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# ASIA PACIFIC DISABILITY REHABILITATION JOURNAL

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## **EDITOR'S COMMENT**

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The successful conduct of the recently held first Asia Pacific CBR Congress in Bangkok was a matter of pride, not just for the organisers and participants, but for all practitioners and promoters of community based rehabilitation in the region. Along with Africa, which has already held 3 such conferences, the Asian region has been witness to the initiation, growth, changes and maturing of CBR over the past 2 decades. The Asian Congress can be viewed as the culmination of the combined efforts of stakeholders in the region to consolidate and strengthen what is probably the most significant development over the last thirty years for people with disabilities, especially for those living in rural areas in developing countries.

The term 'CBR' is now well recognised, and is perhaps the only 'brand name' that has survived for such a long time in the development sector. This is reflected in the 2004 joint position paper of ILO, UNESCO and WHO, the WHO CBR Guidelines under preparation, and the UN Convention on the Rights of Persons with Disabilities that makes implicit reference to CBR in Article 26 where it is stated "Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas." Article 19 of the Convention refers to "the equal right of all persons with disabilities to live in the community, with choices equal to others".

These developments also reflect the changes in CBR from medical orientated, often single-sector approach, to a comprehensive, rights-based approach based on community development principles. The positive benefits of CBR are documented in evaluation studies from different countries

Along with the need for consolidation, there has been much debate about the future directions for CBR. The future of CBR is in working in line with the principles of the UN Convention. The future of CBR is also about building strong partnerships, especially with disabled persons' organisations (DPOs), families of persons with disabilities and with governments. As stated in the 2004 joint position paper of ILO, UNESCO and WHO, "CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services". This implies networking and building of partnerships

at different levels and across different sectors. CBR cannot exist in isolation and needs to build partnerships with different key stakeholders to achieve the goals of inclusion and empowerment of persons with disabilities.

Barriers exist in building these partnerships, especially between DPOs and CBR. There appears to be a gap between big DPOs and CBR because of lack of awareness about each other's strengths. Many DPOs see CBR as a service delivery mechanism in rural areas, while DPOs themselves are seen as urban based and elitist, with little knowledge of the realities faced by people with disabilities living in poverty in many developing countries. Some DPOs at national or international levels are not fully aware of the current understanding of CBR as an inclusive, rights based approach. It is important for DPOs to work with CBR programmes, especially those working in rural and remote areas, to share resources and information. CBR programmes can build capacity of persons with disabilities and their families through self help groups, and link them with the bigger DPOs at different levels; while DPOs can act as the bridge between governments and self help groups promoted by CBR programmes from the grassroots levels.

DPOs can play a role in sensitising governments, including local government authorities, of the importance of the UN Convention, of CBR and of DPOs; DPOs should advocate and work with governments to promote CBR and other programmes for persons with disabilities in their countries through appropriate policies and legislation.

Because of its multi-dimensional nature, CBR needs partnerships between a variety of stakeholders who can contribute to and benefit from it. Dogmatic, 'either/or' approaches are not relevant anymore. Instead of territorialism, all stakeholders need to understand the importance of working together to capitalise on each other's strengths and work in a complementary manner to fulfil the goals and principles of CBR.

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**GUEST EDITORIAL**

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**IS DOING GOOD ‘GOOD’: PROFESSIONAL  
MOTIVES VS. COMMUNITY NEEDS**

Nick Pollard\*, Dikaios Sakellariou\*\*

***ABSTRACT***

*This paper offers a critical discussion of the goodness of fit between professional motives and community needs in the field of community-based rehabilitation (CBR). Data were drawn from the authors’ involvement in a survey of occupational therapists involved in CBR and a search of CINAHL, PsychInfo and Medline online databases for related descriptive and analytical articles.*

*Due to cultural differences and time constraints CBR professionals often are, and remain, ‘outsiders’ to the community they are working with. The focus of CBR is sometimes uncertain. Professional motives do not always meet community needs and good intentions do not necessarily transpire into sustainable, culturally appropriate action.*

*The involvement of the community in all stages of programme development and implementation is important both to ensure relevancy and build alliances with the community. CBR needs to be approached and evaluated as a unique area of professional practice.*

**INTRODUCTION**

Community based rehabilitation (CBR) is a concept which first appeared thirty years ago (1). The working definition developed by the International Labor Organisation, the United Nations Educational, Scientific and Cultural Organisation and the World Health Organisation describes CBR as “a strategy within community development for rehabilitation, equalisation of opportunities, and social inclusion of all people with disabilities” (2).

Despite the existence of a definition there remain many difficulties in establishing focus, terms of reference and objectives (1, 3, 4, 5) and this is, at least partly, due to the fact that

CBR covers a range of interventions which need to be created *with* rather than for disabled people and thus calls for accommodation of diverse cultural values.

The effectiveness of CBR services may be compromised if they are not conceptually equipped to match the local cultural and social needs of the people they seek to engage with. The challenge is to conduct evaluations which ensure these needs can be identified and met (6). However, the process of evaluation can be difficult to organise and contain. Caseloads can be extensive, running into thousands; there can be many layers and sites of interaction between and within groups of stakeholders; the infrastructures on which data systems are based can be fragile; the resources available may be stretched to provide practical intervention without the additional demand of research and outcomes evaluation (3). More importantly, community participation is not always considered as an important parameter and it is often not measured in evaluations of CBR programmes. Out of 22 CBR evaluation studies that were included in Sharma's (7) study, only six considered community participation.

The process of finding out what is appropriate and will be effective is one of experimentation and often involves working according to local needs in ways which practitioners' previous education has not anticipated (8, 9, 10, 11). Given the dearth of critical evaluations of CBR programmes it is hard to establish what is the worth and benefit of CBR programmes for the local populations. To what extent are the goals of CBR professionals relevant to the needs of the community? This paper explores the goodness of fit between professional motives and community needs in the field of CBR. After a brief discussion on the focus of CBR and issues related to culture and timeframes, the latter part of the paper deals with the perception of CBR as a process of doing good.

### **CBR: ESTABLISHING FOCUS**

Sakellariou et al (10) found that none of the occupational therapists who participated in their survey, reported negative experiences in connection with their CBR involvement. Literature suggests this is a common issue (12). It is possible that the training and education of CBR professionals such as occupational therapists makes them naturally adaptable to all kinds of circumstances and therefore bound to experience everything positively, but the process of identifying service learning needs suggests that this is not so (6, 8). Perhaps, particularly where the practitioners are expatriates or from other regions within a large country, the

setting out of objectives is negotiated on an unequal basis. One reason for this may be that the outsiders bring with them the possibility of otherwise unattainable resources, or are understood to have superior knowledge, so that the recipients only partially disclose the issues which are deep in their community in case the aid dries up. Another issue may be that access to funds, and the access of non-governmental organisations (NGO) to disadvantaged populations is also dependent on the communication of positive messages or at least, agreements with policy. Community development operations are a key element of CBR, but are often used as instruments of government policy (13, 14). Some governments have expelled foreign NGO workers or taken over their operations (13), and even in some western countries there have been concerns over proposed changes to charity law that appear to demand accord with government policy (15). The dissatisfaction of community members with the person they are working with, because either they have the wrong kind of expertise to meet their needs or does not match their expectations of expertise is not uncommon (11, 16). The extent to which these interactions are a mutual learning process may not be understood at first; learning on both sides may be recognised but needs a lot of time to drive a path through the hurdles of miscommunication in order to achieve a common understanding.

The uncertainty of the focus of CBR contributes to this dissonance; are CBR projects being designed and carried out for, or in, or with the community concerned? Furthermore, both the understanding of CBR work and motives for involvement vary – as much amongst the recipients or local participants as amongst the professionals and volunteers. This may influence the stance of the professional and thus affect the scope of the intervention and the way that it engages the community, creating a professional-community dissonance in the perception of needs and solutions (4, 17).

Safeguards and well established processes are required so that one can be “good at being good” (18). Complaint handling, codes of conduct, audit procedures, even accreditation by appropriate bodies are among the processes that can be implemented to ensure accountability, relevance of projects and adherence to humanitarian and professional mandates over any personal motivation [18, 19]. Personal motivation is not necessarily negative, nor does it clash with professional ethics to acknowledge that engagement in CBR work may serve individual interests as well as altruistic purposes. However, it is a factor that needs to be explored in relation to the professional’s perceived role within a CBR programme, and as a

component of the initial motivation that drives individuals to seek a career in a caring profession (20, 21). Wanting to travel and experience something new, to offer help, to respond to spiritual callings, to improve one's resumé, or to undo the wrongs of the colonial past of their country are among the reasons professionals decide to volunteer or work in CBR, but they may be the wrong reasons unless they are accompanied by a stronger commitment to social change (11).

Misunderstandings and misinterpretations are often inevitable. The situations in which CBR interventions are applied are often unstable and very few of the world's disabled or disadvantaged population are likely to have encountered any form of service provision (1, 3, 22). Similarly, very few of the professionals involved in CBR are likely to have received training to assist them in the community development role called for by CBR, or to have been exposed to the realities of extreme poverty, exclusion and lack of recourse and access to services faced by the communities they work with, a point made by several respondents in Sakellariou et al's study of professional involvement in CBR (10). Furthermore, conceptualisations of diversity and how it impacts on people's participation can sometimes be vague (23). With so many uncertainties about the form of CBR interventions, it is sometimes difficult to determine the extent to which they actually involve communities in decision making and developing local strategies (3, 10). Failure to involve communities might undermine their sense of ownership of the CBR programme and have adverse effects on its success and eventual sustainability.

Enabling community participation might be complicated by the fact that CBR programmes often involve many stakeholders: professionals, non-governmental and state sector organisations, disabled people, and non-disabled community members being among the main actors, often overlaid with nuances dependent on cultural factors. The resources available can be sparse, and the region the programme covers can sometimes be considerable, with difficulties in communication and logistics due to geography and infrastructure. In these circumstances it can become difficult to define accountability; who is to be held accountable for what and to whom? Even notions of 'accountability' may be very difficult to determine given the complex interplay of cultures. Dorman's (13) review of post-colonial African politics, for example, makes it very clear that Western conceptions may be irrelevant to local needs and there may be significant problems in trying to reconcile these with the demands of

Western organisations. The terms of engagement need to be understood as a process by all parties, especially since the changes they produce can have unforeseen consequences for sustainability (12). On the one hand, if the main goal of CBR interventions is to engage community members in a process of community development through capacity building, skill transfer, emancipation, empowerment, or other culturally appropriate means, then professionals need to be held accountable to the community, thus ensuring their involvement responds to locally identified needs (24). On the other hand the community needs to be enabled in developing realistic, achievable and appropriate objectives with those involved in the intervention.

### **CONSIDERING CULTURE**

Culture refers to one's way of being in the world, learned through behaviours, scripts and beliefs that are shared among members of a community, or people who share a common identity (25). It influences values and understanding of the world. CBR professionals often do not share the same culture with the community they are working with. Professional approaches and ethical considerations may come into conflict with the demands of local cultures, as for example when a Western emphasis on independence or integration is not desired by the community (26). In many communities cultural practices surrounding disability differ from the concept of disability used by professionals (27). The meanings ascribed to disability differ depending on the context. CBR specialists often arrive from a privileged position by virtue of access to education and have to work across indigenous, racial and social class divides. Consequently, there may be a climate of suspicion, and professionals may have to prove their good intentions by passing a series of assessments – for example local people may gauge their attitudes through their reactions to the theft of equipment which may later be returned. This is one of the processes by which both parties recognise and establish a common language and learn to work together. However, the onus is very much on the CBR professional. If a member of the community is offended, or a breach of trust is committed, all the work of negotiation may be undone and the professional excluded (19).

Negotiating the admission of non community members into the community with which they are to work has to be done in a delicate way, or else it may prove impossible to work with people later on (27). On the other hand, gains can be made if something seems to work

despite the scepticism with which the CBR specialist may be met, or if the outsider (as an anthropologist perhaps) represents a mouthpiece for the marginality of a community.

### **CONSIDERING TIME ISSUES**

The duration of the intervention is an important parameter that should not be overlooked and rigorous priority setting is necessary to establish realistic goals to work towards within specific time frames. It may be that through the level of resources available and because of the delicate process of negotiating differences a short term project is all that is possible. In such cases enabling access to the intervention may be more significant than trying to maintain sustainability (1). Pressured for time and resources some interventions concentrate on biomedical and short term psychosocial interventions rather than more loosely structured and longer term social approaches directed towards community developments, empowerment and capacity building.

The quickly achieved outcomes from such interventions do not always translate to long-living strategies, but they are sometimes necessary as part of the process of establishing a working relationship. For example, in the social practices which accompany military interventions, forces may offer medical treatments and aid to the local population as a means of establishing good will. The sustainability of future interventions may depend on these measures, and though pressing needs cannot be ignored once they have been identified, they need to be prioritised and approached systematically (28). It is worth exploring whether opportunities for longer term developments can be incorporated into approaches aiming to address immediate needs, e.g. discussions which identify long term strategic issues for later follow up, or resources that might be developed later on, so that there is a process which can be applied in short term work, but which looks to the future. Addressing some immediate needs, as for example wheelchair provision and maintenance, access to hospitals, the provision of orthotic equipment might also serve to gain entrée in the community, who might resent an invasion of “empty-handed” professionals (29, 30).

These challenges can prove to be the fulcrum of the interaction, the point at which the people involved recognise what really has to be done, if anything is to be done at all. They can also be the opportunity for the negotiation of a shared task, where the practitioner has to be taught by the community to be enabled to act for and with them. The way in which a practitioner

can act as a bridge to the resources that are needed may be more significant than the possession of lofty expertise (31).

### **IS DOING “GOOD” GOOD?**

The notion of “good” can be interpreted in various ways, each of them valid from a particular vantage point. Doing “good” can actually be bad where there are disagreements between community and professional perceptions of needs and the appropriate avenues to address them. A common understanding needs to be reached, which entails the asking of a number of questions, such as: Is poverty bad? If yes, is it the effects of poverty or poverty itself that needs to be eradicated? What are the limits to inclusion? What are the limits to empowerment? These are all philosophical problems which relate to the sustainability and the contexts for CBR intervention. Resorting to simplistic moral judgments, pertaining for example to ideas of human agency and individual responsibility, can only add to the confusion regarding the scope of CBR. These issues are multifactorial and complex.

Based on a Western, middle-class vantage point it is assumed that these issues are ‘problems’, but to what extent are they problems for other people? A simplistic response might be that the sacrifice of Western standards of living may seem like one measure to address them, but the consequences for a global economy may be catastrophic. Lack of food, clean water, and restricted access to physical places is, however, a significant problem for many of the world’s population and demands a sustained approach.

CBR operates in a changing and negotiable framework of cultural and socioeconomic and political sensitivities. It can take the form of a paternalistic practice, a vehicle for benevolence and satisfaction of personal needs of the professionals involved in it. Such attitudes are objectionable and can be detrimental to the aim of empowering disabled people (32). On the other hand, contributions in CBR by religious organisations and people motivated by personal callings cannot be easily dismissed as perpetuating disablement and dependence. Motivation for engagement in CBR can be on the basis of moral responsibility, whether it is about righting the wrongs of a colonial past, or simply doing things for and with other people if this is connected with a desire for social change. As Pande and Dalal (12) argue, CBR interventions inherently assume a need for social change and are formed with a programme in mind for the communities they are intended to reach. These communities are therefore already the

objects of discrimination, since it has been determined by the agency supporting the programme that they lack the means of empowerment, are impoverished, and so on. They have been assessed negatively, rather than in terms of their assets. However, this may not equate with the way the communities see themselves, and making such assumptions may be detrimental to the negotiations which secure the progress of intervention.

In her assessment of what it is to be 'good', Kazez (33) concludes that it is for individuals to do what it is reasonable to do, but in making choices about what seems the best thing to do an individual also makes choices for others. A choice of action sets a precedent for others to follow, or determines the choices available to others. Thus, while involvement in CBR needs to be grounded in professional responsibility to ensure that guidelines for proper engagement with the field are maintained, making the choice to engage in it may lead to a series of assumptions. A perception of the need for social change suggests that a 'service' is being provided for a group of 'victims', and the provision of an intervention can lead to the interpretation that it is a service that can offer resources to people who see themselves as victims. On the other hand, as Pande and Dalal (12) found, if CBR is able to achieve the object of disabled people gaining a sense of empowerment, this can present challenges to other powerful groups in the community who need to be involved as political allies for further community objectives to be met. It also needs to be ensured that it is not only the most powerful community members who have access to CBR (27, 34).

In their description of a CBR programme that failed due to misunderstandings and misinterpretations, Pande and Dalal (12) note that "before one intends to modify the psychological structures of others through any programme, examining one's own motivations is perhaps imperative". In their description of a CBR initiative Mukherjee and Samanta (35) illustrate how good intentions alone are not enough to make a programme work, or even affect some positive change in the community. Failure to consider individual needs and strengths, physical terrain, educational and maintenance issues led disabled people to discard the wheelchairs they were given.

Strategies need to be context specific. Needs as well as actions have to be negotiated between all stakeholders. Failure to do so might lead to failure to affect any sustainable change to the community. It also needs to be recognised and respected that some community members will not want to be involved in a CBR project. For example in interventions which follow on from

disasters or conflicts, engagement in narrative processes which are intended to enable a community to tell its story might mean reliving strong and overwhelming memories of trauma. Often, people react to such events by separating themselves from these events and attempting to get on with their lives as quietly as possible (36).

The silence may also stem from scepticism about telling one's life stories to strangers with solutions to problems they have not experienced. Here, intervention might be perceived as a prurient professional game rather than a real service responding to real needs. The profile of the westerner or the western educated professional can often override the efforts of the community who may feel that, whatever happens through the project, it will be presented as an achievement by the professional. People in experiences of disability rarely get to tell their own tale without it being mediated and shaped by others to suit presentation to an audience, and, often in the case of CBR, a Western audience. After all, this is part of the process of supporting engagement by disseminating evidence based practice, meeting funders' requirements and of obtaining funding for further intervention. These issues have the potential to considerably distort the context of CBR provision, and need to be explored in order to enable the fair representation of community members in all stages of CBR. For these reasons CBR, despite any aims it may have for empowerment and facilitating, can never be a process in which the various actors are equal. CBR is not the product of an equal world, and while it is not the purpose of intervention to perpetuate inequity it is quite possible for the resources which have been provided or developed to remain in the hands of the more powerful groups in the community despite all good intentions (12).

## **MOVING FORWARD**

Community based rehabilitation has a great potential to fulfil. Professionals need to form partnerships with the people they work with, the community members and negotiate goals and process with them, in order to ensure ethical, appropriate and effective interventions. Issues of culture and timeframes, as well as the motives of the professionals need to be acknowledged and addressed where necessary.

The purpose of CBR should not be to imitate institution-based health care services but to address the sociopolitical environment as the major underpinning causes of health disparities. This can best be achieved through community development actions that aim for inclusion,

empowerment and the elimination of poverty. The forms these actions can take may not always be consistent with widely held ideas in the West; for example communities of disabled people may seek to preserve their separateness from the society around them because it feels safer and also provides visibility which might in turn, translate into power.

If CBR is a distinct area of professional practice, then it needs to be introduced as such in relevant educational curricula (eg, occupational therapy, physiotherapy), or through continuing education opportunities. It needs a theory base linked to an identifiable practice base, and in order to gain a wider role in community development effort it needs to be demonstrably applicable in a range of contexts outside of situations of charity or benevolence (37). Professionals need to develop a moving viewpoint perspective that will enable them to acknowledge the needs of the communities they are working with before considering how they can intervene (38, 39). The consequences of this are that it becomes a political practice, because it is a theory for the structuring of community interventions and is therefore directed to social change (12, 27). Once this purpose is clear and formerly disadvantaged communities begin to exercise their new power, they can be seen as a threat to the powerful groups who uphold the status quo. Such groups may use legislation or forceful measures to intimidate or close down new organisations, or else take them over for their own advantage (12, 13, 40). While some projects may limit their scope for action in order to avoid being perceived as a threat, this can mean that development must be slow paced and low key, in order to balance being sustainable with being acceptable.

## **CONCLUSION**

CBR is a strategy that has a great potential to fulfil not least because as yet it has touched very few of the world's population of impoverished and disabled communities (1). CBR can enable people experiencing disabling situations to live in dignity and gain access to the resources they need in order to improve, restore or maintain their well being, but it may also have the effect of generating more resources for those who already have the power to deprive others. For CBR to work positively, its interventions need to be negotiated with the community, not predetermined paternalistically by an external professional group (3, 18, 27, 32, 38) and appropriate evaluation measures need to be established (7). Of course, there are limits to what can be realistically expected by a CBR intervention, especially in cases where short

term involvement is all that can be achieved, but establishing a common ground of understanding between the community and the CBR workers is a prerequisite and its importance cannot be overstressed.

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**ORIGINAL ARTICLES**

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**EVALUATION OF A PILOT COMMUNITY BASED  
REHABILITATION TRAINING PROGRAMME IN EAST TIMOR**

Jane Shamrock\*

**ABSTRACT**

*The first Community Based Rehabilitation (CBR) training programme in East Timor was held in Dili between March 2006 and August 2007 based on the Community Approaches to Handicap in Development (CAHD) model. This article presents the results of an evaluation of the training by studying the impact of the CBR training on the trainees. The evaluation was completed by (a) investigating how the trainee CBR workers experienced their training period, (b) describing the work of the 12 active CBR workers and (c) commenting on the value of the CAHD toolkit as a basis for the CBR training.*

*The evaluation found that CBR workers were providing a variety of CBR interventions with some errors occurring because of insufficient skills in assessment, problem solving, monitoring and evaluation. The CAHD toolkit was found to be a useful framework for the training programme with changes needed in response to the needs of the trainees.*

**INTRODUCTION**

The first CBR training programme in East Timor was developed by Australian therapists and was planned for one week a month over a year, starting in March 2006. The training was based on the CAHD toolkit (1). The training programme was interrupted by a period of civil unrest which began in May 2006, during this time Timorese began fleeing Dili and the expatriate trainers were evacuated.

The training recommenced in October 2006, continuing into 2007 with further disruptions from periods of unrest. Certificates of participation were finally presented to those who attended the last module in August 2007.

### **Learning Objectives of the Training**

The overall learning objectives of the East Timor CBR training programme based on the CAHD toolkit were:

1. Participants will develop an understanding of the need for equal opportunities in development and the importance of advocacy where disability and disadvantage are evident.
2. Participants will be able to make a realistic needs assessment where disability is a major issue.
3. Participants will develop intervention skills to introduce appropriate change.
4. Participants will develop skills in communication to be able to carry out successful interventions.
5. Participants will develop skills in monitoring and evaluating the results of CBR activities.

### **METHOD**

#### **A. During the Training**

Data were collected at the beginning of the training to assess the skills and experience of the new trainees.

During and at the end of the training (2006 – 2007), trainees were asked for feed-back relating to the course, the venue, the translation and personal issues that impacted on their involvement in the training programme. Trainers were asked to fill out a sheet to reflect on their teaching experiences at the end of individual classes. Competencies were developed for each module and participants and trainer/mentors were asked to record trainees' skill acquisition.

Following the break in the training programme caused by the civil unrest in mid-2006, trainees were asked about their CBR activities during that time.

#### **B. After the Training**

During April 2008, a three week visit was made to East Timor where semi-structured interviews were carried out with eleven of the CBR workers, two programme managers and one manager/mentor.

- Three brief field visits were made to see programmes in action; sound recordings were made and backed up by field notes.
- Trainees were asked a series of open questions and particular lines of enquiry were followed through where appropriate.
- Verbatim responses were typed into a table format and coded according to content. The data were then collated using the “sort” function in Microsoft Word. Broad categories were identified and the larger categories were coded further and sorted again; in this way themes were identified.

### **Ethical considerations**

Each respondent was informed that the purpose of the interview was to generate a report to be made available to those involved in planning future training of CBR workers in East Timor. Individuals were assured of privacy and offered the right to decline to be involved in the evaluation process, however, no trainee declined to be interviewed.

Respondents were assured that they would not be named or identified. This was particularly important as at least two trainees believed that a place in the next training could be jeopardised if the “wrong” answers were given.

## **RESULTS**

### **A. Results from the Training Period**

#### **The Trainees**

Twenty-five trainees started the training, 19 male and 7 female. The ages of those starting the programme ranged from 19 to 38 years, with several older trainees joining the programme as the training progressed. The trainees came from 11 of the 13 districts of East Timor. Table 1 shows the previous employment of the trainees who started the training in March 2006. Of the 30 trainees, 54% had been previously employed and 46% were newly employed to start the CBR training.

**Table 1. Previous experience of the trainees**

<b>Previous employment</b>	<b>Number of people</b>
First job	5
Health worker (physiotherapy, rehab, clinic)	12
Indonesian government	1
Unemployed	1
Management	2
Cattle breeder	1

### **Reflections From Trainers During The Training Period**

At times, during the training period trainers were asked to reflect on various aspects of their teaching sessions. The main findings can be summarised as follows:

#### **What went well**

- Practical sessions with persons with disabilities.
- Case studies.
- Problem solving real situations.
- Revision sessions where trainees could demonstrate their new knowledge.
- Discussion of East Timorese cultural beliefs or discussion about problems of language and understanding of words in different parts of East Timor stimulated lively discussion.
- The active teaching methods offered in the CAHD training manual were usually appreciated. These included discussion, games, role-play, activities with large sheets of paper, small and large group activities, debates and didactic sessions.

#### **What could have been better**

- Trainees often needed more time than was initially allowed in the teaching plan.
- At times trainers needed to be better prepared for their session and explanations needed to be clearer.

- The translator needed to understand the subject.
- Complex material was more difficult to teach in the afternoon when trainees and trainers were tired.
- Trainers needed to have a fall-back plan to manage frequent power failures.

### **B. Results from the Interviews May 2008**

Thirty trainees passed through the CBR training programme; 25 started the training, 21 finished the programme and 12 were working as CBR workers at the time of the evaluation. Their locations at the time of interview are outlined in Table 2.

**Table 2. Location of trainees at the time of the study**

<b>Number of trainees</b>	<b>Location of trained CBR workers at the time of the evaluation</b>
3	Working in rehabilitation outreach using CBR skills
12	Working as CBR workers
5	Studying in Indonesia to be therapists
3	Dismissed from their work
3	Did not return after the crisis
3	Unknown
1	Translator did not return after the crisis
1	Translator now living in Australia

### **Evaluation of the Learning Objectives**

#### **1. Development and advocacy**

Most respondents spoke of the importance of explaining the rights of persons with disabilities firstly to village leaders, then to family and neighbours. “There is discrimination in East Timor, we need to explain to friends or family” (respondent U).

One respondent noted a change over the time he had been involved in CBR. “Before people did not understand, now attitudes change. Before, the person was in the back of the house” (respondent O).

Three of the respondents expressed a passion for their work. One respondent reported taking an informal opportunity to speak to a member of parliament to explain the needs of persons with disabilities. Another said that she was respectfully known as “handicap mother” in one of the villages that she regularly visited. One CBR worker was exceptionally zealous in her attempts to improve the lot of a woman with a disability. “I was together with the lady for three days because the family didn’t care for her. The family closed her in the kitchen... I explained to the family and the community and gave her training to stand up” (respondent N).

One trainee described how before the CBR training, she and her family were afraid of persons with disabilities and would not speak about disability for fear of becoming disabled themselves. Since completing the CBR training, this respondent had taken time to explain to her family that disability cannot be caught like other diseases.

The CAHD toolkit encourages persons with disabilities to undertake CBR training to be able to be effective as an advocate for disadvantaged persons with disabilities. Three persons with disabilities participated in the training. At the end of the training, one was working as a therapy assistant, one had returned to his district to take up other activities and one could not be traced.

Several trainees expressed problems with village or family attitudes to persons with disabilities. One respondent explained “the mother wants to get rid of the children and leave them at Taibesse school because this is the place for this child. But we explained this is life and you have to take care, this is your responsibility” (respondent L).

## **2. Assessment**

Respondents made assessments by discussion with families. For example, “I do an assessment and prioritise problems, I talk to the family and decide what to do based on that” (respondent I).

Several problems were noted in descriptions of the assessment process. These included:

- Inaccurate assessment of needs: two instances were reported where promises were made to persons with disabilities to entice them to come to ASSERT (the rehabilitation service at Dili) for assessment: “He was promised a plastic support {i.e. foot splint} and

when we did a thorough assessment he has a spinal cord injury and he should have a wheelchair, this is not good assessment!” (respondent S”).

- Difficulties prioritising needs: two managers expressed concern that the CBR workers’ assessments focussed only on disability when the more basic need of malnutrition was being overlooked.
- The amount of time needed to really get to understand the needs of people in remote areas: “We need to take time to get to know them, the culture is different, we need to know the culture and the language” (respondent L).
- Need for further training in assessment: one of the trainers interviewed was concerned at the lack of time spent on assessment during the training programme: “we taught them how to set objective goals.....but we didn’t follow up enough on that” (trainer K).
- Limited educational background: “{the CBR} worker has only had pre-secondary education” (trainer K).
- Lack of ability for creative problem solving: “they don’t get this whole problem-solving thing..... I see it in our programme, they {the adults} don’t even know how to do a simple child’s puzzle!” (trainer K).

### **3. Interventions for change**

Most CBR workers interviewed felt appreciated by the families that they were involved with. For example “she said.. you want to take care of my child and to help me...we can make them smile and give us thanks” (respondent L).

The range of interventions were usually simple, such as issuing a wheelchair, providing walking aids or other equipment, referrals for specialist services, teaching the person with disability to walk, giving exercise sessions, training a family member to help the person with disability with exercises and making a ramp to improve access to the home of a person with disability and counselling.

At times the interventions were based on advice given by others such as therapists at ASSERT or an expatriate therapist. Generally there were several weekly visits as time had to be taken to meet with local leaders, communities and families. Some interventions took several months with regular visits.

Some CBR workers worked in isolation, making decisions alone about what help to provide to families. At times help was sought from community organisations such as the church or the school. CBR workers at times organised trips to Dili to visit ASSERT for expert help or specialist advice. Usually the trips resulted in the person with disability and family receiving extra support, equipment, therapy or service.

During the field trip in May 2008, three community income-generating projects were seen. In one village a group met regularly to plan for a chicken raising programme. Accommodation was being prepared for the chickens, the local vet had volunteered to provide support and recipients had been identified. Another person with disability received support and US\$500 from an NGO (non-government organisation) to set up a small shop. In another community effort, a respondent was involved in a project where community members removed stones on a pathway to allow easier access for a wheelchair (respondent L).

Some difficulties were found with interventions such as:

- Advice that did not work out: one income-generating project experienced difficulties when the CBR workers advised planting a crop which subsequently failed.
- Not considering the whole picture: One manager quoted the complaints of a disabled person who had been given a wheelchair which was too large for the family home. “She {the client} said, I don’t want this wheelchair, where in my house will I put this wheelchair, this wheelchair doesn’t fit me”(respondent S).
- Difficulties dealing with attitudes of families: “Parents say that the child can’t do anything because he is disabled” (respondent I).
- Difficulties dealing with attitudes of the person with disability: “Often the person with the disability is passive” (respondent C).
- Not enough skill base: “I need training about wheelchairs and nutrition and how to involve the community and the disabled person” (respondent T).
- The need for technical support in the field: respondent C believed that the technical support available to CBR workers was insufficient. “The most important thing that we need in the field is technical advice”.
- Lack of appreciation of the CBR workers’ efforts for some other reason. A client “was given a stick by the church but he won’t use it. When I go to have a meeting with the

family to explain how D could have a better future, the wife says that she doesn't want the equipment. That's because some time in the past something happened so now they don't want the equipment".

- Misunderstanding the limitations of CBR. Following the death of a client a CBR worker was asked for a coffin and candles for the client's funeral (respondent I).

#### **4. Communication skills**

The CBR workers saw communication as important and most were confident of their abilities to communicate with persons with disabilities and stakeholders. "I talk with the family, and the community, it's important that the community understands. CBR must integrate with the community and the families' ideas" (respondent C). Respondent G explained that he has "good relations with the community, hospital, community leaders, no problem. They are happy to help with disability".

Specific communication skills have been used by CBR workers, such as how to get along with a child and the family of a child. "I give toys to play with and I speak to the father and the mother" (respondent U). Most respondents also stressed the importance of talking to the local leaders and gaining their support before becoming involved in the lives of village people, especially in remote areas where the level of education is poor. "People only know what the local leader knows" (respondent A).

One respondent saw her role as counsellor and educator as well as therapist. "Counselling includes the family and is very important. Family education is very important" (respondent L).

CBR workers at times, could not convince families to participate in therapy. "Families are lazy and won't do therapy even when I explain to them" (respondent D).

One respondent joked that his problems in the field came from difficulties explaining the meaning of CBR. He revised the meaning of the acronym to "Confusion Based Reality" (respondent C).

## **5. Monitoring and evaluating CBR programmes**

Most respondents said that they recorded the number of clients they saw and/or kept notes on the type of disability or the type of service, either daily, weekly or monthly. One CBR worker made a monthly report to his NGO, whilst another made notes in the client's file when something changed.

Most CBR workers returned to check on the success of their interventions. "I do evaluation and follow-up whether it's good or not, so we can be satisfied with the wheelchair" (respondent I).

One respondent noted that he needed more training in report writing: "I can manage many things, like exercises, like how to talk to the people but writing the report is the difficult thing for me" (respondent G).

## **Other Findings from the Interviews**

### **Gaps in the training programme**

The CBR workers interviewed were asked what they felt had been left out of their training programme, in the light of their subsequent experiences. All workers contributed comments which included the following needs:

- More information about causes of disability.
- More information about equipment.
- Improved skills in management and report writing.
- How to conduct self-help groups.
- How to conduct vocational groups.
- More information about different diseases.
- More information about nutrition.

Other problems were also identified in the training program. These included:

- The training period was too long.
- A better translator was needed.
- Some of the trainees were identified as not being really interested in disabled people, "we....need to choose participants in the next training who work with handicapped people

and who are interested in handicapped people... some come to the course because they... like the per diem or to get a job with lots of money” (respondent S ).

### **Effect of the crisis on the training**

There was a range of comments about the effect of the crisis period. These included: “We had to keep stopping because of the crisis, it was difficult to think but we continued and we tried hard even though we were afraid” (respondent S). “The crisis was not a problem, it was only in Dili” (respondent A) and “we couldn’t find the patients, some ran away and some went to the IDP (internally displaced persons) camps” (respondent L), “we were afraid that it would happen again and we were afraid that we would lose the training” (respondent E). Trainer B noted “..... individuals whose personalities had changed, whose concentration had changed, whose enthusiasm had been curbed, who were pessimistic rather than excited, who were flat rather than supportive, trainers as well as participants”.

One respondent said that he still does not bring the reference book, “Disabled Village Children”(2) to Dili for fear that it may be lost.

### **Barriers to present work**

CBR workers were asked about the barriers in their present work to see if present barriers related to the training programme. Many of the barriers related to general difficulties of working in East Timor, such as large work loads, poor logistical support or remoteness of many of the communities. More specific barriers included:

- Families’ fears that their disabled child may cause problems if he/she goes to school.
- Discrimination against persons with disabilities in communities.
- Need for specialised transport for persons with disabilities.
- Need for technical supervision.
- Lack of specialist services such as speech therapy.
- Need for more support from managers.
- Families not engaging in the CBR activities being offered.
- An unexpected barrier was described: “People in Oecusse thought that we would sell their information, that we would take their name and address to get money” (respondent L).

### **A creative approach**

CBR workers were constantly being faced with unique situations that called for a creative response. Two notable instances were found of creative problem solving.

One CBR worker taught a disabled child and all his siblings to write, before the family would allow the child to go to school. She also taught him to cook so that he could help his family. In another instance, the same CBR worker convinced the local priest to make the church more accessible for disabled parishioners. The same respondent also reported making parallel bars at a family home to facilitate the exercise programme. Another respondent described how she managed to convince a client to give up smoking, to the delight of the client's wife.

CBR workers, especially older people, may have found a creative problem-solving approach difficult to take up, especially if he/she had previously been of lower status: "before ninety-nine {the year 1999 when the Indonesian occupation ended} the CBR worker was paired with someone who was a nurse who was trained to do rehab, the CBR worker just tagged along and didn't have to make any decisions" (respondent K).

### **The managers' and trainers' viewpoints**

Four people, who were either managers or trainers at the time of the training, were asked for comments on the CBR training programme and subsequent CBR activities. They all reported that some CBR workers were now doing good work and a few still needed significant support to carry out their CBR tasks. "I think most of them are trying hard, but they need good support, they should be getting more training" (respondent S).

All spoke of the need to build on the basic skills given in the training programme. This included: support in developing problem solving skills, support in accurately identifying and prioritising needs, skills in record keeping and monitoring activities, good backup with provision of phones, vehicles and other resources needed to carry out their service. One manager suggested, "regular workshop refresher meetings of the CBR workers across the country to support and share information. Mutual support is very important" (respondent S).

Manager M commented on the importance of cultural relevance and noted that, "we need to consult with various organisations to give some input to see if the material is relevant to East

Timor, otherwise we just try to adapt to East Timor but it's not right for East Timor, for the conditions in East Timor, because of the experience, knowledge, culture, economics and everything.”

### **The CAHD tool-kit**

The CAHD tool-kit provided the trainers with a firm structure on which to base the training programme. The range of teaching methods ensured that therapists acting as trainers had a range of presentation styles to engage their students.

However, adjustments were frequently being made “on the run”. These changes were needed to address issues such as educational levels, cultural issues, the sequence in which information was presented, the trainees’ fatigue levels and their ability to concentrate under difficult circumstances.

### **SUMMARY AND CONCLUSION**

Some of the trainees who completed all, or part of the training have moved on to become CBR workers and are making a difference in the lives of persons with disabilities.

The CBR workers all demonstrated awareness of human rights and were prepared to discuss this with those involved in the lives of persons with disabilities.

CBR workers were initiating mostly successful interventions which were generally appreciated by the recipients. Some mistakes have occurred from lack of knowledge, lack of problem-solving skills and/or difficulty explaining the scope of CBR which had raised unrealistic expectations in recipients. There would likely have been fewer mistakes if all the therapist/mentors had been able to support the trainees for the full training period as originally planned. CBR workers and the managers interviewed agreed that trainees needed on-going support such as regular get-togethers for skill sharing, or training in identified areas to make their interventions more effective (3).

Monitoring and evaluation were not widely considered in the CBR workers' service. Monitoring and evaluation require a good understanding of client needs as well as good record-keeping. There is a risk that if managers and CBR workers do not understand these issues, the impact of CBR programmes will be lost (4,5).

CBR must be relevant to match East Timorese perceptions of disability and relevant to the lived experiences of persons with disabilities (6). The CAHD tool-kit, while providing a very useful basis for the training programme would benefit from revision to make it more appropriate to the East Timorese culture and individuals' education levels. Basic information from a complete needs assessment in the recipient villages, as well as a sound assessment of trainees education levels would help ensure that teaching is relevant and within the abilities of the trainees.

Logistical support from the NGOs was identified as lacking by some CBR workers. Better logistical support would help remind the CBR workers that their work in remote areas is appreciated and would make their service more effective. This support should include suitable transport, time out for training sessions and readily available advice such as nutrition or agricultural information.

In conclusion, although this evaluation does not compare the CBR workers' statements against experiences of the recipients of CBR, the evidence available indicates that the CBR workers' views gave a useful picture of CBR's small start in East Timor. The CBR services were beginning to penetrate areas where previously no support was available for persons with disabilities, their lives were being positively affected and community attitudes were beginning to change.

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## ATTITUDES OF HEALTH PROFESSIONALS TOWARD PERSONS WITH DISABILITIES IN BHUTAN

Sanga Dorji,\* Patricia Solomon\*\*

### ABSTRACT

*This study examined the attitudes and its impact, of physicians and nurses toward persons with disabilities in Bhutan, given their profession, gender, age and past experience. The Scale of Attitudes toward Disabled Persons (SADP) was sent to 269 physicians and nurses at 3 major hospitals in Bhutan. 170 (63%) health professionals completed the survey and it was found that physicians held significantly more positive attitudes than nurses on total SADP score and the optimism-human rights subscale ( $p < .01$ ). The mean scores of both professions were lower than those of other studies. Bhutanese doctors and nurses appear to hold less positive attitudes toward persons with disabilities than their counterparts from western countries. Given that doctors and nurses play a vital role in providing information and support to persons with disabilities in Bhutan, a greater understanding of their attitudes toward this segment of the population will support efforts to implement appropriate interventions.*

### INTRODUCTION

According to the World Health Organisation (WHO), 7 to 10% of the population in developing countries live with some form of disability (1). According to the Population and Housing Census of Bhutan(2), the number of disabled persons is 21,894, representing 3.4% of the country's total population. This relatively low incidence of disabled people in Bhutan, compared to the WHO data, may be related to local definitions of disability, varying cultural perceptions of disability and the types of occupation practiced in the community. Regardless, a significant percentage of the population in Bhutan is living with a disability.

The provision of rehabilitation services for persons with disabilities is relatively new to Bhutan. As in many developing countries, Bhutan's health care professionals are the key persons

providing information and delivering medical and rehabilitation services to the disabled population. They play an influential role in determining the priorities and direction of rehabilitation services (3,4). The quality of medical and rehabilitation services is influenced by the attitudes of health care professionals toward persons with disabilities. If Bhutanese health professionals have misconceptions about disability or have limited experience and knowledge about managing disability, this could negatively impact on the quality of services provided to persons with disabilities. However, as there has been no study of health professionals' attitudes towards persons with disabilities in Bhutan, the extent to which their attitudes impact upon such persons is unknown.

There has been some study on the extent to which personal attributes influence attitudes towards persons with disabilities. While generalisations to the Bhutanese context are questionable, there are several noteworthy trends. Most studies observed that women hold more positive attitudes than men (5-10). Previous contact with persons with disabilities has also been shown to positively influence attitudes (5, 7-9,12-15). The influence of age upon attitudes toward persons with disabilities has shown variable results, as seen from studies of university and high school students demonstrating more positive attitudes than those at higher academic levels (10-16). In contrast, Bakheit and Shanmugalingam (17) reported that the majority of older individuals in rural communities in south India expressed less favorable attitudes toward persons with disabilities than the younger generation.

Several studies have compared the attitudes of health professional students across professions. Tervo et al. (15) and Garven and Stachura (13), whilst comparing nursing, physiotherapy and occupational therapy students, found that nursing students held the least positive attitudes, whereas occupational therapy students showed the most positive attitudes toward persons with disabilities. Garven and Stachura (13) suggested that the positive attitudes of the occupational therapy students may be influenced by the provision of accurate information concerning disability, frequent interaction with persons with disabilities during clinical placements, and through a humanistic and holistic philosophy embedded in the curriculum.

A better understanding of the multidimensional and intricate relationship between knowledge, attitudes, and behaviour would permit policy-makers and health professionals to design intervention strategies to change attitudes towards persons with disabilities and improve medical and rehabilitation services. An initial step toward this understanding is to gather

baseline measures of health professionals' attitudes toward persons with disabilities. This study addressed 3 questions: What are the attitudes of physicians and nurses in Bhutan toward persons with disabilities? Are there any differences in attitudes between men and women, between physicians and nurses, or between those who have a family member or friend with a disability and those who do not? Are age and number of years in practice of doctors and nurses, associated with attitudes toward persons with disabilities?

## **METHOD**

The Scale of Attitudes toward Disabled Persons (SADP), was chosen as the measurement tool for this study. The SADP was developed by Antonak (18) as a measure of general attitudes toward persons with disabilities. The 24 item SADP can be administered to individuals or groups, directly or indirectly by mail. The SADP was subject to rigorous psychometric analysis and has been shown to be a psychometrically sound instrument (11). Spearman-Brown corrected reliability coefficients range from 0.81 to 0.85, and alpha coefficients of 0.88 to 0.91 (11). Principal factor analysis yielded three subscales containing optimism-human rights, behaviour-misconceptions, and pessimism-hopelessness with reliability coefficients ranging from 0.55 to 0.73, and alpha coefficient homogeneity indices ranging from 0.77 to 0.87. The SADP was translated into Chinese for a cross-cultural validation study by Chan, Hua, Ju, and Lam (19), and has been used for research in Hong Kong, Singapore and Taiwan. Its utility in Asian cultures suggests that it may also be applicable to the Bhutanese context. The scale was pilot tested with three Bhutanese health technicians who indicated that the questionnaire was relevant and easy to follow.

This study used a cross-sectional survey study design. Subjects consisted of 269 physicians and nurses working in the three major hospitals in Bhutan: Jigme Dorji Wangchhuk (JDW/NRH) (the National Referral Hospital), Geylephu (Central Regional Referral Hospital), and Mongar (Eastern Regional Referral Hospital). According to the Ministry of Health (20), most of the physicians and nurses in Bhutan work in these three centres. Although there are several categories of health professionals in Bhutan, physicians and nurses were chosen for this study since they have a more homogenous workload than other health professional groups in Bhutan.

In addition to the SADP, the questionnaire gathered data on age, gender, previous experience with a disabled friend or relative and number of years of practice.

Three clinicians working in each of the referral hospitals distributed the questionnaires into the individual mailboxes of all physicians and nurses currently working onsite at each of the institutions. Follow-up reminder e-mails were sent to participants after two weeks and again after the third week. Participants returned completed questionnaires into the respective clinician's sealed mailboxes.

Ethical approval was provided by the McMaster University Research Ethics Board.

## **RESULTS**

All statistics were calculated with version 16.0 of the SPSS programme. A total of 170 (nurses and physicians) completed the questionnaire, providing an overall response rate of 63%. On an average, the respondents had been in practice for 9.5 years (S.D.=7.44). The mean age was 33.4 years (S.D.=8.03). Just over one-half of the respondents were female (52%) and the majority were from the nursing profession (74%). Twenty-nine percent (29%) reported having a disabled friend or relative.

Table 1, shows the comparison of the total SADP and subscale scores of doctors and nurses as calculated by independent t-tests. Missing items were replaced with 0 according to the instructions of the developers of the SADP scale (18). The level of significance was set at  $p < 0.05$  for all statistical tests. Four subjects in this survey omitted more than four items on the SADP. Therefore, only 166 surveys were used in the analyses. As shown, physicians held significantly more positive attitudes than nurses on SADP total score and optimism human-rights subscale.

**Table 1. Comparison of the Total and Subscale Scores of the SADP of Doctors and Nurses**

<b>Attitude Scale</b>	<b>Physicians n=41 Mean (SD)</b>	<b>Nurses n=122 Mean (SD)</b>
Total Score	97.98 (13.34)*	92.09 (12.04)*

Optimism	47.10 ( 7.14)**	42.69 (9.90)**
Misconception	25.24 ( 4.76)	25.07 (5.64)
Pessimism	25.63 ( .89)	24.33 (5.00)

\* t-value = 2.64, p<.01

\*\* t-value = 2.63, p<.01

Table 2 shows the comparison between gender in the total and subscale scores of the SADP. Independent t-test shows that there were no significant differences between males and females.

**Table 2. Comparison of the Total and Subscales Scores of the SADP between Males and Females**

Attitude Scale	Females n=85 Mean (SD)	Males n=76 Mean (SD)
Total Score	92.69 (11.65)	94.78 (13.61)
Optimism	43.67 (9.13)	45.24 (9.79)
Misconception	24.80 (4.92)	25.08 (4.90)
Pessimism	24.53 (4.69)	24.96 (5.79)

Table 3 compares the total and subscale scores of the SADP of those with and without a disabled friend/relative. Independent t-tests show there were no significant differences found between the respondents who have a friend/relative with a disability and those who do not.

**Table 3. Comparison of the Total and Subscale Scores of the SADP of those With and Without a Friend/ Relative with a Disability**

Attitude Scale	Friend/Relative with Disabilityn=115 Mean (SD)	No Friend/Relative with Disabilityn=49 Mean (SD)
Total Score	94.34 (13.10)	92.00 (11.26)
Optimism	44.36 ( 8.58)	42.63 (11.26)

Misconception	25.20 ( 5.53)	24.94 ( 5.25)
Pessimism	24.78 ( 5.57)	24.43 ( 4.38)

Spearman's correlations (rho) were done to determine the relationship of total SADP scores and subscales with age and number of years practised. As shown in Table 4, there is a significant negative correlation of the misconception subscale with age and number of years practised. The misconception subscale scores were lower for older persons who had practised for more years. The total SADP score and the other subscale scores were not correlated with age or number of years practised.

**Table 4. Spearman's Rho of Total and Subscale Scores of the SADP with Age and Number of Years Practised**

Attitude Scale		Age	Number of Years Practised
Total Score	Rho	-.038	.009
	P value	.632	.913
Optimism	Rho	.088	.113
	P value	.725	.162
Misconception	Rho	-.267*	-.222*
	P value	.001	.006
Pessimism	Rho	-.028	-.036
	P value	.225	.657

\*  $p < 0.01$  level (2-tailed)

## DISCUSSION

Physicians had significantly more positive attitudes than nurses toward persons with disabilities on total SADP and optimism-human rights subscales. This could be attributed to the fact that Bhutanese physicians are educated in other countries and therefore likely to have more knowledge and experience with human rights legislation and rehabilitation services for persons

with disabilities. Nurses, on the other hand, may place greater importance on basic needs such as food, clothing and shelter, rather than on human rights, employment and external facilities. It is possible that for many who have no experience with persons with disabilities, the statements under the optimism-human rights subscale which are mostly concerned with employment and rights for persons with disabilities, are difficult concepts to understand.

Both physicians and nurses had similar mean scores on the behavioural-misconception and pessimism-hopelessness subscales. However, the mean attitudes of Bhutanese health professionals were lower than the mean scores of other populations, such as first-year medical students from Canada and the United States (9). This suggests that Bhutanese physicians and nurses have more misconceptions and pessimistic views about persons with disabilities than those in other countries. This may in part be due to frustration with the lack of adequate rehabilitation facilities for persons with disabilities to be referred to when discharged from the hospital. Clearly, many of these assertions are conjecture which must be verified by further study.

Age and number of years practising were significantly negatively correlated with behavioural-misconception scores. This could be a result of a comparative lack of education of older health professionals in Bhutan on rehabilitation and integration of persons with disabilities. Young physicians and nurses may have greater opportunities to interact with persons with disabilities during their education. The younger physicians and nurses who were trained outside Bhutan are more likely to have come across rehabilitation facilities and assistive devices to help persons with disabilities live independent lives. Such exposure could have influenced their attitudes in a positive direction.

Although most studies conducted in Europe and North America observed that older people showed more positive attitudes than younger ones; according to Bakheit Am Shanmugalingam (17), older people in south India expressed less positive attitudes than younger people toward persons with disabilities. It may be that a factor related to Asian culture has some negative influence on the attitudes of older people. Further investigation is needed to determine the cause of negative attitudes of older physicians and nurses on behavioural-misconception scores. Typically, one would assume that with greater experience and wisdom, older doctors and nurses would have more positive attitudes than younger colleagues.

In contrast to previous findings in other countries, there were no significant differences between males and females toward persons with disabilities in Bhutan. The mean scores for both genders were low, indicating more negative attitudes compared to normative data. There are several possible explanations for these findings. Given that the majority of the doctors were males, and that physicians had more positive attitudes, the attitudes of males in this study may simply be a reflection of the attitudes of physicians. A similar interaction between profession and gender may exist for the females, who are mostly nurses.

Also, in contrast to previous studies, prior experience with disability did not significantly influence the attitudes of physicians and nurses in Bhutan. On the contrary, the mean scores of physicians and nurses who responded as having a friend or relative with a disability were marginally lower than those who did not have a friend or relative with a disability. This may be due to the lack of formal social support for persons with disabilities in Bhutan, therefore necessitating that family and friends provide all the required care. The majority of Bhutanese work in manual agricultural jobs and subsistence farming. It is often difficult for people who have disabled friends or relatives, to provide adequate care and support due to the commitments required of their work. This may lead to feelings of frustration and excess burden in relation to persons with disabilities. In this study, physicians and nurses may be expressing the views of Bhutan's majority rural population, rather than their individual or professional opinion.

A possible explanation for the less positive attitudes of physicians and nurses in Bhutan toward persons with disabilities is cultural variation and lack of experience with rehabilitation. Bhutanese physicians and nurses may not have interpreted the statements of the SADP scale in the same context as respondents in Europe, Australia and North America, where most of the previous studies were conducted. For example, the statement "disabled people should live with others of similar disability", could be interpreted positively, because Bhutanese physicians and nurses might support the idea of similarly disabled people being together in a school for the blind or a school for speech and hearing impaired persons, as this is common in Bhutan. Similarly, "simple repetitive work is appropriate for persons with disabilities", may have been interpreted as being caring and comprehensive, rather than persons with disabilities being less capable than persons with no disabilities. Clearly, further investigation needs to be carried out to confirm these hypotheses.

This study is limited, in that it used a convenience rather than a random sample. The problem with such samples is that they may not represent the general population of health professionals in Bhutan. Another limitation relates to the measurement tool. Although the SADP appeared to be the most relevant measure and psychometrically sound scale available, it was developed in the United States. Even though the questionnaire was reviewed by local health care workers for suitability in a Bhutanese context, the possibility exists that due to its complicated terms and phrases, some of the respondents may have found the SADP difficult to understand.

This is the first study on attitudes of health professionals toward disability in Bhutan. Due to the essential role that physicians and nurses play in providing information and rehabilitation services to persons with disabilities and their families, it is essential that they possess positive attitudes, sound knowledge and skill with regard to managing disability. As with many areas of new study, this research raises more questions than answers.

## **CONCLUSION**

The findings from the present study indicate that Bhutanese physicians and nurses are not very comfortable with disability and rehabilitation issues, based on normative data and comparison to professionals in other countries. Further research should focus on establishing a standard definition of impairment and disability based on the Bhutanese context. Due to limitations in the specificity of the SADP to a Bhutanese population, these negative attitudes cannot be separated from a misinterpretation based on cultural context. It is also necessary to explore whether similar views are shared by other categories of health professionals. In addition, the attitudes of teachers, who interact directly with students with disabilities, and engineers, who are responsible for designing adapted environments, are of interest.

Although Bhutan has done well with preventive and curative components of the health system (20), there is a need to improve the integration of persons with disabilities into mainstream society. Placing greater emphasis on rehabilitation, education and employment for persons with disabilities, will aid in achieving Bhutan's Ministry of Health and Education sector strategy: realising vision 2020 (21). Through a greater integration of persons with disabilities into the Bhutanese workforce, rates of unemployment and poverty will also decrease (22). Bhutan has created Gross National Happiness (GNH) as a quality of life indicator (22). Given that one of its four pillars is socio-economic development, it is timely and very relevant

within a Bhutanese context to further research and improve attitudes toward disabled persons, thereby enhancing the quality of life for this marginalised portion of the population.

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**CREATING A REGISTRY OF NEEDS FOR PERSONS WITH  
DISABILITIES IN A NORTHERN CANADIAN COMMUNITY –  
THE DISABILITY REGISTRY PROJECT**

Joy Wee\*

***ABSTRACT***

*This study was designed to explore barriers impacting activities and participation of persons with disabilities in a northern Canadian aboriginal community, and to create a communication and documentation system for health professionals in the community to be able to track and address such factors. This report summarises barriers reported by participants.*

**INTRODUCTION**

Persons with disabilities living in the catchment area of the Weeneebayko Health Ahtuskaywin (WHA), a self-governing Aboriginal Cree Mushkegowuk Territory health board responsible for health services for the West coast of James Bay, have identified concerns with accessibility to appropriate health care and services (1, 2). Persons with disabilities reported a sense of helplessness, and were uncertain how to access appropriate health professionals when they encountered difficulties related to their impairments. According to Robarts (1), persons with disabilities should be the ones who are most able to identify their needs, and outline their individual needs, in order to advocate for improved services through community leaders.

A previous community based rehabilitation (CBR) project attempted to address some gaps in access to rehabilitation by training community rehabilitation aides (3). However, because the infrastructure to employ these persons was missing, such training did not lead to systemic changes. Moose Factory is a community of approximately 2700 persons (4). There are more off-reserve than on-reserve Moose Cree members.

Concepts of CBR include effectiveness and sustainability in the provision of care to persons with disabilities (5). In a community such as Moose Factory, which has a local hospital that serves the region, the goal would be to encourage awareness in local health care professionals and community leaders of the needs of persons with disabilities, and challenges that they face, in order to facilitate their community participation. The International Classification of

Functioning, Disability and Health (ICF), (6) provides a framework for understanding the general relationships between health and functioning. Participation is defined by the ICF as “involvement in a life situation.” Examples of participation include volunteering, participating in community events, engaging in advocacy work, parenting a child, and working at a job. In the conceptual framework described in ICF, problems in body structures and functions, otherwise known as “impairments,” inter-relate with activities and participation through personal and environmental factors. Identification of modifiable factors is key to facilitating participation in persons with disabilities.

Lack of appropriate follow-up was a previously identified area of concern (1). If a registry is successfully implemented and managed, individual persons could be connected with the appropriate health care professionals in their community, and appropriate services to access could be identified. Their needs would be known, and follow-through would be more likely. The family medicine department, based in the Weeneebayko General Hospital (WGH) in Moose Factory, is funded by the WHA. It provides comprehensive health care for approximately 11,300 Cree residents in six communities: Moosonee, Fort Albany, Kashechewan, Attawapiskat, Peawanuck, and Moose Factory. Other institutions in the area include James Bay General Hospital (sites in Moosonee, Fort Albany, and Attawapiskat) and the Federal Nursing Stations of Kashechewan and Peawanuck (7). There is a Physical Therapy department in the WGH that also serves these communities. It would be appropriate for the Family Medicine and Physical Therapy departments to have access to such a registry. Additionally, access by community health nurses might be beneficial. It could indicate duration of time between identification of rehabilitation needs and attainment of appropriate modifications or management. A registry could also allow analysis of common barriers. If enough common needs are identified collectively, such information could be used by community leaders to determine priorities and funding allocation. Support for ongoing management and updating of the registry by users and the WHA would be required for the registry to be practically useful for health care providers in the area.

### **Background of project**

This project started as a result of a pivotal meeting in July 2003, attended by a former family physician at WGH, a physiotherapist at WGH, community leaders in Moose Factory including

the former, and now re-elected Chief and current Health Director of the Moose Cree Nation and a representative member of the Mo Creebec Nation, and the author, a specialist in Physical Medicine and Rehabilitation at Queen's University. The Chief had indicated that if there were data to support community improvements that might improve the lives of persons with disabilities, such information would be considered in community planning. After meeting with the Mushkegowuk Council's Health and Social Services Planner, who indicated a need for data to support development of funding proposals for health and social services, a letter of support for the project was provided through the Chief Executive Officer of WHA. A proposal for the development of a Disability Registry, initially intended for all six communities of the WHA, was drafted with the input of the research director of the time, and ethics approvals were obtained from Queen's University (October 2003) and the WHA (December 2003).

Directions as provided by the WHA research director were then followed: letters were written to the health directors of each First Nation to determine interest in participation in the project. Several inquiries were made to non-responders. Positive responses were obtained from two communities, and approval was provided by the Moose Cree Nation in Moose Factory January 2004. Fort Albany also indicated interest, but did not indicate that processes for approval were satisfied until January 2007. Efforts were then made to connect with local persons identified by health directors, for the purposes of informing persons with disabilities about the project.

## **METHOD**

Information about the registry was posted in the Wawatay newspaper and television channel, as well as at the Weeneebayko General Hospital (WGH) and Health Post in Moose Factory. People who were interested contacted a designated person to fill out a consent to release their contact information to the primary investigator, or they had the option of direct contact with the primary investigator.

Data were collected on-site during the month of June 2008. Twenty-one participants with disability were interviewed, 20 from the community of Moose Factory, and 1 living in Timmins, Ontario, who self-identified as being of the Moose Cree band, Mo Creebec nation, or a community member. The individual in Timmins was interviewed by telephone, and the others

in person, either at their homes, or at the WGH, according to their preferences. Individual impairments and needs were collected and entered into a database; this information was provided to the medical records department, physical therapy department, and research director at the WGH. The intent was for database information to be formatted into a usable format by the WGH, accessed, and added to by health professionals working with persons with disabilities in Moose Factory.

In addition to individualised data, suggestions to facilitate community participation of persons with disabilities were elicited from participants, and are presented in this report. Also, persons involved in health care provision in the WHA shared the realities and challenges in providing care in the region. These observations were recorded and summarised. This report provides collated information on the entire group of participants, identifying collective needs and suggestions. 21 participants signed consent forms and participated in interviews. Almost all were of aboriginal affiliation. Each was scored on the Barthel Index (BI, 8) and Participation Scale (P-Scale, 9), which measure activities of daily living and participation, respectively.

## **RESULTS**

Average age of participants was  $65.9 \pm 13.7$  years. Five individuals lived alone, two in an Elders' apartment, and 14 with family. Average BI score was  $83.6 \pm 22$  (range 15-100). Eight persons scored 100 on the BI, being completely independent in activities of daily living. Average P-scale score was  $21.8 \pm 12.4$ . With respect to impairments, categories from the International Classification of Functioning, Disability and Health (6) were used.

Numbers of persons with individual impairments are shown in Table 1. Musculoskeletal conditions were the most frequent, causing some degree of pain and disability in about half the participants. Approximately half the participants had difficulties related to diabetes, and half had visual impairments. Average age of participants with musculoskeletal impairments, diabetes, or visual impairments were similar, ranging from 67 years to 67.9 years. However, when one looked at the severity of impairments, those with severe impairments related to diabetes were younger (average 61 years) than for musculoskeletal (average 62.5 years) or visual (average 67.3 years) impairments.

**Table 1. Numbers of participants with specific impairments**

Area of Impairment	ICF code	Number of Participants with impairment (%)	Participants with large or total difficulty with impairment
Thinking	b144,160,164	7 (33)	1
Learning	d155	1 (5)	0
Paying attention	d160	3 (14)	0
Calculating	d172	1 (5)	0
Focusing on >1 activity	d220	5 (24)	1
Managing stress	d240	5 (24)	2
Reading/Writing	d166, d170	6 (29)	2
Comprehension	d310, d315	2 (10)	1
Speaking	d330, d350	1 (5)	1
Sight	b210	10 (48)	3
Taste/Smell	b250, b255	2 (10)	1
Touch	b265	6 (29)	3
Pain	b280	11 (52)	3
Vocal production	b310	2 (10)	0
Musculoskeletal difficulty	b710, b715, b720, b729, b730, b740	15 (71)	6
Movement	b755, b760	2 (10)	2
Changing position	d410	2 (10)	1
Maintaining posture	d415	2 (10)	1
Lifting	d430	14 (67)	5
Using fingers	d440	7 (33)	2
Using hands/arms	d445	9 (43)	2
Immunity	b435	3 (14)	0
Temperature regulation	b550	10 (48)	3
Sleep	b134	6 (29)	2
Breathing	b440	6 (29)	1

Blood pressure	b420	8 (38)	0
Heart	b410	5 (24)	0
Gastrointestinal	b515, b525	9 (43)	1
Genitourinary	b610, b620, b640, b650	5 (24)	2
Diabetes	b555	10 (48)	5

Numbers of persons reporting difficulties in specific aspects of participation are presented in Table 2. Barriers to participation are shown in Table 3. Twelve of the 21 reported being about to get out of their homes as often as they would like. With respect to quality of life, on an average, they rated it as rather neutral (0.6 on a scale of -10 to +10, SD 4.9), neither good, nor bad.

**Table 2. Numbers of participants reporting difficulties**

Activity/Role	ICF code	Number of participants reporting difficulty (%)	Number reporting large or total difficulty
Using transportation	d470	13 (62)	1
Driving	d475	5 (24; N/A for 13)	3
Taking care of health	d570	11 (52)	5
Finding accommodations	d610	6 (29)	1
Getting help/food/services	d620	5 (24)	2
Preparing meals	d630	15 (71)	4
Helping	d660	5 (24)	1
Relating with family	d760	3 (14)	1
Relating with strangers	d730	4 (19)	0
Intimate relationships	d770	3 (14; N/A for 12)	2
Informal relationships	d750	9 (43)	3
Work training	d840	8 (38; N/A for 11)	4

Getting a job	d845, d850	8 (38; N/A for 11)	4
Volunteering	d855	3 (14; N/A for 1)	0
Financial management	d860, d865	5 (24; N/A for 2)	3
Supporting oneself	d870	5 (24)	2
Community events	d910	9 (43)	2
Recreation/leisure	d920	10 (48)	3
Practising religion	d930	9 (43)	2
Input into community decisions	d950	12 (57)	1

**Table 3. Factors affecting participation**

Factor	ICF code	Number of participants reporting difficulty (%)	Number reporting large or total difficulty
Beneficial objects available	e115, e120, e125	13 (62)	2
Physical layout of land	e210	16 (76)	9
Weather	e225	14 (67)	6
Light conditions	e240	3 (14)	1
Sound quality	e250	2 (10)	0
Air quality	e260	6	2

More than half the participants experienced difficulties in transportation, meal preparation, and having a say in community decisions. Activities that many had difficulty participating in, included recreational or leisure activities, community events, and religious activities. Finding a job and work training was reported as a challenge by most participants who were not yet retired. Lack of funds seemed to be a barrier in some instances, including the ability to repair or replace equipment that malfunctions, or to pay for dietary supplementation.

The majority of persons with disabilities reported receiving therapy and homecare assistance when required. Most were set up with the locally available transportation service. Many did not seek or receive regular review by physicians at the hospital. Some did not seek help even

with sudden changes in health leading to additional medical impairments. They cited the reason for not seeking help as being a lack of action when they had previously sought assistance. Many voiced concerns that were not previously identified or documented in their hospital charts, as shown in Table 4, which also documents the numbers of actions taken 3 months after the initial registry was provided to WGH shortly after the on-site visit. Areas of participant-identified concern that had not been documented in hospital records in 32 instances, included aspects of bowel and bladder care; equipment and assessment requirements as pertained to hearing, sight, or teeth; education regarding diet; psychological assessment and management; and the need for diagnosis and management of peripheral nerve, circulatory, sleep, and musculoskeletal symptoms. Other areas of concern included assessment of the need for orthotics, pressure stockings, vestibular retraining, and family counseling. Some cited not having a family physician, in a community served primarily by short-term physicians, as a reason for not having these concerns dealt with.

**Table 4. Documentation and addressing of health or rehabilitation concerns identified by participants**

<b>Issue</b>	<b>Number of issues</b>	<b>Health professional aware</b>	<b>Issue resolved 3 months later</b>
Awaiting assessment	19	3	3
Awaiting management	8	4	-
Awaiting equipment	25	12	4
Awaiting home modifications	9	3	-
Action required by participant/family	3	2	-
Action required by Community	15	-	-
Requiring education/counseling	10	2	2

Some concerns related to a lack of local services. These included swallowing, speech and language assessments, identification of resources and funds for disability-related expenses, and management of psychological health. Uncertainties of rebooking cancelled procedures that were to occur outside of the community may linger indefinitely as participants remain uncertain as to whom to contact. Staff reported a concern with respect to discharge of

persons who received care in other communities, and returned with inadequate supports or communication with local health care providers. They also reported insufficient personnel positions, coupled with difficulty in recruiting personnel as a challenge.

Many waited a long time before receiving equipment, probably related to two levels of funding that many have to navigate: the Assistive Devices Programme (10), and the Non-insured Health Insurance Benefits programme (NIHB, 11), which entailed more paperwork and longer waits for approval than for non-aboriginal persons. There was a range in the waiting period for equipment, depending on channels through which they were approved and obtained. For example, most people received raised toilet seats and grab bars almost immediately, whereas wheelchairs and certain types of walkers took much longer, up to 2 years, though there was no consistency reported in the duration of wait. Provision of orthotics has improved recently, since an orthotist has been coming from out-of-town. Also, participants who might benefit from power mobility equipment tended not to have them prescribed, possibly related to funding, access, and storage challenges.

Home modifications generally took longer to complete, from 3 months to 4 years, as reported amongst those who have had them completed. Many others continue to await renovations. The majority of participants rent their homes from one of the two bands with land in Moose Factory, and the housing department is reportedly responsible for renovations. Some participants reported having incurred additional expenditures due to inadequate original construction of ramps.

Terrain, weather, and high cost of food and other essential items were all mentioned as barriers to community participation. Roads are unpaved, dusty when dry, and muddy when wet, despite improvements that have been made in drainage and grading. Being an island, residents of Moose Factory travel off the island by boat for three of four seasons, or by land vehicles in the winter.

Participants were asked for suggestions to improve their participation and quality of life in their community. Some reported motivation as an issue, given the difficulty in actually getting out to do things. Many suggestions were made, from installing higher seats in public places such as the airport and hospital waiting room and cafeteria, to installing an elevator at the WGH, to allowing persons with disability to use the more stable and accessible barge rather

than small motor-boats. Upon further inquiry, prior to a year ago, persons with disability were allowed to use the barge, but current concerns about safety of the barge led to a change in policy.

Table 5 lists some of the more common suggestions, along with the numbers of participants who expressed them. The most common suggestion was to pave the roads in the community, as they offer poor access for persons with mobility or visual impairment, but also cause many respiratory difficulties, particularly on dry, dusty days. Improved access of the main entrance to the community arena was also mentioned. Most houses are not accessible to wheeled mobility equipment, and since many would like to maintain their many social connections, a more accessible general building code may be beneficial. There is a transportation service for elders and persons with disabilities, but ability to transport wheelchairs is limited. Extended hours were suggested, to support participation in social activities on weekends and evenings. There is a reluctance by persons with disabilities to rely on their families for transportation to social events that family members are not involved with, leading to social isolation. Though there are apartments for elders, more are required, and accessibility needs to be improved to support independence. For example, cupboards and counters would need lowering for wheelchair users. Apparently, a nursing facility had been considered in the past, but because of regional limitations, the closest nursing facility remains in a different community quite a distance away. Persons with disabilities wishing to be gainfully employed reported difficulty finding work opportunities. Most persons with disabilities felt respected by others, but a need for general education of the community with respect to the challenges they face, and disability awareness was also identified.

**Table 5. Common suggestions in order of frequency reported**

<b>Suggestion for community leaders</b>	<b>Number of participants reporting suggestion</b>
Improve roads/install sidewalks	15
Improve boat access	5
Install a ramp at the arena	5
Plan inclusive community activities	5

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Provide accessible housing	4
Build a nursing home	4
Educate the public about disability	4
Provide home renovations ASAP	4
Enforce a general accessible building code	3
Provide wheelchair accessible transportation	3
Extend the schedule for accessible transportation	3
Provide raised seats in public places	2
Extend boat operation schedule	2

## **DISCUSSION**

Optimising participation of persons with disabilities is one of the ultimate aims of rehabilitation. This effort to identify the needs of persons with disabilities uncovered several opportunities for improving their participation in this northern Canadian community, largely comprised of First Nations persons. Potentially beneficial changes include improved communication at the individual and community levels, as well as with health providers in distant communities. Larger, systemic considerations of health care provision need to be undertaken. Participants also provided suggestions for community leaders to consider in order to improve community participation, and potentially quality of life, for persons with disabilities and those who care for them in this community, where the family unit appears to be generally strong and healthy.

At the individual level, the registry is an attempt to ensure continuity and completeness of care. The WGH has demonstrated in the three months since receiving it that the registry can be used to document when interventions are completed, and which areas need ongoing involvement. The research director at WGH and the medical records department have assumed responsibility for transforming it into a living document, in other words, an electronic record, with the intent that it be accessible by physicians and personnel in the Physical Therapy Department. In the coming months, management of the registry will lie in the hands of those with access to it. Information can be updated and the registry can be populated with new participants. Statistics may be summarised from time to time, to monitor progress. Perhaps, in time, community health providers might be able to access the registry, since many issues remained undocumented by hospital staff, whereas community health providers

may learn about issues sooner, as they visit patients in their homes. Closer communication between community and hospital providers may reduce the numbers of unresolved issues that are not identified or addressed. Also, closer communication between the housing department that completes home renovations, and the Physical Therapy Department may be beneficial in ensuring that home renovations are the most appropriate for the individuals they are meant to benefit. The services of a social worker would be helpful in dealing with funding issues, and for counseling.

Overall coordination of health care needs to consider ongoing contact with persons with disabilities to ensure completeness, as many seemed to remain silent in voicing their needs, questions, and unresolved issues, unless specifically asked. Some persons with disabilities remain in their homes, relying primarily on family support, and may not be aware of services that may be available or beneficial to their ability to participate in the community. Many are reluctant to ask for help, or use services that seem already stretched, and have demonstrated resourcefulness and relative self-sufficiency. Those awaiting home modifications or equipment often seemed to have no idea as to when these would be provided. More regular communication between various providers may help to answer such questions. Health service planners may wish to consider increasing rehabilitation management in the region. In other areas of Ontario, the Community Care Access Centre (CCAC, 12) provides case managers, and a host of services that are available through this programme, including speech language pathology, dietitian, and social work services. These do not seem to be available in Moose Factory. CCAC services are available in communities such as Timmins, and to a lesser degree in nearby Moosonee. Increased psychiatry involvement might be considered in the Moose Factory area, to provide completeness in rehabilitation management.

Coordinated discharge processes from distant acute hospitals may better support health care provision for the local population. A suggestion by hospital staff included instituting a policy that all hospitalised patients from the catchment areas of the WHA should be transferred to the WGH before being discharged into the community, so that appropriate supports and equipment might be arranged prior to patients returning home. For such a policy to be effectively instituted, all those impacted would need to be informed by appropriate senior management personnel in the WHA: these would include all distant hospital discharge planners, air ambulance and transportation personnel, community health providers, and community

members. Explorations between the WGH and partner hospitals of each hospital's capabilities and limitations may ease understanding and clarify expectations.

A Health Canada website (13) discusses the interesting phenomenon of reduced Ontario Health Insurance Plan (OHIP) use by First Nations communities, and resultant cost transfers to the federal NIHB programme. Services available to First Nations communities should include what is available through OHIP, in addition to what is available through NIHB, and one would expect better coverage than the average population, not worse, for First Nations persons, if availability and utilisation were maximised. Because of the challenges of dealing with multiple levels of funding, and inherent delays or inadequacies in service provision, some are proposing an integrated health funding programme (13), the argument being that if control of funding is put into the hands of the local communities, then perhaps they may be better able to institute services as they need them, and not be unduly affected by other considerations such as structure of Local Health Integrated Networks. They might be able to access the specialists and services they require. As an example, persons with disabilities in Moose Factory, which is within the North East Local Health Integration Network (LHIN, 14) should usually turn to Timmins for specialist care, based on the catchment area of the LHIN. However, there are no psychiatrists based there. Therefore, at the present time, psychiatric care is provided through Kingston, when requested, through the Queen's Weeneebayko Programme (15), with joint provincial and federal funding, and the Ontario Telemedicine Network (16), funded by the government of Ontario. Health service delivery is a complex phenomenon, and much thought and planning would need to be invested for successful transitions.

The cohort of persons with disabilities that was enrolled in this first version of the registry demonstrated some characteristics that community leaders and programme planners may wish to note. The majority had some type of musculoskeletal impairment, with implications of pain and disability. Limited vision was another area of concern for the more elderly participants. Diabetes was present in about half of the participants, and directly contributed to impairments; relatively younger persons seemed to be affected by diabetes, in keeping with other available data, which suggests that incidence of Type 2 diabetes is higher in the aboriginal population, and occurs in children as well (17). Participant numbers was somewhat limited by time available on-site, though the Physical Therapy department indicated that

there were no other persons with disabilities that they were aware of. This study did not include needs of children with disabilities in the community, and a future study of children's needs may be helpful to inform community leaders.

Overall, participants were well satisfied with the level of community support services available to them. Their level of participation could be improved, however, when compared with that of persons with disabilities in other Canadian communities (18). Participants provided inputs as to what community changes may positively influence their ability to participate in the community. Many suggestions related to accessibility, including accessible roadways and sidewalks; accessible land and water transportation services with availability during evenings and weekends; accessible public buildings with appropriately constructed ramps at front entrances and accommodations such as raised seats, in public places such as the local arena; and accessible housing. A meal delivery programme may help people remain in their homes longer, since the majority of participants identified meal preparation as a concern. They often relied on families to provide meals, but some had no such support systems. Supported living, such as a care facility, would help support persons with disabilities in their own community, rather than in distant communities such as Cochrane, where the nearest nursing facility exists. The only other option currently being employed is for persons with disabilities who require care giving to stay indefinitely in hospital. Increased community awareness may allow event organisers to host inclusive activities for persons with disabilities to participate in. In addition, for younger persons with disabilities who would like opportunities to find gainful employment, incentives and a general expectation of employers to provide accommodations, could be developed.

It is hoped that the registry will, in the hands of the WHA, become an active record that can be examined from time to time for data pertaining to persons with disabilities in Moose Factory. More information would be obtained as and when data for more persons with disabilities are added to the registry. Such information could be combined with information from other endeavours, such as the Regional Elder's Programme (7). The data suggest that actions at multiple levels have the capability of positively influencing the lives of persons with disability.

## **CONCLUSION**

Understanding of issues by community leaders is important for persons with disabilities (19). This report shares information about persons with disabilities that community leaders may find useful in community planning. It provides leaders with an awareness of causes of disability in the community, and potentially modifiable factors that impact the lives of persons with disabilities. Leaders may wish to facilitate involvement in persons with disabilities in identifying community needs and decision-making at the community level, encouraging self-advocacy, in order to address environmental and social barriers.

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## LANGUAGE AND LEARNING SKILLS AND SYMPTOMS IN CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

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### ABSTRACT

*While assessment is the key to an intervention programme, it may not generate information precise enough to identify specific behaviours to teach children with autism. The authors studied the clinical presentation of autistic symptoms and the development of language and learning skills in 20 children with autism and compared it to 20 matched controls. Given the nature of the disorder, a global score does not clarify the areas of individual difficulties. Therefore, each item was analysed to see the variation in symptoms and skill development of children with autism. Findings indicate that the manifestation of autistic symptoms varies with each child with autism. The development of language and learning skills was found to be significantly below that of the typically developing children. The results are uniform in showing that children with autism follow individual patterns of skill development and have their unique areas of relative strengths and weaknesses. The findings have implications for assessment and evaluation practices as well as designing intervention programmes for children with autism.*

### INTRODUCTION

The autistic spectrum disorders are a heterogeneous group of neuro-behavioural syndromes characterised by major impairments in basic social relationships, abnormal language development, limited or non-existent imagination and extremely rigid patterns of behaviour. The term 'spectrum' implies a range of severity from mild, allowing close to normal function in many areas, to the most severe in which social function appears to be impossible, but along with restricted behaviour the whole spectrum is defined by the presence of impairments affecting social interaction, communication and imagination, known as the 'triad of impairments' (1). Autism may also result in severe cognitive disabilities that adversely affect individuals'

global development. Individuals with autism display behaviours that are either excessive or in deficit, compared to the general population.

As a spectrum disorder, the level of developmental delay is unique to the individual. Although autism is defined by a certain set of behaviours, children and adults can exhibit any combination of the behaviours in any degree of severity. Children with autistic spectrum disorders differ from one another in the way the core symptoms are presented, in individual characteristics and cognitive abilities, in severity of the disorder and in the coexistence of other medical conditions as well as environmental influences. Two children, both with the same diagnosis, can act very differently from one another and have varying skills (1).

These diverse expressions of autism within and across individuals, present particular challenges for assessment and treatment. The important goals of assessment include a refined documentation of the child's functioning in various developmental domains (2) including intellectual abilities, both verbal and performance, social competence, receptive and expressive language skills, social use of language, motor performance, imitation skills, self-care and other abilities of daily living to place an individual in a broader developmental framework.

Development of language and the communicative competence of children with autism has been an important focus of interventions for children with autism and a number of language training interventions have been developed over the years. Whereas in the past, the communicative means were the main focus, at present the tendency is also to emphasise the communicative functions (3). The question of which means an individual has at his or her disposal to pass on a message is really relevant, but the ultimate question to answer is what the intention of the individual is at that moment. For instance, assessment concerns not only whether someone is pointing, but also whether he or she is doing so to get something or to comment on what is happening in his or her environment.

Although a number of efficient standardised skill assessments are available for children with autism, these assessments typically do not generate information that is precise enough to identify specific behaviours to teach. Educational research has increasingly focused on the value of matching instructional strategies to the student's current skill level. In lieu of standardised assessments, it is recommended that informal assessments be conducted for children with autism by evaluating the child's performance on tasks drawn from a pre-established curriculum (4).

The present research aims to study the clinical presentation of the symptoms of autism and the development of language and learning skills in children with autism and compare it with the profile of the typically developing children. Given the nature of the disorder, a global score for the measures does not clarify the areas of individual difficulties. Therefore, each item was analysed to see the variation in autistic symptoms and skill development of children on the autistic spectrum.

## **METHOD**

### **Participants**

Twenty children (mean age, 4.16 years (0.86)) diagnosed with autism according to DSM-IV–TR (5) criteria, 0–6 months prior to the study, living at home with biological parents and not attending any autism-specific programme, were recruited from out-patient services in New Delhi. Fourteen children (70%) were males. Children with autism were compared to 20 controls (mean age, 3.67 years (0.38)) of which 12 children (60%) were males. The two groups did not differ significantly in age, sex, parental age, parental education, family religion and family income. Families with parents having any psychiatric, neurological or physical disability were excluded.

### **Measures**

**Autism Behavior Checklist (ABC):** The ABC (6) was presented to parents in the simple Yes/No format to obtain a symptomatic profile of the child. The 57 items on this checklist are differentially weighted to reflect the centrality of problem behaviour to the diagnosis of autism and assess five symptom areas of autism.

**Assessment of Language and Learning Skills (ALLS):** Skill areas were assessed on a total of 15 dimensions chosen from two tools: **The Behavioural Language Assessment (7)** and **The Assessment of Basic Language and Learning Skills (8)**. Skinner's (9) analysis of verbal behaviour serves as the conceptual basis. A number of follow-up projects have been done (10) on this. The tools have strong components of language and provide strategies to develop an effective Individualised Education Programme (IEP) for a child.

## PROCEDURE

The researcher contacted each family on the telephone and presented the intent of the research. If the parents met the criteria for the study and gave informed consent, the researcher scheduled a meeting for an assessment of the child. The assessments conducted in the presence of both the parents, were based upon independent observation of the child and information obtained from the parents. Testing time was up to three hours for each child and the researcher completed the measures in the same order over two meetings.

## Statistical Analysis

Analysis was completed using SPSS 10. Groups were compared using an independent sample t-test. The effect sizes were calculated using Cohen *d* to estimate the practical significance of the differences. For interpretation, Cohen's scale of magnitude of effect size was used with values associated with small, medium and large effect sizes as .2, .5 and .8 respectively (11).

## RESULTS

As compared to the controls, children with autism were found to show significantly more difficulties in responding to the sensory stimuli in the environment, relating with people and development of self-help skills. Children with autism also exhibited significantly more stereotypical body movements, preference for routines and self-injurious behaviours as compared to the controls. Language and learning skills (ALLS) were found to be significantly poorer in children with autism than in controls (Table 1).

**Table 1. Group means and differences on autistic symptoms and language and learning skills**

Subscale	Autism (n=20)			Control (n=20)			t(38)	p	ES
	M	SD	Range	M	SD	Range			
ABC									
Total Score	79.00	12.43	58-106	3.10	1.68	0-6	27.07	0.000	8.56
Sensory	13.35	5.71	4-23	0.20	0.62	0-2	10.23	0.000	3.24

Relating	20.45	8.08	4-35	0.30	0.92	0-3	11.09	0.000	3.50
Body/Object Use	15.90	6.40	6-30	1.15	1.09	0-3	10.16	0.000	3.21
Language/Social	14.15	3.83	8-21	0.25	0.55	0-2	15.24	0.000	5.04
Self - Help	14.75	5.35	5-23	1.20	0.77	0-3	11.19	0.000	3.55
ALLS									
CWA	2.35	0.81	1-4	4.60	0.50	4-5	10.53	0.000	3.34
Manding	3.25	0.85	1-4	4.95	0.22	4-5	8.64	0.000	2.74
Motor Imitation	2.65	1.31	1-4	4.85	0.37	4-5	7.24	0.000	2.15
Vocal Play	3.55	0.76	2-5	4.90	0.31	4-5	7.37	0.000	2.33
Echoic	2.70	1.03	1-4	4.95	0.22	4-5	9.54	0.000	3.02
Match to Sample	2.15	0.93	1-5	4.90	0.31	4-5	12.51	0.000	3.46
Receptive	2.95	0.83	1-4	4.95	0.22	4-5	10.46	0.000	3.29
Tacting	2.60	0.75	1-4	4.90	0.31	4-5	12.63	0.000	4.01
RFFC	1.25	0.44	1-2	4.90	0.31	4-5	30.20	0.000	8.86
Intraverbals	1.75	0.64	1-3	4.95	0.22	4-5	21.15	0.000	6.69
Letters/ Numbers	1.90	0.97	1-4	4.95	0.22	4-5	13.73	0.000	4.34
Social Interaction	2.95	0.39	2-4	4.95	0.22	4-5	16.65	0.000	4.64
Gross Motor	11.20	3.56	3-16	26.15	1.09	25-28	17.95	0.000	5.68
Fine Motor	11.95	3.10	8-19	26.95	0.89	26-28	20.79	0.000	6.58
Writing	5.20	1.85	2-8	29.90	1.48	28-32	46.59	0.000	14.74

Note: ABC = Autism Behaviour Checklist; ALLS = Assessment of Language and Learning Skills; CWA = Cooperation with Adult; RFFC = Receptive by function, feature or class.

Given that autism is a spectrum disorder and the clinical manifestation of behaviours varies among children with autism, the authors examined the individual items of ABC and the frequency of occurrence of autistic behaviours among children with autism. Fifty-six of a total of 57 symptoms of ABC were present amongst the children with autism in the present sample. While some symptoms occurred more frequently and were present in 100% of the

children, other behaviours were seen in only 5% of the children diagnosed with autism (Table 2).

**Table 2. Percentage of children showing symptoms on Autism Behaviour Checklist**

Item No	Description	Autism (n=20)	
		n	%
	<i>Sensory</i>		
6	Poor use of visual discrimination	8	40
10	Seems not to hear	9	45
21	Sometimes show no “startle response”	14	70
26	Sometimes no reaction to painful stimuli	2	10
34	Often will not blink when a bright light is directed	14	70
39	Covers ears at many sounds	13	65
44	Squint or cover eyes in natural light	3	15
52	Frequently has no visual reaction to a “new” person	12	60
57	Stares into space for long periods of times	16	80
	<i>Relating</i>		
3	Not attend to social/environmental stimuli	13	65
7	Has no social smile	14	70
13	Does not reach out when reached for	8	40
17	Not responsive to facial expressions/feelings	8	40
24	Avoids eye contact	19	95
25	Resists being touched or held	9	45
27	Stiff and hard to hold	0	0
28	Is flaccid when held in arms	4	20
33	Not imitate other children at play	14	70
38	Not developed any friendships	14	70

43	Often frightened or very anxious	1	5
47	Looks through people	18	90
	<b><i>Body/Object Use</i></b>		
1	Whirls self for long periods of time	9	45
5	Does not use toys appropriately	15	75
9	Insists on keeping certain objects	13	65
12	Rocks self for long periods of time	2	10
16	Lunging, darting, spinning, toe walking, flapping	12	60
22	Flaps hands	4	20
30	Walks on toes	11	55
35	Hurts self by banging head, biting head	12	60
40	Twirls, spins and bangs objects	3	15
51	Will feel, smell and/or taste objects in the environment	6	30
53	Involved in complicated "rituals"	10	50
54	Is very destructive	13	65
	<b><i>Language/Social</i></b>		
4	Does not follow simple commands given once	5	25
8	Has pronoun reversal	2	10
11	Atonal and arrhythmic speech	4	20
15	No response to own name when called out among two others	15	75
18	Seldom uses "yes" or "I"	15	75
20	Not follow simple commands involving prepositions	17	85
29	Gets desired objects by gesturing	9	45
32	Repeats phrases over and over	7	35
37	Cannot point to more than five named objects	9	45

42	0-5 spontaneous words daily to express wants/needs	5	25
46	Repeats sounds or words over and over	14	70
48	Echoes questions or statements made by others	15	75
56	15 - 30 spontaneous phrases daily to communicate	4	20
	<b>Self-Help</b>		
2	Learns a simple task but “forgets” quickly	12	60
14	Strong reactions to changed routine/environment	10	50
19	Has “special abilities” in one area of development.	3	15
23	Severe temper tantrums and/or frequent minor tantrums	15	75
31	Hurts others by biting, hitting, kicking, etc.	8	40
36	Does not wait for needs to be met	15	75
41	Difficulties with toilet training	18	90
45	Does not dress self without frequent help	15	75
49	Oblivious to dangerous situation	20	100
50	Manipulates/ occupied with inanimate things	16	80
55	Identified developmental delay before 30 months of age	1	5

On the sensory subscale which measures the nonresponsiveness or heightened responsiveness to sensory stimuli, five of nine symptoms were reported present in at least 60% of children with autism. Staring into space for long periods (80%) was the most common symptom followed by a lack of startle response (70%), no blinking to bright lights (70%), covering ears at many sounds (65%) and no visual reaction to ‘new’ person (60%).

On the subscale that measures the relatedness of a child with his environment, 6 of 12 symptoms were reported for at least 60% of participants in the autism group. Most children with autism were found to avoid eye contact with others (95%), look through people (90%), have no social smile (70%), do not imitate other children at play (70%), have not developed any friendships (70%) and do not attend to social and environmental issues (65%). Body/ Object Use measures the presence of stereotyped body movements, preference for routines,

and self-injury. Five of 12 symptoms reported present in at least 60% of the children with autism included the lack of ability to use toys appropriately (75%), insistence on keeping certain objects with him/her (65%), running around the house (60%), self-injurious behaviours (60%) and destroying household objects (65%).

The Language/Social subscale measures the achievements on typical developmental milestones in language and the use of language in socially inappropriate ways. The results reveal that 6 of 13 symptoms were reported present in at least 60% of children. The most common symptoms present amongst children with autism include an inability to follow simple commands involving prepositions (85%), inability to respond to name (75%), minimal use of 'yes' or 'I' (75%); echolalia (75%) and repetitive speech (70%). It was found that even if the children were unable to reproduce exact words, they would be echoing the sounds of questions or statements that they heard.

The Self-Help subscale measures the acquisition of adaptive as well as destructive and aggressive behaviour and 7 of 11 symptoms were reported as present in at least 60% of children. All the children with autism in the present sample seemed unaware of their surroundings and danger (100%). This was closely followed by difficulties in toilet training (90%) and a preference towards inanimate objects (80%). Most children with autism also showed severe tantrums (75%) and had difficulties with waiting (75%).

Results also show a wide spectrum in the abilities of children with autism. All the dimensions of ALLS for children with autism were examined (Table 3). The results show that skill development varied in children with autism. While some of the children with autism were at the beginner's level, others in the same group had more developed skills.

**Table 3. Percentage of children at different skill levels on various dimensions of language and learning skills**

Dimensions	1		2		3		4		5	
	n	%	n	%	n	%	n	%	n	%
CWA	3	15	8	40	8	40	1	5	0	0
Manding	1	5	2	10	8	40	9	45	0	0
Motor Imitation	5	25	6	30	0	0	9	45	0	0

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Vocal Play	0	0	2	10	6	30	11	55	1	5
Echoic	2	10	8	40	4	20	6	30	0	0
Match to Sample	4	20	11	55	4	20	0	0	1	5
Receptive	1	5	4	20	10	50	5	25	0	0
Tacting	1	5	8	40	9	45	2	10	0	0
RFFC	15	75	5	25	0	0	0	0	0	0
Intraverbals	7	35	11	55	2	10	0	0	0	0
Letters/ Numbers	9	45	5	25	5	25	1	5	0	0
Social Interaction	0	0	2	10	17	85	1	5	0	0

Note: CWA = Cooperation with Adult; RFFC = Receptive by function, feature or class; Higher score means better skills

Cooperation with Adult identifies the degree to which a child will work with adults. The results reveal that the children with autism cooperated less with adults and had more disruptive behaviours. Amongst the children with autism, three children (15%) were found to be always uncooperative, avoided work and engaged in negative behaviours, eight children (40%) engaged in disruptive behaviours and gave only a single, easy response for a powerful reinforcer, eight children (40%) were able to give up to five responses without any disruptive behaviour and only one child (5%) worked for five minutes without a disruptive behaviour.

On Manding or the ability of the child to get his/her needs and wants known, the results reveal that while one child (5%) was unable to ask for reinforcers and engaged in negative behaviours; two children (10%) pulled people, pointed or stood by the object of their desire. Eight children (40%) indicated their needs using up to five words, signs or pictures and only nine children (45%) indicated their needs using up to 10 words, signs or pictures.

On Motor Imitation, which determines if the child can physically imitate motor movements modeled by another person, five children (25%) could not imitate any motor movements and six children (30%) were able to imitate only a few gross motor movements. Nine children with autism (45%) were able to imitate several fine and gross movements on request.

Vocal Play measures the amount of the spontaneous random sounds produced by a child. The results show that two children (10%) were found to make few spontaneous speech sounds at a low rate; six children (30%) babbled speech sounds with varied intonations, eleven children (55%) were found to babble frequently with varied intonations and say a few words and only one child (5%) was able to vocalize many words with varied intonations.

Echoic measures the ability to repeat sounds and words. The results reveal that amongst the present sample of children with autism, three children (15%) were unable to repeat any words, 13 children (65%) were able to repeat specific sounds or words, two children (10%) were able to repeat close approximations of many words and the rest (10%) were able to repeat some words and short phrases.

On Matching to Sample, the ability to match pictures, designs and shapes to identical samples, four children (20%) were unable to match any pictures, 11 children (55%) were able to match only 1-2 objects to a sample, four children (20%) were able to match 5-10 colours, shapes or designs to a sample and one child (5%) with autism was able to match most items and 2-4 block designs.

Receptive Skills measure the ability to understand and act upon specific words and phrases. The results reveal that while one child appeared to not understand any word, four children (20%) were able to follow few instructions related to daily routines, ten children (50%) were able to follow many instructions and even touch few items, and five children (25%) were able to follow many instructions and touch at least 25 items.

On Tacting, the ability to verbally identify and name items or objects, it was found that one child with autism (5%) seemed unable to verbally identify any object, item or action, eight children (40%) were able to verbally identify 1-5 objects, nine children (45%) were able to name up to 15 items and two children (10%) were able to verbally identify up to 50 items or actions.

Receptive by function, feature and class (RFFC) is the ability to be able to react to an object when told something about the object or when given a verbal instruction that varies from the specifically trained instruction. The results reveal that 15 children with autism (75%) were unable to identify items based on the information about them and five children (25%) identified a few items when given synonyms of common functions.

Intraverbals measures the child's ability of the rudimentary skills necessary for engaging in conversations. While seven children with autism (35%) were unable to fill in any missing words, 11 children (55%) were able to fill in parts of songs. The remaining two children (10%) were able to answer about 10 questions or complete simple phrases.

The results on Letters and Numbers identification show that nine children with autism (45%) were unable to identify any letters or numbers; five children (25%) identified at least three letters or numbers; five children (25%) could identify at least 15 letters or numbers and one child (5%) could read at least 5 words and identified 5 numbers.

On social interactions, two children (10%) were found to physically approach others to initiate an interaction; 17 children (85%) readily asked adults for reinforcers and only one child (5%) was found to attempt verbal interactions with peers with the help of prompts from adults.

Analysis of individual items on gross motor skills (Table 4) shows that while all children with autism in the present sample were able to successfully complete certain activities, other activities could be performed by only some of the children with autism. Few children were found to be able to walk backwards (25%), and skip (25%). No child with autism was able to walk sideways, gallop, jump from a raised platform or balance on one foot. Some children were able to manipulate an 8-inch ball in different ways. It was found that only nine children (45%) were able to kick a ball to a person 6 feet away but most children were able to throw a ball from chest or over hand (90%); underhand (85%) and were able to catch a ball using their arms and chest (80%) at least half of the times. However, none of the children were able to catch a ball using only their hands or bounce a ball at least three consecutive times. None of the children were able to ride a tricycle or a bicycle while pedaling to move the cycle forward, do jumping jacks, climb a 5 feet ladder using reciprocal motion; walk across a narrow board for 8 feet without falling; or hang from a bar. Only five children (25%) were able to pump their legs while on a swing.

**Table 4. Percentage of children on various items measuring gross motor skill**

Item	Autism (n=20)	
	n	%
Creep on stomach	20	100
Kneel	18	90
Walk forward with appropriate gait	20	100
Walk backwards	5	25
Walk sideways	0	0
Run smoothly	18	90
Squat	18	90
Roll sideways	8	40
Hop on two feet	11	55
Skip	5	25
Gallop	0	0
Jump forward	17	85
Jump down	0	0
Balance on one foot for 3 seconds	0	0
Kick 8-inch ball 6 feet to target	9	45
Throw (chest/overhand) 8-inch ball 4 feet to target	18	90
Throw (underhand) 8-inch ball 4 feet to target	17	85
Catch 8-inch ball from 4 feet using chest with arms	16	80
Catch 8-inch ball from 4 feet with hands only	0	0
Bounce ball at least three times	0	0
Roll ball 6 feet to another person	19	95
Ride tricycle while peddling for 20 feet	0	0

Ride and stop a bicycle	0	0
Jumping jacks	0	0
Climb ladder 5 feet in reciprocal motion	0	0
Walk balance beam for 8 ft without falling	0	0
Pump legs while swinging	5	25
Hang from bar	0	0

Analysis of individual items assessing the fine motor skills (Table 5) reveals that some areas of fine motor difficulties were common for most children with autism. Among the children with autism, 10 children (50%) were able to place an object in a form box. All children with autism were able to put a single-piece inset puzzle piece into frames, but only two of them (10%) were able to manipulate multiple puzzle pieces into a frame. All children with autism were able to stack blocks, but none of them were able to place blocks on design cards without prompts. Another area of chief difficulty for children with autism was manipulating a spring-type clothespin which was successfully performed by only two children with autism (10%). All children with autism were able to remove jar lids, but only two of them (10%) were able to replace the jar lids. Even with a powerful edible reinforcer inside, none of them were able to open Ziploc type bags and only five children (25%) were able to snip a paper with a pair of scissors. None of the children with autism were able to cut across paper with the help of scissors, cut out shapes, paste shapes on outline picture or make a picture according to a sample, use a pincer grip and copy shapes and line patterns. Only four of them (20%) were found to be able to fold paper and squeeze a glue bottle.

**Table 5. Percentage of children on various items measuring fine motor skill**

Item	Autism (n=20)	
	n	%
Place object in form box	10	50
Place pegs on board	19	95

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Put single puzzle piece into frames	20	100
Manipulate multiple puzzle pieces into frames	2	10
Stack blocks	20	100
Place blocks on design cards	0	0
Put rings on pegs	20	100
Transfer objects to opposite hands	14	70
Put spring type clothespin on line	2	10
String beads with 1/8 inch hole	14	70
Remove jar lids	20	100
Replace jar lids	2	10
Remove wrappers to get to food items	19	95
Open 'Ziploc' type bags to get to food items	0	0
Snip paper with scissor	5	25
Use pincer grip to pick small items	0	0
Mark on paper with a crayon	20	100
Color within boundaries	14	70
Roughly copy shapes and line patterns	0	0
Accurately copy shapes, patterns with orientation and size	0	0
Cut on a line across a sheet of paper with scissors	0	0
Cut out shapes with scissors	0	0
Independently paste shapes in outlined picture	0	0
Independently paste shapes to match sample	0	0
Trace a line with finger	19	95
Turns one page of a book at a time	11	55
Imitatively fold paper in half	4	20
Squeeze glue from a bottle	4	20

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As shown in Table 6, analysis of items measuring the writing skills shows that 11 children with autism (55%) were able to mark on paper using the writing grip, 12 children (60%) were able to colour between lines and 18 children (90%) were able to trace only straight lines. Children with autism needed physical prompts to copy straight lines (60%) and curved lines (70%) Most children were unable to copy letters (75%) and numbers (90%) and even the rest were able to make rough approximations of a maximum of five letters or numbers. Only two children with autism (10%) were able to independently write at least five letters without a model but none of them was able to print at least five numbers.

**Table 6. Percentage of children at different skill levels on various items measuring writing skills**

Item	Autism (n=20)									
	0		1		2		3		4	
	n	%	n	%	n	%	n	%	n	%
Make marks on paper	0	0	9	45	11	55				
Color within lined areas	8	40	12	60	0	0				
Trace lines, letters and numbers	1	5	18	90	1	5	0	0	0	0
Copy straight line	5	25	12	60	3	15	0	0	0	0
Copy curved line	6	30	14	70	0	0	0	0	0	0
Copy letters from a sample	15	75	5	25	0	0	0	0	0	0
Copy numbers from a sample	18	90	2	10	0	0	0	0	0	0
Print letter without a model	18	90	2	10	0	0	0	0	0	0
Print number without a model	20	100	0	0	0	0	0	0	0	0

Note: Higher score means better skills

## DISCUSSION

The authors studied the clinical presentation of symptoms of autism and the development of language and learning skills in children with autism and compared it with the profile of the typically developing children. The total score on ABC shows that the children with autism

scored significantly higher on all the five symptom areas of autism. Since a global score does not clarify the areas of individual difficulties, all the items have been analysed individually to see the variation in autistic symptoms and skill development of children on the autistic spectrum.

Children with autism had significant difficulties in responding to the sensory stimuli in the environment and multisensory processing appear to be affected among children with autism. This is consistent with other studies which suggest that sensory processing dysfunction in autism is global in nature and sensory processing problems need to be considered part of the disorder (12) and they hinder their daily functioning (13). Leekam et al. (14) also found that only 6% of children with autism in their study were not affected by a sensory symptom and found differences across multiple sensory domains in the frequency and patterns of abnormalities. Children with autism may have hyper (over), hypo (under) or a combination of hypo or hyper arousal sensitivities to sensory stimuli and the same can be seen in the present sample. While most of the children with autism showed no startle response, many of the same children also covered their ears at other sounds.

Results show children with autism have impairment in relating with others indicating a failure to engage with or react to other people. This is consistent with some of the previous findings which indicate that some of the earliest symptoms observed in young children with autism include a lack of orientation to social situations (15). Individuals with autism have none or few friends, and deficits in relating maybe one of the reasons (16).

Children with autism showed significant impairment in body/object use. This is seen in stereotyped body movements and a preference for routines. Deficits in imaginative activities, an important criteria characterising autism is most obvious in a child's play behaviours (1). Most children with autism in the present sample were observed to engage in less elaborate functional play, fewer imaginative activities and showed an impairment in symbolic play, creativity and imagination. They were found to follow some complicated rituals and exhibited self-stimulatory behaviours. Though significantly less, similar behaviour was present in some controls as well. Honey et al. (17) suggest that although repetitive behaviours are characteristic of autistic spectrum disorders, they are also seen in typically developing young children, although their parents may not notice the behaviours. Some repetitive behaviours such as motor mannerisms and stereotyped behaviours can be observed directly; but rituals and routines are more difficult to observe and are often seen at bedtime and mealtimes. As they

are identifying features of autism, parents of children diagnosed with autism are likely to be aware of the repetitive behaviours and activities of their child.

Social interaction is an important deficit especially in children with autism and needs to be a part of the training programme. Children with autism in the present sample have significantly impaired ability to sustain social interactions. In a yet unpublished study, T. Daley found that many Indian families recognise / notice social difficulties in their children first. Indians largely emphasise conformity to social norms and value social relatedness and the mothers being indulgent and protective may be more sensitive to the unusual aloofness of their child and might recognise social symptoms earlier (18). Given that much of social behaviour involves language, it is an important component of an assessment. The results here are consistent with many other similar studies (e.g. 1; 19). Most children with autism in the present sample were found to be able to physically approach others to initiate an interaction, but had an impaired ability to initiate and sustain verbal interactions.

Children with autism failed to achieve typical developmental milestones in language and showed use of language in socially inappropriate ways. The difficulties noted among children with autism in the present sample varied from failure to develop language at all, to a range of language abnormalities. In children with autism, grasping does not spontaneously pass into pointing, and if pointing develops, it is usually pointing to get (protoimperative), rather than the social goal of sharing (protodeclarative) experiences (20). The same was seen true for the present sample of children with autism. The findings indicate that while some children were able to point to objects upon request, the spontaneous interactions initiated by children themselves were purely need-based. While most of the children with autism in the present sample made little use of spoken language, amongst the few children, who did speak, repetitive and stereotypical speech was prominent. Pronoun reversal was also seen amongst the children with adequate speech.

**Vocal plays an important** role in language development because such behaviours not only strengthen the vocal chords, but allows for the random mixture of sounds that often accidentally produces words that parents may react to or reinforce. The existence of substantial vocal play for a nonverbal child can be a good predictor for the easy development of vocal imitation. Children with autism in the present sample showed significant delay on vocal play and a significant majority of them were found to make only few spontaneous speech sounds at a

low rate. This is consistent with other studies which show that approximately 50% of the individuals with autism do not develop sufficient speech to meet their daily communication needs (21).

The present sample of children with autism showed a lower capability of manding. In autism, protosymbolic behaviours take longer to develop, or they may disappear having once emerged. Children with autism often use primitive presymbolic gestures, such as taking someone's hand (13). Establishing a repertoire of mands that are not directly trained is important, because children with autism frequently lack the behavioral flexibility demonstrated in normally developing children (22). For example, while many children with autism in the present sample were able to correctly tact in response to the question "What is this?" they were unable to mand for the same item. Ability to be able to express their needs is also likely to reduce inappropriate behaviors.

Children with autism showed significant impairment in the receptive language, which is the ability to understand and act upon specific words and phrases and is a key indicator of a child's ability to acquire other types of language. Deficits in comprehension strongly differentiate autism from non-autism (23). In children with autism who have functional speech, understanding is frequently more limited than what would be expected on the basis of the expressive vocabulary (21). Schuler et al. (24), suggest that the extent to which people with autism understand speech is usually overestimated. They postulate that language is often only understood in highly familiar contexts and the individual may not really respond to the speech, but to the routine or to other cues such as the location in space.

Children with autism also show lower ability to tact. Tacting involves the child doing the talking rather than the adult and is a more difficult skill because the child must not only come up with the correct word, but also have the vocal control to independently pronounce the word. Vogindroukas et al. (25) found a trend for children with autism to name one part of the picture they were shown. For example, children with autism named a detail from the picture, ignoring the rest of it, which indicated their focused visual attention to detail, whilst missing the whole picture. Thus, they might give the name of 'cable' to the antenna or of 'hazel-nut' to the snail. The analogues of children with autism were found to be based upon the shape of the object and some details. Building a large repertoire of tacts also lays the foundation for building on the intraverbal skills of an individual.

Intraverbals are very important for social interactions as well as for acquisition of academic skills and determine if the child has some of the rudimentary skills necessary for engaging in conversations. Children with autism in the present sample showed significantly impaired intraverbal skills. An important aspect of this skill is that the child has to respond to the spoken words and not to the objects in view. Most children with autism in the present sample were only at the level of filling in missing words of popular rhymes or providing sounds of animals like a dog and a cat. This seems to be a reflection more of their rote memory and reinforcing items than their conversational skills. Part of the difficulty in utilising language appropriately in social interactions may be due to difficulties in taking the perspectives of others. A significant number of children have problems understanding and processing interpersonal cues and planning appropriate responses to these cues (26).

The present sample of children with autism showed significant impairment in the ability to receptively identify items by function, feature and class. RFFC is the ability to be able to react to an object when told something about the object or when given a verbal instruction that varies from the specifically trained instruction. (e. g. touch the thing that daddy drives). Children with autism also show significant impairment in the ability to match objects, pictures and designs to sample, indicating difficulties in creating categories of concepts and understanding the link among objects. A child who is successful at these tasks is often able to attend to visual stimuli, discriminate between differing stimuli and emit specific motor behaviours to complete a task. According to Quill (27), children with autism do not develop the stage of over-generalisation during the process of the acquisition of a concept. This stage is characterised by over-extension of the concepts they are aware of, which helps them to categorise meanings, through the finding of the common characteristics and their similar functions. The absence of an over-generalisation stage in children with autism results in the absence of an established relevance between objects and the category to which these objects belong. As a result, they do not use an object in order to give a name to the whole category, a fact that excludes them from the possibility of using under-extension as a vocabulary error. Nonverbal conceptual weaknesses in autism have been demonstrated in abstract reasoning, and concept formation abilities (27; 28). Bernstein and Tiegerman (29) suggest disabilities in creating categories of concepts and understanding the link among objects among children with autism. They also suggest that children with autism use different strategies of recalling

meanings and tend to define the meaning they do not know, by giving the definition of a relevant object (e.g. pin instead of nail), or a definition out of the same semantic category (e.g. bird instead of chicken).

Children with autism have significantly less knowledge of letters and numbers. It was observed that most children with autism in the present sample were familiar with brand logos of common favourite eatables like chocolates and chips. Though there was a variation in their knowledge of letters and numbers, most children with autism had limited knowledge of the same. Previous studies of academic achievement in individuals with autism (30) show low-average to average mean academic achievement test scores in reading, math, and spelling.

Children with autism showed significantly impaired gross motor, fine motor and writing skills. Studies that have examined prevalence of motor deficits in children on the spectrum have suggested that motor impairments are found in at least 80% or possibly in all children diagnosed with this disorder (31). Motor impairments can lead to great difficulties for individuals with autism in negotiating their physical environment, fine motor control (i.e. writing, tying shoes), and social play (i.e. riding a bike, throwing a ball, and participating in team sports). It has been suggested that children with autism have less practiced motor skills because of less social interaction. For instance, poor ball-throwing skills are possibly because of reduced reciprocal play (32).

The present sample of children with autism showed significant impairment on motor and vocal imitations. While excessive and stereotyped pattern of vocal expressions including echolalia often exists in children with autism, individuals with autism may have a global impairment in novel motor imitation but not familiar imitation (10). Another consistent finding is that this pattern of performance stands in contrast to that of typically-developing children who can copy a broad range of novel and familiar actions from a very early age (33). It is proposed that children with autism have greater difficulty in imitating actions without objects than with objects (10) which may hinder learning conventional gestures, and objects may provide a scaffold for learning conventional actions in play (34).

Children with autism showed less acquisition of adaptive self-help skills and more destructive and aggressive behaviours. Learning self-help skill such as eating, dressing, toileting, and personal hygiene that are essential for independence can be challenging for people with

autism. The authors' findings are different from some of the other studies that found no significant differences between the autistic and non-autistic children on their self help skills (19). One of the reasons for the inconsistency could be the severity of autism amongst the children in the present sample and the fact that the children were not receiving any autism specific training.

Cooperation with Adult identifies the degree to which a child will cooperate with adults and provides information such as the potential need to include behavioural management procedures in the language training programme. Children with autism showed lower ability to cooperate with adults and needed intervention using behavioural management procedures. Barrett et al. (35), demonstrate that as compared to children with a learning disorder, children with autism responded less to compliance of requests. This seems particularly true in the case of the present sample given the young age of the children and lack of adequate teaching techniques.

## **CONCLUSION**

Children with autism show significant deficits in social functioning, language/communication skills, self-help skills, and sensory areas. The manifestation of these symptoms varies with each child. The use of receptive and expressive language; imitation skills; motor skills and knowledge of letters and numbers was found to be significantly below that of the typically developing children. Further, children with autism need training to comply with instructions given by an adult. The results are uniform in showing that children with autism follow individual patterns of skill development and have their individual areas of relative strengths and weaknesses.

These findings have implications for assessment and evaluation practices as well as designing intervention programmes for children with autism and their parents. Taking into account the age of children; the limited knowledge of autism and teaching techniques amongst the parents; and the dimensions of the tools used in the present study, the findings have significant implications towards designing an early intervention programme for newly diagnosed children. Since all children with autism show different sets of symptoms and skills, a detailed analysis provides child-specific information which is helpful in educating parents and professionals on the specific nature of the difficulties of their child. The mode of service delivery has moved away from being child-centered, provider-based, and expert driven towards family centered

and encouraging active participation of parents of children with autism themselves. Parents and professionals both realise the importance of a collaborative approach with a formal focus on family context (36). It is crucial therefore to perform detailed assessments and break them into easily observable and measurable tasks. The parents and professionals can then mutually decide the goals for a child and monitor the developmental and behavioural progress of a child through evaluation of target achievements in IEP.

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**BRIEF REPORTS**

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**PARENTAL PERSPECTIVE TOWARDS THE EDUCATION  
OF VISUALLY IMPAIRED CHILDREN**

H. Venkat Lakshmi\*, C.V. Geetha\*\*, Prof. K.N. Krishna Murthy\*\*\*

**ABSTRACT**

*This study was designed to understand parents' attitude towards the education of their visually impaired children attending special and integrated schools. The study was conducted on parents of 140 visually impaired children aged 11-13 years, attending special and integrated schools in the selected districts of Karnataka State, India. The survey method was used to elicit information about their children in the area of daily living skills, recreation and socialisation, concept of special and integrated education, adjustment at home, social and emotional behaviour and sibling attitude etc.*

*Data were collected using the attitude scale developed and standardised by the investigators. Results indicate that there was a significant difference in the attitude of the parents towards their visually impaired children in the area of social and emotional behaviour, sibling attitude and towards the concept of integrated education.*

**INTRODUCTION**

Attitude is a vital ingredient for the success or failure of children with visual impairment in their optimum development. The attitude of parents can have a profound effect on the social and educational integration of visually impaired children. It makes a great difference to these children whether the attitude and actions of parents reflect considerations for their real needs or are merely prompted by pity or monetary limitations. The adjustment of visually impaired children to society begins with the ability to adjust to their own family members. The child brought up with affection and care in the least restrictive environment would be able to cope up better with the sighted world. Therefore, the family shapes the social integration of the child more than a formal school. Turnbull (1) has identified four basic parental roles:

parents as educational decision makers; parents as parents; parents as teachers and parents as advocates.

Since the parent's attitude is so important, it is essential that the home and school work closely together, especially for children with disabilities. The Warnock Report (2) stresses the importance of parents being partners in the education of their children. The role of parents should actively support and enrich the educational processes.

The present study was undertaken with the objective of examining the attitude of parents towards the education of their visually impaired children attending special and integrated schools.

## **METHOD**

A sample of 140 parents of visually impaired children (70 children attending integrated schools and 70 children attending special residential schools) was selected for the present study. Information about the children was collected by contacting government organisations and educational institutions, and purposive sampling procedure was used to select the sample of visually impaired children from integrated schools. In the case of special schools, the children were selected through systematic random sampling, based on their name entries in the attendance register. The study was conducted over for a period of two academic years.

Tool Used: The Attitude scale for the parents of visually impaired children was formulated and standardised by the investigators. The tool comprised of basic information/data, information pertaining to the daily living skills of visually impaired children such as eating habits, toilet training, hygiene, handling money, recreation/socialisation, concept of special education, concept of integrated education, educational procedure, sibling attitude, and adjustment at home. The formulated attitude scale was translated from English into the local language.

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## RESULTS AND DISCUSSION

**Table 1. Concept of Special and Integrated Education**

Characteristics	Mean $\pm$ Standard Deviation		Significance of 't' value
	Parents of Special School	Parents of Integrated School	
Concept of Special Education	3.00 $\pm$ 0.00	2.80 $\pm$ 0.44	3.8095**
Concept of Integrated Education	2.77 $\pm$ 0.44	2.67 $\pm$ 0.50	1.2578 <sup>NS</sup>

NS : Not significant; \*\* : Significant at 1% level

The study reveals that there is a significant difference in the attitude of parents towards the concept of special education. Parents of visually impaired children attending integrated schools have very little knowledge/awareness about special schools, as right from the beginning of their child's schooling they had an exposure to an integrated school.

In contrast, the parents of visually impaired children attending special school opined that special education is better than the regular programme. They believe that their children will receive education that is tailored to their knowledge, abilities, aptitudes, interests, and personality qualities. According to Kirk and Gallagher (3), special education is, "those additional services over and above the regular school programme that are provided for exceptional children to assist in the development of their potentialities and/or the amelioration of their disabilities".

There is no significant difference between the mean scores of the parents towards the concept of integrated education.

Parents of visually impaired children attending special schools are of the opinion that integrated education is an education programme in which visually impaired children receive education along with their sighted peers. It is a system which provides general education with some special provision. They further pointed out, that in an integrated set up the visually impaired children get the chance to read and learn with the normal children, further, it saves the children from developing various psychological complexes, which promotes normal mental

growth in visually impaired children. The orientation received by these parents during the process of their child's schooling at special schools, has given them the insight and the significance about integrated education. They further pointed out the economic factor as one of the main reasons for enrolling their children into special schools. Glazzard (4) is of the opinion that parents should be informed of the purpose of the mainstreaming programme and the effects of the programme on their child's education.

Parents of visually impaired children attending integrated schools had very little knowledge about the significance of integrated schools. These parents were happy about the fact that their children could be a part of the family during his/her schooling and formative years, as they attend school as day scholars.

### Daily Living Skills

It was noted that there was no significant difference in the parents' opinion towards learning daily living skills in special and integrated schools.

Children attending special schools are trained in the school, while children attending integrated schools are trained by local non-governmental organisations (NGOs).

### Teaching Aspects

**Table 2. Teaching Aspects in Special and Integrated schools**

Characteristics	Mean $\pm$ Standard Deviation		Significance of 't' value
	Parents of Special School	Parents of Integrated School	
Teaching Aspects in Special Education	3.00 $\pm$ 0.00	3.00 $\pm$ 0.00	0.0000 <sup>NS</sup>
Teaching Aspects in Integrated Education	2.80 $\pm$ 0.57	2.84 $\pm$ 0.55	+0.4232 <sup>NS</sup>

NS : Not significant

Parents of visually impaired children attending both special and integrated schools were of the opinion that education for visually impaired children plays an important role, as most of

the learning for these children takes place through auditory and tactile senses/ sensorial experiences.

They further expressed, that in a special school setup visually impaired children are treated equally. Teachers not only focus on the educational needs, but also make use of the necessary learning materials to teach both academics and vocational needs.

Considering the opinion of the parents of both school systems it was observed that the parents of the integrated school setup had a better perspective about the teaching aspect in an integrated setup. They attribute this to the awareness from the NGOs that work with their children. Grossman (5) pointed out that communication should occur on a regular basis so that parents keep in touch with the school programme, are informed of current events and begin to accept and support integration. Kroth (6), states that parents should be recognised as the major teacher of their children and the professional should be considered consultants to parents. Further, parents pointed out that integration can be successful only when there is a modification, omission and adaptation in the curriculum, accepting the child's limitations and capabilities, cooperation from their sighted peers and regular Parent Teacher Association (PTA) meetings to keep the parents abreast of their child's progress in school. Israelson (7), points out that the PTA should feature programmes on the needs of special learners, pamphlets explaining integration can be sent to all parents, and the acceptance of special students can be a topic of discussion at parent-teacher conferences.

### **Behavioural Characteristics**

**Table 3. Behavioural Characteristics of Visually Impaired Children**

Characteristics	Mean $\pm$ Standard Deviation		Significance of 't' value
	Parents of Special School	Parents of Integrated School	
Social and Emotional behaviour	2.89 $\pm$ 0.33	3.00 $\pm$ 0.00	+2.7989 <sup>**</sup>
Sibling Attitude	2.85 $\pm$ 0.37	3.00 $\pm$ 0.00	+3.4013 <sup>**</sup>
Adjustment at Home	1.35 $\pm$ 0.70	1.27 $\pm$ 0.66	0.6968 <sup>NS</sup>
Recreation and Socialisation	3.00 $\pm$ 0.00	3.00 $\pm$ 0.00	0.0000 <sup>NS</sup>

Table 3 shows that there is a difference in the opinion of the parents of visually impaired children, attending special and integrated schools towards the social and emotional behaviour and sibling attitude of visually impaired children.

Parents of visually impaired children attending integrated schools are of the opinion that their children have a balanced social and emotional behaviour. They were of the opinion that since the visually impaired children attending integrated schools are day scholars, their interaction begins at home, continues at school and in the community at large, when compared to their counterparts studying in a special school which is residential in nature. McGuinness (8) compared the social maturity of visually impaired children enrolled in residential and public schools and concluded that those in the public schools had a higher social maturity score. McGuinness (8) attributed the low scores of residential school children to the lack of contact with age-appropriate social behaviour, and the greater availability of special help.

Parents of visually impaired children attending special school attribute the differences among the sibling interaction to the lack of time that both get to spend together, as a result of which there is a strained relationship between the siblings.

Parents of visually impaired children attending special and integrated schools reported that they have not come across behavioural abnormalities like teasing each other, throwing objects or being aloof from others etc. Parents had never considered their visually impaired child as a burden to them and the family.

As far as socialisation of the visually impaired child is considered, parents are of the opinion that like any other normal child of his/her age, the visually impaired children play games etc. but their method of play is a slightly modified one. Tait (9) opines that the parents' psychological well-being and the ease or difficulties with which they decipher the cues that facilitate the socialisation process influence the personal and social development of the child.

## **CONCLUSION**

The family plays a significant role in the development of the visually impaired child. It is the parents who exert the major influence on the development of the visually impaired child from birth to maturity. One of the most important attributes of parental attitude is consistency. The present study also highlights the fact that the parents of the visually impaired children attending

the integrated schools showed a favourable attitude towards the teaching aspect in integrated schools. Their visually impaired children's social and emotional behaviour and sibling relationship was cordial with both the visually impaired children and their sighted siblings experiencing both positive and negative aspects of emotions in their day-to-day life. This was mainly attributed to the factor that these children were a part of the family in their daily routine. The same was not observed in the case of visually impaired children attending special schools, as their interactions with their siblings and their family members was only for a short duration, especially during the vacations. The reason being, that these children are placed in a residential school (special school). It is therefore necessary for the parents to adopt different strategies to help their children better.

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**DISABILITY AND DEVELOPMENT MODULE AT THE VU UNIVERSITY,  
AMSTERDAM, THE NETHERLANDS**

The Athena Institute, Faculty of Earth and Life Sciences, VU University (Amsterdam), together with Enablement (Alphen aan den Rijn) and the Royal Tropical Institute (KIT, Amsterdam) will organise a 4-week module on Disability and Development to be held from **November 23<sup>rd</sup> to December 19<sup>th</sup> 2009** at the VU University. This course, a 4-week elective module, which is part of an academic Master degree programme, is open to external participants also. (<http://studiegids.vu.nl/> type 'disability' as search term).

**Module I:** Disability models and stereotypes, culture and disability, ICF conceptual framework, experience of having a disability, frequencies and distribution of disability, determinants of disability, including stigma and discrimination, poverty, gender and HIV/AIDS, rights of persons with disabilities, the UN Convention on the Rights of Persons with Disabilities, measurement of disability, disability-relevant research methods, survey methods, examples of disability research and an introduction to community-based rehabilitation.

**Module II:** Project planning and management, monitoring and evaluation of community-based rehabilitation (CBR) programmes, management information systems, CBR as a preferred strategy for rehabilitation, organisational and institutional development, Disabled People's Organisations, educational and economic empowerment of disabled people, the role of specific rehabilitation services, and sports and disability.

**Target Group:** Rehabilitation professionals and professionals with an interest in disability and development.

**Requirements:** Good comprehension of the English language; bachelor degree or equivalent (in terms of experience and thinking capacity)

**Course Fees:** Euro 1,000 (excluding board & lodging); students who wish to gain official study credits (ETCS) will have to register as external students at the VU University. This will cost an additional €1,200 for 4 weeks, approximately.

**Further Information From:** Huib Cornielje, Langenhorst 36, 2402PX Alphen aan den Rijn, The Netherlands. Tel: 0031-172-436953, Fax: 0031-172-244976, E-mail: [h.cornielje@enablement.nl](mailto:h.cornielje@enablement.nl)

## APPLICATION OF INSTRUCTIONAL SYSTEMS DESIGN TO DEVELOP AND IMPLEMENT AN EARLY INTERVENTION MODEL

M. Madhavi Latha\*, C. Beena\*\*

### ABSTRACT

*In this study, an early intervention model was developed by applying instructional systems design and implemented on 45 and 30 at-risk and developmentally delayed infants and toddlers aged 4-33 months, who were assigned randomly to the experimental group and control group. The efficacy of the early intervention model, as seen from the Bayleys scale of infant development (BSID), showed striking performance gains in the experimental group on mental age (3.57), mental development index (5.03) and deviation mental quotient (6.17). The t-test measures on mental age were found significant for both experimental ( $t=5.70$ ) and control group ( $t=8.9$ ), while it was significant in the experimental group only on mental development index ( $t=4.09$ ) and Deviation Mental Quotient (2.64). The intervention gains indicate the efficacy of an early intervention model and has implications for application within the community at large.*

### INTRODUCTION

There are varied biological and environmental risk factors that are detrimental and therefore impede the normal course of development in children. These may occur during pregnancy, delivery and early in life, resulting in deficits of the central nervous system. These infants are in risk for a substantial development delay, if timely and appropriate intervention is not provided. Children with developmental delays display deficits in one or more areas of development like motor, sensory, speech, language, communication, and cognition, social and emotional. Hence, early intervention is crucial in bringing about secondary prevention in the affected population.

The existence of numerous methodological problems has posed significant challenges in the ability to establish unequivocal statements regarding the efficacy of early intervention (1, 2, 3, 4, 5). The results of two meta-analyses (6,7) as well as more traditional reviews of effectiveness (8) support the generally held opinion, that early intervention programmes are

indeed effective, producing average effect sizes falling within the range of one half to three quarters of a standard deviation.

Within the framework of early intervention programmes that are essentially parent focused, the involvement of mothers as participants in the training programme is an important aspect of the programme feature.

### **Instructional Systems Design and Early Intervention**

Instructional systems design is based on an open systems theory. An open system receives inputs from the environment, transforms them through operations within the system, submits outputs to the environment, and receives feedback indicating how well these functions are carried out. According to Hackos and Redish, “The use of instructional systems design helps to draw conclusions about how the training works. The main goal to design a product is to adapt the techniques of learning to practical realities for working out suitable and most appropriate methods. Adapting these techniques to practical realities is the basis for the instructional design” (9). The social context that helps to facilitate the child’s development is defined largely by the children’s interactions with their primary caregivers. Developmental systems are so intertwined, that factors influencing any aspect of development, whether internal to the child or part of the child’s physical or social environment, have broad implications (10). It is through the caregiver that the young child gains access to the environments. It is against this background, that an early intervention model was devised by applying the instructional systems design process, to study its impact in infants and toddlers with developmental delays.

#### **The objectives of the study were to:**

1. Devise an early intervention model by applying the instructional systems design process.
2. Implement the early intervention model on infants and toddlers with developmental delays
3. Study the efficacy of the early intervention model.

## **METHOD**

### **Sample**

The children attending Early Intervention Services at National Institute for the Mentally Handicapped (NIMH), Secunderabad, India, were selected for the purpose of the study. Sample I comprised the children, while sample II were mothers of these children. Sample I, (N) comprised of 75 children with developmental delays in the age range of 4-33 months.

A total of 45 subjects were randomly assigned to the intervention group and 30 subjects to the control group. The experimental group of Sample I received both the general cognitive stimulation and early intervention model exclusively designed for the research, while the control group received only the general cognitive stimulation which is part of the NIMH early intervention programme.

The experimental group of Sample II mothers were trained on implementing the early intervention strategy, while the control group did not receive this intervention.

### **Tools**

The tools used included the personal data schedule to information on demographic information about the child and the mother; developmental screening tool of Bharadwaj (11); Bayleys Scale of Infant Development (BSID) standardised on Indian children by Dr. Pramila Phatak (12); the Battery of Problem Solving Tasks (BPST) developed and validated by the researcher on 120 children consisting of 35 problem solving tasks from 0-36 months of age; the Mother-infant interaction observational checklist.

### **Procedure**

The components of the early intervention model comprised of problem solving tasks and mother-child interaction. Enhancing problem solving skills provides a means for teaching children “to think”. Another emphasis of this study was to train the mothers in helping them to understand the child’s development by involving them as facilitators. The early intervention model designed as per instructional systems design process consists of six levels.

Level I-Conduct Needs assessment

A need is a performance gap separating what people know, do, or feel from what they should know, do or feel to perform competently (13). A need assessment of the parents of children with developmental delays revealed the significance of devising the early intervention model. This kind of training that is easy to implement with the available resources in the home environment and can also facilitate optimal development of infants and toddlers, was the need expressed by parents.

Level II- Assess relevant characteristics of the learners

The two categories of learners in the present study were, 1) children with developmental delays and 2) mothers of these children. A broad range of the learner's profile is essential, as the needs of atypical population are addressed. Learner-related characteristics, decision related characteristics and situation related characteristics of children and mothers in this study are given in Table 1.

**Table 1. Learner characteristics for obtaining the performance outcome for children and mothers**

<b>Learner characteristics</b>	<b>Description of profile</b>
Learner related characteristics	Child <ul style="list-style-type: none"><li>• Children with developmental delays</li><li>• Variations with respect to age, etiology, birth weight, gender.</li></ul> Mother <ul style="list-style-type: none"><li>• Maternal education.</li></ul>
Decision related characteristics	Child <ul style="list-style-type: none"><li>• To improve problem solving skills in children with developmental delays.</li></ul> Mother <ul style="list-style-type: none"><li>• To empower the mothers as facilitators for improving problem solving skills of their children.</li></ul>

<p>Situation related characteristics</p>	<p>Child</p> <ul style="list-style-type: none"> <li>• Developmental process is hastened when opportunities are provided through psycho-ecological intervention strategy.</li> </ul> <p>Mother</p> <ul style="list-style-type: none"> <li>• Play a predominating role in fostering child's developmental process.</li> </ul>
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Level III- Understand the learners, to judge what they know and what they do not know

This was done by administration of Bayleys Scale of Infant Development (BSID) and the Battery of Problem Solving Tasks (BPST) for the child. From the observations of mother-infant interactions which were coded, the mothers' training needs were determined.

Level IV-Statements and performance objectives for child and mother

A performance objective is an expression of a desired result of a learning experience. It describes the desired results.

At this level, the training programme was geared to help the learners in understanding the tasks they must learn to do. For the children, the performance objectives were decided by administering the BPST. For the mothers, the performance objective was to modify the interactions with the child and providing training for implementing the problem-solving task with the specified material.

The instruction designed for the mothers and children is presented in Table 2.

**Table 2. Instruction designed for children and mothers**

Child	Mother
<ul style="list-style-type: none"> <li>• Improving problem solving skills.</li> </ul>	<ul style="list-style-type: none"> <li>• Improve knowledge</li> <li>• Improve parenting skills</li> <li>• Understand child's development.</li> </ul>

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<ul style="list-style-type: none"><li>• Four target items for each subject were given as performance objectives.</li></ul>	<ul style="list-style-type: none"><li>• Training by researcher on how to interact Demonstrating to mother on how to teach the problem-solving task.</li><li>• Set guidelines and written instructions to follow at home.</li><li>• implement at home using STEPSS* package</li></ul>
<ul style="list-style-type: none"><li>• To arrive at solutions for the given problem solving task</li></ul>	<ul style="list-style-type: none"><li>• to help child to achieve the task.</li></ul>

\*STEPSS package-The manual titled “Strategies to enhance problem solving skills (STEPSS)” prepared by the researcher for each problem solving task, so as to help the mother to implement the target at home.

#### Level V-Designing training

For the early intervention model, the instructional strategy used was psycho-ecological intervention strategy, which is emphasised because the focus is on child, mother and environment. The components of psycho-ecological instructional strategy are:

- Task analysis-For each of the problem solving task a procedural manual entitled “Strategies to enhance problem solving skills (STEPSS) was prepared for the purpose of the training.
- Target related interactions- mothers were trained on specific interactions to help child to solve the task.
- Target specific materials – For each task, specific material that are most commonly available in Indian homes was selected.

#### Level VI-Performance outcome

In the present study, performance outcome was measured using the Bayleys Scale of Infant Development (BSID), which gives the mental age (MA) and mental development index (MDI).The Mediated learning index (MLI) was derived from Battery of Problem Solving Tasks (BPST), Various statistical measures both quantitative and qualitative, were used to test the efficacy of the early intervention model.

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**RESULTS**
**Performance outcome of children**

The efficacy of the early intervention model was determined from the intervention gain from pre to post test, as seen from the difference on mental age (MA), mental development index (MDI) and Deviation mental quotient (DMeQ), which are derived from BSID. The mean performance at pre and post test in experimental and control group is given in Tables 3a and 3b.

**Table 3a. Mean performance of children before and after intervention in experimental group**

Performance measure	N	Pretest mean +S.E mean	Post test mean +S.E mean	Mean difference	t-value
Mental age	45	8.23+0.63	11.81+0.83	3.57+0.62	26.833**
MDI	45	54.88+2.14	59.92+2.43	5.03+1.22	4.099**
Dmeq	42	31.09+3.48	37.26+4.02	6.17+2.33	2.649**
BPST	45	6.63+0.66	11.20+0.7	4.57+0.16	27.930**

\*\*Significant at .001 level

**Table 3b. Mean performance of children before and after intervention in control group**

Performance measure	N	Pretest mean +S.E mean	Post test mean +S.E mean	Mean difference	t-value
Mental age	30	6.99+0.71	8.77+0.80	1.78+0.2	8.9**
MDI	30	42.09+1.57	41.29+1.45	-0.85+1.22	.694
Dmeq	28	14.65+2.00	13.05+2.00	-1.59+1.51	1.04
BPST	30	3.47+0.56	4.90+0.64	1.43+0.15	9.607**

\*\*Significant at .01 level

As evident from Tables 3a and b, the subjects in the experimental group displayed more striking intervention gains as seen from the mental age and mental development index. The substantial gains as seen from the mean differences of MA (3.57), MDI (5.03), DmeQ (6.17) and BPST (4.57) by experimental group when compared to control group MA (1.78), MDI (-0.85), DmeQ (-1.59) and BPST(1.43), is indicative of the efficacy of early intervention model.

The pre to post measures were highly significant on MA ( $t=26.833$ ), MDI ( $t=8.9$ ), Dmeq( $t=2.64$ ) and BPST( $t=27.93$ ) in the experimental group, while it was significant only on MA ( $t= 8.9$ ) and BPST ( $t=9.607$ )in control group. The significance on MA and BPST in the control group could be attributed to the general cognitive stimulation given as part of the NIMH early intervention programme.

#### **Performance outcome of mothers**

As interactions of mothers formed an important aspect of the present study an attempt was made to provide a comprehensive evaluation of maternal behaviour during mother- child interaction and its effect on the child's ability to solve the given problem. The interactions and verbalisations by the mother were identified as an important aspect of psycho-ecological intervention strategy, which was discussed as part of designing the training programme.

The interactions were coded, by observing the mother and child in a play situation where the mother helped the child to solve the problem-solving task. The mothers were trained after initial assessment by the researcher, to modify the interaction behaviours as per the observations. The interactions were observed and coded again after the training. Maternal task related interactions were coded as per the checklist of interactive behaviours. Table 4 gives the difference on mean percentage of interaction behaviours provided by the mother, before and after the training.

**Table 4. The mean percentage of interaction behaviors before and after intervention**

S No	Interaction behaviors	Mean percentage		
		Before	After	Difference
1	Non verbal and verbal response	78	85	7
2	Calling for infants attention	84	92	8
3	Showing object	82	94	12
4	Gestural imitation of child behaviour	55	74	19
5	Assisting to solve the task	47	84	37
6	Description of the task	65	88	23
7	Positive affect	88	94	6
8	Providing verbal clue to assist recall	52	78	26
9	Providing for trial and error manipulation	65	78	23
10	Verbal statements of praise	85	91	6
11	Reinforcement and explanation	57	89	32
12	Modification to allow success	63	89	26
13	Following the sequence of steps given in manual	48	91	43
14	Sustaining interest by modifying cause and effect sequences	65	77	12
15	Interpreting child's needs	87	89	2
16	Building expectations	44	71	27
17	Making appropriate seating arrangement	58	78	20

Mothers required more input with regard to assistance to solve the task (47%), description of task (65%), providing verbal clue to assist recall (52%), following sequence of steps (48%) and building expectations (44%). Mothers also reported a marked change after training on

these behaviours. The difference indicated the change in interaction behaviours which was 37%, 23%, 26%, 43%, and 27% respectively.

## **DISCUSSION**

In the present study, the problem solving targets, environmental arrangement coupled with mother-child interactions and following the child's lead, were considered important aspects of the early intervention model. Though the control group also showed significant gain with the general cognitive stimulation, the gain made by infants in the experimental group was higher which indicates the effectiveness of the early intervention model. According to Shari and Siegler (14), "It is not that social phenomena are being investigated that is new in the study of children's problem solving. What is new is the increasingly widespread realisation of how deeply the social world is implicated in the development of problem solving, a broadened vision of what the development of problem solving entails, and a growing commitment to explicating the mechanisms through which cognitive and social processes jointly contribute to children's developing ability to solve problems". In the present study, the emphasis is on psycho-ecological instructional strategy which focused on tri-directional reciprocity which requires the influence of mother on child, child on mother and the influence of environment on both. The dyadic system comprising the mother and child exerts a powerful influence in fostering the child's cognitive development. The conceptualisation and development of early intervention models and approaches provide a growing body of evidence, that the goal of early intervention should be to make interactions more enjoyable and more successful (15). Freund (16) investigated the mother-child interaction on the child's ability of problem solving among 60 children from three to five years of age. The results suggested that the mothers displayed more task responsibility and regulation with younger children and the performance of children was found to be related to: the variation in maternal regulation of the child and degree of specificity of maternal verbal content. In longitudinal studies (4), mothers who were more responsive and growth promoting in their interactive behaviours, had children who showed greater growth in mental age, social and communication skills of three groups of children representing Down Syndrome, developmental disabilities and developmental delays.

## **CONCLUSION**

Based on the findings of the study, it can be concluded that:

- The “Early intervention Model” proved to be efficacious in promoting cognitive outcomes in children with developmental delays. This is clearly evident from the pre to post treatment differences, on mental age, mental development index and mediated learning index in the experimental group.
- The differences between the experimental and control groups were highly significant, indicating the efficacy of the intervention.
- The emphasis on the psycho-ecological intervention strategy helped to promote performance outcomes in children with developmental delays.
- Training the mothers on interactive behaviors helped to improve performance outcome of children in experimental group. The control group made lower intervention gains as seen from all performance outcome measures.

### **Application in the community**

The early intervention model finds application in the community as the emphasis is on psycho-ecological intervention strategy, which helped to improve the performance of children with developmental delays. Therefore, awareness may be created on task analysis of problem solving targets, use of specific interactions, task related materials, to mothers of children with developmental delays. The training programme designed as per the instructional systems design is an innovative approach, that makes it more feasible and applicable for use in the rural and urban setting. The mothers can be trained to carry on the programme in the house. As part of this early intervention training, the model can also be included along with physiotherapy, occupational therapy, and speech therapy for improving the cognitive outcomes in children with developmental delays, in the community.

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**AN EDUCATOR'S MANUAL FOR COMMUNITY BASED REHABILITATION:  
COMMUNITY DEVELOPMENT AND THE INTEGRATION  
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While CBR has always focussed on the rights of people with disabilities, it can also benefit from community development strategies that address the human rights and participation of all citizens in the community. A new training approach is needed to support this community development strategy.

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1. Twible RL. *Final Fieldwork Placements of Australian Occupational Therapy Students in CBR Projects in India*. ACTIONAID Disability News 1996; 7(2): 68-72.
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