

EDITOR'S COMMENT

As the recent tsunami in Asia illustrated, sudden, unexpected disasters are devastating, leaving a long trail of deaths and disabilities. The mortality count from the tsunami is still on the rise and it will take some time before the full magnitude of the disaster in terms of mortality and morbidity becomes clear.

There is a growing concern about the way in which disaster management and rehabilitation programmes are conceived and implemented in many developing countries. While swift action is mandatory for immediate relief for affected persons, it is equally important to have post-disaster programmes that strengthen coping capacities of communities and contribute to long term developmental needs, leading to a permanent positive change.

While disaster has an impact on all affected people, it has been noted that in the case of persons with disability, reduced mobility can lead to less visibility, less access and low survival chances. Persons with disability also tend to get excluded from relief and rehabilitation programmes due to various reasons such as

- lack of prior data on persons with disability living in disaster-prone areas
- lack of awareness about their special needs at the time of a disaster
- lack of information and training to persons with disability and their families to deal with their needs at the time of the disaster
- inadequate early warning communication systems that are specially designed for people with different disabilities
- lack of appropriate rescue systems designed for persons with disability
- unequal distribution of relief resources (leading to exclusion of persons with disability)
- lack of special services (including psychological support) for persons with disability, particularly for women with disabilities during and after a disaster
- problems of isolation when persons with disability are separated from their care-givers and support groups at the time of disasters
- lack of long-term social, economic and psychological support that is specially designed for persons with disability after a disaster situation

Disasters that lead to disability, and the plight of persons with disability in disaster situations deserve a prominent place in the international humanitarian agenda. To better the survival chances of people with special needs during disasters, and to address their long term needs, some suggested strategies are

- a paradigm shift in disability and disaster related policy making, to endorse the needs and rights of persons with special needs
- creation of a database on persons with disability in disaster-prone areas
- awareness programmes for the community, NGOs, organisations of persons with disability and service providers about the special needs of persons with disability, particularly women, and rescue issues related to persons with disability
- training programmes for persons with disability, families and local NGOs, regarding safety measures, preparedness related to disability, transportation, access to shelters and services
- training programmes for community volunteer groups in disability specific interventions, to assist persons with disability during the time of a disaster
- development and dissemination of information related to early warning systems and available services, in ways that are accessible to persons with disability
- making shelters accessible and secure for persons with disability, particularly for women with disability
- ensuring of proper distribution of resources by prior information, training and planning to include persons with disability
- ensuring availability of medical care services, rehabilitation interventions and assistive devices
- lobbying with governments, donors and humanitarian agencies to ensure that disability is an integral part of their disaster response programmes
- Counselling and support services for persons with disability who are separated from their care-givers
- Development and strengthening of post-disaster community development activities that include persons with disability

It is clear that every disaster situation that the world has to deal with today, calls for synergy between the various players involved in disaster management, community development and disability issues.

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GUEST EDITORIAL

**BUILDING BRIDGES BETWEEN SPECIAL
AND MAINSTREAM SERVICES**

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ABSTRACT

Many countries in the Asian and Pacific Region and in developing countries throughout the world, are changing their schools to make them more inclusive. In this process, clear policies need to be developed concerning the role of special schools in a more inclusive system. How can special and ordinary schools work together in a closer partnership? How many children now in special schools could be satisfactorily educated in mainstream schools with individualised support, possibly from staff of special schools? What is the role of local and national government in bringing the two systems together?

Countries with well established special school systems, whether run by the state, the private sector or non-governmental organisations, need to develop clear plans and targets for the future role of such schools. This applies to richer countries such as Japan and the United Kingdom which have many special schools but also to developing countries where a small number of special schools, sometimes run by parents' organisations, are the sole providers of education for children with disabilities.

This paper outlines some possible frameworks for collaboration between special and mainstream systems. Although drawn mainly from UK practice, some examples may be relevant for other countries and communities. These include children from special schools spending planned periods in a neighbouring mainstream school; dual registration; clusters of schools working together; special classes in ordinary schools and step-by-step individual inclusion plans for all children in segregated provision.

Despite enormous variation between and within regions, many countries and communities face similar challenges in moving towards the goals of Education for All and the United Nations Millennium Targets. Is there scope for the Asian Pacific Decade of Disabled Persons to provide a framework for progress?

In contrast to most writing on inclusion which is concerned with the reform and restructuring of ordinary schools, this article considers ways in which countries like the United Kingdom

and Japan with well established systems of publicly funded special schools, can develop more inclusive practice by changing the role of special schools and special services.

The challenges will be different in other countries - where for example, special schools are run by non-governmental organisations or the private sector, whether or not financial support is provided by the state. This article therefore, begins by considering what we can learn from developments in other countries and above all, how we can work within the major United Nations programmes on inclusion and disability.

GLOBAL NEEDS AND CHALLENGES

During the last 20 years, and especially since the International Year of Disabled Persons and the subsequent UN Decades for Disabled Persons, we have much more information on what is happening in other countries and also at the global level of some major United Nations programmes and the possibilities which these present, to national governments and to regional groupings.

Some global figures, from UN statistics and estimates:

- 125 million children throughout the world are denied access to primary education - two thirds of whom are girls. This is equivalent to all children aged 6-14 in North America and Europe combined.
- Another 150 million start school, but drop out before they can read and write.
- In the 40 least developed countries of the world, only 21 per cent of males and 12 per cent of females enter secondary schooling.
- 872 million adults in the developing world cannot read or write: two thirds are women.
- Only 1-2 per cent of disabled children in developing countries attend any form of school.

UNITED NATIONS INITIATIVES

The United Nations has provided exemplary leadership in creating a global framework to encourage governments and communities to face up to these challenges. These include:

The **Education for All** initiative, first launched in Jomtien, Thailand in 1990 and at a world summit on children, in the same year. This encouraged each government to set targets to increase the number of children completing four years of free primary education. The education of girls was strongly emphasised. The global initiatives to which most national governments are committed involve children living in poverty and disadvantage, children who are working or living on the streets or in grossly overcrowded homes, as well as children who are dropping out of school after only one or two years of primary education.

Although children with disabilities are meant to be included in the Education for All targets, they are often overlooked and forgotten, unless voluntary organisations and parent groups insist on their inclusion.

Progress in achieving these targets has been very slow, but some very poor countries have made striking progress. Perhaps the most dramatic is Uganda, where the government is implementing a guarantee to provide primary education to four children in every family. Disabled children and girls were given the highest priority - a good example of a truly inclusive policy.

Priority for children

A major obstacle to reaching the Jomtien targets, has been the crippling burden of debt owed by many developing countries to rich countries and to the World Bank. For example, Africa is spending \$US13 billion on debt repayments; Zambia spends four times more on debt repayment than on education.

Ten years after Jomtien, the world's leaders met again in Dakar, Senegal, to review progress and set new targets for 2015. Disabled children were barely mentioned.

It has been estimated, that \$US 8 billion a year would be needed to meet the Education for All targets. This sum is equivalent to:

- four days of global military spending.
- half of what is spent on toys in the USA.
- less than what Europeans spend on computer games or mineral water.

In the last few years, several of the richest countries (including the UK) have reduced or cancelled the debt of some of these countries, on condition that the money saved is invested in education and health. Uganda has shown that even a very poor country can bring education to all its children, including those with disabilities. We can only hope that other countries will follow its example.

Salamanca Declaration and Framework for Action (UNESCO 1994)

The importance of including children with disabilities was strongly reaffirmed at the UNESCO World Conference on Special Needs Education in Salamanca (1). This conference has been very influential in encouraging governments to adopt inclusive policies and in giving examples of progress, in reforming schools to respond to a much greater diversity of need in their local communities.

The UN Standard Rules (UN 1993)

Another UN initiative is reflected in **Standard Rules on the Equalisation of Opportunities for Disabled Persons**, adopted by the General Assembly of the United Nations in 1993. Rule 6 is concerned with education:

“States should recognise the principle of equal primary, secondary and tertiary education opportunities for children, youth and adults in integrated settings. They should ensure that the education of persons with disabilities is an integral part of the education system”.

This is then followed by nine more specific recommendations. The UN has appointed a rapporteur to monitor the extent to which national governments are adopting this and 21 other Standard Rules. The most recent development is the possibility of an international legally binding United Nations Convention to promote the rights of persons with disabilities. There is a role here for parents’ organisations, advocacy groups and movements to work together to remind governments of their commitments to these international initiatives.

Lessons from ISEC 2000

‘Including the Excluded’, was the over-arching theme of ISEC 2000, the 5th International Special Education Congress which was held at Manchester University, from July 24-28 2000. Over 1000 people came from 99 countries to share their ideas, experiences, dreams and frustrations. There were 44 symposia and around 800 individual papers and posters. What lessons can we learn from this wealth of information and experience?

Despite enormous differences in background, culture and economic conditions, some common themes can be traced.

- First, there can be no doubt that the movement towards inclusive education is world-wide and knows no boundaries.
- Second, some of the most innovative and radical developments can now be found in some of the poorest countries of the world, where there is political will, leadership and a commitment to give first priority to children. Uganda, Laos and Lesotho are just some examples. In reconstructing its education system, South Africa is building inclusion of children with disabilities into its foundations.
- Third, there is already a lot of good practice on the ground, much of it taken for granted and not reported. Many teachers are already teaching inclusively; it is easy to exaggerate how much additional training they need.
- Fourth, the biggest single obstacle to progress is not money or lack of legislation but negative attitudes on the part of many parents, teachers, community leaders and politicians. Although there are major obstacles and uncertainties, the evidence suggests that the doubters become much more committed and positive once they have experience of teaching children with special needs in ordinary schools.
- Fifth, more and more parents are insisting on the rights of their children to attend ordinary schools and to receive the necessary support. Parents’ organisations are pressing for change at local and national level and calling for legislation and resources to make this possible.

NEED FOR CLEAR NATIONAL POLICIES

What implications do these international developments have for countries like Japan and Britain, with a strong special school tradition but with a new commitment to inclusion?

The fundamental foundation for progress is that clear policies should be worked out and agreed at the level of central government, local government and above all, by each regular and special school. These policies should result in clear plans for implementation, with target dates for the achievement of goals and sub-goals.

Can we define inclusion?

In order to develop clear policies, it is first necessary to try to clarify what is meant by inclusion and how it differs from integration. Although there is no agreed definition, there is consensus that inclusion calls for a fundamental reorganisation of regular schools and classrooms, in order to cater for a greater diversity of children's needs in the community. Inclusion involves changes at three levels:

- **all children** attending their local school, in the regular classroom and with appropriate support.
- **all schools** restructuring their curriculum, pedagogy, assessment and grouping arrangements to ensure access and success for all children in the community.
- **all teachers** accepting responsibility for the learning of all children, receiving continuing training, support from the Principal, from the governing body of the school, from their colleagues and from the community.

Inclusion and integration are different. Integration assumes that some children have difficulties which require special measures - maybe special environments, special teachers, with specialist training. It is the child who must adjust to the school.

In inclusion, the emphasis is on the changes in the environment of the school and the educational system as whole. These include reform of the curriculum and the methods of teaching, the nature of the interactions between teacher and child, ways in which children are grouped and provided with opportunities to learn together. The active involvement of parents is also essential.

In some ways, we can think of integration as based on a medical model in which the aim is to identify deficits in order to try to remediate them. Inclusion is based more on the social model of disability in so far as it is concerned with ways in which the social and educational environment can be modified, to enable children to participate fully in the life of the school and of society.

For the present purpose, we can assume that a government has made a commitment in principle to promote inclusion, perhaps with reference to the Salamanca Declaration (1), or other international instruments, but that progress towards inclusion is slow and fraught with dilemmas and difficulties.

In the UK, there is now a strong policy framework based on inclusive principles and values, together with some additional funding (2). Furthermore, all mainstream and special schools and colleges of further education have had some 8 years to develop their inclusion policies. On the other hand, there is a great deal of variation among the 200 or so Local Education Authorities who have to administer complex special needs legislation and continue to provide specialist services (such as educational psychology), while delegating some 80 per cent of their funding direct to schools. There are also great variations between schools within the same Local Education Authority (LEA), sometimes in the same neighbourhood or street.

We can consider examples of possible changes under a number of inter-connected headings. These are not mutually exclusive, nor are they in order of priority.

REMOVING OBSTACLES TO INCLUSION

Assessment and decision making procedures can be firmly based on the initial assumption that all children will be educated in regular schools. The aim of assessment is to identify obstacles and difficulties for each child individually and then try to agree on a programme of action to address these.

Individual Inclusion Plan

An individual inclusion plan is not the same as an individual educational plan which is normally concerned with helping children to reach specific developmental and educational targets. Drawing up an individual inclusion plan goes beyond traditional assessment of the child's needs and difficulties, by asking what kind of **environmental** changes would be needed to enable the individual needs of a given child to be met in the regular class of the local mainstream school. This needs to be followed by a decision on the removal of these obstacles and a time table for doing so.

For example, some children will need wheelchair access to classrooms, recreational facilities and toilets; others will need modifications to the curriculum, supported access to the curriculum through computers and communication and information technology; others will need the personal support of a teaching assistant in certain classes or activities.

Reviewing all children in special schools

A similar approach can be applied for all children now in special schools or segregated provision. Many children were sent to special schools at a time when it seemed impossible

for regular schools to meet their needs. Today, many more regular schools are educating children who would have been rejected without consideration ten years ago.

All children in special schools should therefore be regularly reviewed with a view to exploring all possible means of meeting their needs in more inclusive settings. This again, assumes the preparation of an individual inclusion plan. Some children may already be ready for planned transfer to a mainstream class, provided the appropriate supports, the necessary funds and staffing resources can be made available. Others may need a longer period of preparation.

DEVELOPING INCLUSIVE POLICIES

Developing policies for the future of special schools

Although there is general agreement that the work of special schools is changing and must change much further, there is considerable uncertainty in most countries about the future role of special schools. Some argue for a policy of phasing out all special schools over a period of time, on the grounds that the continued existence of special schools is inconsistent with inclusion. In the UK, the government is committed to retaining special schools as part of a broad spectrum of provision and in order to enable parents to choose a special school placement for their child, if that is their considered opinion.

The number of special schools in the UK fell by some 15 per cent in the period 1986-1996 (from 1405 to 1191), though the number of pupils attending special schools has remained at just under 100,000. One LEA has closed all but one of its special schools (the London borough of Newham) and there are very large variations in the proportion of children in special schools, even between adjacent LEAs. In England and Wales as a whole, some 1.2 per cent of all pupils of school age are in special schools, but the figures vary between 0.32 and 2.6 per cent between LEAs in different parts of the country.

In contrast to these figures, some 60 per cent of all pupils with 'statements' of special educational needs, are now in mainstream schools. These pupils are guaranteed additional resources by the LEA after a full multi-professional assessment. Many of these children would undoubtedly have been sent to special schools in the past, but their needs are now met in mainstream schools, with the help of additional funding provided by the LEA through the statement.

These huge variations reflect the lack of clear policy leadership by the government on the role of special schools in the future. Even so, the government has required all LEAs to clarify their inclusion policy as part of their overall Education Development Plan. These plans are subject to inspection by the Office for Standards in Education. A similar requirement is placed on all schools, whether mainstream or special.

Links between special and mainstream schools

The UK government also strongly supports collaboration between special and mainstream schools. A CD ROM has been produced with useful examples of different types of collaboration by the Department for Education and Employment in 2000.

In fact, collaborative links between special and mainstream schools can be regarded as a distinctive feature of the UK practice over the past 20 years. Well over 80 per cent of special schools are currently involved in link schemes. These have been well researched by the National Foundation for Educational Research in a series of reports over a long period (3,4,5). These reports would repay study in countries such as Japan with a strong special school system, since they go beyond mere description and include critical evaluation of the limitations of the link systems that have been developed.

In a typical example, a special school with under 100 pupils with severe and profound learning difficulties, will arrange for some 8-10 pupils to attend classes in a neighbouring primary school for an average of three hours a week. The pupils are accompanied by a teacher, or more probably by a teaching assistant. They usually go individually rather than as a group and are likely to attend classes in literacy and numeracy, physical education and dance, art and social activities. Special schools also use sport and swimming facilities, as well as curriculum materials, especially computers. Some mainstream pupils also spend similar periods in special schools.

The most recent evaluation (5) concludes that the more successful link schemes reflect positive attitudes on the part of both sets of teachers, resulting in joint planning and clear thinking on the nature and aims of the links and whose needs were being served. However, they conclude that:

“ the scope of the activity was relatively restricted in terms of time and numbers of staff involved. So long as links are regarded as optional extras and are not embedded in the plans of every special school and every relevant mainstream school, there will continue to be a divide between two forms of provision and dialogue will remain at the level of counting pupils on roll, rather than discussing effective case management” (5).

This research also confirmed earlier studies which showed that a typical special school in the UK only returned one child a year to mainstream provision. Although there are many reasons for this, it seems likely that numbers could increase if the annual review of each child's progress involved representatives from mainstream schools and included an analysis of the changes that would be needed to enable individual children to be satisfactorily educated in mainstream schools.

Dual placements

One possibility is to **register all new children with Special Educational Needs (SENs) on the roll of a mainstream school**, even though they may need to attend a special school temporarily. This can be the child's neighbourhood school. The aim is to develop an individual inclusion plan which is tailor-made to the needs of the individual child, in relation to the stage reached by the local school in meeting his or her needs and, indeed, those of others in the community.

Special schools as resource centres

As long ago as 1978, the Warnock Committee referred to special schools becoming 'resource centres' (6), but the concept of the resource centre is not well understood or defined.

In addition to the link schemes already described, a school can act as a resource centre by **recruiting staff for outreach work**. This might involve supporting their own pupils in spending an increasing period of time in mainstream schools, or supporting mainstream pupils who are in danger of exclusion to special schools. In either case, they are using their experience in special education, to support inclusive practice. Their very presence in a school can help to create positive attitudes to inclusion, by reassuring their mainstream schools that specialist support is available. On the other hand, the presence of specialists can have the opposite effect to what is intended, if such staff act as 'experts' and leave other teachers with the conviction that special training and special school experience are necessary to teach children with special educational needs.

The point to stress here, is that special school staff may be competent in their own setting, but may lack the tact, sensitivity and consultancy skills needed for working with colleagues. Training, supervision and support are essential.

Similarly, special schools can act as resource centres to mainstream schools in demonstrating specialist equipment, curriculum materials or particular methods of teaching - eg small steps, curriculum adaptation or differentiation.

School clusters

In a densely populated area, schools can benefit by creating structures and mechanisms for collaboration; this is often described as 'clustering' (7). A typical cluster may consist of ten or more primary schools, at least one secondary school and one or more special schools. The schools can agree to work together, to improve the quality of provision for all pupils with special educational needs within their catchment area. For example, they can join forces on school-based training, share ideas on individual educational planning and in general, on moving forward to more inclusive practice. Clearly, the presence of one or more special schools can greatly increase the scope for sharing specialist skills.

Special classes

Many mainstream schools, especially in the United States, have special classes, often containing children with learning difficulties or behaviour problems. Such classes have been heavily criticised for some time, mainly on the grounds that they contain a disproportionate number of Black and Hispanic children, that they provide an inferior education and that their pupils lack opportunities for inclusion into ordinary classes (8). What was once seen as an opportunity for integration is now under criticism for providing an unnecessarily restrictive environment for children whose needs could be met in regular classrooms in a more inclusive system.

Resourced mainstream schools

In some areas, LEAs select a small number of mainstream schools who are given additional financial and staffing resources, to include a number of children with special educational needs who would in other circumstances, be sent to special schools. In general, these children attend the regular class, though they often have a resource room for specialist work or one to one teaching. Additional members of staff are appointed to support mainstream staff as well as the child, in accessing the curriculum and participating in the whole range of school activities.

This model can provide good quality education and support, but has the obvious disadvantage of distance. A child not attending the neighbourhood school, is missing out on social opportunities of going to school together with other local children; furthermore, a disproportionate amount of time may be spent in travelling between home and school.

One version of the resourced school model involves closing all special schools and relocating all special school pupils to carefully selected mainstream schools. A model along these lines, was proposed by Mittler and Farrell (9) some 15 years ago, but can be criticised as involving unnecessary segregation.

The proposal involves closing a special school and relocating all pupils in special classes of up to ten children, together with their teaching and support staff and equipment, to carefully selected and resourced primary and secondary schools, in different areas of a town. The head teacher and deputy head teacher would play a key management role in coordinating the work of teachers, support staff and links with mainstream provision and other agencies, such as health and social services. For example, out of 80 children in a typical special school for children with severe learning difficulties, 40 could be transferred in classes of ten to four different primary schools; another 30 to three secondary schools and ten older students to a college of further education.

Although some of the children would initially be in their special class, each child would have an individual inclusion plan involving increasing periods of contact with the rest of the school.

Some children might be ready to spend a substantial amount of time in mainstream classes, provided they and the class teachers had appropriate support. Others might need more time. On the other hand, some mainstream schools may not be ready for more inclusive practice.

CHANGES IN MAINSTREAM SCHOOLS

The most fundamental pre-requisite for inclusion is reform and restructuring of ordinary schools and of the education system itself. This involves a reform of the curriculum, so that it becomes accessible and relevant to the whole range of pupils in the community, not only those with disabilities. Since the Salamanca Declaration of 1994, this process is better understood; moreover, as we have seen, the education of children with disabilities is increasingly seen as an integral part of the Education for All movement, which aims to improve the quality and accessibility of schooling to all children who are in any way excluded or marginalised. An excellent international resource is provided by the UNESCO **Open File on Inclusive Education** (10) which consists of support materials for managers and administrators and draws on the experience of a range of countries, in moving towards inclusive practice.

The restructuring of regular schools involves change at a variety of levels. In the UK, these include:

- reform of the curriculum with a view to widening access and participation of all pupils.
- reviewing pupil assessment and consequent decisions concerning the grouping of pupils.
- delegating responsibility and funding to all schools, including special schools.
- introduction of an obligatory special needs Code of Practice into all schools, facilitated by the appointment of a special educational needs coordinator to every school.
- provision of detailed guidelines on school-based identification and assessment of pupils at an early stage, with a view to supporting as many pupils as possible within the school and reducing inappropriate segregation and exclusion.
- mobilising a range of support services for schools and pupils.
- recruiting large numbers of teaching assistants for literacy and numeracy, as well as SEN.
- allocating earmarked additional funding for pupils with additional needs in mainstream schools.
- ensuring that inclusion issues permeate staff development at every level.
- ensuring that parents are involved and supportive of change.

Some of these initiatives are still at an early stage; some have been in place for some years; others have hardly started (2). An **Index for Inclusion** has been sent to all schools to enable them to carry out a self-evaluation of progress and problems in developing inclusive practice (11).

It is difficult to assess the strength of either the support or the resistance to inclusion. Although many more children with special needs are being educated in mainstream schools, it is clear from research, that many teachers have serious reservations about accepting children with intellectual disabilities and strongly believe that children with difficult behaviour should be sent to specialist provision (12). This view also finds expression among educational psychologists (13) who express doubts about the ability of regular schools to meet the whole range of educational needs in a neighbourhood.

Inclusion is a long process, a road to travel rather than a destination, but much can be done at every level to work to develop more inclusive practice at every level. Clearly, the classroom of the regular school is the starting point and end point for such a journey.

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DEVELOPMENTAL ARTICLES

**IMPLEMENTATION OF INDIAN SIGN LANGUAGE
IN EDUCATIONAL SETTINGS**

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ABSTRACT

This article reports on several sub-projects of research and development related to the use of Indian Sign Language in educational settings. In many countries around the world, sign languages are now recognised as the legitimate, full-fledged languages of the deaf communities that use them. In India, the development of sign language resources and their application in educational contexts, is still in its initial stages. The work reported on here, is the first principled and comprehensive effort of establishing educational programmes in Indian Sign Language at a national level. Programmes are of several types: a) Indian Sign Language instruction for hearing people; b) sign language teacher training programmes for deaf people; and c) educational materials for use in schools for the Deaf. The conceptual approach used in the programmes for deaf students is known as bilingual education, which emphasises the acquisition of a first language, Indian Sign Language, alongside the acquisition of spoken languages, primarily in their written form.

INTRODUCTION

India, with its one billion people, is the second most populated country in the world. It is estimated that there are over a million people who are profoundly deaf and approximately 10 million hard of hearing people, in India. No formal census data are available. These figures are extrapolated from the number of people who are deaf and hard of hearing, in Western nations (1‰ for individuals who are deaf and 10‰ for the hard of hearing). It would be realistic to believe that the actual number of people who are deaf and hard of hearing is much higher, because of poor hygienic conditions and lack of adequate medical services in India. Based on these numbers, one of every five people who are deaf in the world, lives in India. According to an UNESCO report in the 1980's, only 5% of children

who were deaf attended any special educational programme (1). Applied to the present situation, this would mean that only 50,000 children who are deaf, receive any education while the other 950,000 are left to their own devices.

BACKGROUND: PREVIOUS RESEARCH ON INDIAN SIGN LANGUAGE

For a country the size of India, the paucity of research on people who are deaf and hard of hearing is not understandable. Miles (2), compiled a historical bibliography on the education of children who are handicapped in South Asia and found only a few citations relative to deafness and the education of children who are Deaf over a span of 4,000 years. Miles pointed out that until the 20th century, deafness was considered as punishment for sins of earlier incarnations. People who were deaf were not allowed to inherit property by law, until the beginning of the 20th Century (3). With the prevalence of such beliefs, it is not surprising that Indian society does not make deaf education a priority.

Until 1978, it was generally believed that there was no Indian Sign Language (ISL). Banerjee (4) compared signs used in three schools for the deaf situated in Bengal (present W. Bengal and part of Assam). His conclusion was that gestures used in each school were different. He believed that signing started in India in the 18th century but its use was strongly discouraged, as signing was believed to impede learning to read. In 1975, Madan Vasishta sent a questionnaire to the heads of the 117 schools for the deaf in India. Almost all the respondents agreed that there was no Indian Sign Language. They did, however, acknowledge that deaf children used some kind of “collection of gestures” (5). A similar survey was conducted by D. Deshmukh 20 years later, again using questionnaires sent out to schools for the Deaf. Some of the responses show the same misconceptions about sign language, saying, for instance, that signing is “based on spoken language”, or “is based on English”, or that, “it is difficult to provide a sign for every spoken word”. However, there were also some statements that showed a more positive attitude towards manual communication, and here respondents did talk about “sign language”, rather than “gestures”. Increasing awareness about the nature of sign languages is evidenced in statements such as: “Through sign languages, there is free and easy communication”, “Sign language is the mother tongue of the Deaf”, and the like (6).

Linguistic work on Indian Sign Language (ISL) began in the 1970's. In 1977, Vasishta, Woodward, and Wilson visited India with partial support from the National Science Foundation (USA) and collected signs from four major urban centres (Delhi, Calcutta, Bombay, and Bangalore) for linguistic analyses. Vasishta et al. (7), found that ISL is a language in its own right and is indigenous to the Indian subcontinent. Subsequent efforts by Vasishta et al between 1977 and 1982, resulted in four dictionaries of ISL regional varieties and some articles (8, 5, 9). The All India Federation of the Deaf, supposedly distributed these dictionaries

to selected programmes serving the Deaf in India. In 2001, another dictionary was published by the Ramakrishna Mission Vidyalaya in Coimbatore (10).

Until Zeshan began publishing her work on Indo-Pakistani Sign Language from 1996 onwards, no other work in this area was done in India. However, some efforts were made in inventing sign morphemes on the line of SEE II (Signed Exact English-in this form of sign language, efforts are made to sign every morpheme of English vocabulary) in the United States. Little is known about the actual use of these contrived signs in classrooms. Deaf adults, however outrightly rejected these signs. Some articles on the existence of a rural sign language in India, were also published (11, 12). It is claimed that a rural Indian Sign Language (RISL) also exists and it is very different from the ISL included in Vasishta et al's dictionaries. The examples given by the author, however, do not support this contention. Development of any language, including sign languages, requires ongoing interaction between the speakers of that language. Deaf people in rural areas have little, or no opportunity, to meet other deaf people. What the author had observed, appears to be literally the gestures used by hearing people to communicate with the deaf. Such systems of manual communication used by isolated deaf people and their immediate environment are known as "home signing". Home sign systems lack the linguistic complexity of sign languages that are used in deaf communities (13). Instead, deaf home signers rely on gestures, mime and shared context to communicate with a few hearing people, on an ad hoc basis. Vasishta experienced this himself, while growing up in a small village in Himachal Pradesh. A few hearing people could communicate with him using gestures and mime very effectively, while the rest used writing for communication. The problem of how to provide access to Indian Sign Language for deaf people in rural areas of the Indian subcontinent, is a matter of great urgency and concern.

Zeshan's publication of her Master's thesis on ISL grammar (14), was the first work of its kind on ISL, closely followed by the publication of the more extensive PhD thesis (6). Since then, a regular succession of articles has resulted in ISL being a relatively well described sign language today (In a number of linguistic publications, the term 'Indo-Pakistani Sign Language' is used because deaf communities use the same sign language in these countries) (15, 16, 17). Research by Zeshan has confirmed and expanded earlier work, showing that ISL is indigenous to India and is used in the form of regional dialects all over the Indian subcontinent, that ISL has a complex linguistic structure of its own and is not based on any spoken language, and that its grammar can be described by means of linguistic analysis. However, this literature is not readily available within India, and most of it requires the reader to have at least some background in sign language linguistics. A textbook on a broad range of historical, social, and linguistic aspects of ISL and the Indian Deaf community, written in non-technical language for a general readership, would be greatly needed to fill this gap. Meanwhile, the present article is intended as a first step towards

bringing the results of ISL research and application to the attention of a wider public, within and outside India.

APPLYING THE RESEARCH: AN “INDIAN SIGN LANGUAGE CELL”

During all this time when some research was being conducted, no efforts were made to teach ISL to teachers, parents and professionals working with the Deaf. Teacher training programmes never included ISL as part of their curriculum. Principals of schools for the Deaf, where students used ISL to communicate with each other did not formally acknowledge use of ISL. However, knowing well the importance of communication, they did not discourage its use either. Devoted and conscientious teachers of the Deaf learned ISL from their students and used it in classrooms for instruction and communication. Still, the existence of ISL as a tool for teaching was not wholly acknowledged. Moreover, courses, curricula and teaching materials for ISL instruction were not available, nor were there any training programmes for generating qualified ISL instructors. Therefore, even for schools and teachers with a more positive attitude towards sign language, there were no resources for including ISL in classroom instruction in a principled way.

This situation began to change in 2001, when the second author spent a month at the Ali Yavar Jung National Institute for the Hearing Handicapped (NIHH) in Mumbai. During his stay, he gave several formal and informal talks to faculty, students and administrators about the importance of sign language in deaf education and rehabilitation. The acting director of NIHH showed interest and asked the second author to develop a proposal for starting ISL classes and an interpreter training programme at NIHH. The proposal included in addition to ISL classes and interpreter training, development of curricula and instructional materials, orientation programmes on Deafness for employers, research on the effectiveness of ISL in teaching the Deaf, and Deaf awareness programmes.

The authors of this paper conducted a two-day workshop on bilingual education and ISL in Hyderabad, for educators of the Deaf in March 2001. This was the first national workshop on sign language in India and was sponsored by the Rehabilitation Council of India. While the impact of the workshop was limited due to the small number of participants (150), it was historic in that, the main topics were sign language and bilingualism in Deaf education.

Additionally, this was the first time that deaf researchers were addressing an audience of hearing people. Such an event would have been inconceivable even a few years earlier.

The proposal for starting ISL classes and an interpreter training programme was approved and an ISL Cell was established at NIHH, in May 2001, with a co-ordinator, a deaf university graduate as the first teacher, and two Senior Research Fellows/Consultants. The Director of

NIHH provided full support for these efforts. Over the following years, the ISL Cell developed video-based teaching materials, conducted sign language training for hearing people inside and outside NIHH, trained deaf people to be professional ISL teachers, and organised lectures, seminars and workshops about sign language and bilingual education for the Deaf.

TEACHING INDIAN SIGN LANGUAGE

ISL Teaching Materials

The complete set of ISL teaching materials consists of three courses at the basic, advanced and professional levels (level A, B, and C). The first two courses are completed and have been published (19, 20), the third level is currently under development. The team involved in the development of the teaching materials consisted of a hearing linguist responsible for the development of the course contents, a deaf research assistant responsible for rendering the course contents in ISL on the teaching video, and a number of ISL models contributing scripted signed dialogues and freely signed texts to the courses. The materials correspond closely to, and are officially recognised in a syllabus for sign language interpreter training, that was approved by the Rehabilitation Council of India in 2002.

All teaching materials are bilingual in ISL and English, that is, all explanations, instructions and examples are signed by the deaf assistant, with voiceover and/or written text added in English. It is planned to also include subtitles in Indian languages, beginning with Hindi, as soon as possible. Each course consists of a teaching video and an accompanying workbook. The units in level A and B are built around grammatical topics, so that all the main grammatical structures of ISL are covered, progressing from easier and more basic structures to the more difficult ones. For instance, wh-questions, negation and the expression of possession are part of the basic level course, whereas if-clauses and auxiliaries are part of the advanced level course. Table 1 provides a few examples of the structure of the course materials, based on some of the units in the level A and the level B courses. The course contents are part of the officially recognised syllabus, for the sign language interpreter training programme mentioned earlier.

Table 1. Units in the basic level and advanced level ISL course (level A and B)

UNIT	GRAMMAR	TOPICS
Level A Unit 3	Questions with question words	Places People and professions Actions
Level A Unit 5	Negative sentences (1)	Fingerspelling (letters) Dialogue: The exam Opposites
Level A Unit 7	Numbers	Dialogue: Buying a car Talking about money
Level B Unit 2	Revision: fingerspelling, negation, possession. Place names and pointing signs. Imperative	Activities within the deaf community Co-operation of deaf and hearing people Continents and countries Indian States and Union Territories Cities, towns and languages
Level B Unit 4	If-clauses Enumeration	Communication issues Government set-up
Level B Unit 7	Auxiliary construction Expressing movement	Interpreting

A typical unit first starts with explanations introducing the topic of the unit, for instance, explaining how wh-questions are formed in ISL, followed by examples illustrating the main points, and related exercises, sometimes referring to the workbook. Then, each unit has texts for communication practice with further exercises. In the basic level course, most of the texts are carefully scripted dialogues matching the students' level of initial proficiency in ISL. At the advanced level, there are longer continuous texts in ISL, grouped around various subject areas such as communication, deaf culture, interpreting, and the like. Over the three course levels, the amount of English voiceover gradually decreases, as students become able to work with signed texts directly.

Unlike some sign language course materials in other countries, the ISL course materials do not initially focus on vocabulary, or rely on gesture. Rather, ISL is taught just as any spoken language would be taught and includes a grammar component from the very beginning. This has several consequences for the kind of proficiency that the hearing learners acquire, and consequences for the deaf teachers, when they follow a training programme that builds on the course materials.

From the start, the most salient feature of the ISL classes was that deaf people taught them and that ISL grammar was introduced from the very beginning. In Western nations, most sign language classes in the early days of sign language research and its application were vocabulary classes. People learned sign vocabulary and used it in their respective spoken language syntax. Only recently, have some countries started teaching sign language using the grammar approach. India, on the other hand, started with this linguistically appropriate model from the very beginning.

ISL courses and students

Since its inception in May 2001, deaf staff in the Indian Sign Language Cell has been teaching ISL classes, both within NIHH and outside. Training outside NIHH was sometimes conducted in the form of shorter orientation courses that did not cover the entire content of a course. Table 2 gives an overview of the types of training programmes and the numbers of hearing people who have followed the various kinds of ISL classes taught by staff of the ISL Cell Mumbai, up to May 2003. In July 2003, the ISL programmes were extended to all regional centres of the NIHH network. Thus, ISL classes are now available in Delhi, Hyderabad, Bhubaneswar and Calcutta, with teams of qualified deaf teachers providing the instruction under the same programme.

Table 2. Training in Indian Sign Language for hearing people

Course type	Number of participants
Certificate course in Indian Sign Language (Level A)	61
Certificate course in Indian Sign Language (Level B)	7
Short-term ISL training programmes	61
Internal training for faculty, students and staff at NIHH	29
All courses	158

Students in the ISL classes come from a wide variety of backgrounds. Apart from NIHH staff members who undergo internal training, people from outside the Institute have the option of attending for each course level, full-time classes for three months, or part-time classes for six months. The six-month program is generally more effective, particularly for students who are learning a sign language for the first time. This is probably due to the fact that they have more time to absorb what they are learning when the course spreads over a longer time, and learning is more effective when it is reinforced by repetition over time. However, for people from outside Mumbai, full-time classes initially provided the only opportunity to learn ISL, in a structured programme.

People join sign language classes for a variety of reasons. Many are involved with deaf people professionally, working, for instance, as audiologists or social workers, or they are studying towards a degree in special education, with a focus on hearing impairment or mental retardation. With the expansion of the ISL courses to regional centres, a larger number of hearing students who are enrolled in courses run by NIHH, such as teaching diplomas, or the Bachelor in Education (Hearing Impaired) programme, have also started learning Indian Sign Language. On the other hand, it has not been possible yet to recruit larger numbers of in-service teachers currently working at schools for the Deaf. It will be a major aim for the near future to design special programmes to suit this important target group. These programmes will have to include some practical training on the use of bilingual teaching materials, and the time schedule will have to be compacted and adjusted, to allow for full-time training at suitable times, for example, during school holidays. Similarly, hearing parents of deaf children are a very important target group who will have to be focussed upon in the near future.

Apart from learning actual ISL communication, one of the major achievements of the training programme is to change the students' attitudes about sign language and deaf people. In fact, the basic level course starts with a general introduction to sign language. This introduction consists of a 45-minute signed lecture (with English voiceover and a corresponding printed text in the workbook) that explains the nature of sign language and the status of Indian Sign Language in India. Thus before students learn their first signs, the most common prejudices against sign languages are addressed, and the students learn that:

- Sign languages are NOT the same all over the world.
- Sign languages are NOT just gestures and pantomime, but do have their own grammar.
- Sign languages are NOT dependent on spoken languages and do not resemble spoken languages used in the same region.
- Sign languages are NOT “languages of the hands” only, but use non-manual expressions as well.
- Sign languages have NOT been invented by hearing people.

- Western sign languages (e.g. American Sign Language) are NOT better than Indian Sign Language.
- Signed codes for spoken languages (e.g. Signed English) are NOT better than Indian Sign Language.

Even more important than this theoretical knowledge, is the hearing students' direct contact with an educated deaf person who is their teacher. This novel setting for which there are few precedents in India has a profound impact on both hearing students and on the deaf teachers themselves. For many hearing students, this is the first time that they encounter a deaf person who is professionally qualified, confident, and "in charge" of the situation. Consequently and automatically, the old patterns of patronising attitudes towards deaf people are no longer viable. For here suddenly, is a deaf person who is a specialist in something that the hearing people know nothing, or little about, and rather than being a "patient" in need of "help", the deaf teacher is, for once, in a position of authority. From the very beginning, since all teachers are deaf signers, the only language of classroom instruction is their own language, Indian Sign Language. The slogan that "deaf people can do it" is practically illustrated, and this practical example is naturally more powerful than any theoretical instruction.

The change in attitude among hearing students of ISL is likely to remain even if the signing skills that can be learned in a relatively short time are necessarily limited, especially at the basic level. In countries where university-level sign language programmes exist, studying towards a degree in sign language interpreting, sign language linguistics, or sign language teaching involves several years of study, often in the form of regular Bachelor's or Master's degrees. Such courses conform to the same requirements as courses in any other subject in the humanities. In the near to medium-term future, there is no doubt that the increasing demand for sign language-related services, will also produce the corresponding professional profiles in India, so that it will become viable to offer similar programmes here as well.

Meanwhile, it is a subject of continuing investigation in the Indian Sign Language Cell to study the way that ISL skills are acquired through our current programmes. The first results are in preparation, but have not been published yet, although data collection has been ongoing from the very beginning. ISL students at both levels were regularly videotaped, especially in connection with exams, of which there are two at each level. Since classes taught by the ISL Cell Mumbai have been going on for more than two years, the authors have been able to follow students from the start of their ISL acquisition (usually starting at zero competence) right up to the end of the second level course. Some initial informal impressions and observations can be reported at this stage, until a more detailed analysis becomes available. The aim of the basic level course (level A) is to achieve basic communicative competence in ISL. That is, at the end of the course, students should be able to communicate with deaf ISL signers in casual, informal situations. They should be able to understand conversational

ISL and to express themselves in unrehearsed situations. Students need to have grasped the basic grammatical structures of ISL because they should not only repeat phrases and sentences by heart, but use the language creatively. A basic core vocabulary of about 400 words is taught at this level. If the available interpreting module is also taught as part of the course, hearing people can play the role of a communication facilitator after completion of this course.

The most striking observation about the learning process at the basic level, is that students use genuine ISL structures from the very beginning. Learning a language, including a sign language for the first time, is difficult for most people, and this has to be taken into account when assessing the students' emerging competence in ISL. Although learners' problems and errors have not been studied in detail, preliminary evidence suggests that even at the basic level, students do not simply combine ISL signs with the structures of a spoken language. For example, they do not simply use ISL signs in the word order of a spoken language, be it English, or an indigenous Indian language.

This makes the programme different from many others that used to be taught and to some extent are still taught in India and elsewhere. Some programmes explicitly taught or teach signed codes for spoken languages, most prominently various forms of Signed English. This is problematic in the Indian context because very few deaf people can use and understand any form of Signed English. Therefore, a hearing person with skills in a form of Signed English will not be understood by the great majority of deaf ISL-using Indians. In other cases, a pidginised version of the sign language with heavy influence from spoken language structures is not intentional, but results from the fact that courses are, or were basically vocabulary courses. In this case, it is natural that learners would use the sign vocabulary in the order of their own spoken language.

At the second level of ISL instruction (level B), students achieve greater fluency and also become acquainted with the lives, cultural norms, and experiences of deaf Indians, in greater depth. Initial observations indicate that students at this level are able to communicate adequately with the deaf people they know well, such as their teachers, who communicate with them in ISL, exclusively during classroom time at all levels of instruction. More advanced ISL grammar is taught at this level, and the vocabulary expands to about 1,000 words. Level B students are generally able to understand longer ISL texts, of which there are many in the teaching materials, and they also produce longer signed utterances themselves. Students who do well at this level should also be able to do some ISL interpreting in semi-formal, non-professional settings. For example, a graduate of our last level B course has recently been employed in the ISL Cell in Mumbai as assistant coordinator and also assists with interpretation.

However, we can also note that skill levels in ISL diverge more widely across individual students at this level, than in the beginning. That is, some students' signing skills really take off

during this level of instruction and they become very fluent signers, while others progress at a much slower pace. The main reason for this seems to be the level of involvement with deaf people outside classroom hours. That is, students who have continuous contact with deaf people and spend much time in casual conversations with many different deaf people, become very fluent signers. By contrast, those who only attend the classes, but do not otherwise socialise with deaf people, make slower progress and may have more difficulty understanding deaf people they are not familiar with. This of course is not surprising. As with any language, true competence comes only through using the language in real-life situations on a daily basis. Consequently, one way to improve the signing skills of future students, would be to provide more opportunities for meeting a wider circle of deaf people on a regular basis.

It has been a regular practice from the beginning of the ISL Cell, to evaluate the programme. The following excerpts is from a report in July 2001, relating to the first ISL classes that were run in Mumbai:

“There are approximately 23 students attending classes regularly. Of these, 17 filled out evaluation forms. Eleven of the responding students are attending part time and six are full time students. All of them have been enrolled since the beginning of classes on July 1, 2001. Except for three students, all are attending classes regularly. These three have job requirements that call for periodic absence from Bombay.

The students have a wide variety of professional backgrounds. Thirteen of them are working as teachers or in support services (counsellors, audiologists, speech therapists) for the deaf. Of the remaining four, one is a medical doctor, one a retired counsellor, one an airline hostess, and one is an architect. Six of the students are employed at NIHH and the other 11 came from the community.

Most of the students are from Bombay except for two who are out of state. One is from Andhra Pradesh and the other is from Uttar Pradesh. The two out-of-state students are living in the hostel.

The first and most salient impression of this programme can be summed up in one word: enthusiasm. Teachers, students, and administrators demonstrate a strong commitment to learning and teaching ISL. The result of this attitude is evident from the significant progress made by students and their positive attitude about ISL.

Students spend between one and four hours in commuting to and from the class. This shows their commitment to learning. The regular students are rarely absent, and focus on the subject in class, is exemplary. Almost all students have a professional background and they appear to take this class as a challenging experience.”

Another important source of evaluation comes from the students themselves. The project staff has been collecting questionnaires from ISL learners in which they state their opinion

about the programme. These questionnaires ask students to evaluate, for instance, whether the amount of classroom instruction is adequate, how helpful the teaching materials are, whether the time schedule is appropriate for their circumstances, and how satisfied they are with the teacher's instruction. The first such questionnaires were used for the earlier mentioned report, but not all subsequent questionnaires have been analysed in detail yet, and their analysis is part of ongoing research into the acquisition of ISL by hearing students in this programme. However, one tendency is abundantly clear: virtually all learners rate the teachers' performance very highly, and many individual comments from students in the classes have confirmed that they value their teachers greatly and genuinely enjoy the classes. Indeed, the deaf teachers are the heart and soul of this programme, and their hard work, discipline and enthusiasm has been a large contributory factor in making the programme successful. Throughout the programme, they have been the best ambassadors for their language and the classes, that teach their language to hearing people.

Teacher training for deaf instructors

Right from the beginning of the sign language programmes, training qualified sign language teachers, has been a matter of high priority in the Indian Sign Language Cell. The training courses correspond to the three levels of ISL courses (level A, B and C). Deaf people who are admitted to the courses attend a full-time residential programme for about three months for each course level. Those who pass the exams become certified sign language teachers.

Over the first two years, courses were being conducted by the ISL Cell's first sign language Master Trainer, who had also contributed to the development of the teaching materials as a research assistant in the first place, and was thus most suitable for passing on his skills to other deaf people. The medium of instruction in the teacher-training program was of course ISL. So far, the ISL Cell in Mumbai has run teacher training programmes for four batches of trainees, three at the A level and one at the B level (Table 3). Almost all trainees who have passed the exams are currently employed in sign language teaching and training, and many have been absorbed into our own ISL programs via the expansion to the NIHH regional centres. For the first time in India, there is now a sizeable group of deaf people with heightened meta-linguistic awareness, self-confidence, and the skills to teach about their own language and culture.

Table 3. Trainees in the ISL teacher training programmes

Course	Passed	Failed	Total
level A first batch	6	7	13
level A second batch	5	4	9
level A third batch	8	4	12
level B first batch	9	1	10

There has been a learning curve in the organisation of the training programme, in particular, with respect to the choice of candidates. Out of the first and second batch of level A trainees, about half of the candidates failed the course. This was mostly because their competence in ISL was too low for them to be sign language teachers, and of course excellent ISL competence is a basic precondition for being a good ISL teacher. In the following programs, candidates were selected more carefully, so that the percentage of trainees who passed the course, rose sharply, to the extent where only one person failed the most recent course, the advanced level teacher training at level B.

The effect of the training on deaf people who participate in the course can only be described as dramatic. Usually, deaf Indians do not believe that their sign language is a “proper language” that has a grammar of its own. They think of signing as being some way of communicating that is inferior to spoken language, thus adopting some of the negative prejudice against the sign language that is so widespread among the hearing population in India. Through the training programme, they learn that this is not true, and this awareness, together with the new confidence that they gain through the programme, has a deep effect on their sense of identity and self-esteem. In fact, they all develop a great liking for grammar, which is quite strange when one thinks of hearing people who study grammar in high school and university and usually find the topic immensely dry, boring and abstract.

All deaf teacher trainees, even those who do not pass the exams, also get a new sense of what deaf people in general, and they themselves as individuals can achieve, and this motivates them to pursue goals that they would have thought to be out of reach earlier. In two recent parallel studies (21, 22), teachers and parents of deaf children on the one hand, and deaf adults on the other hand, were asked to name appropriate professions for deaf people in India. Professions mentioned frequently included vocational professions such as tailoring, painting, printing and carpentry, as well as fine art, computerised data processing, and jobs at lower levels of qualification such as typist and shop assistant. This list does not include teaching professions, or in fact any kind of profession which usually requires an academic background.

The deaf trainees generally enter the training programme with similar views and expectations. For instance, one of the recent graduates had passed the 10th standard at school, then dropped out of the school system and worked for an architect doing technical drawing. Everyone, including himself, believed this to be a great achievement, and nobody ever considered that he might have the potential of studying at university. He is now appearing for the 12th standard exams in order to go on to a university-level programme later. A number of deaf people who have passed through these training programmes are similarly pursuing higher levels of education, and in particular, those who work at the level of Master Trainers. Several of them are appearing, mostly for the 12th standard exams, sometimes after years of being out of touch with schooling, and a few are entering or seeking to enter Bachelors' and Masters' programmes. The contact with deaf role models who do pursue higher academic qualifications, and the experience of being able to function adequately in a teaching role themselves, motivates them to pursue higher levels of education.

As far as the training programmes themselves are concerned, the way the teaching materials have been designed, with all relevant explanations signed on the videotape, has proved to be highly effective in training teachers. The teaching videos can thus directly double up as an instructional aid in the teacher training programme. This is especially true of the introduction to the level A course and also of the individual course units. For example, the deaf trainees work with the videotape at one of the units where the signer on the video is explaining the way that questions with question words are formed in ISL. Through trying to understand the signed explanations, they first become aware that there are many specific rules involved here: that question words are always clause-final; that a specific facial expression is necessary in this sentence type; and that most question words are complex combinations of two signs. When they go on to studying the examples on the videotape, they will also notice that all these rules are different from English, and that the English sentences are completely different in structure from the ISL sentences. Finally, they will practice amongst themselves what it is like to stand in front of a class of people and direct them to do sign language exercises. For example, telling hearing people that they are not signing correctly is a novel experience for the trainees initially, and they need to get used to their role as responsible teachers.

The training itself is very practical and provides many opportunities for practising in classroom settings, either in role play among the deaf trainees themselves (a simulated teaching situation), or by assigning some ongoing ISL classes to the trainees to teach (an actual teaching situation). Given both the needs for making sign language teachers available quickly and the limited resources of the ISL Cell, initially there has been no pursuit of more theoretically oriented programmes with a richer academic grounding. However, in due course there should definitely be a next logical step forward, and deaf people should be able to pursue regular university-level degrees in education, so that they can work in schools for the deaf on an equal footing

with their hearing colleagues, as is already the reality in other countries. As has been mentioned above, the deaf teachers who have been working within NIHH are highly regarded by their students, and work with great dedication and responsibility. With the expansion of the ISL programmes to regional centres, the best and most experienced teachers were promoted and can now work as Master Trainers to train further groups of deaf people locally. Two new teacher training programmes started in October 2003, in Kolkata and in Delhi. The ISL Cell in Mumbai, currently concentrates on the development of further teaching materials.

In addition to the personal development of the deaf trainees, there was a second factor which was very striking and initially quite unexpected. The mere fact that the teaching materials are bilingual in ISL and English resulted in a dramatic increase in English proficiency in many deaf trainees, a development that was most marked in those who initially had the least competence in English. Thus trainees with virtually no knowledge of English progressed, within 2-3 months of their first level A teacher training programme, to a stage where they had a vocabulary of several hundred words, could understand the English phrases and sentences that were part of the teaching materials, and developed a basic understanding of English grammar without any formal instruction. For instance, when one of these trainees was asked what the *n't* meant in one of the negative sentences, he was aware that this was the same as the word *not*, and that it was a negative corresponding to a particular ISL sign. To varying degrees, these students were able to translate any English sentence from the teaching materials into ISL, although this was not explicitly practised in their classes. On the other hand, they were of course not able to do translations the other way around, nor were they able to use English structures productively in novel sentences.

Apart from the fact that this progress in English was unplanned and unexpected, another interesting factor is that the whole process took place in an exclusively signing environment, with the instructor and the trainees all being deaf. No effort was made to teach pronunciation or lip-reading in any language, since deaf teachers communicate in ISL (or a written language) exclusively in the classes. Therefore, deaf people who have acquired some English proficiency through various channels as a by-product of their training programme are typically unaware of how words are pronounced. For instance, they have no idea that some letters in the words they know are silent, such as **gh** in **light** and **night**, yet can use these words correctly in written communication. By the end of the training programme, most students have also started communicating their own ideas in written English. All sign language teachers who currently work in the ISL programmes in the five NIHH centres, communicate by e-mail in written English with each other and their project leaders, and some have only just started free writing in English. Initially, their writing is of course quite ungrammatical and heavily influenced by ISL structures, but it serves its communicative purpose and thus provides a strong incentive for making further progress, as well as providing opportunities for practice and fostering a group spirit among all staff in the ISL programme.

As a result of these experiences, the ISL Cell decided to increase work in the area of English language teaching. A partly developed course in basic English grammar that had been on hold for some time was finalised, and the first formal classes using the new teaching materials have started.

BILINGUAL TEACHING MATERIALS FOR DEAF EDUCATION

Background: bilingualism in deaf education

Bilingual education is generally defined as, “an approach to the education of deaf children that uses both the sign language of the deaf community and the written/spoken language of the hearing community.” (23). During the last two decades, bilingualism in deaf education has spread rapidly in many countries, especially in Scandinavian countries and the United States.

Cummins (24) provided the rationale for bilingual education for both deaf and hearing children. He postulated that the underlying proficiency in one language leads to proficiency in the second language.

Sign languages until the 1960s were not viewed as bona fide languages, but just collections of gestures and mime. Dr. Stokoe’s research on American Sign Language proved that it is a full-fledged language with its own grammar, syntax, and other linguistic attributes. These findings have since been replicated for many national sign languages around the world, including Indian Sign Language. Research on the achievement of deaf children in the 1950s and 60s, indicated that deaf children of deaf parents (DOD) performed much better in most subjects, especially in language development, than deaf children of hearing parents (DOH). This superiority in academic performance was attributed to DOD having access to a rich communication environment from birth. Their acquisition of fluency in sign language led to their mastery of one language in the early years. This mastery was later transferred to learning of the second language (spoken and written) in school.

The fact that sign languages are languages in their own right and that their acquisition catapults a deaf child’s ability to learn the spoken language on a par with his/her hearing peers, makes a strong case for the bilingual approach in deaf education. Research has also indicated that parts of the brain used for learning language at birth atrophy if they are not effectively utilised during the crucial years for learning a language (25). Since DOH do not have access to any language at an early age, they have to learn the spoken/written language by rote memorisation and drill when they arrive in school. This is not the best approach to learn a language. Thus, these deaf children spend most of their school years trying to learn a language that they have never heard and without any linguistic base. No wonder that the average reading level of deaf children after 12 years of schooling is about 4.5 grade level in

the United States. This deficiency in linguistic ability leads to poor learning in other subject areas also.

In India, where most children are born in small villages and little or no early intervention is available and where auditory equipment is rare, the benefits of introducing ISL as the first language and then using it as a base for learning the region's spoken/written language are tremendous. Use of ISL will also help facilitate communication and socialisation of the deaf, which leads to better self-esteem. Higher self-esteem leads to better educational achievement and overall adjustment.

Bilingual education is being implemented very successfully in Scandinavian countries and to an extent in the United States (26, 27, 28, 29). India can learn from the successful strategies these countries have implemented. The ISL Cell has been developing educational materials designed to give impulses for the implementation of bilingual deaf education in India.

English through ISL for deaf adults: the “Basic course in English taught in Indian sign language”

The development of a video-based course teaching English to Indian deaf people in a sign language medium, already began before the inception of the ISL Cell, but was not completed until recently. As with the ISL course materials, the course contents in the form of a teaching video and an accompanying student workbook, were developed by a linguist, and the course contents were rendered in ISL on the video by a deaf assistant. This package is complemented by a reader with additional texts and exercises for practice, which is being developed by the ISL Cell co-ordinator. The following paragraph from the workbook introduces the aim and scope of the teaching materials:

“The materials are recommended for use in classes 8-10, or, for use in vocational training institutes for the Deaf. Although these materials can be used for individual study at home, we recommend that they should be used in a classroom. We also recommend that the classes should be taught by a deaf teacher or by a deaf and a hearing teacher together. If this is not possible, hearing teachers should at least be fluent in Indian Sign Language.

This English course is organised in units. Each unit presents aspects of English grammar together with grammatical exercises, vocabulary, texts for reading comprehension, and exercises for writing texts. On the video, we explain the grammar and the meaning of English words in sign language. The workbook includes vocabulary lists, grammar summaries, example texts and exercises. In a classroom setting, the teacher in the classroom will use the video, and each student should work with one workbook.

The video and workbook materials focus on teaching basic grammatical structures rather than a broad range of vocabulary. This approach was taken because English grammar is the area that many deaf Indians struggle with and where they have the greatest deficits. Understanding

grammatical structures and the “logic” of English sentences is essential for being able to read and write English at an adequate level. However, true language competence is only achieved through extensive practice with authentic language in real-life situations. Therefore, the course materials also include a reader where students can encounter authentic English language in texts of many different kinds. The texts in the reader are graded to suit the levels of the individual units in the course and are intended to provide additional practice with written English as it is encountered in everyday life.”

In order to understand what this course can and cannot achieve, a few important aspects need to be considered. First of all, the course is not suitable for young children below their mid-teens. This is because the ability to explicitly reflect on linguistic rules and structures is presupposed in the design of the course. Students following the course have to be able to understand the meta-linguistic explanations included in the units. Younger children, no matter whether deaf or hearing, generally do not have this capacity yet, and thus need a very different approach to second language learning.

The course is also not suitable for older deaf people who do not have sufficient competence in Indian Sign Language, at least not without special provisions being made. This is simply because they would not be able to easily understand the signed explanations on the videotape. This is problematic in particular, for self-study without access to a teacher or tutor. It is less of a problem if people have the opportunity to attend a course taught by a trained deaf teacher. In this case, the teacher’s additional help and explanation may make it possible to follow the course successfully. At the same time, we can expect that such deaf people would also benefit from the teaching situation by acquiring more proficiency in Indian Sign Language.

The focus of the course on grammar, also warrants some explanation. A common practice in India, when teaching the same target group, is to focus on vocabulary, or to have people copy and memorise whole sentences. This is not a very successful way of learning a foreign language. However, it is a valid question to ask whether such a course should not preferably focus on communication in a more practical way, in the sense of teaching “what to say/write in a particular situation”.

There are several answers concerning this issue. First of all, many schools for the deaf in India do teach English. The typical outcome of this learning process when students graduate from class 10 after several years of instruction in English, is that they have quite a sizeable vocabulary, but practically no grammar. That is, they know the meanings of a sizeable number of English words, but they cannot put the words together into even the simplest phrases and sentences because they have no or minimal command of the morphology and syntax of English. Therefore, our course aims primarily at bridging exactly this gap and focus on the aspects where deaf people typically have the most deficits. In nine units, the

course includes core structures of English grammar, such as personal pronouns, possessive pronouns, copula forms, modals, singular and plural in nouns, definite and indefinite articles, prepositions, the use of numbers and time expressions, negation, basic present, past and future tenses, do-support and S-V inversion in yes/no-questions, wh-questions, and object pronouns. Importantly, these structures are not arranged in an order of abstract logic. Rather, their order throughout the course is itself usage-oriented and includes considerations of frequency. For instance, only the first person possessive, 'my' is introduced in unit 3 because it is the most useful for face-to-face communication. Other possessive pronouns are introduced later. Similarly, negative and interrogative forms of 'have' and 'want' already appear in unit 5, whereas the complete negative and interrogative patterns of English are distributed over later units. And rather than teaching all prepositions at the same time, which would be structurally "logical", but hugely impractical from a communicative point of view, prepositions appear as part of various sub-topics throughout the course, for example in temporal expressions in unit 6.

A more communicative approach is also taken in the workbook and in particular in the reader, which is being developed with inputs from deaf learners of English themselves. In the workbook, topics and situations include talking about the family, about professions, visits to the doctor, buying something in a store, going out, getting a railway pass, doing a hearing test, etc. The reader includes all kinds of real-life English texts, ranging from posters and cooking instructions to advertisements, invitation cards, e-mail messages, and newspaper clippings. Moreover, phrases and exercises for basic communicative functions are also included, such as how to make suggestions, how to express opinions, how to make requests, and so forth.

Finally, a particularly salient aspect of the course, is that it focuses entirely on written language in the form of reading comprehension and written composition. Although the video does have voiceover, this is intended as a teaching aid for hearing people who may want to teach the course but do not have quite enough fluency in ISL, to understand all the contents of the video. Typically though, the course would be taught by a qualified deaf teacher in a classroom with deaf students, where the medium of instruction would be Indian Sign Language. No attempt is made in this course, to teach English articulation or lip-reading. In fact, as was mentioned earlier, deaf students learning English in this kind of setting, seem to make no connections between the written forms of English and the way these are pronounced, yet are able to understand and use the English words and structures productively. This aspect of language acquisition is very interesting and will be a topic for further investigation.

The English course, has been pilot tested with a group of deaf sign language teacher trainees, with promising results. The ISL Cells in Mumbai and Hyderabad, are now beginning to use the teaching materials in regular courses for deaf adults. The results from these first courses

will be carefully documented for research purposes, so that the degree of effectiveness of the teaching materials can be established. It will also be necessary at the next step to train teachers in the use of these materials, so that they can be used more widely in classrooms, with the appropriate target groups.

The overall aim of the course (and any advanced-level courses that will follow), is to enable deaf Indians to access written information in English and to use written English productively to communicate their ideas. Once this crucial linguistic access is established, opportunities for deaf people to access information and education are greatly increased. They can surf the internet and read about all kinds of subject matter independently, they can read newspapers and magazines, they can pursue university-level courses in distance education, they can broaden their horizons through world-wide e-mail communication, and they can access professions that are currently out of reach for most deaf Indians. The second language acquisition we envisage proceeds on the basis of sound knowledge of a first language, usually Indian Sign Language, thus realising the tenets of bilingual education as outlined earlier in this paper.

Early linguistic competence for young deaf children: The “First signed stories”

The “First signed stories” project, is the latest addition to the ISL Cell’s activities, and is therefore at the least advanced stage. These materials will focus on a different target group of young deaf children, between about three and eight years of age. The aim of these materials is to stimulate overall linguistic and cognitive development in these children, in a bilingual environment.

In the first stage of this project, a group of fluent deaf signers under the direction of the project’s first Master Trainer, collected children’s stories and filmed signed versions of these stories. This included an initial experimentation phase, where various signing styles and settings were tried out, and has since resulted in a collection of a number of stories in Indian Sign Language. For one pilot story, colour illustrations were also created and experimented with, in ways to integrate these pictures and the signed story itself. Eventually, the project aims at producing a videotape with signed stories and their illustrations, a teacher’s manual with directions and suggestions on how to use these materials in a classroom setting, and further teaching aids to expand classroom activities based on the stories, such as printed versions of the same stories in a written language (English, Hindi, and/or regional Indian languages). Currently, work focuses on finalising the video materials; the accompanying materials will be developed at the second stage.

When the materials are ready for use, it will again be essential to start with a few pilot studies and trial runs in appropriate groups of deaf children, and to carefully document the results of the learning process. For the pilot studies, the best option will be to work with a deaf teacher who is fluent in ISL and has participated in the development of the materials.

The results that can be expected from exposing young deaf children to sign language communication and a bilingual environment with a sign language-competent teacher, lie in the domains of overall linguistic and cognitive development. A major obstacle to educational success in deaf children, is a lack of what can be called “world knowledge”. In bilingual classrooms where similar materials were used, storybooks and their signed equivalents served this purpose: “Storybook reading/signing was one such context that naturally lent itself to building world knowledge. During these readings, the teachers frequently offered asides to explain concepts essential to understand the stories.” (26) Because of a lack of access to communication in any natural language, deaf children especially at younger ages, have severe gaps in the general cognitive and cultural foundations that are necessary preconditions to acquiring language. Stevens (28), discussing the situation in the United States, states the problem thus: “The most prevalent educational goal in schools and classes for deaf children is the acquisition of English. However, this goal is too narrow and the methods used to reach it are too limited, for the goal itself to be obtained. Much of the time and energy devoted toward reaching the goal are wasted, because the cultural aspects of education are ignored, and because the teachers, by and large, do not foster growth in general areas of language and thought development.”

A successful way of building up this missing world knowledge and focusing on the development of cognitive concepts, is through stories that are directly accessible to deaf children in sign language. It is through stories that they can learn. For instance, that people communicate for various purposes, that it is possible to take different viewpoints on the same situation, that conflicts exist between people and can be resolved, that the possibilities of imaginary worlds are different from those of the real world, that one person can imagine what another person feels, and so on. Without a sound foundation of information about the world, making sense of printed texts in any language, is impossible.

However, using materials such as the “First signed stories”, in a classroom, can also facilitate the initial stages of acquisition of a written language at the same time as providing opportunities for general cognitive development. In contrast with the basic English course for teenagers and adults, young children need a different approach because it is difficult to use explicit awareness of linguistic structures for second language teaching purposes at this age. Instead of formal second language instruction, which is possible only at a later age, motivation and communicative intent is of prime importance for younger age groups. Here, the initial acquisition of a written language will primarily be in the form of reading comprehension. On the relationship between motivation, sign language communication, and the point of departure for second language learning in deaf children, Svartholm (27) explains the situation in Swedish bilingual school settings: “Making a Swedish text intelligible to a deaf child at the beginner’s level implies rendering it into Swedish Sign Language. Such renderings, abundantly offered

by the teacher in the classroom, can be said to form the main point of departure for second language teaching to the deaf. The main purpose of these renderings is to awaken the child's interest in the content of Swedish texts, to show that the printed lines on the page contain something and that this something is interesting or exciting or funny."

Besides their role as 'translators' between signed and written language, sign language-competent teachers also serve as important role models for their deaf students. Neese Bailes (26) observed this factor in a bilingual classroom using American Sign Language and written English: "The teachers frequently read and signed stories to their students in ASL. The students observed them in the process of reading English text and subsequently signing the story to them in ASL. Immersed in the literacy activities of their teachers, observing how these ready role models negotiated their way between ASL and English, and indeed observing how they used these languages in purposeful and even playful ways, the children learned by example what it meant to live literate lives as bilinguals."

For the Indian context, where there are few precedents of bilingual classroom settings, the "First signed stories", are expected to provide a structured example of how such a situation is created and what kinds of teaching aids might be used to benefit from the advantages of such a communicative classroom setting. A large number of options are possible, but have not been planned in detail. For example, teachers can use written and signed forms or the stories in parallel, as in the examples from Sweden and the US quoted above; they can focus on the relationship between individual signs and words that occur in the stories; they can discuss the stories with their students and thus foster their "thought development"; they can ask students to retell the stories in ISL, to build up expressive abilities and enhance memory; and they can later add further reading and writing activities, drawing on the interest that has been generated by the signed stories.

These materials are of course only a beginning, and it will be necessary to produce many more ISL materials in the years to come. This first pilot project and the conclusions drawn from documenting its effectiveness, will provide useful clues to developing further such materials that are particularly suitable in an Indian context and tailored to the needs of both teachers and students, at schools for the Deaf in India.

CONCLUSION

The ISL programme so far, has been very productive over a very short period of time. Within two-and-a-half years, more than 250 hearing people received training in ISL at the basic and/or advanced level. There are now 20 trained ISL teachers, and the project has been expanded to four regional centres in addition to the NIHH headquarters in Mumbai. The expanded ISL project will run for a period of five years, and substantial funds have been made available to run this programme and employ its staff.

By way of a forecast of the future, one goes back once more to the evaluation report of the first year of the ISL Cell in Mumbai: “The administration of NIHH has expressed some very positive views and plans for future developments in the use of ISL. There appears to be a clear vision. Some of their goals are:

- Recognise ISL as one of the modes of communication that the majority of the deaf use.
- Recognise ISL as one of the government approved languages in India.
- Prepare curriculum material in ISL that could be used for subject teaching in schools.
- Plan and implement strategies to increase ISL usage by the deaf and teachers of the hearing impaired.
- Update and perfect to the extent possible the ISL interpreter-training programme.
- Provide choices to the hearing impaired with ISL being one of the choices.
- Work towards making ISL a medium of instruction in schools and develop strategies to reduce resistance against it.

These are lofty but achievable goals. Since AYJNIHH is the primary organisation working for the deaf in India, these goals can be achieved within the next few years.”

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USING FOCUS GROUPS IN COMMUNITY BASED REHABILITATION

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ABSTRACT

The purpose of this study was to examine the method of focus group in community-based rehabilitation. An intensive ten year search of Medline database, revealed twenty six articles that had used focus group as primary or secondary method and that pertained to rehabilitation in community settings. The articles were categorized into five categories based on how focus group was used, namely, needs assessment, evaluation, developing an instrument, developing a conceptual framework, and as an intervention. Most of the studies were done for needs assessment (n=19) with very few in the other four areas. Focus groups are an invaluable method that has been underutilised in CBR. These can aid the research enquiry or in participatory paradigm, these can be utilised as a means of community empowerment.

INTRODUCTION

Since 1976, community-based rehabilitation (CBR) strategy has been the chosen approach by the World Health Organisation (WHO), for serving the needs of persons with disabilities in developing countries (1). Over the last two decades, this CBR approach has been applied in more than thirty countries through governmental and non-governmental initiatives (2). The model which was initially perceived as an extension of the medical model linked with the infrastructure of primary health care (PHC), has evolved into a more comprehensive social model, that relies more on voluntary community participation and resources (3). The primary tenet of CBR is to provide primary care and rehabilitative assistance to persons with disabilities, by using human and other resources already available in their communities. The five basic principles of CBR strategy include:

- Utilisation of available resources in the community.
- Transfer of knowledge about disabilities and skills in rehabilitation, to people with disabilities, families and communities.
- Community involvement in planning, decision making, and evaluation.
- Utilisation and strengthening of referral services at district, provincial, and national levels that are able to perform skilled assessments with increasing sophistication, make rehabilitation plans, participate in training, and supervision.
- Utilisation of a co-ordinated, multisectoral approach.

In community-based work and research, a method that is commonly employed is focus group discussion. The purpose of this article is to examine the extent of use of focus groups in community-based rehabilitation and discuss its potential applications. The article begins by discussing the technique of focus group. Next, the methodology for locating published works utilizing focus group in CBR is presented. Then, the published literature with regard to focus groups in CBR is categorised and summarised. Finally, the implications of the findings and applications in CBR are discussed.

Focus groups owe their origin to the field of marketing (4). The marketing researchers primarily use this method for testing the negative and positive perceptions of target audience, about various new commodities or potential ideas. Focus groups are indispensable for community entry to gain early impressions (5). Focus groups are especially important in determining which populations to target. Focus groups are also used in developing and modifying psychometric instruments. These are also being used in evaluation of programmes including critiquing educational materials such as pamphlets, posters, public service announcements, and so on. Focus groups are also helpful in triangulating results from quantitative data.

The focus group method entails developing a detailed protocol (5). In developing the protocol, first the research topic is decided. The time planned for conducting a focus group session is between one and two hours. The guidelines start with directions for recruitment of the focus group members (8 to 12 persons with a minimum of 4 groups for each topic). It is important to keep the recruitment instructions simple and brief, and giving participants some incentive or reward, for participation. The first decision in recruitment is whether to keep only gender or combine the two sexes. If possibility of any potential threat to openness is perceived, the focus group must be restricted to only one sex. The next decision is regarding the socio-economic status of participants. Once again, efforts must be made to keep homogeneity. Similarly, efforts must be made to have homogeneity with regard to race, ethnicity, national origin, and spoken language. Finally, to ensure that discussion is more honest, efforts need to be made, such that participants do not know each other.

The focus group protocol includes direction for conducting the discussion. Each discussion starts with introductory comments from the moderator thanking the participants, explaining the process, making clear that everyone's input is important and introducing rules such as one person to speak at one time, and that people should speak what they think not what someone else wants to hear. It is very important to instruct the participants that there are no correct or incorrect responses, but the purpose is mainly to elicit opinions. An opportunity must be given for the participants to briefly introduce themselves. The questions that follow must be open-ended, with an aim to stimulate the discussion and not tallying responses. The protocol must have examples of questions that will avoid a yes/no response.

In conducting the focus group one must choose a convenient location, and try to create as relaxed and familiar an atmosphere as possible for participants. Nametags with first name only (to allow confidentiality) must be provided. Furthermore, for topics related to health education, one must have a content expert available, who can provide correct misinformation at the end of the focus group discussion. While conducting focus groups, it is also advantageous to have an observer who should note interactions, body language, and record content exchanges. In conducting focus group discussions, having an experienced and competent moderator is an important prerequisite.

The focus group discussion must be tape recorded after consent from the participants. It is also helpful, if the moderator can use flip charts to document the data and seek clarity from participants. In analysing the data the analyst must first listen to the whole tape recording and its transcript, to get an overall impression. Then tabulate and organise discussion group findings and pertinent quotations. Emphasis must be made to evaluate differences between the thoughts, beliefs, and emotions of different people. The analyst must pay special attention to participants' hesitations, silences, and emphases, as well as actual words used.

The chief advantage of focus group discussion, is that these are inexpensive and relatively quick means of collecting data. Focus groups are an effective means to reduce distance between the target population and facilitators. In conducting focus groups, probing an issue is possible, which provides richer contextual information. Often, brainstorming and interaction may result in insights. Another advantage of focus groups, is that these allow expression of honest and spontaneous responses, rather than intellectual opinions.

One of the disadvantages of focus groups is that the group members may not be representative of the target audience. Often, when the moderator is not experienced, the moderator and dominant participants influence the responses. On sensitive topics, group members may be inhibited from discussing private topics in public. A major disadvantage, is that the nature of data precludes drawing firm conclusions. Finally, focus group data is easily subject to misuse, through absence of the required moderating skills and through misinterpretation of the data.

METHODOLOGY

A search of the database Medline using the words "focus group", revealed 5,105 articles. Addition of the word "rehabilitation", resulted in 333 articles. The articles were further narrowed down by hand search to select CBR studies that met the following criteria:

- used focus group as a primary or secondary method.
- based in community setting.
- pertained to rehabilitation.
- published between 1994 and July 2004.

Excluded from the analysis were articles that were: (1) review articles; (2) were primarily based in institutional/hospital setting; (3) did not explicitly deal with one or more aspects of rehabilitation; and (4) were older than 1993.

A total of twenty six studies met the criteria that have been summarised in the results section. These studies have been categorised into following categories:

- Focus group used for needs assessment
- Focus group used for evaluation
- Focus group used for instrument development
- Focus group used to develop conceptual framework for research/evaluation
- Focus group used for intervention

RESULTS

Focus group used for needs assessment (n=19)

A Swedish study for needs assessment of women on sickness leave, was conducted to ascertain how they perceived and described the possibilities and barriers for resuming work (6). The method entailed conducting five focus groups with a total of twenty subjects. In data analysis the researchers were able to identify three themes.

Another qualitative needs assessment study was done in Northeastern China, to discern the perception of quality of life in adults with spinal cord injury (7). The method comprised of conducting six focus groups with 40 subjects. In data analysis, the researchers were able to identify 18 components that they could classify into five domains.

Interactions with rehabilitation workers sometimes influence the reasons for resuming work after a prolonged illness. A Swedish study utilised five focus group discussions among persons who had been absent from work with back, neck, or shoulder injuries, to explore the influence of positive experiences from rehabilitation workers (8). In data analysis, the researchers were able to identify two categories of positive experiences.

In another needs assessment study from Taiwan, six focus groups with forty-four elderly men and women were used to discern quality of life issues (9). The data analysis identified six dimensions of quality of life.

Another study done in Northern Ireland to document experiences of caregivers of people with multiple sclerosis, utilised focus group discussion with sixteen subjects (10). The data analysis was able to identify four phases that caregivers experienced.

Another needs assessment study with 14 Australian Vietnam Veterans diagnosed with post traumatic stress disorder utilised three focus groups (11). The purpose of the study was to prospectively gather perceptions, attitudes, and opinions regarding an exercise programme.

The data analysis revealed three main themes.

A British needs assessment study used focus groups to explore the perceptions and potential role of community nurses in rehabilitation work (12). The findings were able to identify the role community nurses could play and various challenges that confronted this performance.

Another Canadian needs assessment study used focus groups to explore the perceptions of injured workers toward return to work programmes (13). The data analysis was able to identify several common themes.

Another needs assessment study done in Hong Kong aimed at identifying the characteristics of quality of life among elderly stroke survivors using focus groups (14). Results were triangulated by review of literature and data gathered from World Health Organisation Quality of Life Scale. A total of 36 components were identified.

In order to identify barriers to wellness activities experienced by Canadian women with physical disabilities, a needs assessment study was done, that utilised focus group discussions (15). The study was able to identify internal and structural barriers.

A needs assessment study done in Uganda, aimed at identifying factors that influence the use of rehabilitation services at an urban hospital (16). Key informant interviews and focus groups were used to obtain data from injured persons based in the community. Several barriers to service utilisation were identified.

Another needs assessment study done in an urban slum in India, was done to collect data about knowledge, skills, and attitudes regarding disability, feeding and nutrition practices among children with disabilities (17). The authors write that, "The focus-group findings enabled a broader understanding of attitudes towards disability within this population, which can have an impact on the care of the child."

A British needs assessment study aimed at identifying the perceptions of primary health care workers, regarding persons with learning disabilities and the extent to which they are meeting their needs (18). Data was obtained through focus group discussions and semi structured interviews. The study identified several barriers and attitudinal deficiencies.

Another needs assessment study aimed at assessing sexual knowledge, attitudes, and practices of persons with spinal cord injury (19). Eight focus groups with twenty eight participants were conducted. Several issues were identified.

Another needs assessment study done in Taiwan used focus group discussion to investigate perceptions of health-promoting self-care in community-based older adults (20). Three focus groups with 21 participants were organised. Five major themes were identified.

Another needs assessment study was done to determine the impact of stroke and to identify the needs of survivors (21). Focus groups were conducted with stroke survivors, care givers, and other key informants. Several themes were identified.

Another needs assessment study was done in Hong Kong to understand the perceptions of quality of life by elderly (22). Focus group discussions with seven elderly and six healthy elderly were conducted. Several components of quality of living were identified.

Another needs assessment study to explore the experiences, perceptions, and needs of youth with physical disabilities, in transition from adolescence to adulthood utilised focus group interviews (23). Themes regarding context, the transition process, needs, and services were identified.

Another Canadian needs assessment study was done to describe feelings of women with spinal cord injury (24). Focus group discussions with ten participants and key informant interviews with 19 participants, were used. Several feelings were identified.

Focus group used for evaluation (n=3)

A videoconference linked intervention for community-based stroke rehabilitation was conducted in Hong Kong (25). In order to evaluate the one of the qualitative tools utilized in conjunction with quantitative methods was a focus group with nineteen subjects.

A participatory evaluation of a CBR programme done in Vietnam, utilised focus groups along with semi-structured interviews to collect data from village, commune, district, provincial, and central levels (26). Data was examined against the five principles of the WHO model, namely, available resource utilisation, knowledge transfer, community participation, referral services strengthening and multisectoral coordination. The strengths, weaknesses, opportunities, and threats across all levels were identified.

A community based rehabilitation programme was evaluated in the Philippines using focus groups, record review, and in-depth personal interviews (27). The evaluation was able to identify strengths and weaknesses of the CBR programme.

Focus group used for instrument development (n=1)

A Canadian study used four focus groups to develop a questionnaire for persons with multiple sclerosis to gauge their needs (28). Ten persons with multiple sclerosis and five significant others participated in the focus group discussion. Seven themes were identified that became categories for instrument development. The phraseology of the participants served in shaping the items.

Focus group used to develop conceptual framework for research/evaluation (n=1)

In order to develop a conceptual framework of salient areas for evaluation of rehabilitation outcomes in older people, focus group discussions with eight experts were used along with

semi structured interviews and literature review (29). The data analysis revealed four domains for conducting evaluations.

Focus group used for intervention (n=2)

A South African participatory study done with spinal cord injury self-help group, aimed at enhancing empowerment (30). Group management and decision making were assumed by the self help group members. The group was able to generate opportunities for empowerment and self reliance among people with disability.

A Chinese study aimed at enhancing agreement between community members and health professionals, on functional needs of patients with different chronic diseases (31). Focus groups and questionnaires were used to collect data and enhance agreement between community members and health professionals.

DISCUSSION

The purpose of this study was to reconsider the method of focus group in community-based rehabilitation. An intensive search of Medline database revealed twenty six published articles in CBR, that used focus groups in the recent ten-year period. The number of published studies in CBR, that have used focus groups is very few, compared to the use of this methodology in the larger field of health science. Within the field of CBR, most of the studies have used focus groups for needs assessment

Very few studies have used focus groups as a tool for making change or as an intervention itself. In participatory paradigm, focus groups offer tremendous scope for enriching the skills of the participants and must be utilised more by researchers. In this approach, the facilitation of the focus group discussion, after due training of the participants, is assumed by the participants themselves. Likewise, use of focus group for instrument development or developing conceptual framework has also been inadequately utilised. Only three published studies have used focus groups in evaluation of CBR. Focus groups are most practical and invaluable tools for rapid data gathering in evaluations, and must be used more often.

There are several limitations of the present analyses. Only one database namely Medline was chosen for retrieving the articles. As a consequence, several studies published in journals that are not indexed in Medline, were omitted. The search period included a time frame of ten years starting from 1994. Community based rehabilitation as a strategy, is more than two decades old and as a result, once again, several articles from the previous decade have been lost in this analysis. Classically, community-based rehabilitation refers to projects and programmes in developing countries. However, in the present, analysis studies from developed countries have also been included, provided these studies were

related to community settings. This has increased the number of studies and may have inflated the actual number of true CBR studies.

On the whole, it is important to note that focus groups are an invaluable method that has been underutilised in CBR. More use of focus groups either by researchers to aid in research enquiry, or in participatory paradigm, as a means of community empowerment must be done.

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ORIGINAL ARTICLES

**COMMUNITY BASED REHABILITATION IN THAILAND:
CURRENT SITUATION AND DEVELOPMENT**

Tavee Cheausuwantavee*

ABSTRACT

This article is based on an evaluation research to explore available documents and CBR projects in Thailand and determine the current situation regarding CBR, particularly in terms of the WHO concept. Six methods and units of analysis were completed, including questionnaires for 36 CBR workers via mail, 3 available reports of the CBR seminars and workshops, a focus group discussion with CBR workers, interviews of 2 key informants, visit to 2 community projects and the report of a CBR research project conducted and facilitated by the researcher. The research revealed that most of the rehabilitation projects in the Thai community were outreach services. The evolution of concepts of CBR in Thailand is an ongoing process. Most persons with disabilities participated as members and consumers rather than planners and managers of projects. Lack of budgets and external sources of donors were still critical issues for CBR continuation. There was a diversity of rehabilitation services particularly medical, educational, vocational and social rehabilitation. The positive aspects of CBR, included promoting positive attitude of society and community towards people with disabilities, while the problems of CBR were lack of community concern and lack of financial support or donors.

INTRODUCTION

Research projects on community based rehabilitation in Thailand have been rare. Most CBR projects were not only service projects, but were also supported by external donors i.e. international organisations that provided for a specific disability such as children with disabilities or visually impaired persons (1,2,3).

However, there have been some research projects emphasising specific aspects of CBR. Knowledge and understanding among their parents, medical professionals and teachers of children in rehabilitation in some districts of Nakornrachasrma Province were explored (4). Most samples agreed that children with disabilities should study in regular schools and assistive

technologies must be employed. Kanitta (5) indicated that attitudes toward persons with disability and rehabilitation skills of social workers who work with them in the community social welfare office in Thailand, were appropriate and positive. Lack of budgets, personnel, knowledge and information were identified as the main problems of CBR. Aungkana (6), reported that rehabilitation needs of persons with physical disabilities in the community were medical and social rehabilitation, rather than educational and vocational rehabilitation. A qualitative research was also undertaken to determine how persons with disability in the community used their study styles and how the community participated (7). Participation with and attitudes toward persons with disability in the community tended to be good.

Based on the review of existing research, CBR in Thailand has been only segmental and superficially studied. Surveys with questionnaires were a main strategy for identifying some aspects of CBR in a particular sample, with segmental views (4,5,6,7), whereas, the nature of CBR is multidisciplinary. It should be simultaneously evaluated from both qualitative and quantitative aspects for a holistic view.

There are many laws and policies providing for decentralisation and promotion of human rights and community participation for enhancing the quality of life of persons with disabilities, in Thailand. These include the Rehabilitation Act for disabled persons 1991 (8), the 9th National Social and Economic Developmental Plan (9), the Plan for Enhancing Quality of Life for Disabled Persons 2002-2006 (10). Eventually however, they could not be implemented in a practical manner. This limitation may have resulted from lack of representative and empirical data for formulation of comprehensive plans and rehabilitation services including CBR.

AIM OF THE STUDY

This study aimed to explore available documents and CBR projects in Thailand and determine the actual current situation regarding CBR, covering six issues. These issues are: 1) definition and classification of rehabilitation services in community 2) sectors of participation 3) budgets and sources of donors 4) kinds of rehabilitation services and activities 5) positive and negative aspects of CBR 6) sustainability of projects.

METHODS

Participants and units of analysis

This is a descriptive study comparing the CBR situation of Thailand with the CBR concepts of international agencies i.e. UNESCAP (11) and ILO, UNESCO, UNICEF and WHO (12), in terms of the six issues described earlier.

To meet research objectives and for a better understanding of CBR in a holistic manner, analysis of six units were undertaken. First, there were 36 participants selected with snowball sampling from CBR projects or rehabilitation projects who responded to the questionnaires.

Second, 3 available reports of the CBR seminars and workshops in Thailand during 2000-2003, selected with purposive sampling, were analysed. Third, 4 CBR workers were invited to a focus group discussion. Fourth, 2 key informants were interviewed. Fifth, visits were made to 2 community projects related to rehabilitation. Finally, the evaluation report of a CBR project conducted and facilitated by the researcher was reviewed.

Instruments

The instrument used was a questionnaire and an evaluation guideline which emphasised the CBR concept of UNESCAP (11), along with conceptual issues summarised from other literature from International Labour Organization (ILO), United Nations Scientific and Cultural Organisation (UNESCO), United Nations Children's Fund (UNICEF) and World Health Organisation (WHO) (12), apart from using the direct experience of the researcher (13).

The questionnaire consisted of 22 items with close and open-ended questions, such as: general information such as sex, age, education, and name of workplace (item number 1-4); Disability of participants and their relatives (item number 5-6); Time of experience in community project (item number 7); Sources and amount of budgets (item number 8-9); Roles of participation (item number 10); Numbers and sectors of project participation (item number 11); Kinds of services and target groups (item number 12-13); Motivation for participation in the project (item number 14); Salary and other incentives (item number 15-16); Positive aspects of project (item number 17); Negative aspects of projects (item number 18); Opportunity of project sustainability (item number 19); Other comments and suggestions regarding CBR (item number 20); Recommended personnel for further CBR informants (item number 21); and need to know the research result (item number 22).

An evaluation guideline which was a brief version of the questionnaire, was used with participants in focus groups to assess rehabilitation services of community projects from available documents. This consisted of the important CBR concepts from item number 5-18. In addition, tape recorders, cassette tapes and field notebooks were used for interviews, focus groups and field visits.

Procedures

Due to a lack of a systematic database of CBR projects and field workers in Thailand, the following procedure was used. A total of 118 CBR and related workers were screened and listed from available documents (i.e. reports of CBR workshops and seminars, brochure, etc.) and information disseminated by the researcher's friends who were CBR workers, managers and coordinators of governmental organisations (GOs) and non-governmental organisations (NGOs). This sample was located in 27 provinces in Thailand and involved approximately 50 rehabilitation projects in the community. The questionnaires and descriptions

of research purpose as well as needs of correspondence, were distributed to the sample by mail. Forty five questionnaires (response rate 38.1%), were returned a month later. There were 7 incomplete questionnaires and 2 invalid responses. Thirty six valid questionnaires were analysed.

A 2 hour focus group discussion was held with 4 CBR field workers for exploration and sharing of experience, feelings, perception of their work particularly motivation, incentive, positive as well as negative aspects, and sustainability of their current programme.

The 2 key informants were informally contacted by telephone to convey the objectives of research and interview. After 2 weeks, one man and one woman were formally interviewed personally and by telephone respectively.

Available reports of 3 seminars or workshops regarding CBR projects held in 2000-2003 (3,14,15), were evaluated in terms of rehabilitation services in the community, then classified into institutional based rehabilitation (IBR), outreach rehabilitation, community based rehabilitation (CBR) and self-help based rehabilitation.

A visit to 2 community projects, described as CBR projects, was undertaken during the last period of research. The criteria of CBR projects in terms of time period of projects, types of agencies and contextual difference was considered for data comparison and led to purposively selecting those 2 particular projects. Projects of participants who returned their questionnaires, were screened and considered. The projects, that met the research objectives, were approached and eventually visited.

The report of participatory action research (PAR) (13) named “Community based rehabilitation in Phuttamonton District: strength and weakness” carried out by this researcher was shared and discussed; particularly the positive and negative aspects of CBR projects.

Data analysis

The data from questionnaires were verified and analysed using the SPSS PC for Windows programme as frequency, percentages, and χ^2 test (Chi-square test). The qualitative data from the focus group discussion, interviews, available documents, field visits and direct experience of this researcher were analysed as typology, comparison and analytic induction.

RESULTS

A. Data from questionnaires

Characteristics of participants

Of the 36 participants who responded completely to the questionnaire and involved 33 CBR projects or related projects in 17 provinces of Thailand, 18 were men and 18 were women with a mean age of 37.8 years. 23 graduated with a Bachelor's degree (63.9%), 17 worked

at governmental organisations (GO) (47.2%). 24 were persons without disabilities, including family members (66.7%) (Table 1).

Table 1. General characteristics of participants (n=36).

Characteristics		N	%
Sex :	Male	18	50.0
	Female	18	50.0
Education:	Primary school	4	11.1
	Secondary School	6	16.7
	Bachelor degree	23	63.9
	Master degree	3	8.3
Agency:	GO	17	47.2
	NGO	8	22.2
	DPO or Community	8	22.2
Disability in self or family members:	Yes	12	33.3
	No	24	66.7

Profile of field workers known as CBR workers

Of the 36 participants, 22 currently conducted rehabilitation projects in the community (61.1%), 24 had 1-3 year experiences in CBR or related projects (66.7%), 16 were project managers (44.4%) and 20 had routine salaries or other incentives (55.6%). 20 reported that concern to help persons with disabilities (55.6%) was the main reason and motivation for their project participation (Table 2). They also reported that positive aspects of CBR or related projects were promotion of positive attitudes of society towards disabled persons (50%), enhancing quality of life of disabled persons (30.6%), understanding and providing effective services for disabled persons (22.2%), establishing a rehabilitation network in the community (19.4%), accessibility of information particularly human rights, laws and policies regarding disabled persons (19.4%), emotional support for disabled persons and their families (11.1%) (Table 3). They also reported the negative aspects of CBR or related projects as lack of community concern on disability (61.1%), lack of budgets (41.7%), limitation of transportation and service deliveries (25.0%), discontinuity of services and lack of project evaluation systems (16.7%), lack of knowledge and skills for rehabilitation (16.7%), other problems (i.e. no empowerment or psychosocial weakness of disabled

persons, negative attitudes towards disabled persons in families) (22.2%) (Table 4). Promoting and enhancing participation among governmental organizations, particularly sub-district administrative organisations (SAO) and members of the community, for pooling and mobilising resources, establishment of a network of local working groups, and enhancing positive attitudes of their family and community members towards disabled persons, were the important suggestions of this sample. Although the 36 participants reported many negative aspects of their current CBR or related projects, the majority indicated that their current projects would be sustained (60.6%), while the minority indicated no assurance (41.6%) due to lack of participation among governmental organisations particularly sub-district administrative organisations (SAO) and members of the community for pooling and mobilising resources. However, perception of project sustainability (yes and no) compared with other variables such as category of participants (GO and NGO), salary and incentive (yes and no), roles of project participation (manager and member), were not significantly different at .05 level.

Table 2. CBR characteristics of participants (n=36)

		N	%
Experience:	1 year or less	24	66.7
	2-3 years	9	25.0
	4 years or more	3	8.3
Current participation:	Yes	22	61.1
	No	12	33.3
Role of participants:	Manager	16	44.4
	Member	15	41.7
Salary or other benefits:	Yes	20	55.6
	No	16	44.4
Motivation for participation:	Concern for PWD	20	55.6
	Routine job mission	8	22.2
	Other benefits	5	13.9

Table 3. Positive perception of participants about CBR (n=36)

Issues	N	%
Promoting positive attitudes toward PWDs	18	50.0
Enhancing quality of life of PWDs	11	30.6
Understanding problems of PWDs and providing services	8	22.2
Establishing rehabilitation network in community	7	19.4
Access to information regarding disability	7	19.4
Others (i.e. basic health care, emotional support for PWDs,etc.)	5	13.9

Table 4. Negative perception of participants about CBR (n=36)

Issues	N	%
Lack of community concern on disabilities	22	61.1
Lack of financial support or donor organisations	15	41.7
Limitation of transportation and service delivery	9	25.0
Lack of continuity and evaluation system	6	16.7
Lack of skills and knowledge on rehabilitation	6	16.7
Others (i.e. low self empowerment and psychological weakness of PWDs, poverty)	8	22.2

Profile of projects called CBR

The 33 projects belonging to the 36 participants, covered both CBR and other rehabilitation services. 16 were supported by GOs (48.5%), 15 were supported with 500 US dollars or less, 6 were supported with 500-1,000 US dollars, 5 were supported with 2,500-4,900 US dollars and 4 were supported with 5,000 US dollars or more. Focusing on sectors of project participation, the majority of projects were run by persons with disabilities (69.7%), governmental officials (60.6%), and family members of persons with disabilities (57.6%). Additionally, projects also were run by governmental officials of sub-district administrative organizations (SAO) (45.5%), members of community (33.3%), non-governmental officials (30.3%), and others (27.3%) i.e. monks, volunteers etc. (Table 5). Most projects provided

all disabled persons in the community with diverse rehabilitation services including basic health care or medical rehabilitation (78.8%), survey and disability registration (72.7), educational rehabilitation (72.7), social and vocational rehabilitation (66.7%) and psychological support for disabled persons and their families (54.5%). Furthermore, training was conducted for CBR workers, in terms of their knowledge and skills relating to rehabilitation and disabilities before services, were implemented (69.7%) (Table 6).

Table 5: Sectors of project participation (n=33 projects)

Groups of sectors	N	%	Mean (persons/ project)
PWD	23	69.7	20.1
GO	20	60.6	6.7
Family member of PWD	18	54.5	8.9
Sub-district administrative organization (SAO)	15	45.5	6.0
Community member	11	33.3	2.6
NGO	10	30.3	3.2
Others (i.e. monks, volunteers)	9	27.3	0.9

Table 6. Kinds of services and activities (n =33 projects)

Activities and services	N	%
Training before services	23	69.7
Health rehabilitation	26	78.8
Survey and register	24	72.7
Social rehabilitation	22	66.7
Vocational rehabilitation	22	66.7
Psychological support	18	54.5

B. Data from focus group

A 2-hour focus group discussion was held with 4 workers from one of the community rehabilitation projects. They were men without disabilities with a mean age of 35.8 and varied community work experiences ranging from 3-12 years. They called themselves CBR workers. They visited, trained in orientation and mobility, encouraged private occupation, coordinated systems for medical, occupational, educational and social rehabilitation for persons with disabilities, particularly persons with visual impairment and their families in the community including promotion of attitudes towards disabled persons of the community. Matching needs to job placement and income, were important for their motivation and project participation. However, they accepted that positive feedback from disabled persons and their families was the second factor supporting their current participation and work. All of them opined the current CBR projects could not be sustained whenever they and their NGOs withdrew from such community projects, due to lack of community networks particularly SAO participation.

C. Data from key informant interviews

2 key informants were interviewed, of whom one man was interviewed personally. He was the pioneer manager of the CBR or community projects in Northeast Thailand. He explained 2 main points of CBR in Thailand. First, the financial supports for the rehabilitation and disability movement including CBR, has shifted from external donors to more internal donors. In the last half decade, of the total budgets, only 20% has been donated by external donors or international NGOs, while 80% has been donated by internal donors or from the country. Unfortunately, societal attitudes that were capitalised for raising funds for persons with disabilities was compassion rather than concern for empowerment of these persons. Second, the empowerment of persons with disabilities and self-help groups has to be promoted carefully so as not to lead to damage their culture, contextual systems and the actual purposes and philosophy of CBR. Workshops and seminars provided in an urban setting probably leads them to distance themselves from their communities and from the CBR concept.

Another interviewee who was a woman and a current CBR manager was interviewed telephonically. Based on her 10-year experience as a manager and coordinator of CBR projects which were supported by NGOs, she stated that promotion of concern for CBR through policy administrators, at a provincial and district level, was an essential strategy for the success of CBR. She has currently changed her approach strategy from individual or disabled person based approach to systemic approach through social networking, particularly stressing on strengths of self-help groups of disabled persons, or their families and policy administrators.

D. Data from available documents

The 3 documents, “Report of seminar on CBR: Dream to Reality.” (14), “The seminar of national CBR: collaborative learning and development between community and government.” (3), and “Report on workshop for strengthening community based rehabilitation (CBR) movement.” (15), were analysed.

All seminars and workshops were held with the collaboration of governmental and non-governmental organisations. Participants were CBR workers/managers, educators, social workers, physicians, nurses and so on. Panel discussion and small group discussions were traditionally held. Most participants usually reported 5 problems in CBR as follows: 1) lack of knowledge and skills regarding CBR and project administration, 2) negative attitudes toward disabled persons in families and the community, 3) lack of collaborative work among agencies and personnel involving rehabilitation services, 4) lack of budget and 5) limitation of transportation and service deliveries. Based on existing documents, of the 15 CBR or related rehabilitation projects reported in those documents, 9, (60%), 3(20%) and 3 (20%) are run by NGOs, GOs, and both respectively. Even though all these projects called themselves CBR, only 5 projects (33.3%) were classified into CBR according to the WHO definition (11,12). Meanwhile, other projects were outreach services (13.3%), co-ordination of institutional based rehabilitation (IBR) (13.3%), IBR and outreach (13.3%), CBR and outreach (6.7%) and self help based rehabilitation or disabled persons organisations (DPOs) (13.3%). (Table 7). Essentially, all projects were supported by resources from outside the community, particularly budgets and project managers. Even though the SAO was emphasised as the main participant or stakeholder of CBR, this was not actually the case on the ground.

Table 7. Classification of projects called CBR (n=15 projects)

Projects	N	%
Donor organisation		
NGO	9	60.0
GO	3	20.0
NGO+GO	3	20.0
Classification		
CBR	5	33.3
Non CBR	10	66.7
Outreach	3	20.0
Co-ordination of IBR	2	13.3
IBR + outreach	2	13.3
Encouragement of DPO	2	13.3
Outreach + CBR	1	6.7

E. Data from visit to 2 community projects related to rehabilitation

A visit and non-participatory observation of 2 community projects that call themselves CBR projects was undertaken. A GO and an NGO in the northeast of Thailand have run one project since 1992. Rehabilitation services of this project included educational, occupational training and medical aspects. Field workers or CBR workers who were trained in terms of rehabilitation knowledge, skills and community approach, were available in particular communities and urban centres. However, this project provided IBR and outreach services rather than CBR as defined by WHO. (11,12). Furthermore, the emphasis was on rehabilitation services for the visually impaired due to the mission statement of the GO and NGO which supported the budget. Contributions and participation of the community were low. However, the principal leader of this project has currently refocused on strength and participation of the SAO through mobilisation of resources in the community. This approach may help to shift from IBR and outreach, to the CBR paradigm eventually.

Another project was run by educators of the Regional Education Centre of Ministry of Education (GO) in the North of Thailand. This project has outreach services and the main activities were home visits, training parents and families of disabled children in the community about early intervention, daily living skills and self help groups basic physical therapy for their children. Even the director of this education centre understood the concept of CBR according to the WHO's definition. He explained that such a concept had more complexity and was difficult to implement as a holistic approach, particularly in mobilising resources in the community. Thus he has started CBR at some grass root level, i.e. disabled children's parents and families. He believed that this approach would be effective for initiating CBR and promotion of community participation as well. Nevertheless, participation of other community members and SAO was still low and family concerns about their disabled children needed to be monitored.

F. Data from direct experiences of researcher as facilitator of a CBR project

In 2002 the author, conducted participatory action research in CBR projects in Phuttamonton District, Nakornpatom Province, Thailand (13). The CBR concept according to UNESCAP or WHO definition (11,12) was tested for actual implementation through 7 voluntary CBR workers, consisting of one nurse, two women officials of SAO, one man with physical disability, two women with physical disabilities and the researcher as facilitator. Financial support came from an agency sponsoring the researcher. After 6 months of research the result showed that this CBR working group could provide home visits to 108 persons with disabilities. They could also provide basic rehabilitation services in the form of psychological support, coordination of vocational rehabilitation and support of a referral system for medical rehabilitation. They had positive attitudes towards CBR which is a valuable ingredient to

enhance the quality of life for all disabled persons in the community. In particular, participants who were disabled, felt more empowered. CBR workers learned more interpersonal skills such as empathic mutual work and partnership among professional groups (a nurse, SAO officials, and researcher) and the disabled group.

Nevertheless, there were also some negative aspects. The leader of these CBR workers, a nurse, wanted to resign as leader and be only a member of the CBR project. She said that she would contribute to other works, which corresponded to the current policies of her agency, as it was difficult to run the CBR project alone. Additionally, CBR workers reported the following as limitations to the sustainability of this CBR project; inadequate service quality and delivery, lack of knowledge and rehabilitation skills of CBR workers, lack of concern and negative attitudes toward disabled persons in their families and community members, no intentional participation of the directors of SAO and lack of financial support. Although, it is currently supported by Thai Research Funds (TRF), this financial support has still been external rather than internal or from within community. Thus, the steps to develop basic participation among all stakeholders have to be repeatedly emphasised.

DISCUSSION

Based on the research results, a conclusion can be drawn covering 6 issues; 1) definition and classification of rehabilitation services in the community 2) sectors of participation 3) budgets and sources of donors 4) kinds of rehabilitation services and activities 5) positive and negative aspects of CBR 6) sustainability of projects.

First, most rehabilitation projects in the community in Thailand were outreach rather than CBR. There were 33% of rehabilitation projects in the community qualifying as CBR according to the WHO definition. Participants had no greater knowledge or skills related to CBR as compared to those in other countries such as India (16). This shows that the evolution of concepts of CBR in Thailand, is an ongoing process that needs to be shaped and mutually emphasised among the personnel involved in CBR and rehabilitation services, in terms of definition, mission and objectives of CBR. The starting point and strategy for progress in CBR, may vary according to diversity of community contexts and resources, but the aims of CBR should be the same. The personnel who are involved in CBR should understand their role and the tenets of CBR.

Second, sectors of participation corresponded to the recommendation of international agencies in their proportion, but lacked participation quality. Participation of people with disabilities in CBR, or strengthening of disabled people's organisations (DPOs), has been emphasised as the vital part of sustainable CBR (12). Of 33 projects, 23 (69.7%) had people with disabilities participating with the mean of 20.1 persons, but according to field visits and existing data, most persons with disabilities participated as members and consumers, rather than planners

and managers. For instance, of 36 participants who responded to questionnaires, 6 (16.7%) were people with disabilities and only 2 (5.6%) were managers of CBR. Difficulty in operationalising decentralisation and bottom up practices, including interpersonal/social skills of persons with disabilities, may be the barriers to participation in CBR (18).

Third, lack of budgets and external sources of donors were still critical issues for CBR continuity. Poverty at grass root level and the need for incentives such as money and salaries for field workers should be met, before they become providers. Of the 36 participants, 55.6% had routine salaries or other incentives, 77.8% participated in CBR projects due to concern for helping persons with disabilities and routine job mission. In addition, most personnel involved in CBR or rehabilitation projects in the community, indicated that budgets or financial supports were the most common issues threatening continuity and sustainability of CBR. This fact probably illustrates that all participants in CBR were not real volunteers (17,18,19,20), but were “stakeholders”. In short, everyone gained some benefits from CBR work. Those benefits might be money, salary, further study, career path development, political position, social image and so on. Thus, the basic assumption that “all are stakeholders”, needs to be accepted among CBR workers and participants. Then, they may learn to communicate what benefits they need and how to openly share such benefit. However, this assumption is in contrast to Thai culture. It is difficult for a person to tell others his/her needs, particularly regarding disabled persons.

Fourth, the diversity of rehabilitation services, particularly medical, educational, vocational and social by CBR workers for disabled persons in the community were an outstanding feature of CBR in Thailand. These services were holistic, with a comprehensive approach for all disabled persons as indicated in the CBR definition. CBR approach is still a strategy which, on the one hand, aims to improve coverage rates for those persons with disability who cannot access institutional based services because of cost constraints, or distance, and on the other hand, aims to extend services from a medical rehabilitation focus, to address all social and employment needs of persons with disability (21,22). However, skills and knowledge of field workers should be matched with their services and needs identified in the project. Inappropriate skills and knowledge may lead to malpractice and ineffective services.

Fifth, positive and negative aspects of CBR are issues for debate in Thailand. Fortunately, at least 6 positive aspects of CBR or rehabilitation service in the community, were determined. Essentially, CBR could create and promote a positive attitude of society and community towards people with disabilities. This component of CBR projects is essential to ensure equalisation of opportunities for people with disabilities, within their own community. (11). CBR is a set of efforts to change community behaviours to enable community members to improve their understanding about disability issues. As a result, the community provides a positive environment and improves the quality of life of disabled persons over a period of

time (23). However, the negative aspects or problems of CBR were lack of community concern about disabilities and lack of financial support or donor organisations, as in other countries in Asia and Pacific regions. (21,23,24,25). These problems may be resolved by promoting positive societal attitudes and community participation, including human and financial resources in CBR projects.

Finally, sustainability of CBR projects in Thailand can be related to the data discussed previously. There were many negative aspects of CBR in Thailand, including lack of budgets, limitation in service deliveries, lack of knowledge and skills of CBR workers regarding disabilities and rehabilitation, negative attitudes toward disabled persons of society, lack of participation and collaboration of local agencies particularly SAO, being initiated and supported by external resources and difference of CBR concept and definition. Fortunately, there were also two main positive issues of CBR in Thailand. First, there have been more than 50 CBR projects or related projects available for persons with disability and their families. This probably implies that the CBR approach is still an effective strategy for increasing community level activity, equalisation of opportunities, promotion of positive attitudes and improving coverage rates for people with disabilities (12,13,22). Second, there has been international, national and local movement regarding human rights, opportunity of equalisation and participation. As a result, CBR in Thailand can become on-going and sustainable.

In addition, CBR in Thailand may be sustainable and have a more effective approach within a short time, if the negative aspects or problems of CBR are also simultaneously solved. National policies have supported CBR projects through The Constitution of the Kingdom of Thailand 1997 (26), The Rehabilitation Act 1991 (8), The 9th Socio-economic National Plan (9) and The Plan of Development Quality of Life of Persons with Disabilities 2002-2006 (10). These policies focused on decentralisation and participation at grass root level in CBR and other rehabilitation projects, but local administrative structures-the Sub-district Administrative Organisations (SAOs) could not practically correspond to the national level. The SAO Act relating to disabilities, particularly Articles 10 and 67, indicated that SAO has to support and develop the quality of life of children, women, elderly and disabled persons. This study also determined that SAOs are the primary local government organisations to implement CBR and become a key point for co-ordination and support of CBR. This recommendation should be communicated and shared between community members and the SAO, in order to further develop the comprehensive work. However, due to decentralisation of administration in Thailand, many missions and activities in the community have to be run by the SAO with limited personnel. Thus collaborative and empathic work as in mutual partnerships, rather than passive and demanding consumers, should be emphasised among stakeholders. Meanwhile at the "micro level", human resources, particularly field workers, should balanced concern about their benefits with acquisition of new skills and knowledge about basic rehabilitation services, and project administration. In short, communication among

partnerships and stakeholders including policy makers, policy administrators or CBR managers and community members should be facilitated. As Turmusani has pointed out (27), participatory action research rather than emancipatory approach among the stakeholders may be the best solution, right now, for CBR in Thailand.

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ACTIVITY LOG OF PRESCHOOL CHILDREN WITH DEVELOPMENTAL DISABILITIES AND AUTISM SPECTRUM DISORDERS

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ABSTRACT

The present study was undertaken on a sample of 140 preschool children diagnosed as cases with one of the "developmental disabilities", including "autism spectrum disorders". A semi structured "Interview Schedule" and another "Daily Activity Log Schedule", specially designed for the purpose of this study, was used to elicit information on hour-wise engagements of each child from the caregivers/parents of these children. The reported engagements of each child was classified in terms of their time spent on "sleeping", "ablution", "watching television", "playing alone", "playing with peers", "feeding", "attending school" (if any), "home teaching" and "others". The results show, that the greatest part of a day's schedule is spent by this sample of children on "sleeping" (43.24 %), followed by time spent at "school" (for school going kids only) (14.41 %), on "feeding" activities (10.34 %) and "watching television" (9.61 %) respectively. The amount of time per day spent on needed-constructive activities like "home teaching" (4.32 %) or "playing with peers" (4.12 %) are meagre.

A sub-sample analysis of children with autism spectrum disorders alone, reveals that, those who are not exposed to any school experience a double disadvantage. They spend thrice the time on sedentary or exclusion activities like "watching television" (21.23 %), or "playing alone" (14.62 %) than they would have done, if they had been at school. Additionally, they also lose out time in their typical day's schedule for "playing with peers" (1.74 %) and "home teaching" (0.32 %). These differences invite attention to the need for revamping the daily activities of children with developmental disabilities, especially autism spectrum disorders, in favor of group-oriented or inclusive-play activities with same aged peers in preschools, kindergartens, crèche, playpens, Montessori schools, and so on.

INTRODUCTION

Developmental disabilities refer to a mixed group of children designated as, "at risk" and/or those with permanently handicapping conditions especially during their preschool years of life. The "at risk" child may have no existing/current handicaps, but, only a strong disposition for developing one or the other disability in due course of time. Among the common

developmental disabilities reported during preschool years are sensory, locomotor, mental and learning handicaps, specific speech delays, multiple handicaps, autistic disorders, attention deficit and over activity disorders, etc.

Autism Spectrum Disorders (ASDs) is an umbrella-term to refer any or all the Pervasive Developmental Disorders (PDDs) (1,2). Although clinical patterns in individual cases vary according to their severity, all children with ASDs demonstrate some degree of qualitative impairment in reciprocal social interaction and communication. They also show restricted, repetitive and stereotypic patterns of behaviours, interests and activities (3,4). The onset of these symptoms for most children with autism, occurs during late infancy. It is well recognised that some children demonstrate regression in speech and social skills, withdraw and become indifferent to their surroundings during the second year of life, after a period of relatively typical development (5,6).

There is no single pathognomonic developmental characteristic or behaviour that has been featured in all children with ASDs. For example, most of these children have been reported to have early deficits in “joint attention” and “pretend play” (7) with demonstrated difficulties in “proto-imperative pointing” and “proto-declarative pointing” skills even before two years of age. Children with ASD have been known to make poor or no eye contact, seeming totally aloof, imitative of songs, rhymes, television advertisements and jingles without any communicative intent, stereotyped behaviors like hand flapping, finger flicking or compulsive sniffing, etc. They are declared to be deficient in ordinary preschool social skills, such as, group participation in play, waiting/turn-taking during games, comprehension of rules in kindergarten play, empathy-sympathy, imitation, sharing, recognition of body language, expression, etc. (8,9,10).

Even though ASD is generally believed to be a biologically based neuro-developmental disability with a strong genetic basis, the exact cause is still unknown. Before the 1970's, it was incorrectly believed that ASD resulted from a cold, unloving parenting style (the “refrigerator mother theory”)(11,12). While autism seems to be mainly genetic in origin, a number of environmental effects also appear to play a role in modulating the autism phenotype, indicating a multi-factorial mode of inheritance in some cases.

Among the environmental circumstances, early mothering patterns, parent-child interactions, family environment, available levels of infant/child stimulation, daily activity levels, sharing of activities, etc., appear to be contributory, if not, causative variables for the onset of ASD in young children. Under these circumstances, it was considered appropriate to outline a log of daily activities in children with developmental disabilities and ASD, in order to determine whether any anomalies existed in the patterns of their early childhood experiences of rearing or sharing. Such information could be even made part of preventive environmental engineering

programmes for preschool aged children in general and/or children “at risk”, those with DDs, ASDs, etc.

AIMS OF THE STUDY

The aims of this study were:

- (i) to prepare an activity log of daily behaviours as reported by parents/caregivers in a group children with developmental disabilities and autism spectrum disorders.
- (ii) to explore any trends in the profile of daily activity log of children with developmental disabilities and autism spectrum disorders, in relation to associated variables like type of disability, age, sex, type of family, family size, school exposure, etc.

METHOD

The study was conducted by drawing information from a sample of 140 preschool aged children diagnosed as one of the “developmental disabilities” (N: 89) or any of the “autism spectrum disorders” (N: 51). All cases were drawn from the “Psycho-diagnostic and Therapeutic Services”, at All India Institute of Speech & Hearing, Mysore. The chronological age range of the sample is between 18 to 126 months (Mean Age: 65.20 months; SD: 43.13), including males (Mean Age: 68.97 months; SD: 33.39) and females (Mean Age: 63.79 months; SD: 46.46).

The procedure of data collection involved a semi-structured “Interview Schedule” on demographic details followed by a simple “Daily Activity Log Schedule” (DALs) for each index case. The DALs was designed to elicit information about each child and his/her nearest caregivers/family members, on their hourly engagement during a typical day. For every hour in the 24-hour log schedule, data were elicited on the child’s and/or others’ activities in terms of time spent on sleeping, ablution, watching television (or playing computer and video games), playing alone, playing with peers, feeding, attending school (if any), home teaching and others. The total time spent by a given child and/or the significant family members under these activity headings were totalled and rounded off, to the nearest hour. Wherever, informants reported the child’s simultaneous involvement in two or more of the above mentioned categories of activities (such as, feeding while watching television or playing alone while the television is on) within the same hour, they were recorded as such. Thus, there could be more than the 24-hour schedule for some children, when totaling the reported activities for a given day. Data were collected, compiled and computed for descriptive and interpretative statistical inferences by using SPSS/PC version 3.0 (13,14).

RESULTS AND DISCUSSION

The results of this study show that the greatest part of a typical day's schedule of a child with one of the developmental disabilities, is spent on "sleeping" (Mean: 9.74 hours; SD: 1.25; 43.24 %). This is followed by time spent at "school" (for school going children only) (Mean: 4.68 hours; SD: 1.60; 14.41 %), on "feeding" activities (Mean: 3.04 hours; SD: 0.29; 10.34 %) and "watching television" (Mean: 2.16 hours; SD: 2.48; 9.61 %) respectively. The amount of time per day, spent on needed and constructive activities like "home teaching" (Mean: 0.94 hours; SD: 1.09; 4.32 %) or "playing with peers" (Mean: 0.93 hours; SD: 1.01; 4.12 %) is meagre in this sample of children with DDs and ASDs (Table One).

Table 1. Mean and total time reported on various activities for overall sample (N:140)

Activity	TT	M	SD	%
Sleep	1363	9.74	1.25	43.24
School	454	4.68	1.60	14.41
Feeding	326	3.04	0.29	10.34
TV Time	303	2.16	2.48	9.61
Play Alone	249	1.78	1.66	7.90
Ablution	142	1.08	0.19	4.50
Home Teaching	136	0.94	1.09	4.32
Play Peers	130	0.93	1.01	4.12
Others	49	0.33	1.59	1.56
Total Hours	3152			

In terms of school variable, the trend and preference of involvement time in daily activities are different for children going to school and those staying back at home (Table 2). The children, who are not attending school in this sample, are on an average spending more time "sleeping" (Mean: 10.27 hours; SD: 1.12; 43.84 %), "watching television" (Mean: 4.28 hours; SD: 2.76; 18.29 %) and "playing alone" (Mean: 2.77 hours; SD: 2.22; 11.83%) than their peers going to school ($p < 0.001$). Further, these children are also reported to be spending less time on "playing with peers" (Mean: 0.63 hours; SD: 1.07; 2.68%) and on "home teaching" (Mean: 0.35 hours; SD: 1.13; 1.49 %) as compared to their matched companions attending school. These differences suggest that attendance at a school is a critical and statistically significant variable in influencing the daily schedule of activities in children with DDs ($p < 0.05$).

Table 2. Mean and total time reported on various activities in terms of school variable

Activity	School (N:97)				No School (N:43)				T Values
	TT	M	SD	%	TT	M	SD	%	
Sleep*	922	9.50	1.23	42.96	441	10.27	1.12	43.84	3.64
TV Time*	119	1.22	1.62	5.55	184	4.28	2.76	18.29	6.77
Feeding	196	3.05	0.27	9.13	130	3.03	0.35	12.92	0.33
Play Alone*	130	1.34	1.09	6.06	119	2.77	2.22	11.83	4.02
School	454	4.68	1.60	21.16	-	-	-	-	-
Ablution*	99	1.11	0.22	4.61	43	1.00	0.00	4.27	4.92
Play Peers*	103	1.06	0.96	4.80	27	0.63	1.07	2.68	2.26
Home Teaching*	121	1.20	1.21	5.64	15	0.35	1.13	1.49	4.02
Others*	2	0.02	0.21	0.09	47	1.06	2.72	4.68	2.50
Total Hours	2146				1006				

(*) Indicates variables that are statistically significant @ $p < 0.05$ level

The data analysed in terms of the two major diagnostic conditions, show statistically significant differences in the patterns of their daily engagements for children with DDs (N: 89) and those with ASDs (N: 51) ($p < 0.05$). The children with ASDs appear to spend almost double the average time "watching television" (Mean: 3.51 hours; SD: 2.90; 14.47 %) or "playing alone" (Mean: 2.47 hours; SD: 2.08; 10.43 %) compared to children with DDs. They also seem to spend only half the time on "home teaching" (Mean: 0.63 hours; SD: 0.98; 2.59 %) as measured against children with DDs (Table 3).

A similar analysis of data in terms of allied variables like sex (Males: 102 cases; Females: 51 cases), single (N: 85)/multiple (N: 55) diagnostic conditions of children or whether they were receiving (N: 88)/not receiving (N: 52) home training programmes did not reveal any statistically significant differences in the patterns/preoccupations with the daily log of activities. In view of the initial finding that the diagnostic condition of the child is a critical variable, an intense analysis on the routine of activities of children with ASDs was carried out exclusively, in order to explore any particular trends in the daily routines of this sub-sample of children (N: 51).

Table 3. Mean and total time reported on various activities in terms of diagnostic variable

Activity	DD Cases (No: 89)				ASD Cases (N:51)				T Values
	TT	M	SD	%	TT	M	SD	%	
Sleep*	856	9.62	1.18	44.70	507	9.94	1.30	40.99	1.45
TV Time*	124	1.39	1.77	6.48	179	3.51	2.90	14.47	4.74
Feeding	169	3.02	0.30	8.82	157	3.08	0.27	12.69	1.21
Play Alone*	120	1.35	1.17	6.27	129	2.47	2.08	10.43	3.53
School*	333	3.74	2.32	17.39	121	2.45	2.74	9.78	2.83
Ablution	90	1.01	0.11	4.70	52	1.02	1.14	4.20	0.06
Play Peers	89	1.00	0.97	4.65	41	0.80	1.06	3.31	1.11
Home Teaching*	104	1.17	1.58	5.44	32	0.63	0.98	2.59	2.49
Others	30	0.34	1.82	1.57	19	0.37	0.96	1.54	0.13
Total Hours	1915				1237				

(*) Indicates variables that are statistically significant

The sub-sample analysis of children with ASDs revealed that those who are exposed to school apparently spend less time "sleeping" (Mean: 9.40 hours; SD: 1.32; 39.70 %), "watching television" (Mean: 1.76 hours; SD: 2.28; 7.43 %) and "playing alone" (Mean: 1.44 hours; SD: 1.26; 6.08 %) as compared to children with similar diagnostic condition attending school (Table 4). In other words, the children with ASDs who do not attend school, seem to face a double disadvantage. They spend thrice the time on daily activities like "watching television" (Mean: 5.19 hours; SD: 2.42; 21.23 %) or "playing alone" (Mean: 3.58 hours; SD: 2.14; 14.62 %) than they would have done if they were at school ($p < 0.05$). Additionally, they also seem to lose out time in a typical day's schedule for "playing with peers" (Mean: 0.42 hours; SD: 0.76; 1.74 %) and "home teaching" (Mean: 0.08 hours; SD: 0.27; 0.32 %). These differences indicate the need for exposing these children to group activities, preschools, play schools, kindergartens, crèche, etc.

The analysis of sub-sample of children with ASDs in terms of their chronological age, further brings into focus, that children below 36 months old are twice over-exposed to "watching television" (Mean: 5.29 hours; SD: 2.66; 21.35 %), "playing alone" (Mean: 3.21 hours; SD: 1.91; 12.94 %) and/or having "no school exposure" (Mean: 1.00 hours; SD: 1.62; 4.03 %) than their older similar diagnosed peers (Table 5). However, when this sub-sample analysis is extended to other variables like sex of the child, present or absent sibling, family size, etc., it was found that there were no statistically significant differences or trends, in the pattern of time utilisation across the different reported activities. Likewise, the other sub-sample analysis

of children with DDs (N: 89) in terms of variables like sex, single/multiple diagnostic conditions, chronological age, etc., did not elicit any differential patterns of time engagements over the typical day's cycle, as seen in the children with ASDs ($p>0.05$).

Table 4. Mean and total time reported on various activities in terms of school variable for childrens with ASD

Activity	Scool (N:25)				No School (N:26)				T Values
	TT	M	SD	%	TT	M	SD	%	
Sleep*	235	9.40	1.32	39.70	272	10.46	1.07	42.76	3.14
TV Time*	44	1.76	2.28	7.43	135	5.19	2.42	21.23	5.21
Feeding	77	3.08	0.28	13.01	80	3.08	0.27	12.58	0.00
Play Alone*	36	1.44	1.26	6.08	93	3.58	2.14	14.62	4.37
School*	121	4.84	1.60	20.44	00	0.00	0.00	0.00	15.13
Ablution*	26	1.40	0.20	4.39	26	1.00	0.00	4.11	9.99
Play Peers*	30	1.22	1.119	5.07	11	0.42	0.76	1.74	2.85
Home Teaching*	30	1.20	1.12	5.07	2	0.08	0.27	0.32	4.87
Others	2	0.08	0.40	0.34	17	0.60	1.23	2.67	2.05
Total Hours	592				636				

Table 5. Mean and total time reported on various activities in terms of age variable for childrens with ASD

Activity	0-36 Months (N:24)				36+Months (N:27)				T Values
	TT	M	SD	%	TT	M	SD	%	
Sleep	246	10.25	1.19	41.35	261	9.67	1.36	41.23	1.62
TV Time*	127	5.29	2.66	21.35	52	1.93	2.09	8.21	4.97
Feeding*	72	3.00	0.00	12.10	85	3.15	0.36	13.43	2.17
Play Alone*	77	3.21	1.91	12.94	52	1.93	2.01	8.21	2.33
School*	24	1.00	1.62	4.03	97	3.59	2.87	15.32	4.02
Ablution	25	1.04	0.20	4.20	27	1.00	0.00	4.27	0.98
Play Peers	14	0.58	1.06	2.35	27	1.00	1.04	4.27	1.43
Home Teaching*	4	0.17	0.48	0.67	28	1.04	1.13	4.42	3.65
Others	15	0.63	1.24	2.52	4	0.15	0.53	0.63	1.76
Total Hours	595				633		2.14		

CONCLUSION

The results of this study highlight the need and importance of activity scheduling for children with developmental disabilities in general, and those with autism spectrum disorders in particular. The findings indicate that a substantial part of the typical 24-hour schedule of such children is spent on "not-so-productive"/"self-absorbing" activities like "watching television" and/or "playing alone". The negative effect of watching television has been repeatedly emphasised even in "normal" or "non-autistic" children (15,16). Excess television watching has been known to foster solitude (17,18), diminish communicative intent (19), curtail pro-social behaviours (20), aggravate aggression (21,22,23) and curb human/social contacts (24). Therefore, given the content of daily routines as reported in this sample, there is every likelihood that it may become an intervening (though not a causative) variable in the maintenance of some of the behaviors in these children. The parents, caregivers and individual case managers of such childrens need to give utmost priority to rearranging the every day timetable log of activities, for children with developmental disabilities and autism spectrum disorders.

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**EFFECT OF INCLUSIVE EDUCATION ON
LANGUAGE AND SOCIAL DEVELOPMENT OF
CHILDREN WITH AUTISM**

Rubina Lal *

ABSTRACT

A total of 80 schoolteachers and administrators participated in this survey research conducted in the USA. The study investigated the effect of inclusive educational placement, on development of elementary school age children with autism. The subjects were randomly selected from general schools, schools with resource rooms, schools with special classes, and special classes located in Kansas, Missouri and Nebraska. Whereas the teachers (N=44) were required to respond on development of language and social behaviour in children with autism, their teaching strategies and available support system, the administrators (N=36) reported on the existing instructional practices, physical environment and related services in their schools. The results indicated that development of language and social behaviours in autistic children did not differ significantly across the educational settings. A positive correlation existed between teaching strategies and support services and development of language and social behaviour.

INTRODUCTION

During the last quarter of the twentieth century, a number of events have contributed to dramatic changes in the course of public education. A major force in creating a change in school education was the enactment of Education for All Handicapped Children Act (1975), in the USA.

This landmark piece of legislation influenced the course of education and training of children with special needs, world over. The main provision of this Public Law included the mandate for (a) all children, regardless of the nature and severity of their disabilities (b) each child with disabilities to have an Individualized Education Programme based on his/her social needs and (c) all children with disabilities to be educated in the least restrictive environment (LRE).

The Individuals with Disabilities Education Act (IDEA) which was passed in 1990, as reauthorisation of PL 94-142 states a strong preference for educating students with disabilities in general classes with appropriate aids and supports. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act passed by the Govt. of India in 1995, provides for equal educational opportunities to all children with disabilities and mandates that a child cannot be denied education on grounds of disability. The National Trust Act 1999, another disability specific legislation in India, aims to enable and empower persons with disability, to live independently and within the community to which they belong. Autism is listed as a disability under IDEA and the National Trust Act. Autism is a rare disorder that affects multiple areas including thought, communication and behaviour.

Autism has been defined as a developmental disability affecting verbal and non-verbal communication and social interaction, usually evident before the age 3, which adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotype movements, resistance to environmental change or change in daily routines, and unusual sensory experiences. A pervasive aspect of autism is the individual's social or interpersonal detachment to others in his/her environment. These children usually have impaired or delayed speech and language (1). Some people with autism are over or under responsive to sensory stimulation such as light, noise, and touch (2).

Key symptoms of autism include failing to develop normal socialisation patterns; disturbances in speech, language, and communication; unusual relationships to objects and events; unusual responses to sensory stimulations; developmental delays; onset during early years of life (3).

Autism is a disorder that is present from birth or very early in development that affects essential behaviors such as social interaction, the ability to communicate ideas and feelings, imagination and the establishment of relationships with others. It generally has life long effects on how children learn to be social beings, to take care of themselves, and to participate in the community (4).

The primary goals of education for children with autism, include fostering normal development, promoting learning, eliminating problem behaviours and reducing family stress (5). Essential components of effective programmes for such children lay emphasis on functional activities and skills needed to be successful in the real world, chronologically age appropriate activities, instructions, in both, school and non school environments and social integration to the maximum possible degree (6). For children with autism, education must foster acquisition of, not only academic skills but also socialisation, adaptive skills, language and communication, and reduction of problem behaviour.

Students with autism have seriously impaired social relationships. Many students with autism resist human contact and social interactions from a very early age, and they have difficulty learning the subtleties of social interactions. They also experience problems in both verbal and non-verbal communication. They often have significantly delayed language development, and struggle to maintain a conversation with another person. Inclusion is a process by which children with special needs receive remedial services in the least restrictive environment (LRE) especially in the regular classroom. It refers to the practice of placing students who are disabled in a general education classroom, to the extent appropriate to the needs (7).

Inclusion represents the belief or philosophy that students with disabilities should be integrated into general education classrooms, whether or not they can meet traditional curricular standards (8).

Many studies reviewed by Kirk et al (9) indicate that integration influences positive changes in the attitude of the non disabled persons towards their peers with severe and multiple disabilities, shows improvement on social and communication skills of such children, improves positive interaction among all students, and facilitates adjustment to community settings as adults.

While few professionals would question the appropriateness of including students with disabilities, there is a debate about which students should be part of general education classes and how much time they should spend there. Many educators agree that students with disabilities too often have been educated in isolated setting that minimise instead of maximising their potentials, but they recognize that general education setting is occasionally but not always the least restrictive environment (10, 11).

This observation has validity in case of children with autism. The lack of communication abilities and motivation for social interactions in autistic children, make integration of such children more difficult than others with disabilities because the latter are socially motivated whereas children with autism are instrumentally motivated (12). In fact, according to Morris (13), given the deficits in attending, observing, understanding and sustaining engagement in constructive activities that typifies many children with autism, instructions should take place in settings that are quiet and as free of distractions as possible.

The objective of the study was to compare the effect of inclusive educational placements on language and social development of children with autism. Four levels of inclusion (as per IDEA) were used for this purpose.

METHOD

The research was conducted in the USA. Administrators and teachers of schools in the mid-west States of America participated in the study.

The study design was a survey research following a causal comparative approach that attempts to determine the reasons or causes for the status of a phenomenon.

Subjects

Surveys were sent to a random selection of school-teachers (N=70) and administrators (N=50) from the States of Kansas, Missouri and Nebraska. The subjects belonged to (a) general schools (b) general schools with resource rooms (c) general schools with special class and (d) special schools. Since the study required information on children with autism of elementary school level (age 6-12 years), a total of 44 teachers and 36 administrators responded to the surveys.

The subjects were asked to provide information with reference to language and social development of a child with autism in their class/school.

Materials

Two surveys were developed for the study.

(1) Teacher's rating scale for language and social behaviors in children with autism.

The survey had three parts: (a) general information about the teacher, type of school and the selected child with autism (b) a checklist of language and social behaviors as seen in typical children and those with autism and (c) a checklist of teaching strategies, support systems, and professional updating needed for effective development of language and social behaviours in children with autism. The subjects were asked to respond to the questions in part (b) and (c) on a 3-point scale.

(2) Questionnaire for Administrators. This survey asked for information from administrators on (a) educational planning (b) learning environment (c) instruction and (d) support services. Each of these sections included practices that are acknowledged as effective for educational intervention of autism. This instrument also followed a 3-point scale for response.

Procedure

After pilot testing, the surveys were sent to a random selection of teachers (N=70) and administrators (N=50) of elementary schools from States of Kansas, Missouri and Nebraska in USA.

A total of 77 surveys were received, out of which 70 (44 teachers, 36 administrators) were considered valid. A survey was considered valid if subjects responded to all items therein.

RESULTS

Language Development

The first objective of the study was to determine the effect of inclusive educational placement on development of language behaviour in children with autism. The survey included a wide range of communicative behaviours that operationally denoted language development. The items were constructed with respect to linguistic deficits manifested by children with autism, and included such behaviours as indication of personal needs, use of manual and pictorial communication, and initiation and maintenance of conversation etc.

Mean score (based on ratings by teachers) obtained by children in regular schools was compared with that by children in resource rooms, special classes, and special schools. The outcome showed there was no significant difference ($F=1.089$, $p>0.05$) in language development of children from the four educational settings. This indicates that each educational setting provided the instructional, environmental and infrastructural support needed for development of language skills in children with autism.

Social Development

The effect of inclusive educational placement on social development of children with autism was determined by comparing the mean scores of children in each of the four types of educational setting. The scores were based on the teacher's ratings on a variety of behaviors essential for social skills such as eye contact, social attention, toy play, interactive play, sharing, and group interaction.

Statistical analysis showed no significant difference ($F=0.556$, $p>0.05$) in development of social skills among children across the four groups. This finding could be attributed to the uniformity in planning, teaching methods and availability of educational environment required for development of social skills in children with autism.

Instructional Method and Administrative Support

The survey for teachers asked them to rate themselves on use of programme planning, classroom organisation and teaching strategies found effective, for developing language and social behaviours in children with autism. They also rated the administrative support and infrastructure (e.g. provision for paraprofessional teachers, therapists, adaptation of physical environment, staff development programs) available in their schools.

Comparison of means of self-rating score found no statistical difference within the four groups ($F=1.147$, $p>0.05$). This suggests that teachers in all settings used appropriate teaching methods and were given the required administrative support for educating children with autism. Similar findings were presented, when mean scores of administrators across four educational settings were compared. The obtained F-ratio (0.543) was not significant ($p>0.05$)

statistically. This indicates that schools provided the instructional environment and support suitable for autistic children.

The findings were corroborated by correlating the mean composite score (on language and social development) of children, with mean score of teacher on use of effective teaching methods. The coefficient of correlation ($r=0.543$) was highly significant ($p<0.01$) statistically. The children's mean composite score also correlated positively ($r=0.478$) with the mean composite score of teachers and administrators, and was found significant statistically ($p<0.01$). These results suggest that appropriate teaching methods, learning environment and administrative support, contribute to positive outcomes for language and social development in children with autism. Any school that provides the same, could be a good educational setting for such children.

DISCUSSION

Research studies have documented the importance of enhancing communication and social skills in children with autism. Use of applied behavioral analysis (ABA) and discrete trial method show improvement in communication domain (14). Similarly, there is a large body of empirical support based on developmental approach (15, 16). Benefits from use of alternative and augmentative communication (AAC) have been documented too.

Mirenda (17) found AAC to be effective in development of functional communication in Autistic children. With such children, AAC may involve non-speech symbol system, signlanguage, visual schedules, communication boards etc. (4).

The teachers and administrators, who participated in the research study, reported the use of instructional methods based on ABA, developmental approach and AAC strategies. The non-significant difference in language development of children from the four educational settings, may be attributed to this factor.

Social development is an important aspect of education for children with autism. A child's social behaviour with both, adults and peers, should be targeted for intervention. Goals for specific social behaviours identified in interaction with adults, may focus on development of such behaviours as joint attention, turn taking, imitation, responding to adult initiations and initiating social interaction with adults (16).

Interaction with peers, is another dimension of children's social development that becomes increasingly important for a school-going child with autism. Strain (18) found play organisers (e.g. initiating play idea, sharing, affection, helping others etc.) and response to peer social bids as skills that influence development of peer interaction.

Use of visual schedules (19), social stories (20), social games (21), and peer-tutoring and cooperative learning (22), have been found to be effective in teaching social skills to children with autism.

Teachers and administrators from the four educational settings reported use of these strategies. The non-significant difference in mean scores on language development of children may be due to this practice.

CONCLUSION

Educational placement of children with autism has been a topic of debate for a long time. While advocates of placement in a general classroom believe that students receive more appropriate instruction in such a setting, those in favour of placement in a special class, are convinced that children with autism need the highly individualised and structured instruction, that can be available only in a special education classroom.

Results of this study do not subscribe to either standpoint. Development of language and social skills in children with autism in general education classes, was similar to that of those in resource rooms, special classes and special schools. From these findings, it may be reasonable to conclude that if appropriate instructional methods, physical and administrative support and related services are available; any educational placement is suitable for development of language and social behaviour in children with autism.

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BRIEF REPORTS

KNOWLEDGE AND ATTITUDE OF NIGERIAN PHYSIOTHERAPY STUDENTS ABOUT LEPROSY

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ABSTRACT

Knowledge and attitude about leprosy was evaluated in a sample of 63 volunteer physiotherapy students, from various Nigerian universities using a three-part questionnaire. Attitude scores averaged 54.6 ± 21.0 ranging from 0 to 77.8. Eighty-one percent of the students showed poor attitude, 13% showed fair attitude while only 6% showed good attitude. Knowledge scores averaged 41.0 ± 18.6 , ranging from 6.3 to 93.8. Twenty-four percent demonstrated poor knowledge, 44% had fair knowledge while 32% demonstrated good knowledge. Relationship between attitude and knowledge was not significant ($r=0.2; P=0.07$). Relationship between level of study and knowledge was significant ($r=0.6; P=0.00$). Relationship between level of study and attitude was not significant ($r=0.1; P=0.4$). In conclusion, the students have fairly good knowledge but poor attitude about leprosy. There is a need for a well-organised, specifically targeted educational programme for physiotherapy trainees. It is desirable that they spend time in a leprosy setting during their clinical attachment.

INTRODUCTION

Leprosy is still one of the major health problems of developing countries. Nigeria ranks among the six countries with the highest number of leprosy cases (1). Leprosy is a disease associated with a lot of stigma. The stigma against leprosy seems to be related to the fact that leprosy deforms and disables, but seldom kills, so that those who have been crippled, live on, getting steadily worse, with their deformities visible to the whole community (2). Age, gender, educational level and religion have been found to play a significant role in the beliefs with respect to leprosy (2). A study in Tanzania, showed that Stigmatising attitudes and belief were associated with low level of education, female gender and rural residence and religion (3).

Many studies have been carried out concerning knowledge and attitude of health workers towards leprosy. A study in north-western Botswana, found that attitude of service providers towards leprosy was influenced by poor knowledge (4). In a study in Nigeria, about two thirds (65%) of final year nursing students, believed that leprosy was highly infectious and that deformities were inevitable in leprosy (5). It has been shown that training basic health workers on leprosy control programme improved their knowledge, attitude and service delivery (6). An Indian study of 118 secondary school children showed an improvement in knowledge following leprosy education, without any change in attitude towards leprosy (7). This study also showed that these children were able to improve the knowledge of their family members modestly. However family members' attitude towards leprosy was unaffected.

Physiotherapy plays a major role in the management of deformities and disabilities occurring in leprosy (8). Though some studies have examined the attitudes of physiotherapy students about Acquired Immunodeficiency Syndrome (9,10), there is a dearth of such studies on leprosy and physiotherapy students, especially in Nigeria. The National Leprosy Control Programme in Nigeria, specifies at least one physiotherapist in every State control programme (1). It is disheartening to note that over 90% of the State control programmes do not have a physiotherapist. The inability of physiotherapists to take up positions in leprosy programmes may be related to their knowledge and attitude about leprosy. There is therefore need to assess the level of knowledge and attitude of prospective physiotherapy practitioners, about leprosy and their willingness to work in leprosy hospitals.

This study was therefore, designed to evaluate the knowledge and attitude of Nigerian physiotherapy students concerning leprosy.

METHODOLOGY

Subjects

Subjects for this study consisted of 63 volunteer physiotherapy students from various Nigerian universities, who participated in a one-week scientific conference organised by the Nigerian Association of Physiotherapy Students (NAPS). Only students who were in the clinical part of their programme, were surveyed. All students in the pre-clinical years of the physiotherapy programme were excluded from the study. The Students' sociodemographic data is presented in Table 1.

Materials

The instrument used in this study was a self-administered questionnaire designed by the researcher. The questionnaire consisted of **three** major parts.

Part 1, elicited sociodemographic information such as age, sex, ethnicity and religious affiliation. Part 2, contained nine items that evaluated the respondents' attitudes towards people affected by leprosy and willingness to work in an all leprosy hospitals. Part 3, evaluated the respondents knowledge about leprosy and consisted of **sixteen** items on respondents sources of knowledge and information about leprosy, cause, transmission, management and prevention.

Procedure

The test instrument was administered to all volunteer students individually at the venue of the conference, by the researcher. The researcher introduced the questionnaire to the students and provided specific instructions on how to complete it. The students were told to answer the items in the questionnaire as honestly and as accurately as possible, without anybody's influence. No time limit was imposed, but majority of the students completed the questionnaire within 10-15 minutes.

Data analysis

Each student's responses to items on the questionnaire were obtained. The number of positive responses on the items designed to evaluate attitude, was determined. Each positive attitude attracted one mark. Negative or no response attracted zero marks. The total marks scored by each respondent were divided by 9 and multiplied by 100 to obtain a percentage for attitude. Similarly, the number of correct responses on the items designed to evaluate their knowledge, was determined. Each correct response attracted one mark. Wrong or no response attracted zero marks. The total marks scored by each respondent was divided by 16 and multiplied by 100 to obtain a percentage score for knowledge. Knowledge and attitude score were classified into three categories thus; 0 to 39 **poor**, 40 to 59 **fair** and 60 to 100 **good**.

Pearson correlation test was used to test any relationship between knowledge and attitude of the respondents. It was also used to test the relationships between level of study and scores in attitude and knowledge. The data for this study was analysed using the Statistical Package for Social Sciences [SPSS] version 9.0.

RESULTS

Attitude

Mean score for attitude was 54.6 ± 21.0 ranging from 0 to 77.8. Majority of the students (81%) showed a poor attitude about leprosy, 8 students (13%) showed a fair attitude while only 4 (6%) showed a good attitude about leprosy (Table 2).

68.3% of the respondents admitted to ever seeing a leprosy patient before, while 30.1% had not seen a leprosy patient before. 90.4% of the students would not eat with leprosy patients while 95.2% of the students would not marry a lady or man who had leprosy, only 47.6% of them would refuse marrying a lady/man whose parents had leprosy. Table 3 presents responses to specific questions on attitude.

Knowledge

Mean score for knowledge was 41.0 ± 18.6 ranging from 6.3 to 93.8. Fifteen students (24%) demonstrated poor knowledge concerning leprosy, 28 (44%) students had a fair knowledge about leprosy, while 20 (32%) students demonstrated good knowledge about leprosy (Table 2). Many (55.6%) of the students had never had any lecture on leprosy in their physiotherapy training, while 17.5% had 2 to 5 hours and 14.3% had 1 to 2 hours of lecture on leprosy. Forty-four respondents (69.8%) were able to identify **Mycobacterium leprae** as the causative organism for leprosy. Some of the students (21.3%) believed that it can be caused by one's enemies and 14 (22.2%) believed it could be inherited from parents. Twenty-seven students (42.9%) knew that leprosy is transmitted as a droplet infection while 29 (46.1%) believed that in addition to droplet infection, leprosy can be transmitted through sharing clothes and sexual intercourse. Twenty-three (36.5%) students believed that insects could transmit leprosy. Twenty-eight students (44.4%) knew that leprosy affects mainly skin and nerves, while 25 (39.7%) believed that it affects mainly fingers and toes. Twenty-one (33.3%) agreed that absorption of fingers and toes are the first clinical signs of leprosy. Seventy one percent of respondents believed that leprosy could be cured. Twenty-three (36.5%) believed that management of leprosy can effectively be done by an intersectorial approach. Majority of the students (87.3%) felt leprosy patients should be isolated. Thirty (47.6%) felt leprosy can be prevented by vaccine and 18 (28.6%) felt that deformities in leprosy are not preventable. Sources of knowledge about leprosy mentioned by the students were books, journals, and discussion with friends, Bible, television, radio, and seminars.

Correlation

No significant relationship was observed between the scores for attitude and knowledge ($r=0.2; P=0.07$). A significant relationship was observed between level of study and knowledge ($r=0.6; P=0.00$). No significant relationship was observed between level of study and attitude ($r=0.1; P=0.4$).

DISCUSSION

As high as 81% of the respondents in this study showed a poor attitude about leprosy. This suggests a poor attitude among Nigerian physiotherapy students concerning leprosy. Most

worrisome is the fact that 62% of the students would not agree to work in a leprosy hospital and 65.1% would not agree that leprosy patients be treated in all conventional hospitals. This shows the students are not prepared to assist those patients, and would not be in support of the move towards integration. Conversely, only 24% of students showed poor knowledge about the disease. The knowledge of the students about leprosy could be described as fairly good. That, attitude about leprosy was not related to knowledge or level of study means other factors may be accountable for the poor attitude of these students. A majority of the students are from the Yoruba tribe and tribal prejudices against leprosy may be partly responsible for their attitude. In Yorubaland, it is a taboo to marry from a family with leprosy. Religion may be a potential culprit. Majority of the students were Christians and many of them listed the Bible as one of the sources in information on leprosy. The Christian religion teaches that lepers were isolated and treated with disdain. Majorities of the students were in their penultimate or final year but as high as 55% had not had any lecture on leprosy in their physiotherapy training. This may be an indication that the schools' curricula do not consider leprosy a priority area, or defer it until the students are about to leave school. It has been shown that medical students demonstrated a significant improvement in knowledge and attitude about old people after a 5-week attachment in their first clinical year (11). It is desirable that physiotherapy students spend some time in a leprosy hospital or colony, during their clinical attachment in the course of their training.

There are five universities with physiotherapy programmes in Nigeria. Not all the schools were adequately represented by the study sample, but the numbers are reflective of the distribution of student enrolment. While the sample may not warrant generalisations, it may be a pointer to the feelings of Nigerian physiotherapy students about leprosy. It is therefore important to replicate this study on a more representative sample of students.

CONCLUSION

The attitude of Nigerian physiotherapy students about leprosy is poor, while their knowledge is fairly good. There is need for well-organised, specifically targeted educational programmes in leprosy, for physiotherapy trainees. It is also important to study the knowledge and attitudes of qualified physiotherapists in Nigeria, concerning leprosy.

Table 1. Sociodemographic characteristics of the sample

Age	Mean (x) Standard deviation (SD) Range	23.0 1.7 20-27
Sex	Male Female	36 27
Tribe	Yoruba Hausa Ibo Others	49 Nil 9 5
Religion	Christianity Islam Others	60 3 Nil
Institution	University of Ibadan, Ibadan University of Lagos, Lagos Obafemi Awolowo University, Ife. University of Nigeria, Nsukka Bayero university, Kano.	25 32 4 2 Nil
	Level of study 300 400 500	16 24 23

Table 2. Categorisation of for attitude and knowledge scores of respondents

Scores	Category	Attitude	Knowledge
0-40	Poor	51 (81%)	15 (24%)
40-60	Fair	8 (13%)	28 (44%)
60-100	Good	4 (6%)	20 (32%)

Table 3. Distribution of responses to specific questions on attitude

	Yes	No	No response
Have you ever seen a person affected by leprosy before?	43 (68.3%)	19 (30.1%)	1 (1.6%)
Do you think it is possible for you to have leprosy?	16 (25.4%)	47 (74.6%)	-
Would you agree to work in an all leprosy hospital?	20 (31.7%)	39 (62.0%)	4 (6.3%)
Would you eat with a person affected by leprosy?	5 (8.0%)	57 (90.4)	1 (1.6%)
Would you marry a lady/man that has leprosy?	1 (1.6%)	60 (95.2%)	2 (3.2%)
Would you marry a lady/man whose parents have leprosy?	31 (49.2%)	30 (47.6%)	2 (3.2%)
Do you think leprosy patients should be treated in all conventional hospitals?	20 (31.7%)	41 (65.1%)	2 (3.2%)
Would you agree to travel in a bus in which majority of the passengers are leprosy patients?	8 (12.7%)	53 (84.1%)	2 (3.2%)
If you were sick, would you agree to be admitted in the same hospital with leprosy patients?	14 (22.2%)	45 (71.5%)	4 (6.3%)

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A TECHNIQUE FOR MAKING HAND SPLINTS FROM STYROFOAM AND PLYWOOD

David Woodruff Thomforde*

ABSTRACT

A technique has been developed in Paraguay, for making hand splints from styrofoam, plywood and paper. Sheet styrofoam is cut to fit the palmar surface of the forearm and glued to plywood, to provide strength. Pieces of paper are glued over the styrofoam and then painted with oil paint. Velcro is used to make straps. The splints made thus, include a resting hand splint for a flaccid hand, a finger-spreader splint for a spastic hand, a resting hand splint for a patient with shortening of the wrist flexors, a thumb support splint for a weak but functional thumb, a thumb positioning splint for a non-functional adducted thumb, a wrist cock-up splint and a resting hand splint for a person with rheumatoid arthritis to prevent ulnar deviation.

The advantages and disadvantages of this technique are compared with those of other alternative splinting materials (PVC, metal, plaster of Paris bandage, leather, bamboo and polypropylene). The major advantages of this technique are low cost, high adaptability to the individual hand, use of techniques known by local artisans, low-cost tools and ease of repair or modification. The major disadvantages are non-availability of materials in some places, need to develop new relationships between rehabilitation professionals and local artisans and difficulty with thorough disinfecting. Future applications of the techniques for making dynamic hand splints and foot splints are discussed. This technique appears to have promise in low to middle income countries such as Paraguay.

INTRODUCTION

One issue facing rehabilitation professionals in developing countries such as Paraguay, is that of appropriate materials for making hand splints. Low-temperature thermoplastics are used in developed countries, to make high-quality splints in a short time, but are too expensive for the majority of patients in less wealthy countries. The low-temperature thermoplastic needed to make a resting hand splint would cost slightly less than the equivalent of a week's salary for a minimum wage professional in Paraguay, or about \$US40.

Rehabilitation professionals around the world are using alternative materials such as plaster of Paris bandage (1,2,3), polyvinyl chloride (PVC) (4,5), metal (6), leather (7), bamboo (8) and polypropylene (9,10), depending on what is locally available. Some excellent splints are made with these materials, but they also have their drawbacks.

Plaster of Paris bandage splints are inexpensive (around \$US2 in Paraguay) and can be made in 20 minutes, by a skilled rehabilitation professional using widely available tools. They can be made to fit well to the patient's hand and are strong when first made. But they are heavy, are not easy to clean and usually do not last a long time. It is difficult to modify them after they are first made.

PVC splints are made from 2-mm sheets of PVC or from PVC tubes. They are easy to clean, are light, strong and last a long time. PVC tubes are inexpensive and widely available. PVC sheets are less widely available and more expensive. The PVC sheet material is easier to mold than the tube material. Once the process for working with either material is mastered, splints can be made quickly. The splints can be made using a kitchen oven and simple tools. But the material must be heated to be shaped, so must be placed on a plaster mold of the hand (which complicates the fabrication process), or on the heavily wrapped hand of the rehabilitation professional or patient (which limits the degree that the splint can fit to the patient's hand). In addition, the skills needed to work with PVC are rare, or absent, in most communities, so the rehabilitation professional will have to make the entire splint or train others in some tasks. The splints cannot be modified after they are first made. In most cases, technicians make these splints with guidance from rehabilitation professionals.

Splints made of used sheet metal or pieces of tin can, are very inexpensive and light. They are pounded to form the shape of the patient's hand. Communities in some cultures may have artisans with the skills. The tools needed are widely available in most communities. But unless the splints are very well made, they are not strong. They also cannot be shaped directly on the patient's hand, but must be hammered on a form and then placed on the hand, so they may not fit well to the hand. These splints are uncommon, and are not usually made by rehabilitation professionals.

Bamboo splints are light, inexpensive and easy to clean. Most communities, where bamboo grows, have local artisans with the necessary skills and tools to make the splint, after training from a rehabilitation professional. But the malleability of bamboo is limited, so the splint will not fit well to the hand. Bamboo that can be bent may not be strong enough for a splint.

Leather splints are light, inexpensive and last a long time. Most communities have leather-professionals with the needed tools and skills. But the leather must be placed wet on the patient's hand, fastened tightly and left there for a number of hours until it dries; so the method is not appropriate for spastic or painful hands, and the splints are not easy to clean.

The leather needs a metal reinforcement to be strong. These splints are usually made by community artisans.

Polypropylene splints are easy to clean, light, strong and last a long time. But they are expensive (a splint may cost more than 3 weeks salary for a minimum wage professional in Paraguay), require sophisticated heating equipment and skills are not available in many communities, and cannot be modified after they are first made. In most cases, orthopedic technicians make these splints.

A summary of these advantages and disadvantages is presented in Table 1.

TABLE 1. SUMMARY OF ADVANTAGES AND DISADVANTAGE OF DIFFERENT SPLINTING MATERIALS

	Plaster of Paris	PVC	Bamboo	Leather	Metal	Polypropylene	Styrofoam and wood bandage
Cost	+	0	+	+	+	-	+
Time to make	+	0	0	-	-	-	0
Strength	+	+	0	-	+	+	+
Long-lasting	-	+	+	+	+	+	+
Ease of cleaning	-	+	0	-	+	+	+
Ease of modifying	0	-	+	+	0	-	+
Uses locally available skills and tools	0	-	+	+	+	-	+
Weight	-	+	+	+	-	+	+
Good fit to patient's hand	+	-	-	+	0	+	+

Key - (+) - relative advantage

(0) - neutral

(-) - relative disadvantage

In addition, it is my observation that many splints made from these materials place the thumb in extension, in the same plane as the hand. The physical characteristics of the materials may promote this.

I have been experimenting with a new technique for combining styrofoam (to create a shape which molds to the hand), plywood (to give it strength) and paper (to create a smooth

surface). Velcro straps are used to fasten the splint to the patient's hand. Over the past 2 years, I have made over 40 splints, with a gradually evolving process.

I have developed 7 different models thus far:

- a resting hand splint for a flaccid hand
- a finger-spreader splint for a spastic hand
- a resting hand splint for a patient with shortening of the wrist flexors
- a thumb support splint for a weak but functional thumb
- a thumb positioning splint for a non-functional adducted thumb
- a resting hand splint for a person with rheumatoid arthritis to prevent ulnar deviation
- a wrist cock-up splint

The cost of the materials ranges from US\$.50 to US\$ 2.50 in Paraguay. The time necessary to make the splints varies from 30 minutes to 2½ hours. Patients have been using various editions of these splints for up to 1½ years with satisfactory results. Over the past three months, I have also trained 15 professionals and technicians in the process. Currently, one has started independent splint production.

METHOD

The following are the steps for making the resting hand splint for an adult (the steps for a child are the same, but thinner styrofoam is used):

- 1) lay the patient's hand on a piece of paper and trace around the hand and the distal 2/3 of the forearm; mark the metacarpal-phalangeal (MCP) joint arc, the proximal interphalangeal (PIP) joint arc, the thenar crease and the heel of the hand; the fingers should be together and the thumb abducted.
- 2) cut the shape out of the paper, fold the thumb under and mark the shape on 2½ cm-thick styrofoam; cut the shape out with a small disposable blade knife, or cutter.
- 3) cut the paper drawing at the heel of the hand; trace the hand portion on to 5 cm-thick styrofoam and cut the shape out.
- 4) place the hand in a relaxed resting position with the thumb tip and index finger tip almost touching; for a patient with a flaccid hand, this will be the resting position (8) with the wrist at 15-20 degrees extension, the MCP, PIP and DIP (distal interphalangeal) joints in 10-20 degrees of flexion, the thumb in opposition and the thumb flexed about 10 degrees in relation to the forearm; measure the forearm-metacarpal angle on both the ulnar and the radial side of the hand (I use folded paper since goniometers are rare in Paraguay); on the radial side of the hand, this figure can be used for the MCP, PIP and DIP joint angles as well, since they are very similar in the resting position; on the ulnar side of the hand, the MCP and PIP joint angles should be independently measured.

- 5) mark the outline of the hand on both side of the 5 cm-thick styrofoam cutout of the hand, using each joint angle and the distances between the joints as measured on the paper tracing of the hand; use the cutter to shape the styrofoam in conformity to the hand shape, making sure to maintain the metacarpal and carpal arches and the longitudinal arch.
- 6) mark the thenar crease on the styrofoam and cut away the styrofoam proximal to it.
- 7) unfold the thumb from the paper pattern, and cut along the fold line in a distal to proximal direction, until the thumb is almost completely severed; place the paper pattern on the styrofoam; place the thumb so it is slightly flexed in relation to the forearm; mark the thumb position on the side of the styrofoam block; cut out the shape of the thumb.
- 8) put the paper pattern on the styrofoam to make sure the styrofoam is of the right shape; if the patient is available, put the styrofoam under his palm; make modifications as needed to achieve the resting position.
- 9) during shaping process of the 5 cm-thick styrofoam, the piece is shortened; therefore, place the 5 cm-thick styrofoam on the 2/12 cm-thick styrofoam cutout of the hand and forearm, and cut the 2 1/2 cm-thick piece of styrofoam to the new shape.
- 10) place the modified 2½ cm-thick piece of styrofoam on 9 mm plywood, draw and cut out the shape; sand the edges; glue the two pieces of styrofoam together and the plywood beneath them both, using special styrofoam glue.
- 11) carve the forearm portion of the splint until it is gently concave.
- 12) cover the styrofoam with a cooked glue made of flour (manioc, wheat or corn) and water; apply small pieces of cement-bag paper wetted with the glue in collage fashion to cover the splint, smoothing down any rough spots.
- 13) after this is thoroughly dry, use white glue to fasten down any loose piece of paper; mix equal parts of white glue and water and paint the paper.
- 14) after this is thoroughly dry, paint the splint with at least two coats of oil paint.
- 15) glue velcro to strapping material to make three straps; these are fastened to the plywood with screws; the straps are tightened using metal rings.

The other hand splints are variations on this theme. In the finger-spreader splint, the paper pattern is traced with the fingers and thumb abducted. A wooden block is shaped to fit between the thumb and index and fastened to the plywood. The wrist is kept at neutral. Small styrofoam wedges are cut to fit between the fingers.

In the wrist cock-up splint, the wood and styrofoam base is cut at the thenar and the distal palmar crease, and a wooden block is shaped to fit under the palm and padded.

In the resting hand splint for a patient with shortening of the wrist flexors, the base of styrofoam and the plywood are cut at the wrist crease, and are then joined by a triangle of wood at the angle of the thumb and the forearm. In addition, since the patient's hand cannot lay on a piece of paper for tracing, a light plaster of paris bandage cast is made of the patient's hand in the desired position, and all measurements and tracings are taken from that.

The resting hand splint to prevent ulnar deviation has padded pieces of plywood fastened to the ulnar side of the fingers and forearm, and to the radial side of the wrist to maintain the hand and arm in a straight line.

The thumb support splint uses a different process. An oval object is found, or shaped from clay, that fills the space between the thumb and palm while allowing for pinch. The object should extend beyond the IP joint of the thumb, but not extend beyond the proximal index finger crease. This shape is copied on paper, and expanded by 1 cm on all sides, and then a piece of 3 cm-thick styrofoam is cut that shape. The edges that touch the thumb and the web space are carved to be concave to the depth of 1 cm. Stick velcro is glued to the sides and the top of the splint. A strip of loop velcro is cut of length to fasten the thumb firmly to the splint. Another piece of loop velcro is cut to fasten to the radial side of the splint, extend down the arm and around the back of the wrist, loop around the wrist and cross the back of the hand before fastening to the top of the splint. The friction of the velcro on the arm keeps the thumb in opposition. Paper and paint are applied to the exposed styrofoam.

The thumb-positioning splint is made in much the same way as the thumb support splint, but the styrofoam piece is larger, extending beyond the MCP joint of the index finger, and also 5-cm thick, so as to provide stability from adduction pressure.

DISCUSSION

This technique is not perfect, and needs further improvement, hopefully both by other rehabilitation professionals and myself. In its present form, however, it does have some distinct advantages:

- the splints are easy to clean.
- while its cost is not on a par with the cheapest splints (bamboo and leather) it is a similar price to plaster of Paris bandage and much cheaper than high-temperature plastics.
- the tools needed to make the splints are widely available in most communities; many of the materials are also readily available.
- much of the time-consuming process (cutting wood, painting, drilling holes in wood, applying screws, applying paper) can be done by a community artisan rather than a rehabilitation professional; in countries such as Paraguay where rehabilitation professionals have very limited time to spend on each patient, and technicians with

these skills are plentiful and inexpensive in the community, this is an important consideration.

- the result is a strong splint (thus far, lasting up to 6 months without major repair) that can be easily modified by cutting off the paper and paint, cutting away or gluing on styrofoam, and then re-applying paper and paint.
- some problems (worn-out velcro, loose straps, cracks in the painted surface) are bound to occur over time; a family member or community artisan can repair these problems; in addition, since screws hold on the straps, a community artisan or family member can modify the strap length by removing the screws and shifting the straps.
- some patients can perform some of the tasks (painting, papering, cutting) involved in making their splint as therapeutic activities to improve fine-motor coordination, one-handed skills and perceptual skills.
- the splints can be made using hand tools commonly available in Paraguayan communities, although use of an electric drill and jigsaw will speed up the process.
- the splints can be carved to fit well to the patient's hand, even if it is deformed and/or spastic.

There are some disadvantages, some of which may be alleviated as the techniques develop and are adapted to local conditions:

- in areas with few industries, plywood and sheet styrofoam may not be locally manufactured, so may be too expensive for patients to afford.
- in Paraguay, there has been almost no collaboration between rehabilitation professionals and community artisans; communication and payment systems will have to be developed; this will take up already scarce time for rehabilitation professionals, unless facilities can take a role.
- rehabilitation professionals will need to develop a new mind-set; with other materials, the rehabilitation professional shapes the material over the hand or a mold of the hand; with this technology, the rehabilitation professional must develop and use techniques for outlining the negative space surrounding the hand and shaping the splint accordingly.
- during rainy seasons, the paper and paint will dry very slowly and the production will be delayed considerably.
- in their present form, patients who need to have their splints completely disinfected cannot use this kind of splint, since it can neither be autoclaved nor immersed in disinfectant.
- the measure of the angles of the different joints of the hand is a complex process, not normally done by generalist rehabilitation professionals in Paraguay. This will require practice.

There is much room for expansion of this technology. Thus far, only static splints have been made, but if materials are available to make outriggers, these could be attached to the plywood and a finger-extension-assist splint could be made. This is only one option. I could be interested in hearing about the efforts of other people.

I have made 2 ankle-foot splints using this technology, making a plywood case and then molding the styrofoam around the foot and lower leg. The resulting splints were satisfactory for bed positioning but were too weak and too bulky for ambulation. It was also difficult to get the foot in and out of the splint, and difficult to apply the paper and paint. A different approach might be to make a plywood case that could taken apart and assembled around the foot.

Use of styrofoam from packaging would decrease the cost and increase the potential use of the technology. Techniques will have to be developed to fasten pieces together, since package styrofoam almost never has pieces large enough to cut the whole splint from.

For making splints where small structures are needed (active ulnar deviation splints, for example), other materials will have to be incorporated into the splints, and techniques developed to fastening them to the splint, since styrofoam lacks the strength to be used in small structures.

Rehabilitation professionals will continue to use the materials and skills available in their communities to make hand splints. In places where styrofoam, plywood and paper are available and other materials are too expensive, this technology should offer occupational rehabilitation professionals an attractive alternative material. A detailed description of the fabrication process can be obtained from the author.

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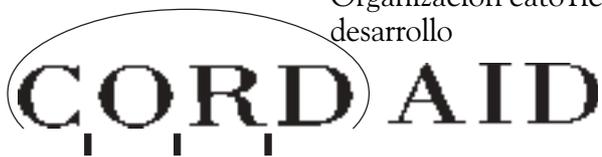
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