance Scheme. They resorted to borrowing money and gifts to pay for rehabilitation services.

Majority of the respondents were satisfied with the health services available to them. This was due to the fact that health services were not only available but the built environment of these facilities was also accessible for them (Yarfi et al, 2017). They could be independent as no functional or human support was needed in accessing the facility. This is refreshing since most persons with disability are considered to be dependent on others for their basic needs.
CONCLUSION

The study findings highlighted the level of satisfaction with utilisation of health services by persons with disability. The findings suggested that few persons with disability reported utilising health facilities, with the majority resorting to alternative forms of medical care. Most of those who accessed health facilities reported that they got a good reception from health professionals there and as such they would visit health facilities for all their medical needs.

It is recommended that society should be made more aware about the abilities of persons with disabilities in order to foster inclusion. It is important that persons with disability take an active role in managing their healthcare needs. Partnerships between persons with disability and the government and other non-governmental organisations should be established, for the mainstreaming of health services to meet their general and specific needs. This will create the right environment for them to access health services.

REFERENCES


Predictors in the Selection of an AAC system:
An Evidence-based Report on Overcoming Challenges

Sita Sreekumar\textsuperscript{1*}, Suja K Kunnath\textsuperscript{1}, Vineetha Sara Philip\textsuperscript{1}

1. National Institute of Speech and Hearing (NISH), NISH Road, Sreekariyam P.O, Trivandrum 605017, Kerala, India

ABSTRACT

\textbf{Purpose}: Identification of the most suitable Augmentative Alternative Communication (AAC) device for individuals with varying degrees of communication impairments is immensely challenging. This study aimed to understand the effectiveness of analysing the various sensory, cognitive and environmental factors during the selection of an AAC.

\textbf{Methods}: Four children with different developmental disabilities were assessed in the domains of sensory ability, cognitive skills and environmental factors. The selection of an AAC was primarily dependent on the positive indicators in these domains and the specific challenges pertaining to each participant.

\textbf{Results}: Participants’ progress was assessed. All the children progressed across the levels of the Communication Matrix.

\textbf{Conclusion}: Understanding of sensory perceptual capacities and an attempt to overcome environmental barriers lead to the successful use of an AAC system. The study attempts to establish a platform for further research on the efficacy of utilising sensory perceptual learning with AAC to overcome communication barriers in children with severe developmental disabilities.

\textbf{Key words}: Augmentative Alternative Communication, developmental disability, sensory perceptual capacities

INTRODUCTION

Identification of the most suitable Augmentative Alternative Communication (AAC) device for a person with a multitude of impediments in various anatomical

* \textbf{Corresponding Author}: Sita Sreekumar, Lecturer, Department of Audiology and Speech Language Pathology, National Institute of Speech and Hearing (NISH), NISH Road, Sreekariyam P.O, Trivandrum 605017, Kerala, India. E-mail: sasasita@gmail.com, sitas@nish.ac.in
and physiological systems poses a huge challenge to the AAC interventionist. With advances in technology an assortment of AAC systems are now available in the market. At present, the selection of an AAC device is largely dependent on its multifarious constituents rather than on the person’s inherent learning capacities. This study proposes to approach the selection of AAC devices on the basis of a physiological model, and elaborates on evidence-based practices for further perusal of its effectiveness. Thus, the aim was to analyse the role of sensory, cognitive and environmental factors in the selection of an AAC system with the following objectives:

1. Profiling the sensory capability of the subjects using AAC;
2. Identifying the positive and negative indicators for the selection of AAC;
3. Distinguishing the best practices during the use of AAC.

**METHOD**

**Participants**

Four participants were selected from the Department of Audiology and Speech Language Pathology at the National Institute of Speech and Hearing (NISH), Kerala, based on the following inclusion criteria:

Children with developmental disabilities who

a) Did not receive any forms of early intervention,

b) Failed to develop verbal communication through traditional speech therapy.

**Assessment Procedure**

Each of the four subjects underwent formal or informal assessments in the domains of sensory ability, cognitive skills and environmental factors. The assessments were done using the following tools:

1. Communication Matrix (Rowland, 2004);
2. Individual sensory learning profile (Antony, 2005);
3. Cognitive orientation measured using Functional communication measure (adapted from The ASHA National Treatment Outcome Data Collection Project, 1997);
4. Informal observation sessions.
Intervention Procedure

The AAC system was selected primarily depending on the positive indicators in the sensory and cognitive domains. A detailed profiling of likes and dislikes of each child was made prior to the intervention. Each child got a minimum of 3 sessions and a maximum of 15 sessions. The duration of each session was 45 minutes, once a week. The responses were charted in a pre-arranged format for ease of analysis, and the observations were analysed to identify specific challenges pertaining to each participant for the selection of an appropriate AAC system. The progress of the child was measured using the Communication Matrix.

RESULTS

The positive and negative indicators for sensory, cognitive orientation and environmental domains were analysed and the subject-wise description is given in Tables 1, 2, 3 and 4.

Table -1: Description of Sensory, Cognitive Orientation and Environmental factors of Subject 1 - a child (4 years old) diagnosed as Spastic CP with cortical blindness

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Auditory</th>
<th>Visual</th>
<th>Tactile &amp; vestibular</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive indicators</td>
<td>Responds to familiar auditory stimuli such as parent's voice. Attends to auditory stimuli such as music or intoned speech and noise-making toys.</td>
<td>No response to visual stimuli with different characteristics.</td>
<td>Sometimes responds to sensations. May respond more when family is present. Occasionally alert to familiar daily routines.</td>
</tr>
<tr>
<td>Negative indicators</td>
<td>No tactile aversion.</td>
<td>Unaware of problems with communication, orientation, motor activities.</td>
<td>Frequent hospitalisations leading to restrictions in communication environment &amp; opportunities. Poor communication partner competency.</td>
</tr>
</tbody>
</table>

www.dcidj.org

Vol. 29, No.1, 2018; doi 10.5463/DCID.v29i1.673
Table 2: Description of Sensory, Cognitive Orientation and Environmental factors of Subject 2 – a child (4 years and 5 months old) diagnosed as Autism Spectrum Disorder with Visual Impairment

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Analysed Domain</th>
<th>Management options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensory</td>
<td>Cognitive</td>
</tr>
<tr>
<td></td>
<td>Auditory</td>
<td>Visual</td>
</tr>
<tr>
<td>Positive indicators</td>
<td>Attends to interested auditory stimuli including environmental and toy sounds. Loves to listen to music and can play keyboard tones.</td>
<td>Responds to brightly coloured and illuminating visual stimuli. Visual responsiveness improved when combined with auditory stimuli.</td>
</tr>
<tr>
<td>Negative indicators</td>
<td>Visually does not respond to human faces.</td>
<td>Responds adversely to being touched and to movement.</td>
</tr>
</tbody>
</table>

Table 3: Description of Sensory, Cognitive Orientation and Environmental factors of Subject 3 - a teenager (14 years and 5 months old) diagnosed as Fragile X syndrome

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Analysed Domain</th>
<th>Management options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensory</td>
<td>Cognitive</td>
</tr>
<tr>
<td></td>
<td>Auditory</td>
<td>Visual</td>
</tr>
<tr>
<td>Positive indicators</td>
<td>Responds to auditory stimuli such as music (favourite songs), Visual responsiveness is improved when accompanied by auditory stimuli. Accepts touch by family members. Aversion to touch</td>
<td>Responsiveness is functional for simple living activities. Requires occasional</td>
</tr>
</tbody>
</table>
Table 4: Description of Sensory, Cognitive Orientation and Environmental factors of Subject 4 - a child (5 years old) diagnosed as Autism Spectrum Disorder

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Domain Assessed</th>
<th>Management options</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Sensory</td>
<td>Cognitive</td>
</tr>
<tr>
<td></td>
<td>Auditory</td>
<td>Tactile &amp; vestibular</td>
</tr>
<tr>
<td>Positive indicators</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Responds to auditory stimuli such as music (favourite songs), environmental</td>
<td>Cues are sometimes needed to begin very familiar and simple activities. Is</td>
</tr>
<tr>
<td></td>
<td>sounds and in-context auditory</td>
<td>oriented sometimes to family</td>
</tr>
<tr>
<td></td>
<td>verbal commands.</td>
<td>members.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Understanding of cause-effect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>emerging.</td>
</tr>
<tr>
<td>Negative indicators</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Responds adversely to movement.</td>
<td>Responds adversely to movement.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Difficulty attending to tasks,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>supervision for safety is required.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Behavioural problems significantly</td>
</tr>
<tr>
<td></td>
<td></td>
<td>evident.</td>
</tr>
</tbody>
</table>

Environmental sounds and in-context auditory verbal commands.

Objects of varied textures at first attempt, but improves with several trials.

cues to start, continue, change, and divide attention during routine activities. Understanding of cause-effect present.

Adversely affected by noise-making sounds.

Aversion to being touched by therapist, and with objects of varied textures.

Less evidence of learning and recall during everyday activities. Social and family interaction and communication significantly affected.

Restricted communication environment and limited communication opportunities. Lack of acceptance of AAC by family. Poor communication partner competency.

After analysis of each factor, best practices were contemplated and these are described in Table 5.

### Table 5: AAC and Best Practice

<table>
<thead>
<tr>
<th>Subjects</th>
<th>No. of sessions</th>
<th>Sensory domain selected for AAC</th>
<th>Progress (using Communication Matrix)</th>
<th>Best Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>Auditory-tactile mode of intervention</td>
<td>Progressed from emerging level I to mastery of level I</td>
<td>Identification of appropriate sensory system for AAC</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>Auditory-visual-tactile mode of intervention</td>
<td>Progressed from level II to mastery of level III</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>15</td>
<td>Auditory-visual-tactile mode of intervention</td>
<td>Progressed from level III to mastery of level V</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>4</td>
<td>Auditory-visual-tactile mode of intervention</td>
<td>At level II (no progress)</td>
<td></td>
</tr>
</tbody>
</table>

### DISCUSSION

Across the seven levels of communication as stated in the Communication Matrix, each of the four subjects exhibited a pre-intentional or an unintentional communication pattern. AAC was introduced into their intervention plan with the objective of utilising each child’s sensory perceptual capacities for learning. Positive indicators in the sensory domains were found to be the suitable predictor for initiating AAC intervention. Capitalising on the stronger sensory modality for learning is well documented (Boulmetis and Sabula, 2011). Similar principles can be incorporated into assistive technology as well. Children who are strong visual learners (e.g., children with severe developmental disabilities or autism) could use assistive systems using visual tools to improve communication, behaviour, socialisation, and independence (Brill, 2011). Reported evidence-based studies on the selection of AAC systems on the basis of a physiological model are scarce. The present study attempts to establish a platform for further research on the efficacy of utilising sensory perceptual learning with AAC to overcome communication barriers in children with severe developmental disabilities.
CONCLUSION

Since perceptual learning through sensory modalities forms an important foundation for complex cognitive processes such as language, it becomes an integral predictor in the selection of an appropriate AAC system. Thus, awareness of the learning style is important to adapt and provide AAC systems to maximise learning potential and communication participation. Understanding the sensory perceptual capacities of a child with developmental disability, combined with an attempt to overcome environmental barriers, will define the success of an AAC system.

Clinical Implication

Developmental disabilities begin anytime during development up to 22 years of age and usually last throughout a person's existence (U.S. Centres for Disease Control and Prevention, 2004). Since the ability for perceptual learning is retained throughout one's life, an AAC system focussed on utilising sensory perception would, at any point of time, enhance learning to communicate in an individual with severe developmental disability.

REFERENCES


Negotiating Future Uncertainty: Concerns of Mothers of Children with Down Syndrome in Kashmir, India

Bilal Ahmad Khan1*, Wakar Amin Zargar1, Shabir Ahmad Najar2

1. Department of Social Work, University of Kashmir, J&K, India
2. Centre of Central Asian Studies, University of Kashmir, J&K, India

ABSTRACT

Purpose: Down syndrome is developmental disorder that poses unique challenges and implications to families. The present paper is the outcome of a study carried out in Srinagar district of J & K in India, on mothers’ apprehensions about the uncertain future for their children with Down syndrome.

Method: A phenomenographic approach was followed. Purposive sampling technique was used at selected special schools in Srinagar. Mothers of 8 children with Down syndrome who were enrolled in school, participated in the study. The mothers were between 31 and 67 years of age; their children were between 2 and 30 years of age. In-depth interviews were conducted in Urdu and Kashmiri, the local languages. The recorded information was subsequently transcribed and classified into themes.

Results: The key theme that emerged was the participants’ worry about the unpredictable future of their child. Once a child is diagnosed with Down syndrome, parents - especially mothers - recognise that their child’s future may not include a carefree childhood and, at a later date, higher studies, an independent life and marriage.

Conclusion: Mothers of children with Down syndrome experience high levels of stress and often have to make adjustments in their careers, finances and lifestyles. There is a need for training programmes to help parents cope with the problems faced by their children with Down syndrome. Stakeholders in the education sector could help in this regard.

Key words: Down syndrome, mothers, special school, future, Kashmir.

* Corresponding Author: Bilal Ahmad Khan, Doctoral Fellow, Department of Social Work, University of Kashmir, J&K, India. Email: khanbilz@gmail.com
INTRODUCTION

Every family of a child with Down syndrome experiences a unique set of stressors according to their child’s age, functionality and developmental stage. Down syndrome is one of the most common genetic disorders, with reports of one infant in every 600-800 live births (Alton, 1998). Down syndrome is predetermined before conception. It is caused by the fertilised egg having three copies of Chromosome 21 instead of the normal two (Davis, 2008). It is considered to be one of the easiest neurodevelopmental genetic disorders to detect because of the physical and mental abnormality and genetic testing. There are also prominent neurocognitive deficits associated with Down syndrome such as communication, language, and memory impairments. Many families in today’s society almost idolise their children, as children carry their parents’ hopes and dreams. Donahoo (2007) noted, “Of course, creating the perfect child or perfect childhood is impossible, but that has not stopped us from expending tremendous amounts of energy trying”. He described the phenomenon as arising from social and economic factors, such as more money and more competition, to the point where children have become the latest status symbol for some parents. Within this context, life with a child with disabilities gives parents unique experiences, with unique joys and difficulties. Previous studies have revealed that mothers of children with Down syndrome face a variety of challenges throughout their children’s lives (Baum et al, 2008). They might experience emotions such as grief, depression, guilt and self-blame (Myers et al, 2009). The burden of caring for children with Down syndrome has been reported to contribute to maternal stress, and the parental function can be affected due to stress and pessimism about the future. While it cannot be disputed that the arrival of a child with a disability results in some distress for most family members, it may be argued that families also have the capacity to make the necessary adjustments and accommodations which are necessary to keep the family functional (Gallimore et al, 1993). There is emerging evidence that following an initial period of shock after the arrival of a child with Down syndrome, many families show evidence of coping during the subsequent stages of early and middle childhood (Mahoney et al, 1992). In fact, almost three decades ago, Hewett (1970) noted that following this initial period, many families make a remarkable adjustment to this situation and show extraordinary levels of resilience. This suggests that it may in fact be the presence of disability and the need to address the related demanding issues which results in the heightened resilience that many families experience (Bower, 1996). Bower et al (1998) found
in their research that the presence of a child with Down syndrome can no longer be seen as a universal catalyst for family difficulties or family dysfunction. They suggested that the ideas and beliefs of family members, including the extended family, need to be understood in order to appreciate how families cope with the challenges of parenting a child with a disability. However, a family may also require different levels of support to manage the demands required by specific health, behavioural and education needs of their child, of which they have little knowledge or experience.

Caring for a child with Down syndrome can be challenging and demanding. Families face unprecedented social and financial difficulties that are not well understood or evaluated by professionals. Previous studies reveal that mothers of children with Down syndrome face a variety of challenges (Gatford, 2001; Cuskelly et al, 2009; Chan et al, 2014).

Despite the incidence of Down syndrome in Kashmir, there is a dearth of research on the experience of local families, especially of the primary caregiver (mother) of a child with Down syndrome. Additionally, the effect on the caregiver’s life is not clear. Accordingly, this study focusses on exploring and mapping the qualitatively different experiences of mothers caring for a child with Down syndrome within the broader context of disability in Kashmiri society.

**METHOD**

**Approach**

This research employed a phenomenographic approach (Marton, 1981, 1986; Marton & Booth, 1997) to identify the qualitatively different ways in which mothers experienced the phenomenon of parenting a child with Down syndrome. While any phenomenon encountered by an individual may be infinitely complex, there are also a limited number of critical features that characterise any phenomenon. Phenomenography is a qualitative research method, used since the mid to late 1970s, that seeks to identify these key aspects in how individuals perceive, conceptualise and understand a particular experience (Marton, 1986). While the current study involved only a small sample, it provides an important example of how phenomenographic research can be used to study the experiences of families with special circumstances to identify the commonalities and variations in their experiences.
Study Sample
The mothers of children with Down syndrome were selected using purposive sampling technique from the selected special schools at Srinagar, in Jammu and Kashmir. The researchers contacted the school authorities to inform mothers of children with Down syndrome about the date of interview. The interview was conducted during their next visit to the special school. At the first interview the researchers obtained participants’ informed consent and permission to tape-record the conversation.

Only 8 children with Down syndrome were enrolled in the schools and all the 8 mothers of these children agreed to participate in the study. Participants ranged in age from 37 - 61 years, and the children’s ages ranged from 2 - 30 years.

Table 1: Participants’ Background Information

<table>
<thead>
<tr>
<th>Number of Participants (N=8)</th>
<th>Age Range (Years)</th>
<th>Locality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Mothers</td>
<td>Females</td>
<td>8</td>
</tr>
</tbody>
</table>

Data Collection
In-depth interviews were conducted in privacy, in a selected room in the special school, in Urdu and Kashmiri, the local languages. The purpose of the research study was explained and the interviews started with open-ended clarifying questions like, “Would you share with me your responses when you heard that your child has Down syndrome?”. The initial interview at the special school was followed by home visits. Each interview lasted for 40 - 70 minutes. The interview records were transcribed later on.

Data Analysis
Phenomenographic analysis is a holistic process. The critical features of the phenomenon (or phenomena) under investigation are represented as categories of description (Ryan, 2000; Åkerlind, 2002). The set of categories of description cannot be known in advance but emerge from the data. The categories of description represent the range of qualitatively different ways of experiencing the phenomenon in question.
RESULTS and DISCUSSION

A hierarchical thematic framework was developed and used to classify and organise data according to a key theme. The key theme that emerged from the narratives of research participants was the worry about the unpredictable future of the child. Furthermore, the theme is categorised into three sub-themes: School Placement, Work and Independent Living and Marital Life

Sub-theme 1: Worried about the Unpredictable Future of the Child (School Placement)

After diagnosis and realising the problems they faced, all the 8 participating mothers were confronted with the task of adapting to the positive and negative impacts of having a child with Down syndrome in the family. This theme captures the unpredictable future experiences and attitudes of the mothers “living with Down syndrome” and describes the perceived toll taken on their well-being.

The immediate challenge that mothers encountered was the child’s school placement after attaining the age of 3-4 years. Their concerns about their child being in school were: their child’s behaviour with other students and the teachers; and, how he/ she would be treated in the absence of the mother. Furthermore, mothers felt uneasy about the child’s self-caring ability, and the ability to earn a living and become independent. Looking ahead to the future, most of the respondents were worried about whether their child would be able to take care of himself or herself in later years.

“She worries whether her child will be able to go to school, behave normally with other mates in the school, and make friends” (M1, mother of a 3- year-old son).

“I am not interested in sending him to special needs school; I think he should not be separated from others” (M2, M8).

The proximate worry that mothers had was about the education system for their child with Down syndrome.

“I can’t send my child to school where normal children who are physically and mentally fit are admitted. Every school within the valley has its own criteria for admitting a new child in their schools. So far my child is concerned she doesn’t fall within the prescribed criteria of selection. This is the thing which hurts me like anything” (M3, mother of a 4-year-old daughter).
“My child with Down syndrome is not accepted in every school except for special schools” (M4, mother of a 3-year-old son).

Parents’ concern about whether their child would ever be able to achieve independence was based on their perceptions of their child’s poor education.

“I am anxious as he cannot speak and learn properly, but it is important to be educated for endurance in the society” (M5, M2, M8).

Rimmerman and Duvdevani (1996) in their study found that the age of a child with intellectual disability has also been found to predict parental stress levels. A family may experience greater stress when their child with intellectual disability enters school and parents become more aware of the achievement differences between their child and same-age classmates. Wikler et al (1981) in their study revealed that when the child enters school, more time and effort is needed on the part of the parent to help the child be successful. Additionally, as children get older, parents may not have access to information on how to cope with older children with intellectual disability.

Sub-theme 2: Worried about the Unpredictable Future of the Child (Work and Independent Living)

Another concern that mothers had was regarding their child’s ability to work and live independently once the child was older. Mothers felt uneasy about their child’s future.

“My son cannot walk properly; I doubt what his ability would be, what level of support would be required for him to walk” (M5, mother of a 3-year-old son).

Parents were worried that their child’s developmental delay would make it difficult for the child to get a job and become financially independent.

“The doctors told me that his mental development will be slow, he may not be able to learn properly like typical children do, it is difficult for him to get a job and live independently” (M1).

The stress factor that mothers discussed referred to the options available to their child once the child had joined school. Some mothers were concerned about their child’s ability to be independent and make complex decisions such as taking the bus or talking to strangers.

“The big stressor is her vulnerability to be able to solve problems and make important
decisions on her own; things like catching the bus and dealing with the people that are not known to her” (M6, M1).

On the other hand, mothers who had made plans for their child’s future, or were aware of transition and employment, were concerned about another aspect.

“My main concern is what will happen to him when I’m not around anymore, will he be able to cope in society, live independently and make a living” (M7, M3).

The major long-term stressors that mothers expressed were their fears about who would take over care of the child in the event of their death. Mothers were also concerned about planning ahead to ensure their child’s future happiness and independence.

“All love and care will be given to my child till he lives with me but the thing that I am most worried about is if I die before my child dies who will take care of him and will he be able to live independently” (M8, M4).

“I am concerned about her future when I won’t be around anymore” (M1, M7, M8, M5).

“I wish and pray to God that I live long enough and can take care of her till she is alive” (M7, M8, M1, M2).

“All the love and care will be given to child till they demand it but nobody knows about the life and death, who will die and when” (M3, M6, M4).

The Bureau of Labour Statistics (2010) reported that only 19.2 % of persons with disabilities were employed. Eight out of ten persons with a disability are not in the workforce at all. There is a wide variability in life outcomes for persons with Down syndrome. The new possibilities are not yet the norm, with much work still to be done. While a young mother worries and tries to prepare for her child’s future, life goes on with a young child with Down syndrome and shapes the family.

Sub-theme 3: Worried about the Unpredictable Future of the Child (Marital Life)

Almost all the mothers shared similar concerns about their child’s long-term future and reduced life expectancy; that they would not be able to complete higher studies, get married, have children and live a happy life. Mothers were very unhappy at the thought that their children would not be able to experience significant events and lead a happy life like normal families.
“Because of her limited life experiences neither she would go to college nor she will get married” (M5).

“Dream of becoming grandmother has shattered forever, as he cannot marry and have children” (M1).

“I don’t know whether he will marry and have children” (M4, M8, M5).

“I know he cannot become a father and I won’t be able to become a grandmother” (M3, M7, M1, M8).

“I don’t know what will happen to her in future, I believe in written destination” (M3, M5, M8).

Some of the parents hoped that their child would find some means of earning a living and lead a normal life by getting married.

“I hope that he will learn some skills so that he may work to help him live his marital life and have children” (M2).

“Unlike normal children my child is having intellectual disability; it is quite clear that he cannot live independently nor can he marry” (M4).

A qualitative study was conducted by Graunngard and Skov (2007) on parents' experiences, coping and needs, when their newborn child had severe disability. Results showed the certainty of the diagnosis was central to parents' experiences. First, the emotional reactions of the parents were highly influenced by the diagnostic process, and secondly they found difficulty in coping with an uncertain future. It can be a very difficult and trying time for families who have just found out that their baby has Down syndrome. They would have many questions, concerns and fears about the future, so adequate support groups and other help-lines should be provided for families of children with disability.

CONCLUSION

The aim of the study was to explore the experiences of mothers who are raising children with Down syndrome and how they have adjusted in different areas of family life following a diagnosis.

There are a lot of challenges for parents in bringing up their children with Down syndrome. Parents have to spend a lot of time in order to meet the needs of these children and tend to neglect the other children in their family. Participants
became anxious and worried when their children did not develop speech, and when behavioural problems became difficult to manage. The findings that emerged from this study were that mothers of children with Down syndrome experienced high levels of stress and often had to make adjustments that affected their careers, finances and lifestyles.

It was found that the school-based clinic was another route for children with Down syndrome to receive primary healthcare as well as physical and behavioural healthcare using multidisciplinary teams of nurses, practitioners, doctors, psychologists and social workers.

There is a need for training programmes to help parents to cope with the problems that their children with Down syndrome face. Stakeholders in the education sector should devise a wide range of programmes aimed at meeting the needs of these parents.

The concerns revealed by most of the parents in this study support the common perception that people with intellectual disability and their families experience burdensome lives. Feelings of sadness were reported by mothers caring for children with Down syndrome; they were generally worried about their child’s future, including aspects of study, employment and marital life in the future. They also explained the differences between their own situation with their child as compared to other children with Down syndrome, and also with families who led a normal life.

**ACKNOWLEDGEMENT**

The authors would like to place on record their gratitude to Indian Council of Social Science Research, New Delhi for supporting this research endeavour and to all the research subjects who contributed to the accomplishment of this study.

**REFERENCES**


Competencies of Students with Visual Impairment in using the White Cane in their Learning Environment: a Case Study at Wenchi Senior High in Ghana

Frank Twum1®, Wisdom Kwadwo Mprah1, Anthony Kwaku Edusei1, Joseph Ampratwum1, Isaac Adu Gyamfi1
1. Kwame Nkrumah University of Science and Technology, Ghana

ABSTRACT

Purpose: This study investigated the competencies of students with visual impairment at Wenchi Senior High School, Ghana, in familiarising themselves with their learning environment using the cane.

Method: A case study design was adopted for the study. A mixed method approach was utilized in this study. A quantitative approach was used to assess students’ competencies in using the cane while qualitative approach was adopted to probe challenges related to using the cane.

Results: Students had reached higher stages on the Conscious Competence Matrix and were by and large competent in using the white cane in their learning environment. However, personal and environmental factors were marring their progress. The personal factors included difficulties with fine motor skills and onset of blindness. The external factors were lack of mobility trainers and canes, as well as barriers within the physical environment. There is generally a positive correlation between onset of visual impairment and specific cane skills.

Conclusion and Implications: It is recommended that resource persons devote more time to developing the competencies of students in cane techniques, especially in skills related to identification of obstacles. Modifying the physical environment, as well as providing more canes and additional mobility trainers, will be useful in facilitating the movement of visually impaired students within the school.

Limitations: A major limitation is the lack of objective assessment of residual vision and motor impairment. Residual vision likely played a crucial role during the competency test.

* Corresponding Author: Frank Twum, Department of Community Health, Kwame Nkrumah University of Science and Technology, Ghana. Email: frankmaxi29@gmail.com
**Key words:** Assistive technology, residual vision, Conscious Competence Matrix

**INTRODUCTION**

There is worldwide concern about restrictions in the movement of persons with visual impairment. Due to poor vision and the likelihood of misinterpreting their relative position in space, they often find it difficult to orient themselves to other people or objects in the environment. Consequently, many persons with visual impairment lack the confidence to move around their environment independently (Crudden et al., 1999).

The white cane is an important assistive device utilized by persons with visual impairment to access their environment. It has many proven benefits, such as improved confidence to travel independently, ease of interactions with the general public and increased safety during travel (Vision Aware, 2016). The cane, as an assistive technology, has had the greatest impact in terms of success in the education and employment of visually impaired persons (Gamble and Dowler-Hirsh, 2004). Thus, it enhances the individual and social life of persons with visual impairment and also promotes their education in inclusive settings (United Nations Economic, Social and Cultural Organisation - UNESCO, 1994). Despite the paucity of research on the number of visually impaired persons who use the white cane, it is generally acknowledged that very few use the white cane for familiarisation with the physical environment (Sah, 2010). Documented reasons for the low usage include difficulty in keeping the cane out of other people’s way when not in use, difficulty in stowing it in a car, and an increased risk of being a target for persons who would want to take advantage of the visually impaired (National Federation of the Blind, 1995). In some instances, these challenges have compelled some visually impaired persons to abandon the cane as an assistive technology (Philips and Zhao, 1993).

The ability of students with visual impairment to move about independently in their environment is one of the primary goals in their total educational development, as it enhances their participation in mainstream society (Wong and Cohen, 2008). The cane comes with a handle, shaft and a tip that allows persons with visual impairment to navigate their environment. Primarily, it is used in identifying obstacles, landmarks, cues and clues within the immediate surroundings. To the best of the researchers’ knowledge, this is the first study...
aimed at measuring the competency of visually impaired persons (students) in the use of the white cane.

Several factors affect competence in the use of the white cane by persons with visual impairment. These can be classified into personal and environmental factors. Personal factors involve the level of training, onset of blindness, fine motor and gross motor skills, as well as choice of length of cane (Miller, 2002). Higher level of training with the white cane, early onset of blindness, and good fine and gross motor skills are likely to enhance effective use of this device. In general, longer canes enhance competence in familiarisation as opposed to shorter ones (National Federation of the Blind, 1995). Environmental factors that influence competency in the use of the white cane include the presence of physical barriers, and may range from the absence of walkways to overcrowded locations (Mettler, 2008).

The cane promotes independent movement for students with visual impairment, especially in a school setting where limited personal assistance is offered (Martinez, 2005). In order to participate fully in academic pursuits, it is essential for such students to be adept in cane usage techniques. The appropriate use of the white cane is therefore crucial to students with visual impairment in familiarising themselves in inclusive education settings (Sah, 2010).

The Conscious Competence Model explains the process and stages of learning a new skill (or behaviour, ability, techniques). It is a useful reminder of the need to learn and train others in stages. The Conscious Competence Learning Model often comes in 4 stages, though occasionally a fifth stage or level is added in more recently adapted versions. The learner or trainee always begins at stage 1 – ‘unconscious incompetence’ - and ends at stage 4 – ‘unconscious competence’, having passed through stage 2 – ‘conscious incompetence’ - and stage 3 - ‘conscious competence’. At stage 1, the trainee is not aware of the skill existence, nature, relevance, deficiency, and benefit offered by the acquisition of the new skill. Stage 4 is the highest level of competence where the trainee has internalised all aspects of the new skill (Pateros, 2016).

**Objective**

The specific objectives of the study are to assess the competence of students in cane techniques, ascertain if there is a correlation between onset of visual impairment and competency level, as well as establish the challenges associated with the use of the cane for familiarisation within the school.
METHODS

Study Design and Approach
A case study design was adopted. A quantitative approach based on the conscious competency model was used to collect information on the competence of participants in the use of the white cane, while a qualitative approach that utilized a semi-structured questionnaire was used for the assessment of challenges involved in cane use.

Setting
Wenchi Senior High School is located in the town of Wenchi, in the Brong-Ahafo region of Ghana. The school has a total student population of 1,400. It was one of the pilot schools for inclusive education at the senior high level and has sustained the practice over the past 8 years. Visual impairment and mobility impairment are the major forms of disability among students admitted to the school. Various resource persons are employed to assist in the management of students with disabilities. Facilitators provided by the school include white canes, ramps and rest zones with seats.

Study Population and Sample
The study population consisted of all visually impaired students of Wenchi Senior High School. Major inclusion criterion was that the participant ought to have spent at least a year in school.

Table 1 represents the demographic characteristics of participants. A total of 35 participants completed the study, with nearly two-thirds being males. The vast majority of participants had no upper limb motor impairment. Nearly half of them had residual vision.

Table 1: Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean/Frequency (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean ± SD)</td>
<td>16.7 ± 2.9</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (62.9%)</td>
</tr>
<tr>
<td>Female</td>
<td>13 (37.1)</td>
</tr>
</tbody>
</table>
Sampling Technique
A sampling frame consisting of all 60 visually impaired students was constructed. Simple random sampling was used to select 35 participants from the sampling frame. This was done using the Stata syntax “sample 58”. Stata automatically selected 35 participants from the list of 60 by simple random sampling without replacement.

Data Collection
Data collection, using participant observation on a test and a semi-structured questionnaire, was done within the school premises. The Competency test scoring was done by the researchers concurrently as a student performed a specific test. Competency was measured by observing the positioning of the white cane relative to the floor, ability to swing the cane on a test trip to the school dispensary, and ability to identify obstacles with the cane. Positioning of the cane was scored based on efficient grip, angle of orientation of cane relative to the participant’s body, and the angle of orientation of cane relative to the ground. Ability to identify obstacles was scored based on time spent to identify the obstacle as well as an accurate determination of the obstacle. Cane swinging in this context refers to the ability to move the cane to the alternative side (right or left) when a particular leg (right or left) is in the mid-stance phase of walking. It was scored based on the angle of sweep to the alternative side and coordination relative to the body. Scoring of competency on the Conscious Competence Matrix for each student was done simultaneously by three researchers, to ensure consistency.

<table>
<thead>
<tr>
<th>Year Group</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Second</td>
<td>20 (57.1%)</td>
</tr>
<tr>
<td>Third</td>
<td>15 (42.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reported Limb Motor Impairment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Present</td>
<td>5 (14.28%)</td>
</tr>
<tr>
<td>Absent</td>
<td>30 (85.71%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residual Vision</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>17 (48.57%)</td>
</tr>
<tr>
<td>No</td>
<td>18 (51.43)</td>
</tr>
</tbody>
</table>

| Time of Onset of Visual Impairment (Years) | 4.1 ± 4.3 |
A semi-structured questionnaire was administered to the students to assess challenges related to the use of the white cane within the school. Questions focused on the nature of the school environment, the nature and number of available canes, motor skills of students and the number of resource personnel in the school. All participants were subjected to the competency test and completed the semi-structured questionnaire as well.

Validity of the questionnaire was ensured by paraphrasing questions to be consistent with research objectives. Ensuring validity of the practical test involved repeated scoring of the same participant by different researchers.

**Data Analysis**

Data was analysed using Stata version 12. Continuous numeric variable was summarised using mean and standard deviation. Categorical variables were summarised by frequency counts and percentages. Spearman’s rank correlation analysis was used for the test of correlation between onset of blindness and competency scores (positioning of cane, ability to swing cane, ability to identify obstacles). Scores of 80% and above, 70% - 79%, 60% - 69%, 50% - 59%, 45% - 49%, 39% and below, correspond to stages 4 - 1 respectively on the aforementioned Matrix. Open-ended questions from the semi-structured questionnaire were analysed based on thematic content that utilised colour codes.

**Ethical Considerations**

Ethical approval was sought from the Committee on Human Research, Publications and Ethics, Kwame Nkrumah University of Science and Technology, School of Medical Sciences. Respondents signed an informed consent form before enrolling in the study.

**RESULTS**

**Components of Cane Technique Competencies and their Scores**

**Positioning of the Cane**

Table 2 presents the ranking of students on positioning of the cane. Majority of the students (60%) were able to position the white cane ‘excellently’ from the starting point. Based on their performance in line with the Conscious Competence Matrix,
these students were judged as having attained ‘unconscious competence’, and are thus at stage 4 within the Conscious Competence Matrix. One-fifth of the participants scored ‘very good’. This group had attained ‘conscious competence’ with positioning of the white cane. In addition, one-fifth of all participants scored either ‘good’ or ‘average’; they were deemed as ‘consciously incompetent’ and ‘unconsciously incompetent’ respectively.

Table 2: Ranking of Students on Positioning of the Cane

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Frequency (n=35)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>21</td>
<td>60.0</td>
</tr>
<tr>
<td>Very good</td>
<td>7</td>
<td>20.0</td>
</tr>
<tr>
<td>Good</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Average</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 3 below indicates that there is a positive correlation between onset of blindness and competence in positioning the cane. The associated P-value indicates that the association between the two variables is statistically significant.

Table 3: Correlation between the Onset of Visual Impairment and Scores related to Positioning of Cane

<table>
<thead>
<tr>
<th>Number of observations (n)</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman’s rank correlation co-efficient</td>
<td>0.57</td>
</tr>
<tr>
<td>P-value</td>
<td>0.00</td>
</tr>
</tbody>
</table>

Ability to Swing the Cane on a Test Trip to the Dispensary

Table 4 represents the ranking of the students in swinging the cane on a test trip to the school dispensary, using the correct techniques. The scores indicated that less than half of the participants were able to swing the cane ‘excellently’ using the correct techniques; they were therefore perceived to have reached the ‘unconscious competence’ stage. Less than 20% of participants scored ‘good’ or ‘average’; they were deemed as ‘consciously incompetent’ and ‘unconsciously incompetent’ respectively.
Table 4: Ranking of Students on Ability to Swing the Cane

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Frequency (n=35)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>16</td>
<td>45.7</td>
</tr>
<tr>
<td>Very good</td>
<td>13</td>
<td>37.1</td>
</tr>
<tr>
<td>Good</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Average</td>
<td>2</td>
<td>5.7</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 5 below indicates there is a positive correlation between onset of blindness and competence in cane swinging. The associated P-value indicates the association between the two variables is statistically significant.

Table 5: Correlation between Onset of Visual Impairment and Scores related to Swinging of the Cane

<table>
<thead>
<tr>
<th>Number of observations (n)</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman’s rank correlation co-efficient</td>
<td>0.69</td>
</tr>
<tr>
<td>P-value</td>
<td>0.00</td>
</tr>
</tbody>
</table>

Identification of Obstacles

On competence in identifying obstacles, only 11.4 % of the students scored ‘excellent’. Over a quarter of the participants scored ‘very poor’; they were perceived as ‘unconsciously incompetent’. Less than 30% of all participants scored either ‘very good’ or ‘good’.

Table 6: Ranking of Students on Ability to Identify Obstacles with Cane

<table>
<thead>
<tr>
<th>Ranking</th>
<th>Frequency (n=35)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>4</td>
<td>11.4</td>
</tr>
<tr>
<td>Very good</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>Good</td>
<td>8</td>
<td>22.9</td>
</tr>
<tr>
<td>Average</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td>Poor</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Very poor</td>
<td>9</td>
<td>25.7</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>100</td>
</tr>
</tbody>
</table>
There is a strong positive association between onset of blindness and scores related to identification of obstacles by participants. The associated P-value indicates the aforementioned association is not due to chance (see Table 7).

**Table 7: Spearman’s Rank Correlation between Onset of Visual Impairment and Scores related to Identification of Obstacles**

<table>
<thead>
<tr>
<th>Number of observations (n)</th>
<th>35</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spearman’s rank correlation co-efficient</td>
<td>0.7026</td>
</tr>
<tr>
<td>P-value</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**Challenges in the Use of the White Cane**

A number of challenges conspiring against the students’ effective use of the cane were identified. These challenges have been categorised under 6 broad thematic areas: the unfriendly nature of the school environment, nature of the canes, inadequate canes, poor motor skills, and inadequate resource personnel.

**Unfriendly School Environment**

The students asserted that due to the absence of landmarks they found it difficult to identify their starting point, that is, their exact point of location at a particular time, and how to get to their designated destination. Furthermore, participants bemoaned the fact that there were no handrails to give extra stability when using the cane to negotiate staircases. They were equally frustrated about the nature of some of the roads. For example, the road leading from the boys’ dormitory to the resource room was not tarred, and this made it extremely difficult to use the cane.

**Nature of the Canes**

Challenges related to the nature of the canes included canes not being collapsible and being fragile. Some of the students indicated that because the canes were not collapsible, they found it difficult to fold them when entering their classrooms. A related challenge raised by the participants was that the fragile nature of the canes resulted in frequent breakages. Additionally, the handles of some of the canes were so worn out that they sometimes hurt the palms of the users. Most students admitted these challenges discouraged them from using the white cane on a regular basis and subsequently impacted their competence negatively.
Inadequate Number of Canes
Another major challenge was the inadequate number of canes in the school. At the time of the study, there were only 18 canes for 60 visually impaired students in the school.

Lack of Fine Motor Skills
Some respondents had difficulty in executing cane techniques due to a lack of fine motor skills. This made them clumsy in using the cane. Fine motor skills refer to the ability to undertake movements that involve small muscle groups such as using the fingers to grip (Kid Sense, 2016).

Inadequate Resource Persons
There were just 4 resource persons responsible for training and assisting 60 visually impaired students. In addition to assisting visually impaired students, the resource persons had other duties which made them rarely available to train the students.

Strategies to Address Challenges
A number of strategies have been adopted by the resource persons in the school to eliminate the challenges that affect students’ competence in the use of the cane.

The first strategy involved regular training in the morning, supervised by the resource persons, to enhance students’ competence in the use of the cane in terms of handling and positioning. A second strategy was aimed at addressing challenges associated with identifying obstacles within their learning environment. This involved identification of obstacles within a specific area of the learning environment and familiarising students with the location of these obstacles. The resource persons changed the site of this activity once students had become familiar with a particular area of the learning environment.

DISCUSSION
Assistive technology is an expansive term that encompasses both assistive technology devices and assistive technology services (Alper and Rahrinna, 2006). Specifically, an assistive technology device refers to any equipment or product system that may be customised or acquired off-the-shelf and used to maintain or improve the functional capabilities of persons with disabilities (Sah, 2013). The
white cane is an essential assistive technology device which allows for independent travel by the visually impaired (Vision Aware, 2016). The ability of students with visual impairment to move about independently in their environment is one of the primary goals in their total educational development (Wong and Cohen, 2008) and the white cane is undoubtedly crucial for this function.

If students with visual impairment are able to exercise control over their movement, it will lead to greater independence, increase their self-sufficiency as well as enhance their self-esteem (Smith, 2008). This will increase their participation in school activities and, subsequently, enhance their academic performances. Thus the findings indicating that students were competent in the use of the white cane in terms of positioning and swinging ability, suggest that many of these students are likely to have some level of autonomy in movement which will enhance their inclusion and participation in school activities. This deduction is consistent with the assertion of Vision Aware (2016) that cane positioning and swinging ability were vital for independent ambulation by the visually impaired. However, this autonomy in movement is threatened by the fact that most students could not accurately use the white cane to identify obstacles in their environment. This inability implies they were prone to bumping into obstacles or tripping, with the possibility of sustaining physical injuries that could interrupt their academic work, or more importantly, endanger their health. A primary reason for this could be the insufficient number of canes in the school. Each student was able to practice identifying obstacles with the cane only because they took turns during the training exercise. However, as the findings indicated, there are few canes compared to the number of students in the school. Consequently some students are unlikely to get the opportunity to practice identification of obstacles with the cane in real campus situations. The lack of landmarks within the school premises is a likely contributor to the difficulties associated with identifying obstacles, as landmarks often give a clearer indication of where to navigate. Fine motor skills enhance an individual’s ability to initiate and maintain a good grip which is essential in using the white cane (Miller, 2002). Visually impaired students without these skills are likely to have difficulties using the white cane. Although motor impairments of students could contribute to poor performance in the identification of obstacles, the condition is not widespread enough to affect most students as just about 14% of them reported motor impairment. A related factor is how consistently orientation and mobility skills are taught in the school. The few resource personnel in the school may be unable to provide adequate orientation and mobility lessons for the students. This may be compounded by
the limited time available for the training, and the tendency to focus more on academic activities.

The varied performances of the students relative to positioning and swinging of the white cane reaffirms that it should not be presumed that all students have learned basic orientation and mobility skills. Mobility and orientation skills for the visually impaired students are often incorporated in the academic curriculum, starting from the basic school level in inclusive education settings. Thus there is a strong tendency for educators and resource persons at the higher educational level (senior high level, in this case) to presume that students have mastered the aforementioned skills.

The positive correlation between onset of visual impairment versus scores related to positioning, swinging, and ability to identify obstacles with the white cane, is an indication that students who acquired visual impairment later in life were generally more competent in using the cane than students who acquired visual impairment at an earlier stage. This is unexpected as students with earlier visual impairment are expected to have better adaptation to assistive devices compared to those who acquire visual impairment at a later stage (Kotain and Sharma, 1999). A possible reason for this could be the presence of residual vision among those who acquired visual impairment at a later stage. Residual vision is likely to enhance grip, angle of orientation of cane relative to the body as well as orientation relative to the ground, upon which cane positioning was scored. An alternative explanation could be the fact that students with previous vision were likely to have better perceived objects and situations related to positioning of the cane, relative to students with congenital blindness. Thus they retain these experiences in spite of their present visual impairment, giving them an added advantage over students who had congenital blindness, in terms of positioning of the cane.

The lack of universal design in the physical environment of the school implies that students are likely to encounter challenges in the use of the white cane. Universal design allows for the presence of facilitators within the environment as well as reduction of obstacles that are likely to impede the movement of visually impaired students. Students unable to overcome this challenge are likely to depend on sighted students for mobility on campus. This dependence has repercussions. Such students are likely to be stranded on the days that their guides do not show up, hampering their academic endeavours.
The fact that canes are not collapsible implies that students were likely to encounter difficulties in areas with restricted space. Long, projecting canes could pose a nuisance in crowded student areas such as the dining hall, assembly ground and, most importantly, the classroom. Thus the long-term effect is that students are likely to abandon the cane when attending school gatherings, subsequently hampering their movement. This corroborates the assertion of Phillips and Zhou (1993) that a change in need or priorities of persons with disabilities could lead to the abandonment of an assistive device. While the non-collapsible canes would have posed few problems in a home setting, the opposite is the case in a school setting.

Fragile canes and worn-out handles have the potential to cause physical injury to visually impaired students. Such incidents may discourage students from using the canes, leading to a loss of independence in mobility and its attendant deleterious consequences. These issues are further compounded by the absence of sufficient number of canes, which suggest there is a lot more pressure on the few available. Consequently, a vicious cycle sets in, where more canes are likely to wear out, making an already bad situation worse.

Overall, the strategies adopted by the school to enhance the use of the white cane are likely to have a positive effect in the longer term. Regular training regimens to improve students’ skills in identifying obstacles within the learning environment are likely to enhance their use of the white cane.

Wenchi Senior High School is one of the three senior high schools in the country that currently practice inclusive education. The challenges discussed earlier are inherently associated with inclusive education in Ghana. Thus, despite the numerous policies brought forth to promote inclusive education, significant challenges remain to be overcome if inclusive education is to succeed.

CONCLUSION

Higher competencies were observed in terms of cane positioning skills and ability to swing the cane. However, in terms of identification of obstacles in the learning environment, majority of the students were either ‘consciously’ competent or incompetent as per the scores based on the Conscious Competence Matrix. The positive correlation between onset of visual impairment and the various competencies measured is likely attributable to the presence of residual vision in some students. Challenges militating against students’ competence in cane techniques in the school cut across personal and external factors.
Implications

Findings from the study have implications for inclusive education that is currently being implemented in Ghana. The findings revealed some of the challenges students with visual impairment encounter when using an important assistive technology in an inclusive setting. These findings point to the need for adequate preparation in terms of provision of resources, both human and material, redesigning the built environment to make it suitable for all students, and training students to master the use of the assistive technologies they need in order to fully participate in the inclusive education setting.

In the case of the school compound, it is recommended that there should be well-demarcated areas to ensure that positions of obstacles are more predictable. This will likely enhance students' ability to identify obstacles. Further to this, a school environment with incorporated universal design will ensure the presence of facilitators such as handrails that would make it easier to use the cane.

It is suggested that more practice time be allocated to enable students to familiarise themselves with the school's environment. Further to this, the training approach with regard to the identification of obstacles needs to be re-examined. For example, assigning resource persons to handle specific training regimens related to identification of obstacles will yield better results in all likelihood.

REFERENCES


**Teacher Trainees’ Perceptions of Inclusion of and its Challenges**

Krishna Duhan*, Chandrika Devarakonda

1. Department of Human Development and Family Studies, College of Home Science, CCS HAU, Hisar, Haryana, India
2. Senior Lecturer, Faculty of Education and Children Services, University of Chester, Chester, CH1 4BJ, London, UK

**ABSTRACT**

**Purpose:** Teachers’ perceptions of inclusion could differ in relation to their knowledge and understanding of inclusion at different stages of the teacher training programme. This paper explores associate teachers’ perceptions of the concept of inclusive education in 21st century England.

**Method:** A group of participants (n=126) in a teacher education course at Chester University, UK, were asked to represent their understanding of the concept of inclusion within the local context. A self-developed questionnaire was used to collect data.

**Results:** Analysis revealed that many teachers had struggled to understand and operationalise inclusion as: everyone included in education under the same roof (57.89 %); catering to individual needs (22.8 %); and, everyone getting equal rights and opportunities (19.3 %). For 85% of respondents the understanding of inclusion came from their school-based learning, for 70% it was from modules, research and discussion, and for 22% it was through lectures and seminars.

**Conclusion:** A shift in conceptualisation of inclusion was observed at different levels during the training. It is therefore recommended that orientation training of policy-makers and education department officials, both at the state and block levels, be conducted.

**Keywords:** Special education, inclusion, disability, integration.

**INTRODUCTION**

Inclusion has become a political and philosophical movement all over the world. All students, regardless of their diverse abilities and backgrounds, are recognized as part of the school community. In an inclusive model, the education
of students with exceptional needs alongside their peers in the general classroom is the first placement option to be considered. From a theoretical perspective, the principle of inclusion is based on the assumption that the general classroom teacher not only ‘includes’ the student physically in the classroom setting, but also delivers effective, individualized instructional programmes (Winter, 2006; Westling, 2010). Consequently, general classroom teachers are increasingly faced with the challenge of meeting a wide range of student needs through inclusive practices. More than ever before, classroom teachers are required to understand exceptional needs, manage a diverse classroom, make appropriate accommodations for individual students, and collaborate with parents, staff, and other paraprofessionals. Since the general classroom teacher is pivotal to the success of inclusive education (Stanovich and Jordan, 2002; Forlin et al, 2009), it is very important that teacher educators consider effective ways of preparing pre-service teachers for inclusive teaching.

Defining Inclusion

What is meant by ‘inclusion’?
The Salamanca Statement (UNESCO, 1994) strongly advocates that:

Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

An educationally inclusive school is one in which the teaching and learning, achievements, attitudes and well-being of every young person matter. This does not mean treating all pupils in the same way. Rather it involves taking account of pupils’ varied life experiences and needs. They identify any pupils who may be missing out, difficult to engage, or feeling in some way to be apart from what the school seeks to provide (Office for Standards in Education - Ofsted, 2000).

Education for All (EFA)
The 2009 Global Monitoring Report drew attention to some positive and inspiring national and regional performances. For example, the UNESCO’s Courier Special Issue (2008) succinctly summarizes that:
An estimated 75 million children of primary school age worldwide are currently out of school with partial projections suggesting that at least 29 million children will still be missing out on their right to an education in 2015. A further 776 million adults, or 16% of the world’s population, lack even basic literacy skills. Two-thirds of these are women.

Hastings and Oakfords (2003) explored the impact of special needs category (intellectual disabilities versus emotional and behavioural problems) and student teachers’ training (being trained to work with either younger or older children) on their attitudes towards inclusion. The results of the study revealed that the majority of the domains of student teachers’ attitudes towards inclusion measured by the IIQ were affected by the nature of the special needs of children considered as candidates for inclusion. Children with emotional and behavioural problems were rated as likely to have a more negative impact on other children, the teacher, and the school and classroom environment. Attitude research in the special needs field in general has found that experience or contact with special needs typically has a positive effect on attitudes in a wide variety of samples (Beh-Pajooh, 1991; Hastings & Graham, 1995). In keeping with this pattern of findings, teachers’ attitudes towards inclusion of children with special needs have been found to be positively associated with their non-working experience of special needs (Harvey, 1985). However, those with more years of teaching experience have been found to express more negative inclusion attitudes (Center & Ward, 1987; Soodak et al, 1998).

Hodkinson and Devarakonda (2011) studied the development and operation of a system of inclusive education in England during the latter part of the 20th and the beginning of the 21st century. Teachers’ perceived that inclusion meant involving all students who are in a learning environment in the experience, and ensuring that they get the best possible outcome from that experience. Although relating that inclusion referred to a range of pupils, the teachers mainly conceptualised it in terms of children with physical disabilities or behavioural difficulties. For many of these teachers, inclusion centered on whether such children could or indeed should be included in mainstream education.

Phillipson and Forlin (2011) explored the use of visual imagery as a strategy for gaining a greater understanding of diversity and inclusion within regular schools from the perspectives of 118 newly-qualifying teachers in Hong Kong. Dyads or small groups of teachers participating in a teacher education course were asked to represent their understanding of the concept of inclusion within
the local context by using a visual imagery approach. Use of visual imagery was found to be an innovative and engaging way to prepare teachers for inclusive education.

Avramidis and Norwich (2002) concluded that although most teachers held positive attitudes on inclusion, feelings of unpreparedness were associated with factors such as including students with severe learning difficulties and behavioural/emotional disorders, as well as a lack of resources, support, and teacher training. The researchers concluded that pre-service training should be a top priority for policy-makers, in order to equip future teachers with the skills required to implement inclusive practices. Hodkinson (2005) conducted a qualitative study in England with 80 pre-service teachers, and found that through inclusion training the participants had a good understanding of inclusive education theories; however, their understanding of the practical delivery was limited. Another study of 120 pre-service teachers in the UK had similar findings (Richards and Clough, 2004). Avramidis et al (2000), in their study of 135 pre-service teachers in the UK, noted that participants lacked confidence in their practical ability to effectively meet diverse student needs, while expressing specific concerns about their preparedness for teaching students with severe behavioural problems.

Jobling and Moni’s (2004) Australian study included interviews with 13 participants, all of whom revealed that they lacked experience, knowledge, and understanding related to teaching students with special needs. The participants felt that more experience and time to put their knowledge and skills into practice would improve pre-service training for inclusion. In addition, Moore-Hayes’ (2008) study with 350 pre-service and beginner teachers in Canada, reported that participants cited the need for more preparation and experience in order to feel equipped to work with students with disabilities. In a study in Mexico, Forlin et al (2010) investigated the perceptions of 286 pre-service teachers and found that most were generally convinced about benefits of inclusion; nevertheless, they continued to demand more experience, training, and support to improve their preparedness for teaching students with exceptional needs. Additionally, in another study conducted by Forlin and Chambers (2011) with 67 pre-service teachers in the USA, the researchers discovered that a unit of study in inclusive education, when combined with applied experiences with a person with disabilities, increased pre-service teachers’ knowledge while also increasing their levels of stress in teaching students with disabilities.
The review by European Agency for Special Needs Education (EADSNE) on teacher education for inclusion in Europe, found that teacher educators lacked "knowledge, understanding, commitment and experience" to teach about inclusive education, yet there is generally no formal induction for teacher educators on this subject. Forlin (2012) highlights this point and states that it is unrealistic to expect teacher educators to use innovative approaches when they have had no preparation themselves. Similarly, reviewing the Indian literature on training for inclusive education, Singal (2005) found there was an over-emphasis on conceptual theoretical models and not enough on practice in schools.

Pre-service teachers who have had regular and systematic course contact with persons with disabilities are more likely to feel positive about including students with disabilities (Sharma et al, 2008). If teachers leave training with negative attitudes towards inclusion, these attitudes can be very difficult to shift (Al Zyoudi et al, 2011). Studying policies and knowledge about inclusion does not necessarily address teachers' apprehensions about inclusion (Forlin and Chambers, 2011), but being exposed to people with disabilities would help.

Hodkinson's (2005) critical analysis of newly-qualified teachers' knowledge and understanding of inclusion explored whether one year's experience of the practicalities of inclusion had altered the participants' conceptualisation of inclusive education. The study suggests that NQTs' conceptualisation of inclusive education is mediated by prolonged classroom exposure to the harsh realities of educational practice. A conclusion forwarded by this research is that a teacher's first year of employment has the potential to negatively affect the teacher's support for the policy of inclusion. However, it is important to note that despite many problematic experiences of inclusion, NQTs do not, in the main, consider that the policy of inclusive education should be withdrawn.

Objective

The purpose of this paper was to explore how the perceptions of associate teachers might differ in relation to their knowledge and understanding of the concept of inclusion at different stages of the teacher training programme. The researchers believe that different understandings of inclusion should be seen, to a large extent, as expressions of different views of what schools should accomplish. The research objective was to find answers to three questions:

1) How do associate teachers and newly qualified teachers (NQTs) define inclusive education?
2) What are the concepts of inclusion held by associate teachers at different stages of their teacher training programme?

3) What are the opinions of associate teachers (ATs) about their preparedness to work with children from diverse backgrounds?

METHOD

Sample
In order to explore the possible change in perceptions of associate teachers in relation to their knowledge and understanding of the concept of inclusion at different stages of the teacher training programme, qualitative research method was adopted to gather data from newly-qualified teachers and Inclusion Teacher Education (ITE) students of the Faculty of Education and Children’s Services, at the University of Chester, UK.

ITE students of the first, third and fourth years, as well as newly-qualified teachers (NQTs) were included in the study. Questionnaires were distributed to 125 first-year students, 86 third-year students’ and 95 fourth-year students at Chester University and to NQTs who came to attend a two-day workshop. However, only 69 questionnaires from first-year students, 57 from third-year students, and 2 from NQTs were received. There were none from the fourth-year students. Thus the study sample numbered 126 respondents at the final count.

Tool
A questionnaire was developed to get answers from the ITE students on the three research questions.

There were some open-ended questions and a few questions about their concept of inclusion.

Data Collection
A research application was first submitted for approval to the Faculty’s research Ethics Committee, along with a copy of the questionnaire, participation sheet and consent form.

Subsequently the printed questionnaire was distributed to all the three groups of students. The students were briefed about the research project and were
provided with a participation sheet that contained additional information about the research and mentioned the implications of participation. A consent form had to be signed by those who decided to fill in the questionnaire.

**Analysis**

The responses to the questionnaire were analysed using thematic analysis, following Braun and Clarke (2006) who developed six phases of thematic analysis. All the responses were read and re-read to familiarise the researchers with the data.

Phase 1: Familiarisation with the data  
Phase 2: Generation of initial codes  
Phase 3: Search for themes  
Phase 4: Review of themes  
Phase 5: Defining and naming themes  
Phase 6: Producing the report

**RESULTS and DISCUSSION**

Frequency and percentages were calculated and results are interpreted question-wise.

**1. Definition of Inclusion**

The definition of inclusion for 43.47% of first-year participants was that everyone is included regardless of race, gender, creed, ability or disability, while 36.23% defined it as being involved in group activities. A small 5.79% of participants also defined inclusion as providing equal opportunities to all, irrespective of race, gender, ethnicity, to feel involved in community; and they reportedly did not understand inclusion as they had just joined the course. Furthermore, around 53.62% did not answer / did not understand the meaning of inclusion, of which 34.78% justified that they were newly enrolled in the programme and had no idea of inclusion. The results are inconsistent with the findings of Clough and Garner (2003), according to which there was no understanding of inclusion due to lack of knowledge, lack of will, lack of vision, lack of resources and lack of morality.
Third-year participants defined inclusion in wider ways. More than half of them or 57.89% stated that inclusion means everyone included in education under the same roof and, according to 22.8%, catering to individual needs. Furthermore, 19.3% also stated that inclusion means everyone given equal rights and opportunities.

2. Which aspects of your course enabled you to develop your understanding about Inclusion?

Majority of the first-year participants (88.4%) had no idea about inclusion as they had recently joined the programme, and their concept of inclusion was not the result of their course and was not relevant to the course (13.04%).

The third-year participants learnt the concept of inclusion in the course of training / studying modules, discussion in classroom situation and research (70%). Majority of them (85%) also gave credit to school-based learning which clarified their concept of inclusion. A good percentage of respondents (22%) also gave importance to lectures and seminars during the course of their training, which had helped to develop the concept.

3. Is inclusion important?

It was stated by 24.63% of first-year participants that inclusion is important as it ensures equal treatment opportunities and equality. No child feels segregated and unwanted, but feels included in class, according to 18.8%. It also boosts equality, self-esteem and independence (15.78%). It also strengthens social feelings/sense of belonging in society or community (14.49%).

The third-year participants elaborated on the importance of inclusion. About 42.1% reported that inclusion is important as it provides equal opportunities for all children, and according to 29.8% every child has the right to learn. Children feel included as part of the class and community stated 28.07%. Only 3.5% stated that inclusion is important due to policy and law.

4. Do you feel you need additional knowledge and understanding to be confident in your future as primary teacher?

Majority of the first-year participants or 81% desired additional knowledge and understanding of the concept of inclusion as they did not have a good enough idea. A miniscule 7% reported that they were already knowledgeable and hence had no need of additional knowledge.
A large number of third-year participants or 68% also desired additional knowledge and understanding of the concept of inclusion, but 23% reported no need for additional knowledge.

CONCLUSION
On the basis of results, it may be concluded that the training of general teachers at pre-service and in-service levels should address the issue of education of children with disabilities, so that teachers are better equipped to work in an inclusive environment. Some of the issues that need to be addressed in training include the methodology to be adopted for identifying children with disabilities; classroom management; use of appropriate teaching methodologies; skills for adapting the curriculum; development of teaching–learning materials that are multi-sensory in nature; evaluation of learning, etc.

Results of the present study clearly revealed a shift in conceptualisation of inclusion at different levels during the training, as the participants had no concept of inclusion prior to joining the course. Furthermore, a shift was also observed from SEN to diverse needs of children. Therefore, based on the findings, it is recommended that orientation training of policy-makers and education department officials, both at the state and blocks levels, is essential. In addition, there is a need to develop on-site support systems for teachers. Grassroots workers, parents, special school teachers, para teachers and other individuals can be shown how to provide the required support.

REFERENCES


Beh-Pajooh A (1991). The effect of social contact on college students’ attitudes toward severely handicapped students and their educational integration. Journal of Mental Deficiency


Harvey DHP (1985). Mainstreaming: Teachers' attitudes when they have no choice about the matter. The Exceptional Child; 32: 163–175. https://doi.org/10.1080/0156655850320304


Dear Editor,

Concern about citation and misrepresentation of our work in recent publication

I am writing to you in relation to a recent publication in your journal titled ‘The Family and Disability in Ghana: Highlighting Gaps in Achieving Social Inclusion’ (2017, Volume 28, No 4), in which one of my articles (Jacobs, P., & MacMahon, K. (2017). ‘It's different, but it's the same’: perspectives of young adults with siblings with intellectual disabilities in residential care. British Journal of Learning Disabilities, 45(1), 12-20) is cited. I and my co-author have some concerns that the conclusions of our study have been taken out of context.

In Opoku et al’s paper, they make the argument that in Western countries many children with disabilities continue to live segregated lives, distant from their families and with weak connections between family members. In fact, there has been a significant shift in public policy since the 1960s, with the closure of long-stay hospital institutions in the UK (e.g., Caruso & Osburn (2011) Journal of Policy and Practice in Intellectual Disabilities). At present, there are only a very limited number of residential placements within the UK, and those are for children and adults with the most complex needs, where local services are not considered suitable.

With regard to our own study, it does not support an argument that siblings, where one sibling has a disability, do not have strong relationships with each other. First of all, our study examined sibling relationships where brothers or sisters had severe intellectual disability, and very complex needs, that are considered to be best met within residential care. Thus, this is a very select group of individuals and does not reflect the situation for the vast majority of children with disabilities. Furthermore, despite the physical separation, my study highlights the close emotional bond and involvement of young adults in the lives of their siblings with disabilities. In fact, participants expressed feeling emotionally very close to their brother or sister, they did know about their sibling’s life and were involved in the residential community and all anticipated supporting their sibling within adulthood.
While I feel uncomfortable with the interpretation of my study, I do, however, wholeheartedly agree that in the current climate of austerity there is a lot to be done to improve the lives of families with children with disabilities.

**Paula Jacobs**

* PhD researcher at the University of Edinburgh  
  Email: s1368461@sms.ed.ac.uk
Netherlands Leprosy Relief (NLR) is a Dutch non-profit organization committed to a world without leprosy and its consequences. It tries to achieve this by supporting health authorities in countries where leprosy is prevalent. NLR promotes the independent social and economic functioning of leprosy patients and their families. By supporting scientific research NLR wants to improve the effectiveness of leprosy control.

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

* * * * *

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

* * * * *

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

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

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

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

* * * * *

The Liliane Foundation contributes to a world that is open to everyone and in which poor children with disabilities can develop and use their talents. The foundation collaborates with local partners in Africa, Asia and Latin America to raise awareness of the ‘exclusion’ of these children and to remove the barriers that they suffer because their environment is not set up to allow their participation.
VU e-Publishing
De Boelelaan 1103
1081 HV Amsterdam
The Netherlands