



# ASIA PACIFIC DISABILITY REHABILITATION JOURNAL

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*Manuscripts, requests for the journal and all editorial correspondence should be sent to :  
Dr. Maya Thomas, Editor, Asia Pacific Disability Rehabilitation Journal, J-124, Ushas Apartments,  
16th Main, 4th Block, Jayanagar, Bangalore - 560011, Karnataka, INDIA.  
Tel and fax : 91-80-6633762 Email : thomasmaya@hotmail.com*

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**Produced by:** *Shree Ramana Maharishi Academy for the Blind, 3<sup>rd</sup> Cross, 3<sup>rd</sup> Phase, J.P. Nagar,  
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**ACTION FOR DISABILITY, HUNTERS MOOR REGIONAL REHABILITATION CENTRE  
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**NEWCASTLE UPON TYNE NE2 4NR, UK**

**TEL : +44-191-21995695, FAX: +44-191-2195665**

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**CORDAID**

**PO BOX 16440, 2500 BK, THE HAGUE, NETHERLANDS**

**TEL : 31-70-3136412, FAX: 31-70-3136301, email : cordaid@cordaid.nl**

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## **EDITOR'S COMMENT**

Over the last 2 decades, community based rehabilitation (CBR) has gained acceptance as the preferred approach of service delivery for people with disabilities in developing countries. However, many questions remain about CBR. There is little published literature about different aspects of CBR, including cost effectiveness or cost benefit, as in other areas such as community development, primary health care, and so on. There are still many different interpretations of CBR, making it difficult to compare different programmes. There has been little research on outcomes, and little effort to develop indicators with which to measure success. Many evaluations of CBR programmes continue to remain as mere descriptions of practice and of the perceptions of different stakeholders about the programme.

*More rigorous evaluation of CBR and indicators to measure outcomes of CBR are vital if the field is to grow and develop further. CBR managers, field workers and professionals need to show the benefit of their programmes, especially in the present times of market economy. Without this, governments and policy makers would find it difficult to justify increased allocation of resources for CBR programmes.*

*Of late, different groups, working in Canada, Netherlands and UK, have started stressing the need for more rigorous evaluation of CBR to inform planning, along with appropriate indicators to measure successful outcomes. It is generally accepted that any indicators that are developed must be useful for all stakeholders of the programme, be related to the aims of the programme, and easy to use. At the same time, it is acknowledged that it is difficult to develop indicators which will be acceptable to the range of people involved in disability issues with different underlying philosophies.*

*Some of the groups working on indicators have published lists of possible indicators that could be used in future evaluation studies in CBR. If indicators are to be used to determine effectiveness of programmes at field level and to inform future planning, they need to be used by service providers in their programme evaluations as part of their work. Field testing across different cultures may also help to determine which indicators could be culture-free and which are culture-dependent.*

*People involved in disability programmes especially in developing countries are still not sufficiently aware of the importance of evidence based practice, which is gaining ground in the fields of health and development. Donor agencies, policy makers, programme implementers and user groups increasingly require evidence of value for money, value for input and value for effort. Evidence based practice requires clear statements of activities, outcomes and indicators. In a field like community based rehabilitation, which has grown mostly based on experiential accounts over the last two decades, a move towards evidence based practice is vital at this point in time, if interest in this field is to be sustained.*

*The Editorial Team of the Asia Pacific Disability Rehabilitation Journal Group wishes the readers a Happy New Year!*

**Dr. Maya Thomas**

Editor

J-124 Ushas Apts, 16<sup>th</sup> Main, 4<sup>th</sup> Block, Jayanagar

Bangalore – 560 011, India

Tel and fax: 91-80-6633762, Email : [thomasmaya@hotmail.com](mailto:thomasmaya@hotmail.com)

## **EDITORIAL**

### **A DISCUSSION ON SOME CONTROVERSIES IN COMMUNITY BASED REHABILITATION**

*Maya Thomas\*, M.J. Thomas\*\**

#### **ABSTRACT**

*This paper deals with the changes that have taken place over the last decade in community based rehabilitation (CBR) and then discusses some controversial issues in CBR in developing countries, with particular reference to South Asia. These controversies have already been debated in the past using different arguments, and hence it is pertinent to state here that this discussion is based on the work of the authors in South Asia over the last fifteen years.*

#### **INTRODUCTION**

CBR was promoted as an alternative service programme in the early eighties by World Health Organisation (WHO) and other UN agencies, for the rehabilitation of people with disabilities in developing countries who had no access to services (1,2). Since these countries had limited resources to provide high quality institutional services, the emphasis was on developing a method which provided wide coverage, at costs that were affordable to governments of these countries. In CBR, interventions were to be shifted from institutions to the homes and communities of people with disabilities, and carried out by minimally trained people, such as families and other community members, thereby reducing the costs (3).

In the early eighties, CBR was conceptualised and evolved primarily as a service delivery method with a medical focus, since the WHO had recommended that it be integrated into the primary health care (PHC) system, that was already well established in many developing countries. The International Classification of Impairments, Disabilities and Handicaps (ICIDH), published in 1980 by WHO, also encouraged a medical approach to rehabilitation (4). As a result, the early CBR programmes tended to focus on restoring functional ability in disabled individuals in order to 'fit' them into their community.

During the eighties and the nineties, there was a substantial growth in the number of CBR programmes in different developing countries. Along with the quantitative growth, there were also major changes in the way it was conceptualised (5). One of the early changes was the shift from a medical focus to a more comprehensive approach. With the realisation that stand alone medical interventions did not complete the rehabilitation process, CBR programmes gradually began to add on interventions such as education, vocational training, social rehabilitation and prevention. Along with this came the recognition that CBR needs to deal with issues related to disabled people's lives at all times and to change not only the disabled individual, but the context in which he or she is located. Changes in contextual factors involved changing attitudes of non-disabled persons in the community to accept people with disabilities, promoting their social integration, and provision of equal opportunities in education and employment, in the same way that they are available to non-disabled persons. Protection of rights of people with disabilities, and empowerment of the community to manage their programmes are other aspects of the contextual changes.

Thus CBR today follows a social model rather than an exclusively medical model as in the past. In our observation however, there are still many questions that remain to be answered before CBR can be implemented effectively. The following discussion deals with some of them.

## **SHOULD CBR BE STARTED AS AN EXTERNALLY INITIATED PROGRAMME BEFORE THE COMMUNITY EXPRESSES ITS NEEDS, OR SHOULD IT BE STARTED ONLY WHEN THERE IS AN EXPRESSED NEED FROM THE COMMUNITY?**

In the earlier years when CBR was a form of service delivery, this question was irrelevant. Today however, CBR is viewed as a development process, and the question of whether CBR should be imposed by outsiders or initiated by the community, is debated widely.

In the earlier years, CBR tended to be a form of 'community therapy', where services were physically shifted to the community, but the clients remained as passive 'beneficiaries' (6). Subsequently it has changed to a community development programme where disabled persons and their families are actively involved in all issues of concern to them, with the ultimate goal of full ownership of their programme by the clients. 'Community participation' is thus a central and essential tenet of CBR as it is conceptualised today, in the social model. In practice, however, most CBR programmes in South Asia find it difficult to achieve this goal (7).

Usually we assume that communities are homogenous, cohesive and mutually supportive entities, but in reality, it does not appear to be so. They are, in most instances, quite heterogeneous, with wide differences in socio-economic status, educational status, religion, ethnicity and so on (8). This diversity sometimes causes friction and affects services, because different groups in a community have widely differing needs and priorities, and usually the needs of disabled persons who are in a minority, are not considered as a priority by others (7).

Given this background, how does one define the 'community' in a CBR programme? Does it comprise only of people with disabilities and their families who are a minority and are the primary clients, or is it the larger community that may not want to share its resources with disabled people?

In developing countries, poverty is a major barrier to participation in development programmes, as people have other pressing needs to be fulfilled before they can take charge of their programmes. Corruption and cornering of wealth by vested interests is another issue that mitigates against participation by all. People in developing countries also have difficulty in operationalising decentralisation and 'bottom-up' practices due to a cultural reluctance to take charge of their affairs. Because the local communities usually expect benefits from the Government as a permanent dole, they also tend to resist suggestions about taking charge of programmes on their own (7, 8, 9).

Consequently, the issue for debate among planners today is whether CBR should be initiated in a community by an external agency, or should one wait for the local communities to start CBR on their own? The votaries of the former opinion advocate starting services for disabled individuals without waiting for community participation, as it may take a long time, and in the meantime the needs of many disabled persons would remain ignored. They argue that community ownership of the programme, where people take on the responsibility for planning, implementing, sharing the risks of and monitoring their programme, is unlikely to be achieved in the foreseeable future. There is also a suspicion in the minds of many people that the rhetoric of 'community participation' is used by governments as a ploy to abdicate their responsibility, because the taxes collected are spent on causes other than development.

The opposing argument is that CBR is a developmental issue and as such, it needs to be initiated by the concerned groups themselves, who in this case are people with disabilities and their family members (10, 11). If it is externally initiated, the clients will continue to remain passive recipients of services, with expectations of charity, and without the initiative to manage their own affairs and to contribute to society.

Since people in developing countries are largely ignorant about consumer ownership of development programmes, it is not feasible in most instances to begin the programme with full ownership by the communities (7). There is however, a possibility of striking a balance between the two opposing arguments. CBR programmes will need to motivate the local community to participate in their development to begin with, and over time, to shoulder the responsibilities of the programme. In this process, the community will gradually acquire the management skills to take over their programmes as well (7).

### **WILL THE SOCIAL MODEL OF CBR IGNORE THE 'REAL REHABILITATION' NEEDS OF PEOPLE WITH DISABILITIES?**

When CBR was initially promoted by WHO, it was to be integrated into the PHC system, and thus many early CBR programmes followed a medical model, which came in for criticism in the eighties as not being sufficiently sensitive to all the needs of people with disabilities (12). As a result, most CBR programmes evolved subsequently as separate programmes addressing an array of needs, in a comprehensive manner. The perception then was that unless a special focus was given to disability, the 'specialised' needs of people with disabilities would remain unmet (13). However, with the shift from a medical model to the social model, the emphasis today is on integrating disability into development processes. According to votaries of this model, it is more cost-effective, and promotes better social integration by ensuring that people with disabilities have access to the same benefits and services as others in the community, unlike a 'specialised' CBR programme that concentrates on people with disabilities and may actually isolate them from the mainstream (14, 15). Besides, community participation is likely to be greater in a programme that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programmes can ignore 'real rehabilitation' needs, such as mobility, special education, vocational rehabilitation and so on. In turn, this can contribute to increased marginalisation of people with disabilities, rather than their integration into the mainstream (15).

The last few years have witnessed attempts to integrate disability into community development projects, that showed some tangible benefits for disabled people from the integration (14, 16, 17). Many problems were also encountered in this process. Lack of organisational ability and knowledge about disability on the part of community development organisations acts as a major barrier to integration. Disability is seen as a 'specialist' issue, and hence these organisations feel that they do not have the expertise to deal with it (15, 17). Further, disabled people tend to be recognised only by their disability and not by any other parameter such as gender, poverty level, ethnic status and so on, resulting in their exclusion from the benefits of integration in a development programme. Lack of mobility, education and skills in disabled people prevents them from being a part of development programmes, while expectations of charity and poor motivation on the part of disabled people also contributes to their exclusion (17).

Integration of disability issues into development programmes implies a high degree of co-ordination and collaboration between different sectors such as health, education, employment and

so on. Often, such co-ordination works better at local, 'grass-root' levels, but fails at higher regional or national levels. Difficulties in multi-sectoral collaborations can be due to many reasons. In developing countries, programmes tend to be 'porous' and as a result, the different players in the field take time to trust each other (18). Secondly, there are differences in the management culture of government organisations and non-governmental organisations (NGOs), with the government operating in a top-down manner while the NGOs are usually 'bottom-up' and democratic in their management style. These differences can become a barrier to effective collaboration. Thirdly, under the cover of 'collaboration', members often try to gain control over each other rather than to work towards a common goal, and hence multi-sectoral collaborations get submerged in power and control issues between the different sectors. Lack of commitment to the goal from all partners can also be a problem in multi-sectoral collaborations. Usually, a powerful minority controls the process while the rest are passive participants. As a result, in many instances the decisions are finalised by the minority and the majority is made to merely endorse them.

Many of these issues will need to be solved before a social model can become effective. Until such time however, it may be more realistic to pursue a plan that is most feasible in a given context, focusing on the goals of the programme as the central issue at all times.

### **IS CBR INEXPENSIVE? IF SO, FOR WHOM?**

CBR was promoted to achieve wider coverage, at costs that are affordable. This was to be achieved by shifting rehabilitation interventions to families of disabled persons, thus reducing the expenses on institutions and personnel, and consequently reducing the unit costs of rehabilitation. The question is, who carries the burden then? Although CBR programmes appear to be cheaper because of the home based interventions, in reality, the costs to consumers in terms of their efforts, time and money, may turn out to be much higher than what it is generally believed to be (13).

The point then is, whether the consumers are ready to take on the additional burden of costs of CBR interventions? Secondly, even if they are willing to do so, can they afford to do so? Many families in developing countries who are struggling for their daily survival, feel that it is a waste of effort and money to address the rehabilitation needs of their disabled children, preferring instead to spend on other children without disability in the hope that they would support them in their old age. In an environment of increasing competition for resources, their reasoning is that unless the other children are well placed, they may not be in a position to support their disabled sibling in the future, especially since few protective social security schemes are available in these countries (19). Until some of these issues are addressed, it is unlikely that consumers would be ready to bear the costs of the rehabilitation programme on their own.

### **IS CBR THE ANSWER FOR ALL DISABLED PEOPLE OR ONLY FOR A SELECT FEW?**

It is estimated that 70% of people with disabilities could be handled at the community level, while the remaining 30%, comprising of people with severe and multiple disabilities, would require specialist interventions that are not available in the community (20). Evaluations of CBR programmes in the eighties and early nineties endorsed this view (21). With the change towards a social model that emphasised equity and integration, CBR as it evolved subsequently began to address the need to include all people with disabilities within its ambit of services and interventions. In reality, however, the desired level of equity has not been achieved, leaving out some sections of people with disabilities.

It is estimated that about 20% of the disabled population that requires interventions from a CBR programme are people with severe disabilities, many of whom would also have multiple disabilities (22). In poorer communities, the percentage of people with severe disabilities is low, as the families may not seek help for their survival. In some communities, mortality of children with disabilities reaches almost 80%, leading to a 'weeding out' phenomenon (22). However small their number may be, CBR programmes face many difficulties in dealing with severe disabilities. Many programmes are initiated by external agents, who need to build a rapport with the community and show quick results, which they achieve by working with mildly and moderately disabled persons. As a result, people with severe disabilities tend to be left out of interventions. Most CBR programmes also do not have personnel who are adequately trained to deal with this group. Sometimes, in the process of promoting 'community participation' and 'rights' of disabled persons, the severely disabled persons get neglected. As yet, there are no valid methods to effectively address the needs of this group at the community level.

Women with disabilities are another group whose needs are not adequately addressed by CBR programmes, particularly in traditional cultures. Although disability leads to segregation of both men and women, women with disabilities face certain unique disadvantages, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services which are dominated by male service providers (23). Concerns of women with disabilities also tend to get neglected in organisations of people with disabilities that are usually dominated by disabled men. Even the women's organisations in developing countries consider these women as disabled first and as women only secondarily. CBR programmes will need to develop appropriate strategies to address issues related to traditional, social and cultural perceptions. Strategies such as awareness building to dispel misconceptions about disabled women's gender roles, skills development training to carry out their tasks and home adaptation where feasible, training of women CBR staff, provision of educational and employment opportunities to women with disabilities, and sensitisation of women's organisations and disabled persons' organisations to include the issues of women with disabilities in their agenda, can help to reduce the inequality between women and men with disabilities.

### **CAN VOLUNTEERS IN CBR 'AFFORD' TO VOLUNTEER?**

In an international workshop on CBR in 1998, participants from twenty-two CBR projects were asked to identify the major challenges facing them. Problems linked to community volunteers were identified as one of the significant issues by almost all of the participants. The problems had to do with difficulty in finding new community volunteers, fast turnover of volunteers, need for additional resources for continuously training new volunteers, lack of motivation among volunteers, and need for paying incentives or small salaries to volunteers (24).

The role of community volunteers is perceived as one of the major issues for CBR projects in different parts of the world, particularly in the light of the current emphasis on 'community participation'. There are examples of CBR programmes that have successfully used volunteers (25), but these are probably the exception rather than the rule.

The point of debate is : can there be true voluntarism in developing countries where a majority of the population cannot afford to 'volunteer'? The dictionary defines 'volunteer' as a person 'who voluntarily undertakes or expresses a willingness to undertake a service while having no legal concern or interest'. Thus the term has a dual connotation, that of 'own free will' and of 'without interest or payment'. Though the term 'volunteer' is used often in CBR, in reality it covers a variety of identities and roles that do not confirm to the definition of the term (24). Thus, there may be persons who have the time to dedicate to their chosen task, or may have some time in specific periods of the month or year, or may be available only for a limited period of time. In the

last decade, with a move to market economies in many developing countries, most people need paid employment to survive and are therefore less able or willing to volunteer. Those who do volunteer often use their training and experience as a stepping stone to paid employment. Under these circumstances, expectations of free work over a long period of time by volunteers, in the same way as paid CBR workers, may not be realistic.

## CONCLUSION

After more than two decades of CBR in different parts of the world, many people believe that it may be an appropriate approach for people with disabilities in developing countries. But many controversies and questions remain about different aspects of CBR. If sufficient attention and resources are allocated to research in this field, it is possible that some of these questions may be answered in the coming decade.

\* J-124 Ushas Apts, 16<sup>th</sup> Main, 4<sup>th</sup> Block, Jayanagar,  
Bangalore - 560 011, India  
Tel and fax: 91-80-6633762,  
email : thomasmaya@hotmail.com

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## DEVELOPMENTAL ARTICLES

### A CASE STUDY OF THE COMMUNITY BASED REHABILITATION PROGRAMME IN MONGOLIA

Manoj Sharma\*, Sunil Deepak\*\*

#### **ABSTRACT**

*This paper presents a case study of the status of the community based rehabilitation programme in Mongolia. The case study is based on participatory dialogue conducted in the summer of 2000 with key personnel associated with the programme. The country has tried to implement a different model for the implementation of a CBR programme and must be one of the rare examples where such a huge geographical coverage has been achieved. At the same time, the difficulties in monitoring make it difficult to assess the real coverage in terms of access, acceptability and impact on the lives of disabled persons in the rural areas.*

#### **INTRODUCTION**

Mongolia is among the poorest nations in the world with a per capita GNP of \$400 (1). Geographically, it is a large landlocked country with a total area of 1.56 million square km but with a population of only 2.6 million people, giving the country a population density of merely 15 persons per hectare (2). The country is located in central Asia, bordering with Russia in the north, the People's Republic of China on the east and south and marginally with Kazakhstan on the west. The average altitude of the country is 1,580 m above sea level, characterised by undulating steppes covering about 45% of the country, mountains with dense forests in the north and the Gobi desert in the south that cover about 35% of the country (3). About a third of the population lives in the capital city of Ulaan Bataar, another third in 21 towns or Aimag (Province) centres, and another third in isolated hamlets or as nomads floating from one place to another.

Politically, the country, became the world's second communist country in 1924 and experienced decades of Stalinism under the local leadership of Choibalsan until the fifties. The fifties witnessed the regime of Tsedenbal that saw a stronger influence of Soviet and Chinese governments. In the sixties, with the Sino-Soviet split, Mongolia sided with Soviet Union. During this time the Mongolian script was changed to Cyrillic script. Throughout the seventies, the Soviet influence continued, along with the influence of several countries of the East-European Bloc - East Germany, Poland, Czechoslovakia and Hungary. In 1984, Batmonkh succeeded Tsedenbal and embarked upon economic reforms known as *il tod*, the Mongolian counterpart of perestroika and glasnost. The period also saw enhanced relations with China. However, in 1990, large pro-democracy protests erupted in Ulaan Bataar, leading to amendment of the constitution to hold multi-party elections that paved way for the establishment of democracy. The nineties witnessed several teething problems as are common to the evolution of a new democracy undergoing rapid economic changes. Adding to the teething problems, the constraints to Mongolian economy have been Mongolia's severe climate, scattered population, wide areas of unproductive land, and primary base in agriculture, livestock breeding, and mining-based economy. Some of the salient problems that the country has been struggling with in recent times have been frequent government changes, repeated restructuring, high inflation rates, high level of poverty (about 40% of the population lives below the poverty line), budget cuts for education and health sectors (as high as 40-50% since 1990), soaring of school drop-outs and non-enrolments (as high as 20-25% since 1990), rising unemployment, growth in the number of street

children in the capital city, and a deteriorating quality of the environment (4). In such a situation it is easy to imagine that the needs of persons with disability can easily be neglected.

## **DISABILITY IN MONGOLIA**

Accurate data about disability in Mongolia are lacking. However, according to some estimates and survey by the Office of Mongolian National Statistics, in 1999 there were 45,000 persons with disability (1.73%) in the country, of whom 15% had vision difficulties, 20% had speech and hearing difficulties, 35% had mental handicap, and 30% were classified in other categories (5). Furthermore, 34,000 (75%) out of these persons with disability are children in the school-going age.

## **PURPOSE AND METHOD FOR THIS CASE STUDY**

The purpose of this case study is to summarise the status of the community based rehabilitation programme in Mongolia. The case study is based on participatory dialogue conducted in the summer of 2000 with key personnel associated with the programme. In gathering information for this case study discussions were held with the following stakeholders:

- Key personnel in the Policy and Co-ordination Department at the Ministry of Health and Social Welfare, Government of Mongolia, who are closely working with the present project (n=3)
- Key personnel at the National Rehabilitation and Vocational Training Centre for the Disabled (NRVTC), Government of Mongolia, which has been identified by the Government as the key implementation agency for all rehabilitation related work (n=6)
- Key personnel of the present project implementation team including the AIFO representative, designated country project co-ordinator, and designated senior trainer (n=3)
- Sample of functionaries of the CBR committee (n=7) at one sample aimag (Bayankhongar) of the present project including personnel at the vocational training centre (n=3)
- Sample of persons with disability and their family members at one sample aimag (Bayankhongar) of the present project (n=8)
- Key members of a new emerging non-governmental organisation (NGO), “*Tegsh Duuren*” (n=5)
- Key representatives of existing local non-governmental organisations (NGOs) of disabled persons including the federating organisation (n=12)
- Sample representatives of Buddhist religious organisational orders (n=2)

## **COMMUNITY BASED REHABILITATION PROGRAMME ACTIVITIES IN MONGOLIA**

In 1991, the Government of Mongolia solicited the assistance of World Health Organisation (WHO) for initiating community-based rehabilitation (CBR) services for its disabled population. In August 1991, the Rehabilitation Unit (RU) of WHO and Associazione Italiana Amici di Raoul Follareu (AIFO), an Italian non-governmental development organisation, conducted a joint feasibility assessment (6). Given the geographical, climatic and logistical peculiarities of the country, it was decided to follow a ‘top-down cascade’ approach for implementation of a CBR programme and it started by identification and training of a four-member national CBR team. According to this plan each level would have trained the following lower level, starting with the national team of CBR, through the Aimag doctors at provincial level, the somon (district) doctors and family doctors, and finally the health workers (feldschers) at the village (Bag) level. Thus it

was hoped that through the community level health workers, community involvement and ownership of the CBR programme would be achieved.

Initial activities focused primarily on training national and intermediate level health personnel for rehabilitation related work. Between 1992 to 1996, training and capacity building of the national personnel working with the Ministry of Health was undertaken along with organisation of district level training courses with the assistance of expatriate consultants. In 1997, an extensive three-year plan (1998-2000) was formulated to systematically expand the implementation of the community based rehabilitation programme in Mongolia to almost 56% of the national territory, with the assistance of funding from the European Union (EU) and AIFO (7). The two primary activities that were identified for implementation in collaboration with the Ministry of Health were:

1. Training of health personnel at intermediate and peripheral level, namely, family doctors (for urban areas), Aimag (province) doctors, somon (district) doctors, feldshers (rural health workers), in techniques of medical rehabilitation and making of simple appliances. Each training programme was planned for three weeks with ten-day refresher courses and also included translating and distributing the WHO Manual and other teaching materials in Mongolian. The trained personnel were to transfer the information and skills to persons with disability and their families in the communities. Eleven aimags (provinces) in the western part of the country and six districts in Ulaan Bataar were selected for implementing the training.
2. Support for production of orthopaedic appliances through improvement of a national orthopaedic workshop at Ulaan Bataar and creation of two regional orthopaedic workshops in Zavkhan and South Gobi.

In addition to the above, two primary activities, the plan included components for collaboration with other Ministries, national and international NGOs, strengthening of organisations of persons with disabilities, promotion of inclusive education for disabled children, micro projects for vocational training, and promotion of economic self-sufficiency of persons with disability through rotating credit funds.

### **ACCOMPLISHMENTS OF THE CBR PROGRAMME IN MONGOLIA**

The most visible accomplishment of the national CBR programme has been the training of intermediate level functionaries using the WHO manual. By the end of 2000, close to 5,336 intermediate level functionaries, village workers and community volunteers had been trained. Among them, seventy two percent were women.

The training programme has mainly focussed on community level workers as 27% of all persons trained by the programme were community volunteers, 18% were village health workers (feldschers) and another 18% were other community workers. Thus 63% of all the persons trained by the programme were going to work at the community level. Many of these community workers had had no other opportunities for participating in any training courses for the past many years. Further workshops for making simple rehabilitation aids have also been organised. As a result six orthopaedic workshops have been set up at Aimag (Province) level. Also, ten senior level personnel at the national level have been trained in rehabilitation related planning and management.

The data collected by the CBR programme seems to be very different from the data provided by the National Statistics Office. Between 1992 and 2000, the project has covered 6 districts of Ulaan Baatar city and 11 provinces, and in a total population of 1,427,608 population it has

identified a total of 47,050 persons with disability (3.3%). Out of these persons with disability, 13% are children below 5 years and another 12% are children of 6-15 years, while 75% of disabled persons are adults. Similarly the percentages of persons with different disabilities emerging from the data collected by the CBR programme, seem to be very different from the national data provided by Statistics office, especially for persons with intellectual impairment. Among the disabled persons identified by the CBR programme, 24 % have visual impairments, 15% have hearing and speech impairments, 15% have impairments related to movement, 6% have convulsions, 4% have mental illness, 10% have intellectual impairment and 26% have multiple disabilities. Forty nine percent of the disabled persons identified by the programme are women and 51% are men. Such differences in data can be partly explained by differences in survey methodology and definitions of different disabilities used during the surveys.

The activities of the CBR programme at the village level included home visits, making of simple mobility aids, referral services, training for starting rotating savings and credit funds, parent training, vocational training courses, support for strengthening of organisations of disabled persons and so on.

In the nine years since the programme has been launched, there also have been some national level accomplishments. Two of the significant achievements of the national rehabilitation effort in Mongolia are firstly, the development of a National Programme on “Improving the quality of life of people with disabilities” in 1998 and secondly, the creation of a National Rehabilitation and Vocational Training Centre for the Disabled (NRVTC), in November 1999. The first development is significant in terms of the national commitment and political will to work for the cause of persons with disability. The creation of NRVTC is a step toward national capacity building. The centre consists of three units, namely, vocational training department, orthopaedic workshop, and rehabilitative therapy unit.

At the national level, another accomplishment has been the establishment of a central rehabilitation management and training team. In the summer of 2000, this team consisted of the Director General of the Department of policy and co-ordination at the Ministry of Health and Social Welfare, Director of NRVTC, project co-ordinator of the CBR programme, the Director General of the Department of policy and co-ordination at the Ministry of Enlightenment (Education), and the Director of Social Welfare at the Ministry of Health and Social Welfare. The existence of such a team is vital for sustaining and directing efforts for activities that look at the totality of rehabilitation needs and are multi-sectoral.

As far as non-governmental organisations (NGOs) in the country are concerned, many of them emerged in Mongolia after the establishment of democracy. NGOs can serve as important partners for rehabilitation related work where either they can deliver small projects or they can serve as “watchdogs” for monitoring the activities. For the CBR programme, the organisations of disabled persons have had special importance. A national level federation of organisations of disabled persons has been created, partly also due to efforts of the CBR programme. The Buddhist organisations are also gaining re-emergence in the country and some monks have participated in the training courses. Their participation in the CBR programme can play an important role in promoting community awareness and involvement.

## **CHALLENGES FOR THE COMMUNITY BASED REHABILITATION PROGRAMME IN MONGOLIA**

While the Mongolia CBR programme has made significant progress in increasing the coverage to almost 56% of the population, all the activities have been concentrated in the western half of the country. For the national authorities as well for provincial administrations in the eastern half of the country, it is important to extend the programme activities to the uncovered areas. For those unfamiliar with the country, the organisation of any services at the village (Bag) level, where a few houses and a small population may be spread over a large geographical area, would seem a daunting task. However, the role of community health workers (feldscher), often women, is closely integrated in the social and cultural life of these villages and may enjoy an important social position and prestige, even if the salaries may be very low. Sometimes they may travel on horses for days, travelling up to 80 km to reach a sick person, and often stay with the sick person for a period, before coming back to their homes (tents). In addition, they visit all the families of their village, at least twice every year. Theoretically, such prolonged home visits would provide an ideal opportunity to interact with disabled persons and their families for transfer of information and skills. Whether this is happening in practice and whether the training provided to them answers the needs of the communities, still needs to be evaluated.

The main difficulty for implementing the CBR approach in Mongolia's rural areas is the sparse, nomadic population. 'Community' has a totally different meaning in the Mongolian context where one family is separated from another by 20-40 kilometres and families move their living place several times during the year to find newer pastures for their animals. Communication and transportation between the provincial centre and districts, and between districts and Bags (villages), is difficult due to lack of basic infrastructure. Thus, it is difficult to organise any supervision and referral support to the community health workers. This lack of accessibility is further compounded by an extreme continental climate of only 100 frost-free days a year. All these factors make it very difficult for persons of the same village to come together, and organising meetings of persons from different villages even more daunting.

Thus, communication and sharing of knowledge and experiences between different communities is much more difficult, which hinders a wide base of community based movement. This is a big challenge for the CBR programme in Mongolia. It also affects the quality of data collected from the different provinces about the CBR activities.

Frequent transfers and high turnover of higher and intermediate level functionaries of Ministry of Health trained by the programme is another challenge for the programme. Involvement of the ministries of infrastructure, finance, agriculture, and education is vital. The first two can serve as important resources in strengthening local sustainability of the programme, while the third will be helpful in planning for rotating credit funds, as many of the micro projects are agriculture related activities. Representatives from Aimag levels are completely missing in the core planning team. Also missing are the representatives from emerging and existing NGOs. While the present capacity of some of these players might be weak, it will not be helpful to neglect these partners completely and to deprive them of building their potentials for future.

The other challenge pertains to improvement in training. The training content and process also need further refinement and updating. At present all the major training activities are planned and supervised by the central training team. However, with the extension of the programme coverage it is under strain. Incentives for trainers remain a challenge as also the issue of "burn out".

The programme needs to decide if it should focus on extension of activities of the remaining uncovered parts in the eastern half of the country or if it should further consolidate its activities in

the covered areas. In any case, the programme needs to evaluate its impact at the most peripheral level.

## CONCLUSION

Mongolia presents a unique situation for community based rehabilitation programming. Over the past decade, the country has been able to identify and devote significant political will towards improving the situation of disabled persons in some parts of the country. However, the lack of infrastructure, scattered nomadic population, severe climate, frequent governmental changes, and repeated restructuring make planning and management of rehabilitation particularly difficult. The country has tried to implement a different model for the implementation of CBR programme and must be one of rare examples where such a huge geographical coverage has been achieved. Even if the programme has been implemented through the existing governmental structures, the specific role of village health workers (feldschers) in Mongolia can provide a bridge between these structures and community involvement. At the same time, the difficulties in monitoring make it difficult to assess the real coverage in terms of access, acceptability and impact on the lives of disabled persons in the rural areas.

\*Associate Professor, School of Health, Physical Education, & Recreation  
University of Nebraska at Omaha  
6001 Dodge Street, Omaha, NE 68182-0216  
Tel: (402) 554-3245, Fax: (402) 554-3693, email: Manoj\_Sharma@unomaha.edu

\*\*Chief, Medical Support Department  
Associazione Italiana Amici di Raoul Follereau (AIFO)  
4-6 via Borselli  
40135 Bologna, Italy  
Tel: 39-051-433402, Fax: 39-051-434046, email: sunil.deepak@aifo.it

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# **DISABILITY AND DEVELOPMENT IN KOSOVO: THE CASE FOR COMMUNITY BASED REHABILITATION**

Majid Turmusani\*

## ***ABSTRACT***

*After completion of most of the planned reconstruction work, Kosovo is now in the process of rebuilding civic and public life which was substantially disrupted during the war of 1999, apart from the disruption caused in the previous ten years of a parallel system under Serb Milosevic's rule. Health and social issues are receiving fair attention with emphasis on principles of equality and equity. Disability issues are amongst those that received particular attention from the international community.*

*Reducing inequality between sections of society requires changes in attitude, creation of sustainable structures, introduction of legislation, policies and working strategies. Equally important is providing services for the vast unmet needs of disabled people, using appropriate approaches that enhance self-capabilities and create a feeling of ownership. This paper argues the case for a more comprehensive approach to disability such as community based rehabilitation (CBR) to be introduced in Kosovo where local people and users of services are involved in the rehabilitation process actively. Employing a participatory approach to rehabilitation such as CBR, in reality however, is a challenging task, given the historical context of Kosovo under a communist regime with limited grassroots participation.*

## **DISABILITY AND DEVELOPMENT**

Although community based rehabilitation (CBR) has been known as a strategy for rehabilitation, in recent years, it is being also used as a vehicle for creating social change and as a means for political mobilisation of disabled people at grass-roots level (1). These aspects have been neglected in most CBR work in Kosovo. It is important for emerging disability organisations in Kosovo to recognise these issues, for them to achieve their vision of a disability movement with nation-wide membership.

Of late, disability is also considered as a development issue by planners and policy makers in an increasing number of countries across the world (2). Disability and development are closely linked in a cycle of cause and effect, and both are regarded as political issues because the way they are defined by society will influence the measures taken to deal with them. The political implication of this understanding of disability can be seen in Kosovo in the way in which the disability sector has been supported and developed in recent years. Because functional limitation is considered as most restricting to individuals, attention has been directed towards those with physical mobility. Other impairments and disabilities that are not so obvious receive less attention from planners and policy makers although they are as restricting to the concerned individuals as other impairments. National and international initiatives in Kosovo have historically focused on physical and mental impairments, and more recently on other kinds of impairments, employing a medical approach to rehabilitation. Only recently have some international NGOs been involved in policy development, and they support local efforts to set up a task force on disability policy. The association of paraplegic children Handikos, with its 10 community centres and 25 community groups throughout Kosovo, has been the main partner to most international NGOs. Handikos' experience in policy development is still modest and it is expected to produce a Green paper on disability by end of 2001. However, Handikos' experience in physical rehabilitation has been commendable in Kosovo and this will be analysed in some detail in the proposed document.

The current trend of supporting local disability service providers to reach the status of an umbrella organisation and to influence policy are important and needed in Kosovo, but this process should not force premature changes in existing structures. In changing their role, such organisations should not neglect their obligations to service delivery. Drawing from the experiences of other social and political movements in the world including those of disabled people, it is seen that often the needs at the grassroots level generate the impetus for social change and changes in policy. Volunteers at the grass roots level can also lend support to community organisations, strengthening their position as service delivery organisations and justifying another potentially important role of these agencies as advocacy organisations (3). This bottom up approach from the grass roots has helped to highlight the situation of disabled people in Kosovo, and has proved to be sustainable after overcoming many obstacles so far. It is important that this approach continues at both policy and service delivery levels so that ordinary disabled people continue to feel part of a movement and to extend appropriate support to their leaders when necessary.

## **APPROACHES TO DISABILITY IN KOSOVO**

The complexity of the situation in Kosovo, including the fragile peace process in the region, the repeated clashes between ethnic groups in neighbouring Macedonia which has the potential to develop into a civil war, the increasing number of refugees from Macedonia, many of whom have disabilities, have necessitated the development of different approaches and methods of work. The needs of disabled people have been met through institutional residential approaches provided by the previous regime, specialised medical rehabilitation centres established by both international and local initiatives and of late, community based approaches promoted mainly by international organisations. International involvement in disability issues in Kosovo now focuses on building partnerships with local organisations such as Handikos and its network, in five major areas.

### **1. Assistance in service delivery**

This approach was prominent in Kosovo especially after the war. This kind of assistance is provided directly to local disability organisations or to disabled individuals. Different kinds of organisations are involved in service delivery, including those that serve a single group such as landmine victims, those that have a special project for disabled people as one of their range of activities, and those that include disabled people as part of the group of disadvantaged persons such as the poor, minority groups, unemployed, and so on.

### **2. Capacity building**

This kind of support started after the war, in line with the United Nations Interim Mission in Kosovo (UNMIK) ideals of building a sustainable society and effective organisations. There are a number of international NGOs working on capacity building of local disability organisations such as Handikos, deaf clubs and others. Support for capacity building includes two aspects. The first is strengthening of management and administrative structure within the headquarters, and of the network of community centres and local groups. The second is support for building a base of knowledge and skills for field staff through training workshops, seminars and follow up visits.

### **3. Support in policy development**

This work was pioneered by some European agencies from 2000 and is in line with the democratisation process promoted by UNMIK and Organisation of Security and Cooperation in Europe (OSCE). It focuses on developing policies for disabled people at the national level in the form of Green and White papers, which will form the basis for legislation on disability subsequently. This is a collaborative effort with Handikos association along with associations of

persons with visual and communication impairments. UNMIK had showed interest in supporting policy development but there is still no single specialist person or unit at UNMIK to provide the technical backup to partners involved in this process. It is obvious that partners are motivated to advance the cause of disabled people at the policy level, but it is also clear that technical knowledge is limited in many ways.

#### **4. Support to co-ordination between partners**

There are around 300 international NGOs operating in Kosovo, some of whom (approximately 30) work with disabled people in one or more of the above mentioned areas. UNMIK by virtue of their mandate, issues policies and lays down the procedures to regulate the work of NGOs. There is however, a clear lack of co-ordination and co-operation between partners. Potential areas of co-operation could be information sharing, co-ordination in planning activities and their implementation, joint funding when applicable and influencing of policies.

#### **5. Funding support**

This includes bilateral and multilateral co-operations, government funds and other forms of local financial support.

Another area for co-operation between partners in Kosovo is research. Planning services for disabled people based solely on reports and outside expertise is not sufficient to gain insights into the situation of disabled people. Proper research practices such as a situational analysis, are missing. Two important areas for the future are policy research and research on social change and community mobilisation.

### **SHORTCOMINGS IN THE EXISTING STRUCTURE**

The humanitarian situation in pre and post-war Kosovo necessitated a quick response on the part of UN and other international agencies to the vast needs of Kosovars, using methods different from what were used in other parts of the world. To prevent starvation, ill health, violence, abuse, and post war complications, a great deal of resources have been invested by the international community (4). However, there have been some limitations in delivering assistance to local people, particularly when working in partnership with local organisations.

In addition to creating an artificial environment in Kosovo which does not seem to be sustainable, international NGOs have also promoted a feeling of dependency and reliance on external help, rather than creation of self capabilities, self confidence or local strength and resources. This happened because the emergency practices have continued until now and the agencies have been slow to adopt a more sustainable approach to community development.

It is fairly easy to identify western influences on Kosovar society, especially in Prishtina. The designer shops, 'high tech' stores and mobile phones are visible everywhere, like in any other western country. Although this may be the situation to aspire for in many underdeveloped countries, the process may have happened too soon and too suddenly in Kosovo, such that the local people are not even able to figure out what is going on around them, what will occur in the near future and how they are going to maintain the same level of living in the future. Creating a free market economy and culture can be important to the development of society, but it should be in the context of local norms, values and traditions. Moreover, market economy needs to also take note of promoting local industries, local capabilities and community wealth. Foreign aid regardless of the political reason, is not in itself sufficient for nation-building, although it may be essential for the development of Kosovar society.

International NGOs have been influential on a smaller scale relating to the disability sector in Kosovo, and have been successful in bringing it to the world's attention. Despite positive contributions to the disability sector, these agencies have also had their limitations. A critical review of the current involvement of international NGOs in disability issues in Kosovo shows that the work was mainly carried out by expatriates, and local capacity building has been limited. Despite the great potential of existing resources in terms of staff, funding, skills and so on, the majority of workers employed by these agencies (locals and outsiders) lack proper qualifications, knowledge and attitudes with regard to disability interventions (5). Their partnership has also focused on Handikos as the main association of physically impaired people and not enough efforts have been made to include other categories of impairments or other organisations and groups. Although other groups of disabled people are represented at a policy level in task force meetings, their voices are not heard and their presence takes the form of representation without active participation. Even the support to develop Handikos as an umbrella organisation has neglected some fundamental issues relating to NGO structure, such as voluntary membership status. Currently individual members of Handikos are those employed at the network, who are considered as volunteers. Their remuneration however, is higher than full time employees of state run services. Existing forms of support to disabled people obviously lack strategic thinking in terms of long term development of Handikos association and its network, apart from the disability sector at large. Creating an umbrella organisation requires different inputs, process and outputs (5).

Overall, work in the disability sector in Kosovo has focused on reactive planning in delivering services instead of a proactive approach to planning. No mechanisms were set up to measure outcomes or to monitor performance. In conclusion, the work to date, remains scattered and ineffective as every partner has their own different and sometimes contradictory approach to disability in Kosovo, method of work and political priorities. Kosovo lacks a comprehensive disability policy starting from definitions and ending with inclusion and beyond. It becomes essential therefore to involve all stakeholders in a dialogue and consultation process in order to reach a single policy position and plan of action regarding disability issues in Kosovo.

### **FUTURE DIRECTIONS IN THE DISABILITY SECTOR IN KOSOVO**

The timely debate about moving towards a disability and development perspective by the international community in Kosovo, means engaging in politics because the proposed process promotes participation, partnership and empowerment. In a sense, everything becomes political, from terminology to policy to service provision. It does not mean that service provision is ignored in focusing on disability policy and disability politics. But rather, it means a consideration of politics as an underlying principle in service delivery, in line with the ideals promoted by the disability movement and disabled people's organisations.

Active participation, control and ownership by disabled people who are service users are the key issues for the future of the disability sector in Kosovo. This includes their involvement in assessing their needs, making priorities and designing interventions. Involvement in policy making at all levels is also necessary to the development of the disability movement's identity and character. The political insights drawn from the 'disability approach' can also serve as a guiding experience to other oppressed and marginalised groups in society such as ethnic minorities, women and poor people. This can help to facilitate the goal of inclusion of disabled people into society with equal access to services and opportunities in line with a citizenship approach to disability (6). In the long run, inclusion leads to empowerment in the sense that disabled people will realise their potential and get more power over their lives.

Generally speaking, without feedback, the desired impact over any issue can not be ensured. On a more specific scale, development interventions in disability can only be verified and validated when feedback is given and evaluation is undertaken to see whether objectives have been achieved within specified timeframes and levels (7). Many international NGOs have neglected this important aspect of the project cycle and have continued to provide their support based on political grounds, or on requests based on estimated needs by other partners. Very little effort has been made to evaluate previous and existing support or to develop monitoring criteria. Standards for monitoring and evaluation of disability projects are necessary not only for planning services but also for decisions concerning future support. Future investment in disability issues needs to be based on evaluation and proper situational analysis. Any evaluation process should focus on activities and how much they relate to the stated objectives. Quality of service, level of performance, satisfaction of users, and development of the community are some of the parameters to be considered for evaluation. It is crucial to reach a balance between professionals' views and those of service users about the achievements.

In Kosovo, although various training courses have introduced the social model of disability and the CBR approach, their application remains limited. For example, until now, the assessment of disabled children and adults relied solely on a medical model. This only serves to locate disability issues within the individualistic medical understanding and not within its wider societal and political context (8).

#### **TOWARDS A DEVELOPMENT APPROACH TO DISABILITY: THE CBR MODEL**

The socio-cultural and economic construction of disability suggests a solution within societal boundaries. Given its developmental nature, the notion of disability can best be addressed under a community development framework such as CBR. CBR is built on four main developmental principles namely, 'minimum approach to assistance', 'participation', 'sustainability', and 'empowerment'. These are discussed below.

When initiating CBR, it is important to reach a balance between outsider support and local contribution. Although most CBR projects world-wide were started by outsiders, there is always room for greater involvement of local people (9). The 'minimum assistance approach' aims at enhancing self-reliance of the local community and utilisation of local resources. This approach involves a partnership with the local community where locals are required to contribute actively as equal stakeholders, and encourages independence and creativity in handling community affairs.

The active 'participation' of the local community including users of services and their families in the rehabilitation process, creates a feeling of ownership and promotes a sense of control over community development initiatives (10). This can be valuable for sustainability of any project. Participation is a never ending process and the development approach to disability strives to achieve a high level of participation of local people and other stakeholders in all stages of CBR starting from identification of needs and project design, and ending up with evaluation and decisions about the future (11).

'Sustainability' is often the number one concern of any development project, including CBR. It means more than securing enough funding to keep the project running, as it involves skills, human resources and other contextual issues. For planners, sustainability is an ethical issue in the sense that providing services should be guided by thinking of the long lasting effect on the local community and on those who will benefit from the intervention, enabling them to become self sufficient.

Increasingly, CBR initiatives have emphasised the concept of 'empowerment' of those involved in the rehabilitation process, especially users of services. CBR can in fact facilitate the emancipation of disabled people by letting them be part of such a process and thus serve as a political tool which may contribute towards empowerment. Disabled people are often the last on the list to be consulted regarding the way services are delivered to them and their views are often neglected by a strong presence of professionals at all levels (12). Perhaps, the most current controversial issue in disability and rehabilitation is 'power relations' between professionals and disabled people. Historically, professionals and able-bodied people have maintained control over disabled people's lives perpetuating their passivity and contributing to their dependency (8). The latter was one of the reasons for the emergence of the disability movement and de-institutionalisation of rehabilitation services across the world. Debate concerning this move is still growing in Kosovo, but at a slow pace.

There are variations in different societies regarding what CBR means and involves. Applying an imported definition of CBR into a certain context should thus be treated with caution. Successful CBR initiatives are those which take note of 'cultural issues'. This primarily means the way cultural belief systems define and perceive a disabled person, as well as societal attitudes towards that person. A CBR that is based on women as the workforce for example, would not win local support in a male dominated society although women usually end up doing most of the labour required by CBR in most instances. In Kosovo, Werner's 'Disabled Village Children' (13) is widely used as a 'curriculum' for rehabilitation in the community centres of Handikos. Werner's work which has been translated into many languages including Albanian, can be useful in the Kosovar context, but needs to be modified to suit the current state of development in Kosovar society. The philosophy underlying this work nonetheless remains important as it encourages local solutions to local problems employing simple community based technology.

To sum up, CBR aims to mobilise disabled people to achieve their own empowerment (14). The fact that traditional approaches have been unable to reach those in need efficiently and in a cost effective way, has led to the emergence of CBR as an alternative approach. This new approach promotes greater involvement of disabled people in the rehabilitation process and utilises local resources to the maximum level possible, both of which are greatly needed in Kosovo.

Given the complex situation of rehabilitation services in Kosovo in terms of existing skills and knowledge and how they respond to the needs of disabled people, starting a CBR at national level as being promoted by some international NGOs would not be practical. By definition, CBR is based on active local community participation and utilises available resources. Setting up a CBR project requires a different approach which considers quality of services as most important together with reaching wider target groups, ideally through sampling or small scale projects. CBR aims not only to provide rehabilitation services to those in need but also to change attitudes of the local community towards service delivery itself. The ultimate goal of CBR is to make people responsible for their own rehabilitation process and subsequent outcomes.

At present, CBR services in Kosovo are provided by Handikos. Its operation consists of 10 community centres and 25 local active groups with a total workforce of 135 people including those at the headquarters, all of whom are considered as volunteers. The network (community centres and local active groups), are linked with regional co-ordinators who in turn report to the Handikos headquarters. A local active group consists of a field co-ordinator, medical health technician and the person in charge of the group. They are responsible for identification of new cases, registration, referral to community centres and distribution of materials. At community centres there are 2 physiotherapy technicians, a psychosocial worker, a centre co-ordinator and a

driver. Workers at community centres provide physical rehabilitation services (physiotherapy and play activities) to children attending the centres.

There is a need for more appropriate tools to monitor the progress of rehabilitation interventions at community centres. The tools adapted from 'Disabled Village Children' are not sufficiently developed for accurate measurement of performance. Monitoring tools need to answer the following questions: what level of functioning does the disabled person have at present? What targets are to be set for interventions, focusing on ability and not disability? What interventions will achieve the targets, with family involvement in the process? Such information can help in further planning.

## **CONCLUSION**

There are two polarising positions with regard to disability and rehabilitation in Kosovo, namely, rehabilitation as an emergency response, versus rehabilitation as a form of development. Sponsors of the disability sector, including the international community and UNMIK, are moving slowly towards a development approach to disability. Present practices, however, are still biased towards an emergency approach, with little efforts towards capacity building and skills transfer to local partners.

Current practices in CBR are also lacking in contemporary and sustainable methods of work. For example, existing CBR training is medical in nature, and would benefit from a more holistic view of community and inclusive ideals. Disabled people have needs other than medical rehabilitation and these should be assessed and addressed properly, including the needs for education, vocational training, employment and involvement in political life. Although the needs of disabled people across societies are similar in some way, the priorities of disabled Kosovars might be substantially different from other countries due to the particular nature of the society in terms of political, socio-economic and cultural circumstances. Regardless of which country disabled people live in however, they need to have a source of income as a priority to meet their everyday needs (15).

The lack of a clear policy on disability and rehabilitation at Kosovo leads to much diversity in the different players in terms of focus, methods of work and political priority. Setting a common framework of action for policy on disability issues would be particularly relevant in this context. Furthermore, encouraging debate concerning empowerment of disabled people might be one way to bridge the gap between the various players in the disability field. On a larger scale, co-ordination between partners is needed and should be taken forward so that the needs of disabled people are better served. There is also a pressing need to develop 'disability and rehabilitation research' where planning is based on real needs.

\*People Potential

Plum Cottage, Hattingley road, Medstead, alton, Hampshire GU34 5NQ, UK

Email: turmusani@hotmail.com

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## ORIGINAL ARTICLES

### TEMPORAL DYNAMICS IN SOUND / SYLLABLE REPETITIONS OF STUTTERERS AND NORMAL NON-FLUENT CHILDREN: A PILOT INVESTIGATION IN TAMIL<sup>1</sup>.

Prakash B\*, Susha S. Verghese, Glory E. Dhanaraj

#### **ABSTRACT**

*Attempts to differentially diagnose stuttering from normal non fluent children acoustically have received central, theoretical and practical attention in recent years. However, temporal aspects of acoustic analysis of speech in dys / disfluent children has been relatively neglected, and this is the focus of the present study. The study investigated durational aspects of the silent intervals (IID), spoken repetition units (ITD), fluent portions (FTD), total duration (TD) and the number of iterations within sound /syllable repetitions in the speech of stuttering and normal non fluent children who speak Tamil as their native language. The results reveal significant differences between the groups in all the parameters. The discussion focuses on the results from a theoretical (stuttering as a motor control disorder) and a clinical (differential diagnostic cue) perspective.*

#### **INTRODUCTION**

The crucial issue of differentiation between cases of early stuttering and normal non fluency in its incipient stage, is one that has received considerable attention from the field of research for many years. Efforts to distinguish normal non fluency from stuttering in a categorical way have focused on the identification of specific features in early disfluency, but have yielded little success. Various researchers (2,3,4,5) have considered aspects such as type of disfluency (syllable/word repetitions, prolongation, interjections etc.), frequency of occurrence and number of repetition units as some of the indicators for differential diagnosis of stuttering and normal non fluency.

More recently there has been a surge of interest in the objective analysis of disfluencies (6,7,8,9,10). Durational aspects of part word repetitions and sound prolongation have also been studied (11,12,13). But short segment repetitions and silent intervals between repetitions were not given relative importance until recently where Throneburg and Yairi (14) and Yairi, Hilchie and Hall (15), reported data on the durational characteristics of several identifiable segments within single repetitions of single syllable words. Their results indicated that the ratio of the silent interval to the total disfluency was smaller for stutterers than non stutterers. They speculated that the silent interval was a crucial factor to differentiate the speech of stutterers from normally non fluent children. Zebrowski (13) used acoustic analysis to measure the duration of part word repetitions and sound prolongation in the speech of stutterers and normally non fluent children. She found no significant differences in duration between the two groups.

Thus, no conclusive data are available on the durational characteristics of disfluencies. Studies till date have focused on single unit repetitions, however, multiple unit repetitions which may be speculated as a crucial diagnostic tool, have not been investigated adequately and this is the focus of the present study. The present study aims at evaluating the significance of durational characteristics of single and multiple unit repetitions as an important tool to differentiate between childhood stuttering and normal non fluency. It is hypothesised that there is no significant difference between the two groups on the durational parameters studied namely, Inter-iteration

duration (IID), Iterated token duration (ITD), Fluent token duration (FTD) and Total duration (TD).

## **METHOD**

### **S u b j e c t s**

The subjects included ten Tamil speaking children in the age range of 3-8 years. They were divided into two groups. Group A consisted of five moderate stutterers, four males and one female, while Group B consisted of five normally non-fluent children, three males and two females (diagnosed by Speech-Language Pathologists). The subjects had no other speech, language or hearing deficits other than stuttering.

### **P r o c e d u r e**

The children were comfortably seated in a noise free room at the Speech Science Laboratory. They were involved in two tasks:

- a task of general conversation with at least one of the investigators for a duration of 5-8 minutes, and
- a picture description task / a story narration task, using a standard Indian (Panchatantra) story.
- These were audio recorded using a stereo cassette deck on a high quality audio cassette, using a high fidelity microphone kept at a distance of 12 centimetres from the speaker. The recordings were transcribed verbatim and the dys /disfluencies were identified. These dys /disfluencies were required to meet the following criteria:
- Dys /disfluencies other than sound / syllable repetitions were not included.
- Dys /disfluencies having sound / syllable repetitions along with other dys / disfluencies (e.g., Prolongation, interjections etc.,) were discarded (e.g., p.p.o..t pot).
- Tokens having iterations in the final position in a word were not included (e.g., pot....t...t).
- Tokens selected had to be free of interfering noise (recording).

Group A yielded a total of 46 dysfluent tokens, of which 25 were single unit repetitions and 21 were multiple unit repetitions. Group B provided a total of 11 disfluent tokens, of which 9 were single unit repetitions and 2 were multiple unit repetitions. This formed the material for the acoustic analysis.

### **A c o u s t i c a n a l y s i s**

Temporal analysis was carried out using the software programme “Vaghmi”.

The following acoustic measurements were made based on the waveform displays:

1. Inter Iteration Duration (IID): The time difference between the end of an iteration and the beginning of the next iteration / fluent utterance in milliseconds.
2. Iterated Token Duration (ITD): The time difference between initiation and termination points of an iterated token in milliseconds.
3. Fluent Token Duration (FTD): The time difference between the initiation and termination points of the iterated sound / syllable in the fluent token in milliseconds.

4. Total Duration (TD): A combination of inter-iteration duration, iterated token duration and fluent token duration in milliseconds.

On the display, the end of an iteration and the beginning of the next iteration / fluent utterance were marked using the cursors. Initiation was visually defined as the first peak (maximum amplitude in milli volts ) judged as the first sound of the disfluent episode. Termination was defined as the last consecutive peak in the waveform. Initiation and termination points were also verified auditorily. Apart from these the number of iterations, both single and multiple, were also noted.

## S t a t i s t i c a l   a n a l y s i s

Because of the small sample, a non parametric statistical procedure, the Walsh test (16) was used to estimate the significance of difference between the two groups on the various parameters.

### RESULTS

#### 1. Inter-iteration duration (IID)

**Table 1: Means (S.D) of IID (in msec) and number of tokens (single iterations) measured in Groups A and B.**

GROUP A (stuttering)				GROUP B ( normal non fluent)			
1.	S1	5	105.2(34.59)	1.	N1	1	25.0
2.	S2	3	64.3(62.94)	2.	N2	-	-
3.	S3	7	132.14(70.12)	3.	N3	4	280.5(52.26)
4.	S4	7	170.57 (163.7)	4.	N4	3	142.0(203.04)
5.	S5	3	114.0 (36.0)	5.	N5	1	594.0(167.31)
<b>Mean (S.D)</b>			<b>5(2) 117.24 (38.81)</b>	<b>Mean (S.D)</b>			<b>2.25(1.89)</b>
			<b>260.38(245.71)</b>				

The IID (single iterations) for Group A (stutterers) ranged from 64 msec to 170 msec [mean 117.24 and (S.D) 38.81], while the IID for Group B (normal non fluent) ranged from 25 msec to 280 msec [mean 260.38 and (S.D) 245.71]. There was a significant difference between the two groups at the 0.031 level. On comparison of the means of IID for single iterations (shown in table 1) it was found that IID for stutterers was shorter than for normal non fluent children.

**Table 2: Means (S.D) and number of tokens for the IID (multiple iterations) measured in groups A and B.**

GROUP A (stuttering)				GROUP B ( normal non fluent)			
1.	S1	4	213.79(63.96)	1.	N1	-	-
2.	S2	-	-	2.	N2	1	268.0(65.05)
3.	S3	9	219.96(203.6)	3.	N3	-	-
4.	S4	3	108.4(28.24)	4.	N4	1	9.8(2.97)
5.	S5	5	172.06(40.77)	5.	N5	-	-
<b>Mean (S.D)</b>			<b>4.2(3.63) 178.55(51.38)</b>	<b>Mean (S.D)</b>			<b>0.4(0.75)</b>
			<b>138.9(182.6)</b>				

The IID (multiple iterations) ranged from 108 to 219 msec for Group A (stutterers) [mean 178.55 and (S.D) 51.38] and from 9.8 to 268 msec for Group B (normal non fluent children) [mean 138.9 and (S.D) 182.57]. There was a significant difference between the two groups at the 0.031 level. The IID (multiple iterations) for normal non fluent children as a group was less than the stuttering children.

## 2. Number of single and multiple iterations

Tables 1 and 2 also reveal the number of single and multiple iterations in both the groups. The number of single iterations ranged from 3 to 7 [mean 5 and (S.D) 2] in Group A and between 0 to 4 [mean 2.25 and (S.D) 1.89] in Group B. The number of multiple iterations ranged from 3 to 9 in Group A [mean 4.2 and (S.D) 3.63] and between 0 to 1 in Group B [mean 0.4 and (S.D) 0.75]. Stutterers as a group had more single and multiple iterations.

## 3. Iterated Token Duration (ITD)

**Table 3: Means (S.D) for ITD of single and multiple iterations measured in Groups A and B.**

GROUP A (stuttering)				GROUP B ( normal non fluent)			
1.	S1	10.8(8.14)	20.4(12.17)	1.	N1	6.0	-
2.	S2	149(94.84)	-	2.	N2	-	71.15
3.	S3	120.6(106.5)	85.21(98.95)	3.	N3	156 (143.6)	-
4.	S4	116.28(77.7)	128.7(83.79)	4.	N4	142(47.82)	7.4
5.	S5	170.3(40.45)	233.9(127.1)	5.	N5	215	-
<b>Mean (S.D)</b>		<b>113.4(61.43)</b>	<b>117.07(89.7)</b>	<b>Mean (S.D)</b>		<b>129.9(88.4)</b>	
		<b>39.45(43.3)</b>					

The ITD for single iterations for Group A (stutterers) ranged from 10.8 to 170.3msec [mean 113.40 and (S.D) 61.43], while the duration for Group B (normal non fluent) ranged from 6.0 to 215msec [ mean 129.87 and (S.D) 88.40]. The difference between the means of the two groups was statistically significant at the 0.031 level. The ITD in single iterations as a group was less for stutterers than for normal non fluent children.

The ITD for multiple iterations for Group A (stutterers) ranged from 20.4 to 233.96 msec [mean 117.07 and (S.D) 89.74]. Only two multiple iterations were measured in Group B where N2 and N4 had 71.5 and 7.4 as ITD (in msec) respectively. A significant difference was found between the means of the two groups at 0.031 level.

## 4. Fluent token duration (FTD)

**Table 4 : Means (S. D) for FTD for single and multiple iterations in Groups A and B.**

GROUP A (stuttering)				GROUP B ( normal non fluent)			
1.	S1	64.4(57.3)	62.25(39.6)	1.	N1	108.0	-
2.	S2	176.6(120.9)	-	2.	N2	-	89.0
3.	S3	101.43(70.9)	79.89(78.3)	3.	N3	126.0(78.8)	-
4.	S4	107.14(65.4)	64.67(63.0)	4.	N4	120.0(41.04)	138.0
5.	S5	121.0(79.9)	195.6(104.0)	5.	N5	104.0	-
<b>Mean (S.D)</b>		<b>114.11(40.7)</b>	<b>100.6(63.8)</b>	<b>Mean (S.D)</b>		<b>114.5(10.25)</b>	<b>113.5(34.65)</b>

The FTD for Groups A for single iterations ranged from 64.4 to 176.6 msec [mean 114.11 and (S.D) 40.72], while the same in Group B ranged from 104 to 126 msec [mean 114.5 and (S.D) 10.25]. The difference in the duration of fluent token for single iterations was found to be statistically significant at the 0.031 level.

The FTD for Group A for multiple iterations ranged from 62.25 to 195.6 msec and for Group B subjects N2 and N4 had 89 and 138 msec as FTD respectively. Other subjects revealed no multiple iterations. A significant difference was found between the two groups on the FTD for multiple iterations.

### 5. Total duration (TD)

**Table 5: Means (S.D) for TD for single and multiple iterations in Groups A and B**

GROUP A (stuttering)			GROUP B ( normal non fluent)				
1.	S1	180.4(88.4)	756.78(245.9)	1.	N1	139.0	-
2.	S2	390(190.6)	-	2.	N2	-	768.0
3.	S3	354.14(97.2)	1366.2(697.8)	3.	N3	563(256.13)	-
4.	S4	394.6(216.1)	741.3(317.65)	4.	N4	524(167.31)	224.0
5.	S5	405.3(146.9)	1109.4(507.8)	5.	N5	594.0	-
<b>Mean (S.D) 344.86(90.59)</b>			<b>993.43(203.0)</b>	<b>Mean (S.D) 455.0(212.6)</b>			<b>496(384.7)</b>

The TD of the single iterations in Group A ranged from 180.4 to 405.33 msec [mean 344.86 and (S.D) 90.59] and the same in Group B ranged from 139.0 to 594.0 msec [mean 455 and (S.D) 212.6]. However, N2 had no single iterations. The test of significance revealed a significant difference at 0.031 level.

The TD for multiple iterations in Group A ranged from 741.3 to 1366.2 msec [mean 993.4 and (S.D) 203.0]. However, S2 had no multiple iterations. On analysing the same in Group B, three subjects viz., N1 N3 and N5 revealed no multiple iterations. Subjects N2 and N4 had 768.0 and 224.0 as their TD ( in msec) respectively. This showed multiple iterations were more likely to be seen in the stuttering group than in the normal non fluent group. On the values measured, TD was shorter for stutterers as a group when compared with the normal non fluent group.

### DISCUSSION

In concurrence with the results reported by Throneburg and Yairi (14), the present study also reveals that stutterers exhibited shorter silent intervals between spoken repetition units i.e., inter iteration duration were shorter in stuttering children than normally non fluent children in single iterations. But an opposite trend was obtained on analysing multiple iterations. However, the number of multiple iterations in Group B was small and so the result should be viewed with caution. This trend indicates that stuttering children tend to repeat faster than children who do not stutter, giving relatively lesser time for motoric self-correction.

The ITD was found to be lesser in stuttering children than normally non fluent children. Zimmermann (17), views repetitions as reflexive responses in an attempt to correct various spatial and temporal articulatory relations. Making an inference from the above, the relatively shorter time of the iterated token may reflect a reflexive correction of movement velocities, inter articulatory relations, tensions and so on, effecting a better approximation of the intended target, which indicates a more central strategy of correcting errors.

The FTD were very similar for the two groups of children which reveals that the fluent tokens were produced in more or less the same physiological time.

The TD of the stutterers' dysfluencies were significantly shorter because of their shorter silent intervals, when compared to the disfluencies of the normal non fluent children. This finding concurs with that of Throneburg and Yairi (14).

Finally, the number of single and multiple repetition units in stuttering children were more than normally non fluent children. Yairi and Hall (18) suggested a heavier reflexologic role in stutterers as a reason for faster repetition rate. Based on this notion, it may be concluded that in normal children the system allows sufficient time to make necessary adjustments between one attempt and the next. The result is a net reduction in the number of repeated units in the normal group. However, in stutterers, corrective responses may be reflexively rigid, allowing only brief intervals for readjusting. Thus the corrections may not accurately match the target, requiring more corrective attempts. This may account for the fact that the stuttering children exhibited more number of iterations within a dysfluent episode.

## CONCLUSION

According to Yairi and Hall (18), 'Data on subtle temporal characteristics of segments within disfluencies provide information that is not detected when instances of disfluency are treated as a whole'. The results of the study strongly affirm this statement, and highlights the need to probe into subtle temporal dynamics in routine evaluation for a better differential diagnosis. However, further research with a larger sample, and refined temporal parameters (multiple iterations) in greater numbers is warranted to throw more light on this area.

\*Department of Speech, Language, and Hearing Sciences  
College of Allied Health Sciences  
Sri Ramachandra Medical College and Research Institute  
No.1, Ramachandra Nagar, Porur, Chennai 600 116  
Tamil Nadu, India.

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## SECONDARY DEFORMITY IN LEPROSY: A SOCIO-ECONOMIC PERSPECTIVE

M. Ghimire\*

### ABSTRACT

*This study describes the demographic and socio-economic status of patients admitted to Anandaban Leprosy Hospital, Nepal, who had deformities, using a case study and descriptive approach. During November and December 1997, 100 inpatients (70 male and 30 female) who were available during that period of time were taken for this study. Non-Nepali citizens were excluded. Deformity was categorised into 2 groups. Those that were a result of direct nerve damage by invasion of *M.leprae* were categorised as primary deformity (e.g., anaesthesia, claw hand, foot drop etc.). Those that were a result of neglect of primary deformities, were categorised as secondary deformity (e.g., ulcers, loss of digits etc.) The EPI-INFO package was used to analyse data. The proportion of secondary deformity was found to be higher in an urban resident, female, lower caste, illiterate, no income group and manual workers in comparison to reciprocal groups. However statistical differences were not significant for any of the mentioned variables. A significant difference was found in comparing the age groups of those below and above 30 years of age. Only 29% of respondents below 30 years of age had secondary deformity while percentage was higher (70%) for those above 30 years of age. Further qualitative research is needed to explore risk factors in the development of deformities in patients with leprosy related neuropathy.*

### INTRODUCTION

Leprosy produces disability and deformity through nerve damage (1). The fear and strong stigma associated with leprosy are mostly due to the deformities and mutilations generally regarded as essential features of the disease (2). Patients who are not treated at an early stage of the disease develop anaesthesia and/or deformity of the eye, hands and feet. As a single disease entity, leprosy is one of the foremost causes of deformities and crippling (3).

Primary deformities (e.g. anaesthesia, lagophthalmos, claw hands etc.) are directly caused by the tissue reaction to infection with *M. leprae*. Secondary deformities (e.g. ulcer, loss of toes and fingers etc.) occur as a result of damage to the anaesthetic parts of the body. Several factors are associated with secondary deformities in leprosy. Age, sex, occupation, education and socio-economic status play a significant role in the development of such kinds of deformities (3).

The main aim of this study was to see if there is any relationship between secondary deformities and demographic plus socio-economic status. This study was conducted in the Anandaban Leprosy Hospital, which is situated at Tika Bhairab, Lele VDC of Lalitpur district in the central region of Nepal. Nepal is a country with different ecological conditions and diversified cultures. Thus the patients admitted in Anandaban Leprosy Hospital are not wholly representative of Nepal, although leprosy patients from different parts of Nepal are admitted in this hospital according to medical need irrespective of demographic and socio-economic status. So it was assumed that the information collected from this centre could be used as a representation of the Nepalese situation.

### MATERIALS AND METHOD

During November and December 1996, 100 in-patients who were available during that period were considered for this study. Data were obtained directly from the primary sources. This study followed a case study approach which is descriptive in nature. While collecting information, non-Nepali citizens were excluded. The male: female ratio was taken into consideration because

among the leprosy patients in Nepal this ratio is 2:1. Thus among the 100 persons in the sample, there were 70 males and 30 females. Data were collected through a pre-tested structured and semi-structured interview schedule. To avoid a biased response (that they might expect to receive some benefits by taking part in the study), the subjects were informed that the study was for academic purposes and that the information gathered would be confidential. The interviews were conducted within the hospital campus according to the convenience of patients. The nature of the deformity was categorised into 2 groups. Deformities which are the result of direct nerve damage by invasion of *M. leprae* were considered as primary deformity (e.g. anaesthesia, claw hand/toes, wrist/foot drop etc.). Those that were the result of neglecting primary deformities were considered as secondary deformities (e.g. ulcers, loss of digits, contracture of skin, stiffness of joints etc.). The EPI - INFO computer software package was used to analyse the data.

## **RESULTS**

Attempting to find out the effect of demographic and socio-economic factors on occurrence of primary deformities is not appropriate because these are directly caused by the tissue reaction to infection with *M. leprae*. The secondary deformities occur as a result of neglect of the primary deformities. Therefore it can be assumed that the secondary deformities may be associated with demographic and socio-economic factors. Hence the following variables were taken for analysis.

### **DEMOGRAPHIC FACTORS AND DEFORMITY STATUS**

#### **R e s i d e n c e**

While comparing the deformity in rural and urban residents, 58 % of the rural respondents had secondary deformities where it was higher at 75 % for the urban respondents. It appears to be a remarkable finding because there is a pre-existing notion that the rural patients are more likely to develop secondary deformity. However, the reason for the finding of higher deformities in urban patients is unknown. It may be due to the life style in urban society in which people are mostly self-dependent to perform their own work, have more exposure to technological facilities and face a greater struggle for survival.

#### **S e x**

In comparison to males, females had a higher percentage of secondary deformity. Among the male respondents, 59 % had secondary deformities while this was 67 % for females. This may be due to the pattern of work in Nepalese cultures where females use their hands and feet more frequently than males in their daily house hold work such as cooking, washing, cutting etc. This is opposite to the findings of a study done by Kartikeyan and Chaturvedi (4) where they had reported that the percentage of deformity in males was 13.5 while in females it was 10.3.

#### **A g e**

A significant difference was found in the occurrence of secondary deformity in two age groups. While 29% of those below 30 years of age had secondary deformities, 70% of those above 30 years had the deformities. This may be due to the hazardous exposure in occupations, which is more likely to be faced by people of older age in comparison to the younger age group. Even chi-square test was significant ( $X^2 = 10.09$ ) for these two age groups. However the question remains: is it due to older age or due to the longer period of disease? This could not be clarified in this study because while analysing data for secondary deformity and age, duration of the disease was not taken into consideration. However, this result suggests the need to explore the reason of higher percentage of secondary deformities in people over 30 years of age.

#### **E t h n i c i t y / c a s t e**

Nepal has always been a meeting ground for different peoples and cultures, and the Nepali society is constituted of a number of ethnic groups. Moreover, the society is divided into various castes and sub castes. The caste/ethnicity of the respondents was divided into 4 groups – the high caste comprising brahmins and chhetris, the low caste comprising the damai (tailor), kami (black smith), sarki (cobbler), the Mongoloid group comprising rai, tamang, gurung, magar, sherpa, newar etc., and the Terai origin caste group comprising tharu, teli, sah and others of Indian origin.

Among the higher caste respondents, 63 % had secondary deformities while this figure was 78 % for the low castes, 55 % for the Mongoloid group and 58 % for the group of Terai origin. The lower caste patients are more susceptible to develop secondary deformity in comparison to the other castes. This may be due to their lower socio-economic conditions. In the Nepalese context, more lower caste people are in the lower strata of occupation as well as economic conditions, as shown in Table 1.

**Table 1: Demographic factors vs deformity status of respondents**

<b>Residence:</b>					
Rural	34 (42%)	46 (58%)	80		NS
Urban	5 (25%)	15(75%)	20		
Total	39	61	100		
<b>Sex:</b>					
Male	29 (41%)	41 (59%)	70		NS
Female	10 (33%)	20 (67%)	30		
Total	39	61	100		
<b>Age:</b>					
<30 years	15 (71%)	6 (29%)	21		
>30 years	24 (30%)	55 (70%)	79	$X^2=10.09$	
Total	39	61	100	$P<0.01$	
<b>Ethnicity/caste</b>					
Higher	15 (37%)	26 (63%)	41		NS
Lower	2 (22%)	7 (78%)	9		
Mongoloid	14 (45%)	17 (55%)	31		
Terai origin	8 (42%)	11 (58%)	19		
Total	39	61	100		

## **PRIMARY SOCIO-ECONOMIC FACTORS AND DEFORMITY**

### **E d u c a t i o n**

While comparing the secondary deformities rates between literate and illiterate groups, it was found that the proportion of secondary deformity was higher in the illiterate (64%) in comparison to literate people (57%). This finding suggests that illiterate patients are more likely to develop secondary deformities. This may be due to the capacity of literate patients to understand and follow the instructions given by medical workers to protect themselves from secondary deformity. Similar findings have been reported by Kartikeyan and Chaturvedi (4). In their study, illiterate patients had a higher deformity rate (14.5%) as compared to literate patients (7.3%).

### **I n c o m e**

The respondents showed a wide disparity in terms of income, with the income ranging from zero to more than ten thousand rupees a month. The respondents were broadly categorised into “No income” and “Some income” groups. It was found that 68% of the respondents with secondary deformities had no income at all, while only 50% respondents with secondary deformities had some income. In the “some income” group, there was no difference in the occurrence of primary and secondary deformities. In the ‘no income’ group, the occurrence of secondary deformity was much higher (68%) than primary deformity (32%). This may be due to the pressure of work to earn their living because of which the ‘no income’ group is more prone to develop secondary deformity from their existing primary deformity, or due to failure to get work on account of severe deformity.

### **O c c u p a t i o n**

The respondents were of various occupational statuses. The respondents were categorised into two groups according to the nature of their work. Those who need to use their hands and feet more frequently to perform their jobs were categorised as ‘Manual Worker’ and the rest as ‘Non Manual Worker’. Most of the patients (69%) were manual workers. This may be due to two reasons. Firstly, Nepal is an agricultural country, so most of the population depends on agricultural subsistence, which requires manual work. Secondly, after contracting leprosy, the patients are likely to be left alone to address their daily needs (cooking, washing etc.) by themselves due to the high stigma even within the family. While comparing the occurrence of secondary deformities, 64% of the manual workers have had secondary deformities while this percentage was only 55 % in the non-manual workers.

**T a b l e 2 : P r i m a r y S o c i o - e c o n o m i c f a c t o r s v s d e f o r m i t y s t a t u s o f r e s p o n d e n t s**

Socio-economic factors	Deformity status		Total	X <sup>2</sup>	
	Primary deformity	Secondary deformity			
<b>Education:</b>					NS
(1) Literate	18 (43%)	24 (57%)	42		
(2) Illiterate	21 (36%)	37 (64%)	58		
Total	39	61	100		
<b>Income:</b>					NS
(1) No Income	16 (32%)	34 (68%)	50		
(2) Some Income	25 (50%)	25 (50%)	50		
Total	41	59	100		
<b>Occupation:</b>					NS
(1) Manual Worker	25 (36%)	44 (64%)	69		
(2) Non Manual worker	14 (45%)	17 (55%)	31		
Total	39	61	100		

### **CONCLUSION**

In this study, while examining the relationship between secondary deformity and other variables, no significant differences were found except in relation to the age group. The existing notion that

rural people have higher chances of developing secondary deformity is not supported in this study where three fourths of urban residents had secondary deformities while only fifty percent of rural residents had secondary deformities. However, in this study, the difference in the proportion of these three variables (education, economy and occupation) and secondary deformities are not significant possibly because of the small sample. But it is seen that there is a trend towards a possible relationship between secondary deformity and educational, economical and occupational status. The findings suggest that if people are from a lower educational and economic status, they have more chances of developing secondary deformities. Similarly, the secondary deformity is higher in manual workers compared to the non-manual worker.

This study could not determine the causation of secondary deformity because it was confined to a limited number of patients in the hospital setting. Further qualitative research is needed to explore risk factors for the development of secondary deformities in patients with leprosy related neuropathy in the community. It is important to know the patient's explanatory model of secondary deformity, that is, what they think is the cause and what they did to deal with the problem of deformity, in order to plan appropriate interventions.

\*Anandaban Leprosy Hospital, PO Box - 151, Kathmandu, NEPAL  
Tel : 977-1-290545, Fax: 977-1-290538 , Email: anandaban@mail.com.np

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## BRIEF REPORTS

### ISSUES AND OBSTACLES IN DISABILITY RESEARCH IN SAUDI ARABIA

Salah I. Al-Gain\*, Sami S. Al- Abdulwahab

#### ABSTRACT

*Despite the growing awareness in the public, the health and education professionals about the economic, psychological and medical impact of disability, limited research has been carried out on disabilities in Saudi Arabia. This paper reviews the issues related to the progress of research on disabilities in Saudi Arabia and the deterrents that have limited its progress.*

#### INTRODUCTION

Disability can be defined within the context of an interaction between the functional decrease and the demands and conditions of the environment. Historically, disability studies have examined how people with disabilities have been rehabilitated, or they have delineated the nature of their treatment progress. These studies can be viewed through a medical model in which people with disabilities are perceived as sick and in need of a cure (1,2), through a sociological model where people with disabilities are labelled and characterised by others, through a psychological model where their experiences have been individualised, or through a combination of both a medical and social model or other perspectives (3).

More modern disability studies seek to examine the social, economic, and political forces that serve to marginalise and oppress people with disabilities. The field has evolved over the last several years, drawing on theories and perspectives from sociology, social science, women's studies, cultural studies, and education. It often focuses on the idea that people with disabilities are a minority group that has been discriminated against. In this sense, the study of disability is similar to the study of race, class, and gender inequalities. In addition, disability studies provide the intellectual and methodological tools needed to create disability research and policy. The theories and philosophies of disability studies can then be applied to real issues in law, in community inclusion, and in public policy (3).

Issues in disability research cut across many disciplines simultaneously, which is why much disability research is interdisciplinary, and includes health, economics, sociology, and law. In order to understand some of the disability issues, often integrated data sets are needed, where topics from these varied disciplines can be addressed.

#### DISABILITY RESEARCH IN SAUDI ARABIA

The topic of disability in Saudi Arabia is an important societal issue. Depending upon the definition used, it is currently estimated that 3.73% of the population has functional disabilities which limit their independence (3). To address disability issues one must make better use of the existing information about the prevalence of disability. Further, it is necessary to address the gaps in existing knowledge concerning the nature of disability, and to develop appropriate support programmes to address the needs.

In the Saudi society, the incidence of consanguineous marriages is high. As a result, the risk of disabilities associated with genetic causes is significant. Further, the awareness of inborn errors of metabolism among parents is very low. Over 50% of parents, in response to a questionnaire, had no knowledge of the causes of their children's diseases, their symptoms and their inheritance patterns (4).

Saudi society's view of people with disabilities is based on a simple notion of disability, and comprises helplessness, continuing dependence, being home-bound, low quality of life and lack of productivity. In accordance with these attitudes, small scale educational programmes are provided for the parents of children with disabilities. Most of these programmes are arranged by charitable organisations supported by the Ministry of Labour and Social Affairs. There are also a few programmes on Saudi TV or radio for children with disabilities and their carers. How effective and helpful these educational programmes are in minimising the impact of disabilities on the family and community and in changing the attitude of the community toward disabled people, are issues that are yet to be answered. Therefore, studying the prevalence, characteristics, psychosocial aspects and economic impact of disabilities in Saudi Arabia would be of great value, to help to guide policy and programmatic decisions as well as to enrich the understanding of disability. It can also help to develop a more effective approach to the adequate assessment and management of disability.

In order to have a global national vision about disability in Saudi Arabia, research in disability should also consider demography, epidemiology, health status, access to health care and its costs and coverage, employment and earnings of people with disabilities, social services, benefits, and activity. Research in disability should also consider the impact of impairment on employment and the range of life functions, the ways in which people with disabilities participate (or not) in public and private programmes, and the values and attitudes of disabled and non-disabled people about disability. A few limited attempts at research have considered some of these issues (5,6).

In a research study in Qaseem in 1993, incidence of disability was assessed in 13,841 children below the age of 15 years. According to this study, the most common disability was physical disability, comprising 1.7% and mental retardation, comprising 1.4% (7). The results of this study prompted the Disabled Children's Association to establish a branch in Madina. Recently a national survey on disability showed that there are 3838 disabled children among the 60,630 children surveyed, representing 6.33% (6). These research surveys involved only children, not adults. In these three studies (6,7) that investigated the incidence of disability among children, there is high variation in the incidence figures. This may be due either to varying levels of medical and educational services provided between regions or to the use of different definitions of disability. Methodological errors or high / low percentage of consanguineous marriages in the different regions may be other factors for such variation in disability incidence. Therefore, any interpretation from these studies should be made with caution.

### **OBSTACLES IN DISABILITY RESEARCH IN SAUDI ARABIA**

There are a number of difficulties associated with conducting research on disability related issues in Saudi Arabia. Some of these difficulties are associated with the characteristics of Saudi society such as the high incidence of consanguineous marriage (4), the high incidence of car accidents, and the fact that some families feel ashamed about having a child with a disability and as a result, tend to avoid participation in such research.

Perhaps the most important obstacle is the complete lack of appropriate epidemiological research. Such research could contribute to information about prevalence, type and distribution of disability in Saudi Arabia (5,6,7). How many people with disabilities are there in Saudi Arabia? Information specialists in government or in disability statistics research have difficulty answering this question, because there is no simple, single answer.

Another shortcoming that has limited the nature and extent of information about disability is that much of the research that has been conducted consists of surveys (5,6,7). There is limited research on intervention management or early identification of disability (8). Also, there is no

standard outcome measure used to assess or identify the degree of disability. As a result, there is little validity in comparing the outcomes of two or more different treatments in a clinical trial, or of the same treatment in two or more reports from literature.

Poor data collection procedures and other issues including data linkages, data matching, data analysis, sampling, and international comparability are another problem. The development of better statistical information will obviously be a long-term project, involving a number of researchers with different backgrounds.

Two national surveys showed that the incidence of disability in cities is higher than in villages and small cities (5,6), though this is in seeming contrast to the fact that medical services and health education programmes are better in large cities than in small ones. These results probably reflect more accurate reporting practices in cities as compared to rural areas. Finally, there is no specialised institute for dealing with or collecting data such as those in the USA where specialised studies offer a good basis for understanding disability statistics. There is also the absence of library services on disability issues that provide reliable scientific information about the field.

### **FUTURE DIRECTIONS IN DISABILITY RESEARCH**

In order to expand research on disabilities in Saudi Arabia, it is necessary to determine the exact incidence of disabilities and their nature. Well established programmes for rehabilitation and disability prevention also need to be initiated, followed by frequent and systematic reviews of these programmes by a qualified expert committee. Finally, the authors recommend that a committee on disability statistics should be created to co-ordinate ideas and to develop research funds for disability-related issues. This committee might also consider issues such as the addition of more specific disability questions to national surveys. Without clarity of definition, interpretation of measures for policy purposes is difficult.

### **CONCLUSION**

There are great opportunities in Saudi Arabia to develop new information about disabilities, particularly their nature, their incidence, and their impact on society. These research efforts could be conducted to the betterment of science and society as well as to contribute to the development of new and better services and supports for persons with disabilities and their families.

\*Prince Salman Centre for Disability Research, Resource of Information Department  
PO BOX 94682, Riyadh 11614, Kingdom of Saudi Arabia  
Fax 4826164. E-mail: salah@psedr.org.sa

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# **SUPPLY AUGMENTATION IN THE EMPLOYMENT MARKET FOR PERSONS WITH DISABILITIES**

Rakesh Arora\*

## ***ABSTRACT***

*This article focuses on the ways to move away from low levels of employment and low remuneration, to high levels of employment and reasonable remuneration, for persons with disabilities. It illustrates steps to increase the supply of persons with disabilities and make their presence more conspicuous in the labour market. The author points out that a different set of instruments is needed to augment supply of persons with disabilities in the labour market as compared to augmenting the demand. In an earlier article the author had described methods to improve demand through short-term measures like a government fiat on concessions and facilities and so on, through an administrative order (1). Enhancing supply needs long-term investment in the development of persons with disabilities for their education, vocational training, skill development and other requirements of the work place.*

## **INTRODUCTION**

Economic independence through wage or self-employment of persons with disabilities is arguably the single most important component in empowering them. All other aspects like provision of assistive devices, barrier free environment, education, training and so on are almost always aimed at providing employment opportunities to them. It is an established fact that there is a burgeoning gap between demand and supply of labour in India. With the move towards liberalisation and laissez fair economic system, especially since 1991, the protected labour market is giving way to market led demands for labour. The employment in the government sector is actually declining (2) making it extremely difficult for persons to enter the government sector. The difficulties are further compounded in the case of persons with disabilities who require additional support and assistance. There are about 7 million disabled persons awaiting employment (3). As per the Working Group on Empowerment of Persons with Disabilities, the projected estimate of persons with disabilities in the employable age for 2001 is 163.71 lakhs (4). The changing economic scenario therefore, makes it imperative to provide a level playing field to persons with disabilities by providing the necessary supports.

The supply of persons with disabilities in the short run is inelastic and therefore any plans to increase employment potential have to be for long-term (5). Equal opportunities, one of the three goals of the Persons with Disabilities Act (PDA) 1995, can only be realised through long-term investment in education, vocational training, skill development and other needs of the work place. Each of them requires careful planning, co-ordination, funding and execution with additional support services, in an inclusive environment.

## **VOCATIONAL TRAINING AND SKILL DEVELOPMENT**

Vocational training and skill development form the crucial link between education and actual placement. Like any component of augmenting supply of employable persons with disabilities, imparting vocational training and skill development is an ongoing phenomenon, necessitating a perspective plan. While vocational training has to be specific to the capacity and capability of the concerned persons, it also entails the provision of many supportive services. The government has a key role to play in this, especially in preparing persons with disabilities to join the private sector or to take up self-employment. Vocational instructors and trainers require to be sensitised to the capabilities and the needs of persons with disabilities. Many more training centres are required in remote and rural areas. The government will have to facilitate the changes in physical

environment to make it disabled friendly and barrier free, and promote modification of tools and equipment. There is a need to promote research for implementing these changes. The private sector activities in this area need to be subsidised or fully paid by the government.

The government has already initiated several measures and accelerated many others for skill development and vocational training of persons with disabilities. There are 17 Vocational Rehabilitation Centres located in 16 States, providing vocational training and professional enhancement (6). There are also some special employment exchanges and special cells in general employment exchanges. The government implements a Scheme for Promotion of Voluntary Action for persons with disabilities, under which vocational training is carried out. The expenditure under this Scheme has gone up substantially in the last few years. The Scheme is implemented through Non-Governmental Organisations and financial assistance is provided under the heads like 'Equipment', 'Vocational Counsellors', 'Vocational Instructors' and so on. During 1999-2000, the government assisted 56 organisations providing vocational training facilities. In addition, there are approximately 125 other organisations that are involved in vocational training. Approximately 181 organisations impart training to about 7500 persons with disabilities today. The government has also initiated the process of reserving, in selected polytechnics, a high percentage of seats for persons with disabilities. At present the scheme is being implemented through the Department of Education in 50 selected polytechnics, where additional support services like barrier free features, modified tools and equipment and re-orientation/training of instructors are being implemented.

However, a study by the National Centre for Promotion of Employment for Disabled People pointed out that in terms of employment the voluntary sector had very little to offer (3). While there were many benefits from implementing the Scheme for Vocational Training, its biggest drawback was the failure to link vocational training to employment. The implementation of the scheme was highly skewed in favour of a few States. For example, of the Rs.62 Crores distributed under the scheme, as much as 35% was allocated to organisations from 2 States and 55% of the total was spent in just 4 States. Further, although these schemes were making important contributions to skill in persons with disabilities, the effects were negligible in comparison to the demand for it. The scheme's coverage was limited.

In order to promote employment opportunities, some specific measures need urgent emphasis. The work environment should be altered so that persons with disabilities can freely and easily use them. Efforts should be made to train them in vocations that can lead to their employment in large numbers. Vocational instructors should be sensitised to their needs, capabilities and limitations. Over and above, changes have to occur in the attitude of employers and their beliefs about the capability of persons with disabilities.

## **CONCLUSION**

In order to enhance the employability of persons with disabilities, certain urgent measures have to be undertaken. They are as follows:

- Training courses for vocational instructors should include a module on disability issues to increase their sensitivity to persons with disabilities, besides the vocation they are being trained in.
- Release of grants to Non-Governmental Organisations for vocational training under the 'Scheme of Promotion of Voluntary Action' should be conditional to building barrier free environment, their vocational instructors being trained in disability issues and availability of necessary equipment and learning materials for training with them.

- There are over 4100 Industrial Training Institutes in government and private sectors, with a capacity of over 6 lakh trainees. They should be encouraged to reserve at least 3% of seats for persons with disabilities.
- As most of the vocational training institutions are in the government sector, supported by the government, besides a 3% reservation, its utilisation by persons with disabilities should be ensured by providing facilities suitable for them.
- The number of vocational training institutions at present is only 17. The numbers should be enhanced to at least one in every state. Existing vocational rehabilitation centres should be modernised to keep pace with emerging market opportunities.
- Efforts should be made to establish self help groups so that the relatively more capable persons with disabilities can become leaders and trainers.
- A national programme of vocational training and employment of persons with disabilities in rural areas should be undertaken. Under the programme, continuous identification of new self and wage employment opportunities for persons with disabilities should be carried out, along with skill development, employment linked vocational training, and marketing support.
- As information technology is emerging as a very large avenue for employment, persons with disabilities should be trained in these facilities through appropriate modification in hardware and software.
- Applied research, technology up-gradation, improvement in tools, assistive devices and work environment, should be continuously carried out and funded.
- Awareness generation and dissemination of information should be carried out actively.

\*Project Director (DRC)  
Ministry of Social Justice & Empowerment, Govt.of India  
4, Vishnu Digamber Marg, New Delhi 110 002, India  
email: pddrc@ren02.nic.in

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## **DISABILITY IN EAST TIMOR AND CAMBODIA**

*Kozue Kay Abe-Nagata\**

### **ABSTRACT**

*The author, deployed to the United Nations Transitional Authority for East Timor during January to July 2001, reports her observations about the emergence of disability rehabilitation services in war torn East Timor. This article briefly describes a few services that are already functioning in East Timor and suggests the type of supports that are required to enhance their effectiveness.*

### **INTRODUCTION**

East Timor has recently emerged from a period of mass destruction of dwellings and infrastructure in addition to loss of human lives, due to the violence after the referendum for its independence. There are still 250,000 displaced East Timorese who are sheltered inside the Indonesian territory of West Timor. The United Nations Transitional Authority for East Timor (UNTAET) is the official transitional government. It works with international and local civil society, to keep the people alive with supply of food, shelter, rehabilitation and operation of clinics, re-integration of returnees from Indonesian West Timor, and assistance in the process of democratic national building. The country is very poor with a GDP per capita of US\$ 431 and average life expectancy of less than 50 years. About 80% of the people are farmers, living on subsistence economy. During the initial nation building process, those considered as in need of assistance for survival were neglected.

Disability statistics in East Timor are almost non-existent and inaccurate. Therefore it is very difficult to estimate the number of disabled persons in this country. A well-known international NGO, the Cambodian Trust, undertook a preliminary survey in East Timor in January 2000. According to their sample survey, the prevalence of disability in East Timor was estimated to range from 1.5 % to 2.5 %, which amounts to some 10,000 to 17,000 of the total population of 750,000. Those requiring prosthetic, orthotic or medical rehabilitation are estimated to be around 1% of the total population, consisting of approximately 7000-8000 individuals. However, for various reasons, these statistics could be significantly under-numerated. In addition to physical disabilities, there are also a significant number of people suffering from post-traumatic stress disorder.

The level of physical disability in East Timor is similar to other low GDP countries, and other landmine affected countries such as Cambodia, Mozambique and Angola. It is related to the usual causes of disability in any resource poor country, such as poor nutrition, insufficient preventive and early intervention measures, substandard medical care, poverty and so on, that are also indirectly related to the last 25 years of civil conflict.

### **THE CURRENT EFFORTS TO DEVELOP DISABILITY SERVICES IN EAST TIMOR**

#### **1 . U n i t o f S o c i a l S e r v i c e s , U N T A E T**

Currently the social welfare and developmental projects for disadvantaged groups including disabled persons receives the lowest priority in the UNTAET budget. Unfortunately there was no policy regarding disability issues at the national level, though issues concerning disabled persons, women, youth and children have been incorporated into the framework of the new government lately. Now, the unit of social services has one section focusing on the issue of disabled persons with two national officers to handle social welfare and social integration programmes of disabled persons. The United Nations Economic and Social Commission for Asia and Pacific (ESCAP)

along with Disabled Peoples International had also sent a fact-finding mission in August 2000, to study the requirement of integrating disability issues into the ongoing development efforts in East Timor.

## **2 . M a r y k n o l l S i s t e r s a n d o t h e r C a t h o l i c O r d e r s i n A i e l u**

East Timor is a resource poor country and without qualified personnel. Hence it is necessary to promote community based rehabilitation (CBR) programmes as a strategy for East Timor. There are already a few good CBR programmes carried out by the catholic churches in the country. The CBR programme in Aielu, a village within 2-hours from the capital, Dili, run by the Maryknoll mission since mid 1990s, has good referral services. Maryknoll mission also provides services for the landmine and polio victims in Cambodia. This programme offers students from many provinces in Cambodia courses in tailoring, weaving, or more modern skills such as computer and English. Graduates can continue learning skills even after they leave, in tailoring and traditional Cambodian Takeo weaving.

This Catholic order has identified 700 East Timorese disabled persons, some of whom can not be dealt with medically within their community. In the past, some professional medical care was provided for them through referrals to Indonesian prosthetic and orthotic practitioners in Flores and West Timor. Now with East Timor's independence, such referrals are not possible. Currently, services are provided by visiting surgical teams from Australia and other developed countries. These services are important and need to be strengthened further.

## **3 . T h e ' A i s h u n F o u n d a t i o n ' i n D i l i**

The 'Aishun Foundation', which was established by a Catholic priest in 2000, is a home for about 20 children and youth with various kinds of disabilities. The home is managed by 3 staff, and located in Delta, a suburb community of Dili. The students are trained in various skills such as painting, music, carving, computers and so on, as well as daily living skills including proper hygiene. It is expected that the skills obtained by training will enhance their self-esteem and lead to increased respect from the community. The overall objective of this foundation is to develop a comprehensive training centre with a dormitory in Dili.

## **5 . G r a s s r o o t s c o m m u n i t y g r o u p a c t i v i t y : ' A c t i v e R e h a b i l i t a t i o n ' i n D i l i**

A large influx of expatriates (e.g., aid workers) working for developmental projects in East Timor, has created community initiatives outside of their work for disabled persons. A UNDP computer staff member with a decade of experience in the field of rehabilitation engineering, has started an innovative voluntary activity, called 'Active Rehabilitation', involving the local community and expatriate community in Dili. 'Active Rehabilitation' is a unique rehabilitation forum for wheel-chair users, based on the concept promoted and spread from Sweden, and now becoming popular throughout Europe. It is different from the more orthodox rehabilitation since the skills training takes place in the community by wheelchair users themselves rather than by the medical staff. The skills taught by 'Active Rehabilitation' includes basic necessities such as maintaining balance, stability, negotiating ramps, techniques of transfer to and from a wheel chair, as well as getting dressed by oneself, personal health care and hygiene. Since the group of disabled persons is still very small in East Timor, non-disabled volunteers also learn wheelchair

techniques so that they can transfer the knowledge to others when experienced disabled participants are not available. This community activity is gradually expanding and empowering a small group of disabled persons in Dili.

## **6 . ‘ C a m b o d i a T r u s t ’ p r o j e c t**

The ‘Cambodia Trust’ is planning to develop a 5-6 year project of establishing a prosthetics and orthotics production workshop, together with physiotherapy and CBR, in East Timor. The ‘Cambodia Trust’ was founded in 1989 as a response to the humanitarian crisis in Cambodia after almost 2 decades of civil war, foreign occupation and genocide. In the beginning, the trust concentrated on the supply of appropriate prosthetic and orthotic care for Cambodia’s over 35,000 landmine victims. Since it opened the first prosthetic and orthotic clinic in Phnom Penh in 1992, it has rehabilitated around 10,000 clients. Currently it runs the ‘Cambodian School of Prosthetics and Orthotics’ (CSOP), a regional school, and CBR outreach programmes, to meet the needs of Cambodia’s large number of disabled persons. The CSOP has also started to train students from the neighbouring Asian countries such as Laos, Sri Lanka, etc. and has planned a project in East Timor. The purpose of the new project in East Timor is to train a few students at the regional CSPO course in Phnom Penh, to establish a national clinic, a prosthetics and orthotics workshop in Tibar and to develop a CBR network with the existing community-oriented services in the country. The project will be implemented when funds become available together with the Government and an Australian NGO, the ‘Ryder Cheshire Foundation’ that is providing residential services at Tibar. The graduates of the regional 3-year CSPO, upon their return, are expected to run the national Prosthetics and Orthotics workshop in East Timor.

### ***CONCLUSION***

There is an urgent need for good projects in East Timor to meet the needs of disabled persons. A key to success will be the active role of non-governmental organisations that have been working in war torn Asian countries for a long time, and the Government’s support for their work, such as co-financing, disability policy formulation, logistical support, etc. Another key to success will be the capacity of newly trained local staff, their determination to provide quality training, and quick action for integrating the planned projects into the comprehensive disability policy of the country. A parallel but important element will be the capacity to develop self-help groups and self-advocacy groups of disabled persons in East Timor.

*\*Social Affairs Officer  
United Nations Economic and Social Commission for Western Asia  
P.O. Box. 5749  
Grand Central Station  
New York  
NY 10163-5749, USA  
e-mail: nagata.escwa@un.org*

### **A C K N O W L E D G E M E N T**

The views expressed in this article are those of the author and do not necessarily reflect the views of United Nations.

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The **Asia Pacific Disability Rehabilitation Journal** is a bi-annual Journal, for private circulation only, for researchers, planners, administrators, professionals, donor organisations and implementing agencies involved in disability and non-institutional rehabilitation. The major emphasis of the Journal is on articles related to policy development, concept clarification, development of methodology in the areas of service delivery, training of manpower and programme evaluation, and development of technology related to rehabilitation. Other information related to rehabilitation of disabled people that may be of use to implementing agencies, academicians and donor organisations are also welcome. The views expressed in the Journal are those of the contributors alone. Articles sent to the Editor will be published after they are edited to suit the format of the journal, under three different sections, namely, Developmental articles, Original articles and Brief Reports, subject to their suitability after **PEER REVIEW**. They may also be published elsewhere if so desired, after acknowledging the source. Copies of the Journal are mailed free of cost. The Journal and its associate publications are available on the Internet at

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**E.g.**

1. Twible RL. **Final Fieldwork Placements of Australian Occupational Therapy Students in CBR Projects in India.** ACTIONAID Disability News 1996; 7(2): 68-72.
2. Pandey RS, Advani L. **Perspectives in Disability and Rehabilitation.** New Delhi: Vikas Publishing House Private Ltd., 1995.
3. Thomas M, Thomas MJ. **Evaluation Based Planning for Rehabilitation Programmes in India.** In: O'Toole B, McConkey R, eds. *Innovations in Developing Countries for People with Disabilities.* Chorley, UK, Lisieux Hall Publications, 1995: 243-254.

For more detailed information about the Vancouver system, authors should consult 'Uniform requirements for manuscripts submitted to biomedical journals' (Br Med J 1988; 296: 401-405).

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**Dr. Maya Thomas, Editor, Asia Pacific Disability Rehabilitation Journal, J-124, Ushas Apartments, 16th Main, 4th Block, Jayanagar, Bangalore - 560 011, Karnataka, INDIA. Ph: 91-80-6633762 Fax: 91-80-6633762 Email: thomasmaya@hotmail.com**

The Asia Pacific Disability Rehabilitation Journal has an associate publication called "**Friday Meeting Transactions**". This newsletter, which is mailed free of cost on request, carries reports of different aspects of CBR application, and the summaries of transactions of the "**Friday Meetings**" held at Bangalore, India, on the last Friday of every odd month between 2 and 5 pm at Spastics Society of Karnataka, 31, 5th Cross, 5th Main, Indiranagar 1st Stage, Bangalore - 560 038. These meetings are open to all those who are interested in updating their knowledge on community based rehabilitation and related topics. The "**Friday Meeting Transactions**" is also available on the Internet at <http://www.aifo.it/english/apdrj/apdrj.htm> Those who wish to receive a printed copy, may contact the Editor, Asia Pacific Disability Rehabilitation Journal.

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