

## **EDITOR'S COMMENT**

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Globally, the disability scenario today is at an exciting stage. After many years of effort, there are moves towards a UN Convention on rights of persons with disabilities, which will give a great impetus to the field, and which will be binding on governments to protect the rights of their disabled citizens. At the regional level, the Asian and Pacific Decade of Disabled Persons (1993-2002) is extended from 2003 to 2012, and follows the Biwako Millenium Framework for programmes for persons with disability in this region. The period of 2000 - 2009 was formally proclaimed the African Decade of Disabled Persons, while the Arab Decade is launched from this year. All these international statements focus on rights of persons with disabilities and their inclusion in the mainstream.

The Biwako Millenium Framework, on which the other regional decade declarations are based, talks about an inclusive, barrier-free and rights based society for people with disabilities. The Framework highlights seven priority areas for action, including self-help organisations of persons with disabilities and their families; programmes for women with disabilities; early detection, intervention and education; training and employment; access to built environment and public transport; access to information and communication; and poverty alleviation through social security and livelihood programmes. If one looks at the activities of community based rehabilitation programmes (CBR) in different countries, it appears that the seven priority areas of the Biwako Millenium Framework are included, and have been so for more than a decade in some instances, under the purview of these CBR programmes. The point of debate here is: what many of these programmes did achieve in terms of rights and inclusion of persons with disabilities, having followed the priority areas as outlined in the Framework. No doubt many of them provided access to opportunities - for education, employment, information and livelihoods. Many CBR programmes have of late emphasised facilitation of self-help groups, as a way of improving community participation and ownership. Although a start has definitely been made, people with disabilities in many developing countries are still far from the ideal of an inclusive, rights-based society. Perhaps one key issue that has not been sufficiently emphasised is the paradigm shift from a charity-based approach to a rights-based one in many programmes for persons with disabilities, initiated by governments and the non-governmental sector.

This paradigm shift is rightly emphasised in the Biwako Millenium Framework. With the Framework and other global movements and international statements emphasising similar issues, it is hoped that such a shift will occur across the board. Without this shift at all

levels, including persons with disabilities, their families, service providers, donors and governments, it is unlikely that the dream of a rights-based, inclusive society, will be realised in the immediate future.

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**GUEST EDITORIAL**

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**DESIGNING PROGRAMMES TO ADDRESS STIGMA IN LEPROSY:  
ISSUES AND CHALLENGES**

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**ABSTRACT**

*Leprosy stigma is still prevalent in both endemic and non-endemic countries, and is a major factor leading to delay in patients seeking treatment. This paper reviews studies on factors influencing stigma in leprosy and the effectiveness of programmes targeting it. Most research showed that high level of knowledge of the curability and non-infectiousness of leprosy was not correlated with more positive attitudes and acceptance of leprosy patients. The mixed effects of interventions ranging from worsening stigma, to no change or slight change in positive attitudes suggest that stigmatising attitudes are difficult to change. There is a need for more integrated psychosocial, cultural and behavioral studies to identify important independent predictors of stigma. More rigorous study designs are needed to evaluate intervention programmes targeting stigma to provide evidence on what approaches work and what do not work.*

**INTRODUCTION**

The implementation of multidrug therapy since the mid-eighties has been highly effective in curing patients and reducing prevalence of leprosy. Registered cases have fallen from 5.4 million worldwide in 1985 to below 1 million in 2000(1). Presently, the global prevalence of leprosy is less than 1 case per 10,000 people. However, in many developing countries, a significant number of cases remain undetected or are detected late. WHO estimates that during the period 2000-2005, about 2.5 million people affected by leprosy need to be detected and treated. Stigma still remains a major factor leading to delay in patients seeking treatment (2). Stigma towards persons affected by leprosy and their families has also adversely affected their quality of life due to its impact on their mobility, interpersonal relationships, marriage, employment, leisure and social activities. Recent studies indicate that leprosy stigma is still a global phenomenon, occurring in both endemic and non-endemic countries. This paper gives an overview of factors influencing stigma in leprosy and reviews the effectiveness of programmes targeting stigma. It concludes with a discussion of the issues and challenges in designing programmes to reduce stigma.

The word 'stigma' was first used by the Greeks to denote bodily signs that expose something unusual and bad about the moral status of the signifier. Goffman (3) defines stigma as an attribute that is deeply discrediting, and the stigmatised individual is one who is not accepted and not accorded the respect, rights and regard of his peers; one who is disqualified from full social acceptance. He describes three groups of factors leading to stigma: physical abomination, blemishes of individual character, and tribal stigma. If this is applied to leprosy, we can see that all three groups of stigma are encompassed by this one disease - leprosy.

With regard to the group with physical deformities - there are the visible deformities of a leprosy patient; in the group with blemished character is the belief that leprosy patients are of blemished character and hence the disease is a punishment for their sins; and in the group with tribal stigma, leprosy is looked down upon as the disease of poverty or of a person 'of a inferior class'.

## **RESEARCH ON STIGMA**

The operational definition of stigma varies across studies but most of them examined at least one of the following negative attitudes or behaviours towards leprosy patients: (i) refusing to eat food with persons affected by leprosy (ii) not allowing them to enter one's home (iii) segregation (iv) social-public restrictions such as not allowing them to use public facilities or go to school and (v) expressing hatred at them.

### **Prevalence of stigmatising attitudes**

Although some studies have shown that stigmatising attitudes are on the decline (4,5), research over the last decade generally showed that prevalence of stigmatising attitudes toward leprosy is still high with some countries reaching levels as high as 80%.

Most studies (6,7,8) also showed that high level of knowledge of the curability and non-infectiousness of leprosy was not correlated with more positive attitudes and acceptance of leprosy patients. A study by Croft et al in Bangladesh (8) showed that 90% knew that leprosy was curable, yet about a quarter would not eat with leprosy patients.

### **Factors associated with stigma**

Studies have also been carried out on factors associated with stigmatising attitudes, and these may be categorised into mediating (direct) factors and indirect factors.

Mediating factors are those factors directly related to peoples' attitudes of fear and to their rejection of people with leprosy.

All the following four categories of mediating factors, namely (i) visible deformities (ii)

perceived incurability and chronic course of disease, (iii) perceived infectiousness and (iv) perceived 'bad' origin of disease have led to people's fear, rejection and hence stigmatisation of leprosy patients (9).

Why have visible deformities led to stigma? Some researchers (10) have explained that this was due to the fact that punishment for crimes in ancient society was dismemberment of parts of the body, consequently mutilations produced by the disease were associated with retribution for sins in the human mind.

Beliefs about the contagion of leprosy are still prevalent among most communities. A recent community survey in Singapore in 2002 (unpublished data) found that about half (41.3%) of adults still believed that persons always have deformities and that leprosy spreads easily, and about one-third (32.3%) believed that leprosy is incurable. Misconceptions regarding the infectiousness or contagion of the disease could have been perpetuated by past practices of institutionalisation and the enforcement of the Leprosy Act in some countries to segregate people affected by leprosy.

The perceived bad origin of leprosy may be attributed to cultural beliefs that leprosy is a punishment for sins and that it is hereditary. Most of these misconceptions were found to be rather similar across wide geographical and cultural backgrounds. The Hindus (11) consider deformity resulting from leprosy as divine punishment and the Chinese (12) believed that leprosy is sexually transmitted by contact with a prostitute and hence a punishment for immoral behaviour. The belief about heredity of leprosy is prevalent among communities in India (3), Malaysia (13), China (12) and Africa (7). Ironically, even in Norway (14) where Hansen identified the leprosy bacilli, the medical profession firmly believed that leprosy was hereditary and promoted the idea of segregation to prevent procreation.

Other factors that have led to stigma included the depiction of the horrors of neglected leprosy and the use of the words "leprosy", "leper", or "leprous" to imply something evil, degrading or immoral by writers, journalists and even politicians.

The mediating or direct factors leading to stigma are in turn influenced by indirect or socio-demographic factors and the findings appear to differ from one country to another. Studies in India found that stigmatising attitudes were associated with older age (6) but in Tanzania it was associated with younger age (7). The study in India (6) also found that stigmatising attitudes were associated with lower educational level, lower socio-economic status, female gender, and the muslim religion. Another study in India (15) found lower acceptance of deformed and handicapped patients by families of the lower caste groups (54%) compared to higher caste families (80%). Some studies in Africa found stigma to be higher among Christians than Muslims (16). While Christians perceived it as a punishment for their sins, Muslims believed it is God's will. This may explain why leprosy patients are better accepted

by Muslims compared to other religions. Stigmatising attitudes were found to be more prevalent among rural communities in India but in Myanmar stigma was more prevalent among urban communities.

The stigmatisation in leprosy is frequently extended to the families having members suffering from leprosy. A study revealed that families with a patient who had deformities faced ten times more societal problems than those having patients with no deformities (15).

### **Level of awareness of leprosy among health care workers**

Misconceptions about the causes of leprosy, that could have perpetuated stigma, were also prevalent among health care providers. In a study in Nigeria in the early eighties (17), about two thirds (65%) of final nursing students said that leprosy was highly infectious and that deformities were inevitable in leprosy. Another study in Philippines around the same time (18) found that while 88.4% of the health service providers agreed with the germ theory of disease, about 70% believed leprosy to be highly contagious and a small but significant (11.6%) proportion believed leprosy to be caused by “unclean blood” and witchcraft. In a study among health workers in Botswana (19), more than a third of respondents believed that patients should be isolated and treated.. A more recent study conducted among health care workers in Guyana (20) in 2000 still found a low level of knowledge: half of the respondents did not know that leprosy was curable and 15% thought it could be spread by touch.

### **Intervention programmes to reduce stigma: current strategies**

Since the seventies, governments and non-governmental organisations have implemented measures to reduce stigma.

Efforts at policy level included the use of non-discriminatory terminology such as Hansen’s disease to describe people with leprosy. In Brazil, the use of the word ‘lepra’ which means dog mange is discouraged by law. More support and rehabilitation services have also been provided to patients and their families. In some countries, leprosy control programmes have been integrated into the general health care system. As stigma may be perpetuated by the negative attitudes of health care providers themselves, many leprosy programmes have also focused on training health care providers to be more sensitive and empathetic to leprosy patients’ concerns.

To dispel the fears about the non-curability and infectiousness of the disease, community health education programmes have stressed on the following main messages: (i) Leprosy is 100% curable (ii) Leprosy does not spread easily as 99% of people have resistance to immunity to leprosy (iii) Deformities do not occur with early treatment and (iv) Patients are not infectious once they have been started on treatment.

Recently, some countries have used the mass media to disseminate more positive messages about leprosy. Instead of showing a child or mother with facial deformities, pictures showed a healthy, normal and happy child or mother with no deformity as a result of seeking early treatment. A public education programme in Sri Lanka (21) showed a perfect hand of a leprosy patient holding a flower instead of depicting a hand with unsightly deformities. Many countries such as Malaysia (13), China (12) and Botswana (19) have also involved traditional healers, community leaders and community in disseminating health messages on leprosy and facilitating early detection and treatment.

### **How effective are current interventions targeting leprosy stigma?**

Very few studies have been conducted to evaluate the effectiveness of intervention programmes targeting leprosy. The best evidence of programme effectiveness comes from randomised controlled trials. However, none of the studies used a randomised control group design, probably due to the fact that it is often not feasible to use this design in community settings.

Where randomisation is not feasible, the greatest evidence comes from quasi-experimental study designs in which the intervention group or community is compared with a concurrent comparison group or community without the intervention on prospective measurement of exposures and outcomes (22). In this review, only those studies with a comparison group were considered.

Croft et al (8) used a post-intervention control group study design to evaluate the effectiveness of a community health education programme in Bangladesh. Markedly lower levels (28-30%) of prejudice were found in a rural intervention community of 50 household respondents provided with community education compared to another similar number of households in a comparable rural community without the health education programme. In the village that had not received health education, over 75% of the families reported that they would not share a meal with a leprosy sufferer and 94% cited that they would not permit their son to marry a girl who is cured of leprosy, compared with 28% and 30% respectively in the intervention community. Another study in Bangladesh (23) also found that overall knowledge in leprosy and positive attitudes towards leprosy patients were significantly higher in a slum area of 200 household respondents that had received a community health programme compared to another comparable control slum of 200 household respondents which had not received the programme. More respondents (60%) in the intervention community reported that they would eat with a leprosy patient compared to 38% from the control community. However, as baseline data on stigmatising attitudes and behaviours before the intervention were not available, it could not be ascertained whether the two communities had similar levels of prejudice before intervention.

A seven-year intensive community health education campaign on leprosy in Tanzania (7), also using a post-intervention control group study design, did not find a significant improvement in knowledge or attitudes of the general adult population or health staff in the intervention community receiving the intensified health education programme compared to a control neighbouring district that did not receive the health education programme. However, the campaign had a favourable effect on knowledge and attitudes of schoolchildren. Slightly more than one third (38%) of children in the intervention area were willing to share food with a person affected by leprosy compared to 21% from the control area. The case detection rate in the intervention area was also higher in the intervention area (2.4/10,00) compared to 1.3% from the control area.

A study in India (24) showed moderate increase in level of knowledge but no detectable change in expressed prejudice towards people with leprosy after a community health education campaign. Another study in India, found no change in negative attitudes of children towards leprosy patients after health education, but showed increased fear towards leprosy patients (6). Thus an increase in knowledge per se may not lead to positive change in attitudes, and can in fact, have serious detrimental effects on attitude.

A qualitative study in India (25) compared acceptance of leprosy patients in a village, in which leprosy control activities were integrated with primary health care services, with a socio-demographically comparable village with the vertical approach. Focus groups and observations were used to assess specific and actual practices related to stigma such as relationships with specific family members, economic and social interaction such as whether they were gainfully employed, received economic support from service providers, got invited to social functions and have access to local services. Patients from the integrated care village faced less discrimination and stigma with regard to social acceptance compared to those from the village with vertical care. However, this study was conducted on only 24 families.

## **DISCUSSION**

### **Summary of findings**

A review of the literature showed that causes of stigma are multifactorial and misconceptions and negative attitudes towards leprosy patients are still prevalent. The varying success rates in interventions, ranging from worsening stigma, to no change and slight and moderate change in positive attitudes, indicate that attitudes related to stigma are difficult to change.



### **Gaps in knowledge**

Gaps still exist in our current knowledge on causes of stigma in leprosy. There is considerable research on the descriptive aspects of stigma such as the frequency distribution of cultural beliefs and stigmatising attitudes but there is a lack of analytical research on the independent associations or interaction between various beliefs and stigmatising attitudes. Data are still lacking on the relative importance of the various cognitive dimensions or mediating factors influencing stigma in leprosy. For example, which of these factors: disfigurement or beliefs on bad origin: is a more important determinant of stigma in leprosy or is the stigma due to a combination of both factors? If it is disfigurement that leads to stigma, why is a condition like Rheumatoid Arthritis less stigmatising than leprosy? Is it because it does not cause facial deformities like leprosy or is leprosy stigma due to the interaction or combination of beliefs about its infectiousness and bad origin, and deformities. These issues have not been addressed yet by research.

It is also unclear what interventions work best in reducing stigma as there are few rigorous studies that evaluated the effectiveness of the intervention programmes. In addition, the effects were mixed with some showing reduction in stigma while others reported an increase in stigmatising attitudes. It is not known what led to these differential effects as qualitative analysis and process evaluation of programme activities were not described in-depth in these studies.

## **RECOMMENDATIONS**

### **Designing programmes to reduce stigma**

Research has shown that it is difficult to change people's attitudes and that high knowledge of the curability and non-infectiousness of leprosy did not necessarily lead to more positive attitudes towards persons affected by leprosy. This could be because beliefs about the bad origin of leprosy are so deeply rooted in people's culture that a simplistic approach of just presenting the scientific facts may be ineffective in addressing their concerns and beliefs. Community health education campaigns should therefore provide accurate knowledge of leprosy by working their way around the local community's cultural beliefs and misconceptions rather than denouncing them outright. For example, the message that is often used – 'Leprosy does not spread easily' – may be too simplistic. It is important as well to talk about local beliefs and change them gradually through exploration and clarification and in consultation with local community leaders.

The challenge for health educators is to get the right mix of traditional beliefs and modern theory of medicine which neither offends community sensitivities nor compromises on the accuracy of the message.

More holistic multi-component programmes are needed to address stigma, with interventions targeting individual, interpersonal, health system, community and policy levels. Discriminatory attitudes of the health personal should also be addressed.

We should use comprehensive planning models and conduct needs assessment before planning programmes. Assessing local educational needs is very important as needs and factors associated with stigma have been found to differ among countries.

A well-planned needs assessment will also help in designing more appropriate health education strategies and more specific and relevant messages that relate to the community's concerns.

### **Research**

An understanding of the determinants of stigma and the process of stigmatisation is an essential step towards developing effective interventions to address stigma. There is a need for more rigorous research such as the application of a holistic framework of psychosocial, cultural and behavioral models and theories, and the use of multivariate statistical techniques to identify important independent predictors of stigma and the relative importance of each of these factors.

Cross-cultural studies should be also carried out to compare factors that have led to the differing attitudes towards leprosy patients in different countries. We can learn from communities with more favourable attitudes and adapt what we have learnt from them, to less favourable communities.

While many health education programmes have been implemented with the goal of reducing stigma, few have been evaluated to assess their impact. A validated stigma scale should be developed to assess and monitor the effectiveness of such programmes. Data obtained with such an instrument would not only be useful in monitoring and evaluation of interventions against stigma but also in needs assessment to determine factors influencing stigma. The findings would help in more effective programme planning and advocacy work.

More rigorous study designs are needed to evaluate intervention programmes targeting stigma. This will provide evidence on what approaches work and what do not work. If it is not feasible to use randomised controlled trials in community settings, quasi-experimental designs should be used to compare changes in attitudes and practices from pre-intervention to post-intervention between an area with the intervention and a socio-demographically similar area without the intervention. Both outcome and process evaluation are needed to evaluate programmes on their effectiveness. While outcome evaluation assesses the effectiveness of a programme, process evaluation will explain why a programme failed or succeeded in reducing stigma. This information would help leprosy programme managers to plan better programmes.

For example, detailed information of interventions such as to how and why they work in a particular context will enable programme managers to replicate or adapt successful, sustainable interventions to their own setting.

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**DEVELOPMENTAL ARTICLES**

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**ADOLESCENTS AND YOUTH WITH DISABILITY :  
ISSUES AND CHALLENGES**

Nora Ellen Groce\*

**ABSTRACT**

*Globally, almost 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability significant enough to make a difference in their daily lives. The vast majority of these young people, some 150 million (80%) live in the developing world. Routinely excluded from most educational, economic, social and cultural opportunities, they are among the poorest and most marginalised of all the world's young people. This paper reviews issues that must be considered in assessing the needs of disabled young people and urges the inclusion of this all too frequently overlooked group in all international development policies and programming.*

**INTRODUCTION**

Globally, some 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability significant enough to make a difference in their daily lives. The vast majority of these young people, some 150 million (80%) live in the developing world (1). They are among the poorest and most marginalised of all the world's young people.

This paper provides an overview of the prominent challenges currently faced by disabled young people. Adolescents and young adults are grouped together and discussed jointly because they share common characteristics: they are often bypassed both by the programmes and policies designed for disabled children and left out of advocacy initiatives and employment schemes targeted for adults with disability. Nor are their unique social, psychological, education and economic needs addressed by programmes designed to reach their non-disabled age-mates.

Of all groups with disability, the groups about which we know the least are disabled adolescents and young adults. This category encompasses both individuals in the age range labelled by UNICEF as "adolescents" (those between age of 10-18) and by the United Nations as "youth" (19-24). Subgroups within this category have distinct issues

and concerns. The needs of a disabled 12 year old are very different than for a disabled 21 year old, however, for the purposes of this paper, they have been brought together because of the large number of issues and concerns they share. In transition between childhood and adulthood, these are the years when young people are expected to acquire skills, go through physical and psychological maturation and assume a social identity that will enable them to fully participate in their communities.

It is easier to list what is not known about disabled young people, than what is. With several notable exceptions, there has been virtually no research on disabled young people as a distinct group in developing countries and what exists on young people with disability in the developed world focuses on them largely in the context of formal educational systems and transition to work programmes. The call made by UNICEF in 1999 in its global survey on adolescents, for more research on the wide array of issues that influence the lives of disabled young people, remains largely unanswered (2).

While research may be lacking, extrapolation from available data on youth in general and disability in general can provide a starting point. This is because the needs of disabled young people are strikingly similar to those of their non-disabled peers - the need for education, job training, employment, and inclusion through participation in social, cultural, religious and economic affairs. What distinguishes this large group of youth are not their common needs, but the fact that these needs continue to go so largely unmet.

## **DEMOGRAPHICS**

World-wide, estimates of the number of adolescents and young adults who live with a disability vary widely. Estimating the number of disabled young people is complex, for two reasons. The first is that frequently, disabled young people are grouped together with children or adults, blocking attempts to estimate their numbers as a distinct group. The second is that definitions of disability vary widely. In some nations, only individuals with significant disabilities are identified; in others, even those with mild disabilities are included. Issues of accuracy and reliability of statistics have been raised for individuals with intellectual disabilities and individuals with mental health concerns, as well as those with physical and sensory disabilities (3). Indeed Suris and Blum (4) note that the lack of homogeneity in definition, survey procedures and data collections “makes international comparisons almost impossible.” They report that disability rates are higher in wealthier countries. This seems to be because screening programmes are more available, allowing identification of more adolescents with moderate and mild disabilities (5). While high infant and child mortality rates in poorer countries may contribute to this discrepancy, under-reporting of disability also cannot be ignored. Suris and Blum (4) analysing the United Nations International Statistics Database for 42 countries, report wide disparity of rates. In the 10-14 year old

group, rates range from 108 per 100,000 in Myanmar to 6726 per 100,000 in Canada. Among 15 to 19 year olds, rates range from 142.6 per 100,000 in Myanmar to 5099.5 per 100,000 in Austria. There is sometimes a lack of consensus on what constitutes a disability even within countries. In 2002, the United Nations established a new international consortium the Washington City Group to more accurately determine national and international statistics on disability, including those for disabled adolescents and youth. However, its recommendations are still several years away (6).

Here is what is currently known. By 2005, the UN estimates that there will be roughly 1 billion adolescents in the developing world (1). If one uses the UNICEF (1) and WHO estimates that one in every ten of these adolescents is disabled, then by 2005, the developing world will have 100 million 10-19 year olds. If a more conservative estimated rate of 5% is used, this still means 50 million disabled adolescents by 2005.

To this number must be added the number of disabled youth between the ages of 19 and 24. Again, specific global figures must be extrapolated on the basis of general population estimates. It is estimated that there are 500 million youth between the ages of 19 and 24 living in the developing world. Assuming 10% of this population is disabled, there would be 50 million individuals between the ages of 19-24.

Combining the statistics on adolescents and young adults from the developing world yields as many as 150 million young people who live with a significant disability. Using the lower calculation of only 5%, still yields a global population of 75 million young people.

To this number can be added an additional 30 million adolescents and young adults with disability representing the 20% of young people who live in developed nations, assuming a 10% prevalence rate. Using the lower estimate of 5% yields 15 million individuals in developed nations.

The overall total globally for this age range, assuming a 10% prevalence, is 180 million, (assuming a 5% prevalence rate, the number still remains a very significant 90 million young people). Moreover, with half of the world's population below 15, the number of young people with disability can be expected to rise markedly over the next decade, particularly in the developing world. This will not simply reflect a rising birth rate. Better medical interventions, both in developing and developed countries, will allow growing numbers of disabled infants and children, who previously would not have survived childhood, to grow into adolescence. Young people are also at increased risk due to work-related injuries, risk-taking behaviour (including motor vehicle accidents, experimentation with drugs, and risk of violence). Many chronic disabling illnesses and mental health conditions appear only during adolescence.

The sensory, physical and mental health impairments associated with the HIV/AIDS virus will add millions of young people to the growing ranks of those who are disabled (7). Of equal concern, is the increased risk for young people with disability of becoming infected by the HIV/AIDS virus. Too often, it is incorrectly assumed that these young people are not or will not become sexually active, use intravenous drugs or be victims of abuse or rape, and so they are not provided basic sex education and the resources protect themselves (8).

Nor are disabled young people evenly distributed within the general population. Experts generally agree that disability disproportionately affects the poor (9,10). Moreover, those few national data sets that do exist suggest that throughout the developing world, disability affects more males than females, and is found more commonly in rural than in urban areas (1). However, such data may also reflect survival rates, access to diagnostic services, census collection techniques and definitional differences of what constitutes a disability. These issues make conclusions about the distribution of disability within populations, especially for the very poor and for young women with disability, open to question.

### **DISABILITY, STIGMA, GENDER AND MINORITY STATUS**

Globally, it is widely acknowledged that the greatest impediment to the lives of young people with disabilities is prejudice, social isolation and discrimination (11). While all individuals with disability may be affected by this lifelong cycle of stigma and prejudice, females are at increased risk (12). In societies where girls are valued less than boys, the investment in education, health care or job training that families are willing to make in disabled girls are often substantially less than for disabled boys (13). Some discrimination may be subtle, for example, a poor family may wait a few days more to invest in an antibiotic for an ill daughter with a disability than they would for a son with a disability, hoping that the condition will clear on its own. A study by the International Labour Organisation in six Asian Pacific nations found that the incidence of disability was in fact higher for women than for men (14), making the higher survival rates for men with disabilities in the countries surveyed, more strikingly unequal (12).

Young people with disability who are members of ethnic and minority populations are also at increased risk. Coming from different cultural, linguistic and religious traditions, these young people are less likely to be included in whatever services and programmes that exist. An ethnic or minority status can also compound the discrimination already encountered by disabled young women, who find themselves contending with forces that would exclude them on the basis of their gender, their disability and their heritage.

### **THE INVISIBLE POPULATION**

Despite growing numbers and striking needs, adolescents with disability have historically fallen through the cracks. General programmes for adolescents and young adults rarely



include those with disabilities. Programmes for disabled populations where they do exist, are usually not more inclusive. Programmes for those with disability generally are either intended to provide services and general advocacy for all disabled members of a society or fall decisively into one of two categories - programmes for disabled children or for adults with disability. Programmes and advocacy for disabled children usually focus on issues of family, education and socialisation. Programmes and advocacy for adults with disability are largely focused on issues of employment and to some degree, housing and community integration (15).

Adolescents and young adults are rarely excluded from these child-focused or adult-focused disability programmes. The needs of a disabled five-year-old however, are usually strikingly different from those of a 13 or 17 year old. Those who run child-focused services report a marked decrease in participation by children once they enter adolescence (2). On the other hand, adult oriented disability organisations tend to concentrate on job training, often emphasising re-entry to the work place after an accident or injury. Such programmes are of little relevance to older adolescents or young adults who have never participated in the work place. The result is that in many countries, adolescents and youth with disabilities are alienated from those few disability support organisations that do exist.

Even within the United Nations, acknowledgement of or protection for adolescents with disability, is frequently overlooked. For example, in the United Nations General Assembly's Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (16), an opportunity for underscoring the needs of adolescents is missed when groups of individuals with disability at particular risk are enumerated. Children are mentioned, as are members of ethnic and minority communities and adult women. Adolescents with disability however, are not.

### **THE CYCLE OF DISABILITY, POVERTY AND ISOLATION AMONG YOUNG PEOPLE**

Young people with disabilities have needs very similar to the needs of all other young people, as clearly stated in Article 23 of the United Nations' Convention on the Rights of the Child (UNICEF, 2000). They need a safe and supportive environment, education, health services and access to sport and recreation. They also need to develop skills that will serve them well in the community and the work place. In many cultures however, the traditional approach is to acknowledge that they are no longer children, but to assume that they will never be accepted or able to function as adults. The problem of where they should exist is often dealt with poorly, if at all.

Disabled children, particularly those with more visible disabilities, are frequently assumed to be in frail health and unlikely to survive into adulthood. Indeed, in many countries, a significantly disabled child is referred to as "an innocent" or a "little angel" (17). Sending such children to

school, including them in social interactions or preparing them for participation in the adult world seems unnecessary. Families with significantly disabled children have often anticipated their early deaths, but not their possible survival. Bjarnason (18) discussing the transition to adulthood of young people with disability in Iceland describes this as “eternal youth” - a limbo in which these young people are not expected to reach adulthood, but remain enmeshed in segregated services. Where no services exist, such young people usually continue to live as “children” in their parents’ households, or find themselves on the street. In many countries, particularly where extended family units are still the norm, it is considered appropriate for all young people to remain at home, including those with a disability. Personal assistance, if needed, is provided by immediate family members, (most commonly the mother), which means that these young people often have little or no say over even the most basic aspects of their lives. This limits a disabled young person’s ability to establish a sense of autonomy or gain experience in making independent decisions. Elsewhere, rapid moves towards modernisation have led to the expectation that young non-disabled adults will eventually live independently of their parents. Young disabled adults however, are often expected to continue living at home - making their lived experiences as young adults increasingly different from that of their non-disabled peers. In many cases, poverty and lack of viable options will force many young adults, particularly young males, to leave home for a life without family supports or a life on the streets.

## **EDUCATION**

Lack of education is a key concern for most disabled young people in the developing world. In many countries, children with disabilities are considered to be incapable of learning, no matter what their disability is. Often a disabled child is considered a distraction to other students and simply sent home. Lack of schooling may reflect the belief that such children cannot learn, that such children should not be put through the stress of learning or that such children are an embarrassment (evidence of bad blood, incest or divine disfavour) and should not regularly be seen in public. School buildings are routinely built with stairs, or far from community centres, making them inaccessible to those with mobility impairments. Lack of trained teachers, appropriate teaching materials and an unwillingness to include disabled children in the regular classroom limits access to education for millions of blind and intellectually disabled children as well as those with mental health difficulties. Perhaps the primary reason these children are so rarely in school however, is that their families and societies may not perceive that they need an education (2) This general lack of access to education is cumulative and by the time children with a disability reach early adolescence, the vast majority find themselves far behind the educational and skill levels of their non-disabled peers.

Gender further compounds inequities in education. As Russo (19) notes, cultural bias against women in general and reduced expectations for disabled females in particular, further limit

what funds families and schools are willing to spend on academic and vocational training. Compounding this, where school fees and barriers make universal education unavailable, anecdotal reports indicate that some parents choose to put all the family resources into educating non-disabled siblings, with the expectation that these children will be better able to support their disabled sibling in adulthood. The option of educating the child with a disability to ensure he or she will be self-supporting is often not considered as an alternative.

A few studies have found some inclusion of disabled adolescents and youth in general classrooms without special consideration being given to their disabled status. Miles, in a study in rural Pakistan (20), found 22% of all disabled children had received some schooling within the general classroom setting and reports similar observations from Sri Lanka. This “casual integration” is hard to track, but represents an important area for further study, not only for its implications for education, but also because it might provide functioning models of inclusion that may be of relevance to subsequent job training and economic development schemes.

Additionally, there has been growing interest in “inclusive schooling practices” with UNESCO and UNICEF promoting greater integration into the general classroom. However, most of these efforts have been directed towards younger children, not disabled adolescents. In fact, by the time they reach adolescence, the vast majority of young people with disabilities world-wide are no longer in school.

The social isolation, poverty and discrimination faced by children with disabilities also sets up an interconnected pattern of problems (21). Many children with disabilities do not attend school or leave school early. Millions of these young people end up on the street, unemployed and often involved in crime, sex work and drugs, frequently at the behest of others who see them as easy prey. It is estimated that at least one-third of all street children have a disability (2).

There are some exceptions. In developed nations there exist extensive educational systems for most children with disabilities through late adolescence. Some nations integrate these adolescents into general classrooms. Others provide specialised classes and training in social and job skills to help in the transition to adulthood. These programmes have varying degrees of success. An extensive body of research has documented this process of transition in some detail, although there is still relatively little information on the effects of this process on the social integration of the individual, and its implications for the family unit. Comparable data from the developing world are hard to come by.

However, presence in a classroom alone does not guarantee education. For example, the average reading level for deaf American high school graduates is at a third grade level (22).

Students with disability are often formally restricted in what course of study they are allowed to pursue. In a recent study from Ireland, Shevlin et al (23) report that disabled high school students are not allowed to enrol in the full range of academic courses. In China, disabled university students are not allowed to major in most sciences, as it is felt that the degree would be 'wasted' on an individual who would never be able to find a position in the field. This systematic lack of education has immediate relevance to disabled young people. At an age when non-disabled individuals are beginning to define themselves through their anticipated careers, most disabled young people enter the workforce strikingly unprepared.

### **JOB-TRAINING AND EMPLOYMENT**

Globally, employment is a problem for all adolescents and youth. Formal education for most of the world's young people ends by mid-adolescence after which most males and many females are expected to work outside the home. The ILO has termed the problem of growing global youth unemployment as "stark" (24). Young people world-wide are at higher risk for unemployment, partial employment or full employment at lower wages than adult workers. Adolescents with disabilities are at even greater risk. Coming on to the job market with little education and few or no skills, they have difficulty competing (25). For some, specific physical or intellectual impairments may further limit their job options. For most, social prejudice makes employers hesitant to hire them.

Employment rates of disabled youth are rarely tracked in developing countries. However, if the general pattern of unemployment and underemployment for the rest of the disabled population holds true, it can be anticipated that unemployment rates among youth with disability will be the higher than for all other young people. Rates of unemployment among adults with disability vary from country to country, but on average, tend to be about 40-60% higher than for the non-disabled population (9). This is true even in developed countries with sophisticated school-to-work programmes and reserved employment schemes (9, 26). Overall, the ILO estimates that the unemployment rate among people with disabilities in the developing world is an overwhelming problem - up to 80% in some countries (27). Furthermore, even when they enter the work place, adolescents with disabilities often find they have little margin for error. Unlike non-disabled adolescents who frequently fail at a first job or apprenticeship, adolescents with disabilities are rarely allowed to explore their options. Should they not succeed in an initial apprenticeship or be fired from their first job, those around them are quick to label them unemployable and refuse to let them try again.

Unemployment among disabled young women in all societies, averages 50% higher than unemployment among comparably educated disabled young men, (which itself is double that of their non-disabled male peers). Disabled young people from ethnic and minority communities

also routinely have unemployment rates that are significantly higher than those of their non-minority disabled peers. For all these reasons, young people with disabilities are more likely to be unemployed, underemployed (working fewer hours, working at seasonal jobs) or employed at a lower wage, than their non-disabled peers. Moreover they are often the last to be hired and the first to be laid off or fired.

Not only is their employment status in a continual state of flux, but young people with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Even when well educated, they take longer to find a position, have less job security and less prospect of advancement than do their non-disabled peers with comparable levels of education. This is true even for individuals with disability who have received a college education, and particularly true for college educated women with disability (28, 29).

Citing employment figures however, may be misleading. Presumably, only those whose disabilities are too severe or whose families are wealthy, do not contribute in some way. Most young people with disabilities world-wide do work, although they usually are officially listed as unemployed. Millions work outside the home, doing menial tasks or working as street beggars. Millions more work long hours within the family home or on the family farm. They cook, clean, baby-sit, care for ailing and aged relatives, or tend gardens, fields and flocks (2).

For the non-disabled young adult, assuming an increasing number of chores within the family unit is often a way of building skills that will eventually lead to more independent adult status. Identical work is frequently viewed as an end in itself for those with disabilities, or as a way of helping to justify the costs of their food and housing. Such work, even when it is of great financial significance to the household, may go unnoticed by economists, local communities and even by their own families. Moreover, many young people with disabilities working on the family farm or assembling piece-work in the kitchen, may have their work brought to the marketplace by others who receive the credit and collect the wages for that work.

Again, much more research is needed on young people living in these types of household arrangements. It is known that millions of adolescents and young adults with disabilities are unable to support themselves for the present or to plan for the future. Moreover, not only do they routinely earn far less than their peers, but in many cases, society and their families allow them little or no control of what income they do manage to bring in.

## **SOCIAL IMPLICATIONS**

The period between childhood to adulthood is a period that prepares the individual for successful adulthood. Yet for young people with disability, there is an almost universal lack of inclusion

in activities that build fundamental social, educational and economic skills. This exclusion is often formally sanctioned, with adolescents and youth with disabilities being barred from participating in formal cultural and religious ceremonies that help define an individual's changing status in the eyes of the community. Disabled young people are also often left out of the less formal 'rites of passage' such as joining a sports team, courting, learning to drive the family vehicle. This exclusion distinguishes young people with disability from all other groups of young people in every society and this exclusion has profound implications for their personal lives (2).

A major issue in the lives of all non-disabled young people is the growing physical maturation and changing social role that prepares them for marriage and children. Yet young people with disability often have little or no say over where they will live, whom they will live with and what role they will play within their families or communities. Disabled young people are often denied the right to build families of their own. Social and family constraints make it unlikely that many young people with disabilities will marry. Indeed, in some countries, individuals with certain types of disability are unable to legally obtain a marriage license. This is particularly true for disabled young women (12). Without the prospect of marriage, in many societies, these young people cannot hope to be accepted as full adult members of their communities.

This does not mean that young men and women with disability are not involved in relationships, or do not engage in sexual activities, only that there is often no social acknowledgement (and often no sex education) provided to them (15, 30). This places adolescent girls and young women with disabilities in particular, at increased risk for pregnancy, as well as sexually transmitted diseases. In one of the few studies of its kind, the United States National Longitudinal Study (31) found that three to five years after completion of high school, females with disability were significantly more likely to be mothers than either non-disabled females or disabled males. Although 23.7% of all youth in this demographic pool had had children, only 16.5% of disabled males had become fathers. In contrast, 40.6% of all disabled females in this age range had given birth to one or more children. For young women with emotional disturbances, learning disabilities or those with hearing impairments, almost 50% had become pregnant in the years immediately following high school. For disabled females who had dropped out of school, 54% had become mothers. The majority of these pregnancies occurred outside of marriage. Already struggling to earn a living, the necessity of providing for a child, particularly in those cases where they are not married, places yet an additional burden on these young disabled mothers (14, 32).

In those societies where men take more than one wife or routinely keep mistresses, a teenaged girl or young woman with a disability is more likely to become a second or third wives or a mistress within a larger household, than to be a first or primary wife.

In these types of arrangements, the young women with disability, and their children, often will have less right to play a key role in family decision making and significantly less claim to both household resources and inheritance. Finally, not only do expectations for what is an appropriate role for young men and women with disability vary from one country to the next, expectations often vary from one ethnic or minority community to the next. (33).

### **HEALTH AND MEDICAL ISSUES**

Globally, social, economic and educational issues are far more pressing issues for many young people with disabilities than medical issues. However, the availability of rehabilitative care, prosthetic devices and age appropriate health care need to be singled out both because of a significant lack of such services and because all too often, social and economic discussions about disabled young people are side tracked by their presumed medical or rehabilitative needs (34). There are two areas of concern: unmet rehabilitative needs for some young people that may lessen their ability to fully participate in society; and lack of access to general health care and health promotion services that may lessen a young person's ability to maintain good health and productivity.

Rehabilitative services tend to be concentrated in urban areas and are prohibitively expensive. Programmes that require long-term care are unavailable to many. This is particularly true for young women in societies where females not allowed to travel or live away from home unescorted once they enter puberty (14). Globally women and children receive less than 20% of all rehabilitation services (12). Prosthetic devices, (artificial limbs, wheelchairs, hearing aids, eyeglasses, etc.) are often difficult and expensive to acquire, and a rapidly growing adolescent will need a replacement every year or two. The issue is not simply cosmetic. A poorly fitting artificial limb has profound psychological and social implications for an already marginalised young person. A wheelchair that has become too small limits the ability of a young person to leave the house to attend school, work or establish any measure of autonomy. Community Based Rehabilitation (CBR) efforts, while offering significant benefits, too often concentrate either on younger children or on adults, again missing the opportunity to address the specific needs of young people with disability.

Lack of access to general medical care is also reported widely. In many cases, health care facilities are simply inaccessible - stairs block access for wheelchair users or there is a lack of sign language interpreters, making medical consultation virtually meaningless for deaf individuals. Additionally, health care workers often refuse to provide basic vaccinations or reproductive health information to disabled young people because it is felt that they do not need such information or should not utilise scarce resources (8).

An additional concern related to the health and well-being of young people with disability is their increased risk of being victims of violence. Many young people are initially disabled through violence, either through violence within the household or community, or as a result of warfare, child soldiering, landmines or other forms of civic strife. Once disabled, these individuals as well as all other disabled young people, are at increased risk of being victims of physical and psychological abuse, domestic violence and rape. Again, few statistics are available, but what exists, indicate that individuals with disability are three times as likely to be the victims of domestic violence, violence in the community and rape as their non-disabled peers (35, 36, 37). These young people also face a profound lack of legal protection. In many countries, police and prosecutors will not even take complaints from disabled individuals or allow them to give testimony in courts - which means that such violence can continue unchecked. Indeed, in both developing and industrialised countries, there has been a growing number of accounts of disabled young people being targeted by sexual predators specifically because they either cannot report the abuse or will not be believed when such abuse is reported (8).

Violence and sexual abuse are also of great concern for the significant number of young people who continue to be institutionalised in schools, hospitals and asylums. Some young people have been consigned to such institutions as young children; however, many are institutionalised during adolescence by families who feel their disabled child has grown too big or too old to be able to live at home. Reports of violence in such institutions, as well as other significant human rights violations, are of particular concern (38, 39).

### **PROGRAMMES FOR YOUNG PEOPLE WITH DISABILITY**

There are an increasing number of programmes that address the specific needs of young people with disabilities, organised by government agencies, private voluntary organisations, religious organisations and community groups. However, globally the number of such programmes remains small. In an international survey on the status of disabled adolescents (2), only 12% of all experts and organisations surveyed were able to identify programmes that targeted disabled young people as a distinct group. Almost all the programmes identified were very small, serving fewer than 100 young people in nations where millions are disabled. Such programmes furthermore, are more likely to be urban based and only available to more affluent young people. These small programmes can provide models, but have not yet been scaled up or systematically evaluated.

In recent years, some disability organisations have begun to address the needs of young people with disabilities as a distinct subgroup. For example, the World Blind Union has established a Committee on Youth to improve outreach. In several cases, organisations have been formed to focus wholly on adolescents or young adults with disabilities. For example, in



Russia, the new National Federation of Hard of Hearing Young People, is bringing together adolescents for mutual support and social interactions. In the United States, there is now a National Centre on Youth with Disabilities in Minnesota.

With such a diversity of programmes for young people with disabilities, it is difficult to establish universal criteria for why certain programmes are judged to be successful. However, programmes identified as successful in the UNICEF study (2), seem to share a common attribute. Whether serving young people with disabilities separately from or alongside of their non-disabled peers, such programmes encourage them to engage in activities that build the skills and confidence they will need to function effectively in society. These programmes have well thought out outcomes, sufficient organisation structure and funding for on-going support. They include an evaluative component to ensure that programmes and services provided meet the actual needs of young people as well as their long-term goals. Finally, such programmes were felt to be particularly effective when young people with disabilities themselves help design, oversee and evaluate them. Such programmes also appear to be more successful when they help to foster leadership, advocacy and self-sufficiency skills in young people with disability through the mentorship of older disability advocates (32).

The need for more gender sensitive programmes that ensure that the specific needs of girls and young women are addressed, has also been reported. Russo (19) notes that adolescent girls and young women are less likely to participate in programmes than their disabled male peers and are more likely to leave such programmes if their specific needs are not met. Of additional concern is the fact that in a number of countries and regions, the leadership of disability advocacy groups remains predominantly male. Where females are included, they are often assigned to oversee and advocate in arenas traditionally defined as 'female' - for example, the welfare of disabled children or education. A similar pattern has been noted for individuals with disability who come from ethnic or minority communities: they are often asked to concentrate on disability advocacy efforts or outreach programmes targeted to their particular ethnic or minority populations. While such advocacy initiatives are often very important, broader leadership and policy roles in organisations are often denied to women and members of minority populations - no matter what their own interests and aspirations might be.

#### **TRANSITIONAL PROGRAMMES: SCHOOL TO WORK**

Where transitional programmes exist, research is needed to better assess their effectiveness. In many industrialised nations, adolescents with disabilities remain in school until their late teens after which, they enter formal government sponsored transition programmes. Such programmes are not without problems. A study by the UN Office of Economic Co-operation and Development shows a consistent lack of co-ordination within many national programmes (40). It is not unusual to find that one government department puts resources into programmes

that enable “disabled school leavers” to keep a job and live independently, while another agency uses even more resources to award pensions provided the adolescent remains dependent and unemployed (41).

While research on various types of income maintenance schemes and reserved employment programmes can be found primarily from North America and western Europe, such programmes are often very closely tied to specific national social security programmes and health care systems. These programmes reflect specific national ideologies about the rights of citizens and the responsibility of the community. They are also a product of idiosyncratic historical factors. The support system available to disabled youth in Sweden or Canada looks quite different from those in the United States or Germany. While developing countries can draw a number of valuable lessons by reviewing such transitional mechanisms, it is important to note that such systems have not eliminated the substantial differences that continue to exist in employment rates and income levels between comparable groups of disabled and non-disabled young people. Of even greater significance, as Elwan notes, “income maintenance schemes and even reserved employment schemes have limited applicability where there is no effective labour market” (9). Moreover, there remain many issues for these young people in transition (family, home, social lives), about which relatively little is known.

Models for transition to the workplace have also begun to appear in developing countries (32). For example, the Barbados has had a successful small programme for adolescent girls with disabilities, to teach them job skills. Recognising that many adolescents with disabilities lack inputs from family and friends to help them learn how to present themselves well in public, this programme provides such training (2). In Cambodia, the ILO with funding from the Japanese Ministry of Labour, and human resources from Cambodia’s Ministry of Social Affairs, Labour and Youth Rehabilitation have field-tested the Disability Resource Team concept. The programme assists young people with disabilities with training and support to enter mainstream vocational training programmes, and helps them find a job or use their skills to start a business. So far, it has helped 180 people, 67% of whom are now employed (27). The possibility of linking adolescents with disability through the internet to allow them to share experiences and resources including those of transition to adulthood has also received growing attention since 1995 (42). Organisations such as the World Deaf Congress, the American National Spinal Cord Injury Association and others have established web pages, chat groups and bulletin boards for children and adolescents. Many sites target specific subgroups, such as blind adolescents or deaf young adults. Studies of these networks indicate that they provide a social support and resource network that allow adolescents with similar types of handicaps to compare experiences and help each other make the transition into the adult world. The potential benefits of linking an adolescent in a remote village or isolated farmstead with others facing similar health and social concerns are great. Unfortunately,

only a small number of adolescents with disability world-wide currently have access to the computer or have enough education to be able to use it effectively.

Programmes that provide a solid grounding for disabled young people, particularly as they enter the workplace, fall roughly into one of two categories - those that are separate from and primarily or exclusively for individuals with disability, and those that are inclusive, allowing disabled young people to participate alongside their non-disabled peers. Ideally both types of programmes should be available.

Separate income producing programmes have existed for years, often in the form of sheltered workshops in both the developed and developing world. In a sheltered workshop the initiative for the programme and decision making for the programme are generally not under the control of individuals with disability, who function as workshop employees. Increasingly however, disability-led co-operatives, using micro-credit models, have been successfully introduced. For example, small loans of capital have allowed women with disability to invest in small-scale income generating endeavours (e.g., a sewing machine or chickens) which have resulted in real social and financial independence. Comparable co-operatives for young people with disabilities, and the inclusion of young people in on-going disability co-operatives, where they can be mentored by adults with disability, are much needed. Such co-operatives, where young people with disability learn production and marketing skills in addition to earning extra money by selling their crafts and produce, hold particular promise (10, 32). Ideally, disability-led economic enterprises could have a mechanism in place to regularly bring in and train disabled adolescents and youth, thus allowing them both to assume a measure of economic independence and to receive guidance and mentoring from older, more experienced adults with disability.

Historically, many co-operatives have concentrated on areas such as handicraft, dressmaking and carpet weaving, skills that are time consuming, low paying and offer little opportunity for advancement. Many of these skills are also oriented to the production of non-essential items or items for the tourist trade, the first markets to slump when economic times become hard (43). However, such co-operatives could also allow disabled young people to develop and market skills that will be needed in the coming decades, such as computer training.

## **INCLUSIVE PROGRAMMES**

Separate programmes for disabled young people are not the only answer. All too often, young people with disabilities are not included in broader village-wide, regional, and national development schemes targeted to all young people in the general community. Given the prevalence of disability, some 10% of any group of young people receiving skills or job training should be young people with disability. If these young people with disability are missing from a skills building initiative or local development project, then the question for

whomever is organising the programme is: where are they and why are they missing from a programme designed to benefit the general population? Innovative examples are beginning to appear, such as the World Bank's recently initiated Velugu project which is intended to systematically integrate disabled people into the mainstream of rural poverty alleviation programmes, but more is needed.

### **DEVELOPMENT OF AN ADVOCACY BASE**

While the past decade has seen a blossoming of disability-directed advocacy groups worldwide, in fact, only in a small percentage of these groups do young people with disability play a significant role. However, there are some examples of programmes that already focus on the development of specific skills or provide unique experiences for young people with disability. For example, Mobility International USA (MIUSA), brings disabled adolescents from around the world to leadership training programmes at its home base in Eugene, Oregon; specifically targeting young women with disability for leadership training (32). The Japanese Society for Rehabilitation of Persons with Disability has an international Fellows Programme that identifies and brings to Japan a select group of disabled young people from developing countries who have shown great promise as future leaders. Such leadership among disabled young people at the local, national and international levels, must be fostered as part of overall advocacy, both to strengthen the present and to guarantee the future.

Of particular note are Centres for Independent Living, both in industrialised countries and increasingly in developing nations. In countries where the norm is for young people to establish independent households, develop job skills, enter the workforce and establish social networks separate from those of their families, such centres have been instrumental in reaching out to young people in transition. They provide young people with disability, access to information, choices and supports that allow them new options and ideas. Most importantly, such centres often put young people with disability in touch - sometimes for the first time - with other disabled young people and adults with disability who can provide them with crucial support networks and mentoring relationships. Currently, such centres tend to be poorly funded and urban based. How they can be better adapted to reach young people with disability in rural areas, those living within more traditional family and traditional community structures, still needs to be more systematically examined.

### **CONCLUSION**

Millions of young people between the ages of 10 and 24 are disabled and only a small percentage of these currently have lives or will have futures as rich as those of their non-

disabled peers. These individuals' physical, intellectual or mental health impairments are not what will hold them back. At issue are common social, economic and cultural prejudices against disability that are particularly pronounced when viewed in conjunction with the widely held social discomfort with the needs of adolescents and youth.

While specific policy, programmes and initiatives for disabled young people will vary from one culture to the next and the expectations of young people in general must be assessed in light of social and cultural expectations, the basic question of whether young people with disability have the same right to education, employment, social participation and self-determination as their non-disabled peers, offers a starting point for assessing the economic and social inclusion of adolescents and young adults in a broader cross-cultural framework.

In too many countries, disability is seen as a transient state. The expectation that a child with a disability will either recover or die does not fit the realities of those young people who will survive, often for decades to come. These young people will survive whether or not they receive an education, are provided medical and rehabilitative care or are included in the social, religious and economic life of their communities. Their existence and the well-being of society as a whole however, will be much richer if these young people are allowed to develop to their full potential. Young people with a disability will continue to be seen as a problem only so long as their potential goes unrecognised.

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## **RATIONALE FOR AN APPROACH TO IDENTIFYING DISABLED PERSONS IN COMMUNITY BASED REHABILITATION PROJECTS**

Joy Wee\*

### **ABSTRACT**

*This paper outlines the considerations that need to be made when taking steps to identify the disabled population in a given community, as part of planning for a community based rehabilitation (CBR) programme. An overview of the literature and lessons learned, and discussion of important issues is provided. It emphasises the extent of thought and considerations suggested for engaging in the first stages of CBR planning, in order to promote successful CBR efforts.*

### **INTRODUCTION**

This paper explores various issues that need to be considered in planning steps for the identification of disabled persons in isolated communities with limited rehabilitation resources. Basic epidemiological information about how many disabled persons live in the community of interest is required, before any appropriate and responsive planning by the community can be made with respect to provision of health care for the disabled population. Also, the most common causes of disability in the region should be clarified. Planning for social and health services cannot adequately proceed without such information.

There are several approaches that one could take in trying to identify disabled persons. However, important principles of programme planning in community based rehabilitation (CBR), gained through collective knowledge and experience, should be applied from the start, in order to maximize long-term successes in any community endeavour that seeks to promote health.

### **OVERVIEW OF CBR (1)**

Community based rehabilitation became acknowledged and gained acceptance with its promotion by the World Health Organization (WHO) in the late 1970s. Initially, CBR consisted of small projects in developing areas of the world, primarily as a means of service delivery (2), with a focus on restoring functional ability in disabled persons.

In the 1990s, CBR evolved to include comprehensive intervention in education, prevention, social rehabilitation, and vocational training, along with a shift to changing community attitudes and other contextual factors, acknowledging that disabled individuals do not live in isolation, but are influenced by community factors such as attitudes and acceptance, promotion of social integration, opportunities in education and employment, and community ownership of CBR programmes. This was reflected in the joint position paper of WHO, International Labour Organization, and United Nations Educational, Scientific, and Cultural Organization (UNESCO) (3), whereby CBR was defined as "a strategy within community development for rehabilitation, equalization of opportunities, and social integration of all people with disabilities" and is implemented "through combined efforts of disabled people themselves, their families and communities, and with appropriate health education, vocational and social services." The International classification of functioning, disability and health (ICF, 2001) reinforces the notion of contextual factors impacting impairment, activity, and participation (4).

Another influential movement is the disability rights movement, that stemmed from the Independent Living Movement (5) and the creation of Disabled People's International (DPI), leading to the development of international laws intended to protect the rights of disabled persons (6,7). One should be aware of local laws in planning for CBR. For example, in Ontario, Canada, the recent Ontarians with Disabilities Act, 2001 (8), would need to be acknowledged, and may spur communities to examine the issues in greater detail. This act was passed to improve opportunities for persons with disabilities, and "provide for their involvement in the identification, removal, and prevention of barriers to their full participation."

When it comes to prevention of disability, it is helpful to look at health promotion literature. Since ill health in society is often outside the individual's control, and could be socially, economically, and culturally constructed, Whitehead (9) proposes socio-political health promotion as an approach that avoids individualised behavioral-change programmes, and emphasises participation in public health policy making, social education programme development, political advocacy, and critical consciousness raising. Appreciation of lay knowledge regarding disability issues is therefore important.

Community participation is recognized as an important component of CBR planning, though full ownership by communities may not be possible at the beginning of programme development, as some communities are ignorant about consumer ownership of development programmes (1). Social learning theory supports effort being made to motivate the local community to participate. Participation by those who would be impacted by a programme would also be important for successful programme evaluation and revision (10). Integration of disability into development programmes requires cooperation between health, educational, municipal, and employment sectors. One could expand the effort to include all important

subsystems in community life (11): economics, health and social services, government, education, transportation, recreation, environment, communication, in the identification of strengths and stressors. Multi-sectoral collaborations can be impeded by power and control issues; a focus on goals may assist in facilitating the process.

An estimated 70% of people with disabilities could be handled at a community level, while 30%, those with multiple and severe disabilities, would require specialist intervention (1). Therefore, it is important to develop mechanisms for referral in order to access specialist intervention, and methods to recognize when such referrals need to be made. Those with severe disabilities tend to be neglected when it comes to community interventions, and it is important to include them from the start.

CBR in the 21st century requires evaluation to be incorporated into program planning. The need for evidence based practice and sharing of effective methods internationally is driving a move towards the development of accepted systems and good practice guidelines.

### **EFFECTIVE PRACTICE**

Lazenbatt (12) identifies eight characteristics of effective practice: 1) holistic view of health and social need; 2) health alliances and inter-agency work; 3) empowerment; 4) research-based approach; 5) multidisciplinary team work; 6) needs assessment; 7) community development; and 8) audit and evaluation in practice. Empowerment may require a change in attitudes of both lay persons and professionals. Research into patterns of care, population needs, and resource availability is required. Community health analysis uses various data sources to look at health needs, strengths, and limitations in the community (13). Partnership and trust is essential, and involves clarification of roles and expectations of each partner. Time commitment is an important element in building trust. Financial and other potentially contentious issues must be frankly discussed. Good communication is important for the health of the partnership. Both quantitative and qualitative evaluation is important, as it has been acknowledged that quantitative methods that meet the criteria of statistical robustness can leave minority and vulnerable voices unheard.

### **IDENTIFYING DISABILITY**

Traditional biomedical models of disability focus on impairment and functional abilities when it comes to identifying disabled persons, and rating severity of limitations. This stemmed from the 1980 WHO publication "The International Classification of Impairments, Disabilities and Handicaps" (ICIDH) (14). Using this model, disability can be quantified by functional scales such as the Barthel Index (15), or even the ICF itself, if qualifiers of body function, body structures, and activities are included in data collected.

The social model of disability, traced back to 1976 by the Union of the Physically Impaired Against Segregation (UPIAS), and adopted by the DPI (16), separates 'impairment' of the physical body, from 'disability' which is "a consequence of the failure of social organization to take account of the differing needs of disabled people and remove the barriers they encounter" (17). Only each disabled individual would be able to voice societal barriers encountered that contribute to disability. Priestly (18) outlined the interrelatedness of concepts in his four category classification of disability. One relates to the medical model, in which disability is an individual condition. Another takes account of personal interpretation of disability from experience. A third looks at social structures in creating disability, while the fourth relates disability to cultural roles and expectations. The ICF provides a means of methodically enumerating environmental factors that can be qualified and documented for each disabled individual, but personal factors have not yet been developed.

Some severely disabled persons may not be able to indicate their level of activities and participation. Unfortunately, there does not seem to be good correlation between measure provided by patients and those provided by proxy, by their caregivers or family members (19). Therefore, even early stages of data collection in CBR planning may exclude the most severely impaired people. When looking at strength of patient/proxy agreement, it appears that agreement is higher when using dichotomized responses (yes/no) or those with numeric information (20,21), and one would recommend the use of such questions if required.

Another subgroup of disabled persons that may be under-represented is disabled women, who in their relative state of isolation may be more vulnerable to exploitation and violence than their male counterparts (1). On the other hand, in some cultures, disabled men may be less inclined to seek help than women when they run into difficulties in functional tasks.

In assessing needs, Thomas and Thomas outline several questions that need to be considered (1):

1. What are the expressed needs of clients/families/community?
2. What are the current priorities of clients/families/community?
3. What are the existing beliefs and attitudes related to rehabilitation in the community?
4. How do different groups estimate the efficiency of existing rehabilitation services if any?
5. What are the gaps in existing rehabilitation services?
6. What changes do they feel are necessary to existing services?

Such information should be gathered early in the process, to allow for an accurate overview of the breadth of locally perceived needs, wants, and interests.

## **INDICATORS**

Decisions as to what indicators to collect during the initial data gathering stage are critical in the ability to draw conclusions from a study or project. Short and long-term indicators can be considered (22,23). Examples of short term indicators could include service utilisation or access, and activities of daily living, while long-term indicators could include such measures as participation of disabled individuals in community activities, and changes in community attitudes. Boyce (22) identifies four main types of indicators, including those covering 1) policy 2) rehabilitation care provision 3) social and economic issues, and 4) disability status. It is important to give thought to indicators early.

## **COMMUNITY PARTICIPATION**

It is acknowledged that the word 'community' has different meanings, and could comprise of various affinity groupings. For the purposes of this paper, 'community' is defined as a geographical region. It is generally believed that community participation is key for sustainability, which is defined by Thomas and Thomas as "the ability of a programme to perpetuate itself using appropriate strategies until its goals are fulfilled." They also outline different levels of community participation, from passive recipient to active involvement at all levels. Presumably, the greater the level of community participation there is, the higher the chance of ownership and sustainability.

## **PLANNING A STUDY TO IDENTIFY DISABLED PERSONS IN A COMMUNITY OF INTEREST**

Research Ethics Board approval is required prior to beginning a study. One must educate oneself as to the appropriate procedures to be followed, for institutions, as well as for populations. For example, the right of self-determination of First Nations people in Canada includes the ability to make decisions about research in their communities. The National Steering Committee recommends that fact finding and analysis be participatory, and had approved a Code of Research Ethics July 1997 (24).

Once ethics approval is obtained, one could conceivably initially conduct a house to house survey to identify disabled persons, but such a low profile method would not necessarily increase early awareness of disability in the community. From the literature discussed above, it seems obvious that one should involve as many community members as possible in the development of a project. Therefore, even the beginning steps of a study should be designed to cast a wide net.

Informational campaigns could be employed in order to alert residents to the impending study. These campaigns could enlist the involvement of the community, perhaps in planning

an "activities and participation awareness week" or similar activity. During a campaign week, existing information about disabled persons and local efforts to improve services for disabled persons could be published, through a medium that most would have access to, such as radio programmes, and school/community programmes. Existing national survey information should also be shared, if available. The goals of the study would also need to be outlined, clearly stating its objectives of assisting the community to identify the scope of disability and issues to consider, while clearly declaring what it cannot accomplish. It cannot come up with solutions for the community, but could enable the community to address possible solutions from within.

After the awareness week, fliers and posters could be employed, just as Badger et al. (13) did, to maximise participation in their study. Two levels of fliers would be suggested: one aimed at individuals, and one aimed at community leaders, such as teachers, religious leaders, community health representatives, health policy makers, physicians, heads of policing and safety, and community administrators. Preparation for this would entail identifying and contacting these administrators about the study, and enlisting their cooperation. Individual fliers could be handed out door-to-door, after translation into the local language. For those who are illiterate, one could also advertise through local health radio programmes. Essentially, these fliers, posters, and air-time messages would encourage disabled persons to identify themselves, either directly to the primary investigator, or through their local leaders. More severely disabled persons may be identified by their caregivers or health professionals, with their consent. Radio broadcasts could be repeated to encourage maximal participation. Sufficient time should be allowed for reflection, participation, and identification of disabled persons in the community.

Once all, or most, of the disabled persons in a community are identified, a next step would involve collection of more detailed data, both about individual participants, and about the community. Is it important to document bodily functions and structures, or is it enough to collect data on activities and participation? This would depend on the purpose such data is collected for. Careful consideration needs to be made in design of data collection sheets. It is likely that one would need to collect information about impairments, activities, participation, environmental and social factors, most pressing needs and wants, and existing knowledge about disability management. Once again, sufficient time would need to be allowed for this stage of data collection.

Community knowledge about disability issues, disability prevention, disability rights, and barriers to participation, can only accurately be assessed by a full community survey. However, such an effort may not be feasible. Therefore, it may be necessary to randomly sample community members for potential participation in such information gathering processes.

As for existing community programmes and resources that address disability issues, one could survey leaders in the various sectors, using qualitative methods. For example, school

principals, religious leaders, administrators, and heads of relevant public institutions could be asked to provide such information.

Thus, at least three different types of surveys, targeting three different populations, need to be developed. Additionally, one could survey family members of disabled persons, such as their caregivers, children, or parents, to further identify important issues.

Once the issues are identified, and a broad overview obtained, one should involve all sectors of the community, as identified above, in determining priorities for change. Those who would directly be impacted by proposed change, disabled persons, would need to provide feedback on such ideas. Efforts must be made to prevent a powerful minority from controlling the process, and allow all groups voice. Skilled facilitators may be crucial during this stage of the process. As previously mentioned, focusing on goals may be a way to work around potential barriers, if they develop. It may be helpful to look at accepted corporate strategies for cooperation as a model for communities (25). Programme planning could then occur, based on the priorities developed. Discussion of programme planning is beyond the scope of this paper, but community involvement would be crucial for long-term success.

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### **The Leprosy Mission International Announcement for the Wellesley Bailey Awards 2005**

The Leprosy Mission International (TLMI) invites nominations for the Fourth Wellesley Bailey Awards. The Awards will be presented in the first week of June 2005 at a unique awards ceremony in Dublin.

The Awards are presented to people who have had leprosy and who have made an outstanding contribution to society - this can either be nationally in their community, or internationally. The person nominated must have shown courage and achievement in overcoming the challenges faced through leprosy.

Two separate awards will be given: one male and one female. Unsuccessful nominations from previous years can also be submitted for reconsideration. Please note the person nominated must not be told and self nominations will not be accepted.

The deadline for nominations is 10 January 2005.

Further information and background information can be obtained from:

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**ORIGINAL ARTICLES**

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**AN INTERNATIONAL COMPARATIVE STUDY ASSESSING  
IMPAIRMENT, ACTIVITIES, AND PARTICIPATION IN  
SPINAL CORD INJURY REHABILITATION - A PILOT STUDY**

Joy Y.M. Wee,\* Richard Schwarz

**ABSTRACT**

*This qualitative comparative cross-sectional study attempted to identify existing gaps and differences in health care processes and societal structures supporting the spinal cord injury population in two countries with different socioeconomic profiles, Nepal and Canada, by looking at incidence of preventable complications, and measures of activities and participation. Subjects were recruited from two comparably sized spinal cord injury rehabilitation units in both countries, during a two-week period at each site. Interviews were held, along with brief physical assessment for injury classification and preventable complications. Prior to rehabilitation, preventable complications had already developed in 15 of the 17 subjects: 12 pressure ulcers, 10 urinary tract infections, 3 blood clots, and 6 joint contractures. Results show a need for greater consistency in efforts to prevent complications in this population, particularly within acute care settings. Activity (Barthel Index) and participation (P-scale) scores were higher in the Canadian setting ( $p=0.06$  and  $0.05$  respectively).*

**INTRODUCTION**

The International Classification of Functioning, Disability and Health (1) clearly sets the framework that one should consider when assessing disability of any kind. Even though not yet specifically outlined, it does acknowledge environmental and personal factors as contributing to disability and disablement, in addition to impairments and their effects on body functions. In evaluating rehabilitation programmes, one needs to gather information to evaluate all four categories of factors included in the framework (body structures and functions, activities, environmental factors, and personal factors).

This study was undertaken to identify improvements that could be made in health care provision, and societal structures, for persons with spinal cord injury (SCI), particularly in the immediate post-injury period. The question studied was whether there exists a difference in the occurrence of preventable complications after SCI in countries of vastly different economies and social structures. By definition, preventable complications need not occur, if

appropriate health care processes and subject compliance with recommendations are applied. Since complications cause impairments, they would be expected to impact negatively upon activities and participation. Level of activities and participation of individuals living in settings of different societal structures was also looked at in this study.

As a starting point, two inpatient rehabilitation units that the authors are affiliated with, were chosen for study, one in Nepal, one in Canada. The units are relatively similar in size, serving regional catchment areas, and localised within mid-sized cities (150-300 000 population). It was recognised at the start that such a cross-sectional study would provide only a snapshot, and its value would lie more in qualitative information gained, than in allowing definitive quantitative conclusions.

## **METHODS**

During the months of August and September 2003, the principal investigator obtained consents from, and interviewed, all inpatients that were on the SCI rehabilitation unit in a two-week period, at each site. Approval to conduct the study had been obtained from the appropriate research ethics boards. Individual interviews were conducted in each subject's usual language of communication, through an interpreter where necessary.

Measures collected included the Barthel Index (2) to measure activities of daily living, Cantril Self-Anchoring Striving Scale (3) to measure personal ratings of various aspects of their life (such as spiritual, emotional, independence ratings), Participation Scale (4), and Community Outcome Scale (5), as an indicator of each subject's community participation. There were no available records indicating whether initial post-injury instructions were given, for any of the subjects. Participants were asked to provide details about their SCI, and recall any instructions or procedures they may or may not have been provided with, as pertaining to preventing complications such as urinary tract infections, pressure ulcers, joint contractures, and deep vein thromboses or pulmonary emboli. Information regarding supports, home accessibility, and transportation was also obtained from each subject.

Descriptive statistics were used, including two-tailed t-testing for demographics and scales, and Fisher's exact tests to look for differences in preventable complication rates between the two groups.

## **RESULTS**

All eligible subjects consented to be participants; 9 Nepali and 8 Canadian subjects were recruited in consecutive two-week periods. Ages ranged from 24-60 (mean 38) in the Nepali setting, and 18-73 (mean 49) in the Canadian setting. Median time from injury at the time of data collection was 10 months in the Nepali setting (range 1.5 months to 9 years), and

10.5 months in the Canadian setting (range 2 months to 34.5 years). 5 Nepali and 4 Canadian subjects were at 12 months or less post injury. Most subjects sought help almost immediately (6 in Nepal and 5 in Canada presented on the day of injury to hospital or clinic, whilst 2 from each setting presented within 10 days, and 1 from each within 3 months). 1 incomplete paraplegic Nepali subject only had access to a local clinic acutely, was advised on leg massage, and sent home. It was not until years later that admission to a rehabilitation unit was sought by the subject for skin ulcer complications. 1 Canadian subject was offered stabilisation surgery acutely, but decided against it until months later. Time to admission to a rehabilitation unit after initial spinal cord injury varied from 7 days to 9 years (median 2 months) in the Nepali setting, and 18 to 300 days (median 1.5 months) in the Canadian setting. Table 1 shows demographics of the subjects. All the Nepali subjects with complete injuries were paraplegics. The non-traumatic causes of SCI were: tuberculosis (Nepali), multiple sclerosis, myelomeningocele, spinal abscess, and cancer.

**Table 1. Demographic information of subjects**

	<b>Nepal</b>	<b>Canada</b>
Male:Female	5:4	5:3
Age <60: 60 years or older	8:1	5:3
SCI level Cervical: Thoracolumbar	4:5	4:4
Traumatic:non-traumatic SCI	8(1 iatrogenic):1	4:4
Complete: incomplete SCI	3: 6	0: 8
Acute rehab: post-acute management	5:4	5:3

With respect to complication prevention prior to rehabilitation, only 2 Nepali and 5 Canadian subjects recalled any instructions about preventing skin ulcers acutely after SCI. Of the 3 Canadian subjects that did not recall instructions about skin ulcer prevention, one had been managed 13 years prior, one was managed in a remote northern community, and one in a smaller community hospital in the region, before the current rehabilitation admission. None of the Nepali subjects recalled being provided any bowel or bladder care instructions, or instructions regarding prevention of joint contractures or deep vein thromboses. Little is known as to the standards of complication prevention efforts in acute hospitals in Nepal. Both rehabilitation settings from which subjects were recruited routinely emphasise prevention of skin ulcers, and joint contractures. However, in the prevention of urinary infections and blood clots, care processes differ between the settings, due to differences in availability of diagnostic equipment and medications. No statistical differences were found in rates of preventable complications in the two settings.

Table 2 outlines preventable medical complications present prior to admission to the in-patient rehabilitation units. While on the rehabilitation unit, 1 Nepali subject developed contractures, 2 Canadian subjects had joint contractures released, and 1 Canadian subject had experienced complete healing of a pressure ulcer, while the other subjects with pressure ulcers continued in their healing. One Canadian subject was still on an anti-thrombotic agent to dissolve a blood clot, and 4 of 5 subjects with urinary tract infection on each unit had been successfully treated. Table 3 indicates other common medical issues that were being managed in these subjects. 8 of 9 Nepali and 4 of 8 Canadian subjects experienced ongoing bowel or bladder concerns of retention/ constipation or incontinence.

**Table 2. Preventable complications present prior to rehabilitation admission**

Preventable complications	Nepal (n=9)	Canada (n=8)
Pressure ulcers	7	5
Urinary Tract Infections	5	5
Blood Clots	1	2
Joint Contractures	2	4

Measures of activities (Barthel and Modified Barthel scores), participation (P-Scale and Community Outcome Scale), and quality of life (Cantril Self-anchoring Striving Scale) are presented in Table 4. When trying to determine the main differences between groups contributing to the trend seen in Barthel Index scores, p values were determined for each category of the Barthel Index for tetraplegics and paraplegics. The only categorical difference that reached statistical significance was in "controlling bladder" (p=0.04) for tetraplegics. A differing trend was seen in "walking" (p=0.09). For paraplegics, differing trends were found in the categories of "bathing" (p=0.07) and "controlling bladder" (p=0.09).

**Table 3. Ongoing medical issues reported by subjects in rehabilitation**

	Nepal (n=9)	Canada (n=8)
Musculoskeletal pain	2	4
Neuropathic pain	3	2
Autonomic symptoms	1	1
Urinary retention/incont	5	3
Bowel incont/constipation	7	3
Spasticity	4	6

**Table 4. Activities, Participation, and Quality of Life scores**

Scores Mean $\pm$ S.D. (best possible score)	Nepal	Canada	P value between groups
Barthel Index (100/100)	39 $\pm$ 32	68 $\pm$ 23	0.06
Modified Barthel Index (100/100)	45 $\pm$ 32	72 $\pm$ 24	0.07
P-scale (0/72)	36 $\pm$ 13 (3 unable to complete)	20 $\pm$ 13	0.05
Community outcome scale (0/24)	13 $\pm$ 5	8 $\pm$ 5	0.07
Cantril scale (60/60)	34 $\pm$ 12	39 $\pm$ 8	0.3

In terms of seeking paid employment, only 1 Nepali subject indicated that this was expected. Another thought of possible self-employment activities that could be pursued from home. Eight of the 9 Nepali subjects reported, or could envision, a contributory role in their household. One was retired. Of the Canadian subjects, 2 continued self-employment businesses while in hospital, 1 had a job to return to, and 1 felt optimistic about returning to work. Another younger subject had firm plans to return to school, and one was retired. Seven of the eight reported a contributory role in their households.

In order to understand activities and participation in context, contributory factors are listed in Table 5. One Canadian subject in a northern community had limited public support to the home, and had to re-locate to another community with a nursing facility. This same subject had variable access to public transportation, and was dependant upon a functioning hospital

**Table 5. Environmental factors contributing to activities and participation**

	Nepal (n=9)	Canada (n=8)
Access to family support	9	6
Access to government (villager) support	0 (5)	8
Access to some funds	5	8
Access to transportationown: public: private	0: 3: 5	5: 3: 0
Access to equipment	4	8
Accessible accommodation	6	8

vehicle. No Nepali subjects owned cars, and most had to use public or private transportation means, including porters, and non-adapted buses, jeeps, or taxis. The Nepali subjects who reported access to funding usually meant that they could borrow it, or obtain funds from relatives. Only one had a pension, and one could rely on some insurance money to cover expenses. Access to equipment meant that the subjects were provided with equipment intended to enhance their functional abilities, during their stay on the rehabilitation unit.

## **DISCUSSION**

The mix of subjects during the period of study was surprisingly similar in the two units. Subjects were generally older in the Canadian setting (11 year difference in mean values). This seems consistent with a previous study by McKinley, that found, in a group of 220 subjects, those affected by non-traumatic causes of SCI, to be older than those with SCI from traumatic causes (mean ages of 61.2 and 38.6 years, respectively) (6). In our study, there were more subjects with non-traumatic causes of SCI in the Canadian group than Nepali group. In some studies, up to one-third of SCI admissions were due to non-traumatic causes (7). Life-expectancy in Canada is also higher (74 years for men, 81 years for women) than that in Nepal (60 years for men and women) by about 15 to 20 years (8,9); therefore such a difference is not surprising. More of the Canadian subjects had lived with their SCI for longer periods of time. Three Canadian and four Nepali subjects were admitted to the inpatient SCI rehabilitation unit for management of issues other than their initial SCI because of special care considerations required for this population. In this subgroup, the Canadians as a group were older, and further along in time after their initial SCI. A similar proportion of tetraplegics to paraplegics were admitted in the units during the two-week periods studied.

The number of subjects who had experienced preventable complications was similar. While only 2 of the 9 Nepali patients stated that instructions were provided for prevention of pressure ulcers, the fact that only 5 of 8 Canadian patients recalled receiving such instructions indicates a need for better attention to complication prevention in acute care settings. In Canada, information about prevention of pressure ulcers has been known for decades in the Canadian setting, is found in standard textbooks, and should routinely be provided to patients. Even if instructions had been provided to subjects who did not recall receiving them, they were perhaps not impressed well enough, therefore leading to poor recollection. Of course, some subjects may have been well aware about the risks, yet permitted pressure ulcers to form. In both settings, the majority of subjects who experienced skin ulcers developed them prior to admission to the rehabilitation unit. Periodic educational campaigns targeting health care providers in hospitals and clinics where persons with SCI are regularly seen acutely could be beneficial in both countries. In addition to providing instructions for prevention, such as regular changes of position at least every two hours, it is clear from the subjects that the

gravity of developing skin ulcers, and prolonged healing periods, needs to be stressed in patient education. For example, some subjects admitted to being instructed about pressure sore prevention, but did not realize how difficult and serious the situation would be once these ulcers develop.

Joint contractures occurred in both populations, indicating that range of motion exercises and control of spasticity might not have been optimised in either setting. It is clear from the results that spasticity is a significant cause of ongoing medical concern for many of the subjects, both in the short and long-term. Deep vein thromboses and pulmonary emboli were experienced by more Canadian than Nepali subjects, despite the widespread use of anti-thrombotic medications in the former setting and the complete lack of such use in Nepal. There could exist a difference in population susceptibility to such incidences, or there may be a decreased level of detection in Nepal, given the lack of diagnostic equipment available. If detection rates are different, then one cannot realistically compare the rates of blood clots in the two populations. Occurrence of urinary tract infections could be dependent upon health care practices, such as the use of intermittent catheterisations, as opposed to indwelling catheterisations, as well as cleanliness of technique. However, in this study, similar numbers in both groups experienced urinary tract infections, despite the preferred application of clean intermittent catheterisation in the Canadian setting, and prevalent use of indwelling catheters in the Nepali setting. Prevention of urinary infections, joint contractures, and blood clots is generally considered, but not necessarily equally applied in all Canadian acute care settings. Once again, education of health professionals in acute care settings would be desirable for these complications that are generally considered preventable.

Little is known about the standards of complication prevention efforts in acute hospitals in Nepal. Both rehabilitation settings from which subjects were recruited routinely emphasise prevention of skin ulcers and joint contractures. However, in the prevention of urinary infections and blood clots, care processes differ between the settings, due to differences in availability of diagnostic equipment and medications. In a recently published article (10), six common complications presenting early after SCI included trophic skin changes (skin ulcer), heterotopic ossification, urinary complications, respiratory complications, pulmonary embolisms, and deep vein thromboses. Of these, skin complications were the most frequent (up to 30%). They too found at least one complication on admission, in up to 40% of subjects in Italian rehabilitation centres. Complication rates increased with duration between SCI onset and admission to the rehabilitation centre. They concluded that the most desirable set up for care of SCI patients is one that spans acute care, immediately post-SCI, through rehabilitation, to discharge home. Therefore, it would seem reasonable to educate acute care hospitals about the existence of rehabilitation centers, to facilitate timely referral and coordination of transfer after SC stabilization.



Other preventable complications, such as renal failure and hydronephrosis, could not be studied because regular monitoring for them only occurred in one setting. The necessary tools for detection of these long-term complications were not available in the Nepali setting. We did not study the incidence of complications such as respiratory conditions, or heterotopic ossification, as they are not necessarily preventable.

The Barthel Index is a measure of ability to perform activities of daily living. It was chosen instead of other measures, because of its universal availability and non-proprietary nature. It has also been shown to be sensitive to change over time, predictive of rehabilitation outcome, and useful for follow-up of subjects (11). A score of less than 100 indicates the presence of some disability. According to Shah's guidelines (12), the average Nepali subject scored in the severe dependence range, while the average Canadian subject scored in the moderate dependence range. However, these results could have stemmed from the differences in proportion of complete injuries between the two groups. A larger study with matched subjects would be able to examine if such differences truly exist. There was only one subject with neoplasm as a cause for SCI, in the Canadian group. Previous research suggests that subjects with neoplasm may not experience as much of a gain in functional ability during inpatient rehabilitation, when compared with subjects with traumatic causes of complete injury (13). This information may be helpful when planning a future study, with respect to comparisons between subgroups of subjects.

The Modified Barthel Index, developed in an attempt to increase sensitivity for stroke rehabilitation, did not seem to have any advantage in discriminating between groups. In general, Modified Barthel Index scores were higher than the Barthel Index scores. Given the results, and the relative difficulty and interpretational variability in scoring the Modified Barthel Index when compared to the ease of applying the Barthel Index, it would seem more practical to employ the Barthel Index in future studies.

The Participation Scale is a newly developed measure based on the ICF, that provides a quantitative measure of individuals' participation restrictions. Its validity, reliability, and stability has been checked in Brazil, India, and Nepal, by the development team (4). The authors felt that this might be an appropriate tool to use in this study, since it had been partially developed in one of the countries in our study.

With respect to community participation, it would appear that Canadian subjects are more able to participate in community activities than are Nepali subjects, possibly a result of differing access to resources and physical environmental access. The former system is a social democratic one, in which public services are available. The latter is largely a user pay system, with little in terms of municipal or national infrastructure, whether it be road or building accessibility, accessible transportation, or publicly funded supports, for disabled persons.

Nepali subjects are more dependent upon family and neighbours, and therefore benefit from a strong community belonging, whereas autonomy in Western countries is highly influenced by the individualist-liberal view, in which freedom of choice and action is important (14), and money can be an important means of enhancing autonomy (15). In studies based in user pay systems in the United States of America, where standards of living are generally higher, access inequities are acknowledged (16), with the poorest individuals being less able to pay for needed care. Negative long-term consequences of unmet health care needs may result in declining health and reduced social participation (17).

With respect to employment, the social environment in Canada seems to be more supportive of employment in the SCI population. One subject who was not employed was on a disability pension. It is common for disabled persons in Canada to receive funding support from government. Canada's Constitution outlines citizens' rights; perhaps this has strengthened the importance of supportive environments (18). Specific Acts have been developed in individual provinces to protect the rights of disabled persons (19). It is interesting to know that until recent years in Nepal, patients with SCI were often sent home to die, without receiving rehabilitation. There seems to be a need for better ongoing supportive environments in the community in Nepal. As the disability rights movement in Nepal gains prominence (20), perhaps changes in health care provision and social systems will follow.

Interestingly, self-reported quality of life seemed comparable in the two groups, as indicated by Cantril Self-Anchoring Striving Scale scores. Quality of life is a complex concept, and if it is an indicator of overall well-being of subjects, our results point to comparable states of well-being in the two groups, in spite of large differences in circumstance. Past research into life satisfaction in persons with SCI has indicated that satisfaction is not related strongly to impairment severity, but to measures of activities and participation; for example, life satisfaction is greater for those involved in productive activity (21). Unless one understands the various contributory contextual factors in each setting, validity of comparing self-reported quality of life measurements may be limited, and may be more appropriately used to measure changes in time for each subject. Some advocate the use of quality of life measures that include both objective and subjective components; these could be considered in future studies, for comparing two groups.

It is recognised that this cross-sectional study has many limitations in ability to generalise its findings. Sample size is small, and may not be representative of the majority of patients seen in each rehabilitation unit. Ideally, a larger prospective study, which matches SCI levels and types would be conducted. Participation scales can only be completed by those who have had opportunity to experience life in their own communities. In this study, all Canadian subjects but only two-thirds of the Nepali subjects could complete the P-scale. This is because the Canadian subjects had opportunity to experience life in their communities during the

weekend passes that are incorporated into their rehabilitation. Weekend passes are not currently part of standard practice in the Nepali rehabilitation setting, and not likely to be easily implemented due to geographical challenges. Therefore, follow-up measures of participation would be more beneficial to more accurately measure participation.

## CONCLUSION

Our study outlines the importance of providing early education about complication prevention after spinal cord injury, since they often occur before patients arrive on rehabilitation units. Acute care settings and primary care providers should be targeted in efforts to improve education, and coordination of referral to rehabilitation centres. The study also demonstrates differences in activities and participation in the two settings, which are related to contextual factors such as environment and available resources. It is therefore inevitable that one should examine health care systems, when attempting to assess care for disabled populations. In order to improve activities and participation in the SCI population, changes would be required in health care provision, as well as societal factors.

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## IMPACT OF SERVICES FOR PEOPLE WITH SPINAL CORD LESION ON ECONOMIC PARTICIPATION

Momin A.K.M.\*

### ABSTRACT

*In Bangladesh, economic participation is crucial for disabled people, as there is no social security for them in Bangladesh. However, economic participation receives little attention from service providers and policy makers who view disability as a medical problem and focus on medical interventions. They give little consideration to social and economic support for disabled people. Only a few Non-Governmental Organisations (NGOs) provide training and employment for disabled people. The Centre for the Rehabilitation of the Paralysed (CRP) is the only organisation in Bangladesh to provide specialised services for people with spinal cord lesion (SCL). CRP focuses on the whole person rather than treating the person's impairment alone. Interventions of CRP include treatment within hospital, as well as social and economic rehabilitation in the community (1, 2).*

*This paper illustrates the barriers to economic participation that government policy and practices fail to address, and compares them with the holistic approach taken by CRP. Further, a list of suggestions to improve economic integration of disabled people in Bangladesh is also presented.*

### INTRODUCTION

Participation in paid work is vital during adulthood in most societies. Economic participation covers both formal and informal economic activities. Formal economic participation includes paid employment in public and private sectors, which is regulated by laws, and the informal sector covers self-employment or unpaid work within the home. In Bangladesh many people are self-employed rather than employed in the formal sector (3). Paid work is a matter of economic survival for disabled people and their families (4). However, they are often excluded from work because they are viewed as unable to work due to their physical impairment and/or psychological consequences (5, 6).

Disabled people are among the poorest of the poor in Bangladesh (8). Women are generally worse than men and they are engaged in unpaid household work (9). As there are no social security benefits for disabled people, and no financial help to compensate the additional costs of living with impairments, paid employment is vital for their survival (2). A study commissioned

by Department for International Development (DFID-UK) in 1999 to evaluate the impact of services of CRP revealed that 75 percent of users of CRP's services come from the poorer sections of society (10).

The population of Bangladesh in 1996 was 122 million, out of which 54.6 million people were employed. Of all employed people, 30 percent were self-employed, 12 percent were employed in the formal sector, 18 percent were employed as daily labour and 40 percent were employed in unpaid work. Out of all people employed in unpaid work, 10 percent were employed in household work (3). Some studies in Bangladesh suggest that prejudice against disabled people contribute to low numbers of disabled people in paid work (2, 11, 12, 13). Many disabled people are even denied Micro-Credit (non-formal loan for poor people) for income generation (13).

This study identifies barriers to employment and economic participation of people with SCL and recommends measures to improve the economic participation of disabled people

## **METHODOLOGY**

The approach to this study was participatory, using principles of emancipatory research (14, 15). People with spinal cord lesions played a key role in developing methodology. It was considered vital that their views were presented as accurately as possible. Forty-eight respondents were involved as research participants for face to face interview. Half were from Centre for the Rehabilitation of the Paralysed (CRP), selected through stratified random sampling and the other half were from general hospitals selected through quota sampling. In addition to this 16 participants were involved in focus group sessions, half of whom were from CRP and the other half from general hospitals, all selected using purposive sampling method. The participants were aged between 10-59 years and all had received services between 1994 and 1999. The participants lived in the Dhaka, Narayanganj, Gazipur, Manikgonj, Munshigonj and Narshingdi districts of Bangladesh. Gender and severity of injury were considered to be key selection criteria. Data were generated through semi-structured face to face interviews with 48 participants on 3 occasions and from focus group discussions with 16 participants. In addition, background information on all 64 participants was elicited at the outset from structured interviews. A team of eight 'research associates' conducted the research constituting the non-disabled author of this paper, four people with spinal cord lesions (two from CRP and two from general hospitals), two CRP staff, and one non-disabled person who was selected from the community. The research associates arranged a workshop to determine the best method of data collection to be used. During this workshop decisions were also made about issues to discuss with participants. The research associates conducted the interviews and analysed the data to identify themes concerning economic participation.

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**RESULTS AND DISCUSSION**
**Table 1: Gender of respondents with SCL**

Gender	CRP %(no)	General hospitals %(no)	Total %(no)
Male	50(16)	50(16)	50(32)
Female	50(16)	50(16)	50(32)
<b>Total</b>	<b>100(32)</b>	<b>100(32)</b>	<b>100(64)</b>

**Table 2: Age at injury**

Age (in years)	CRP %(no)	General hospitals %(no)	Total %(no)
10-14	09(03)	06(02)	08(05)
15-25	41(13)	34(11)	38(24)
26-39	31(10)	37(12)	34(22)
40-59	19(06)	22 (07)	21(13)
<b>Total</b>	<b>100(32)</b>	<b>100(32)</b>	<b>100(64)</b>

Two-third of the respondents was injured between 15 and 39 years. The mean age of CRP respondents was 31 years, while that of general hospital respondents was 33 years.

**Table 3 : Severity of injury**

Severity of Impairment	CRP %(no)	General hospitals %(no)	Total %(no)
Complete Tetraplegia	25(08)	25(08)	25(16)
Incomplete Tetraplegia	15(05)	15(05)	15(10)
Complete Paraplegia	25(08)	35(11)	30(19)
Incomplete Paraplegia	35(11)	25(08)	30(19)
<b>Total</b>	<b>100(32)</b>	<b>100(32)</b>	<b>100(64)</b>

Thirty percent of general hospital respondents had complete paraplegia in contrast to 25 percent of CRP sample, while 35 percent of CRP sample had incomplete paraplegia in contrast to 25 percent general hospital sample.

**Table 4 : Classification of respondents according mobility aids used**

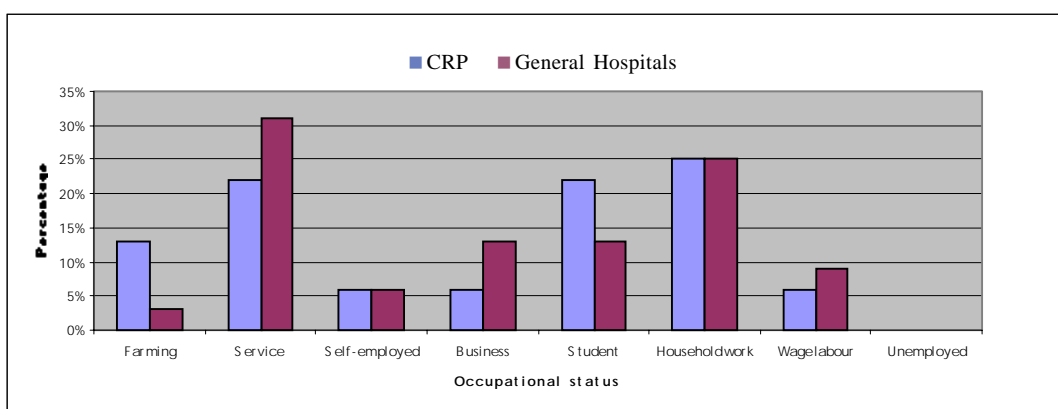
Mobility aids	CRP %(no)	General hospitals %(no)	Total %(no)
Wheelchair	47 (15)	06(02)	26(17)
Walking Stick/Crutch	03 (01)	12 (04)	08(05)
Walking without Aids	44 (14)	38 (12)	41(26)
Without Mobility Aids	06 (02)	44 (14)	25(16)
<b>Total</b>	<b>100(32)</b>	<b>100(32)</b>	<b>100(64)</b>

Forty seven percent of CRP sample had wheelchairs as against only 6 percent from general hospitals.

**Table 5: Respondents' level of education**

Education	CRP % (no)	General hospitals %(no)	Total %(no)
No Education	19 (06)	21 (07)	21(13)
Primary School	21 (07)	33 (10)	27(17)
High School	41 (13)	27 (09)	34(22)
GCSE and above	19 (06)	19 (06)	19(12)
<b>Total</b>	<b>100(32)</b>	<b>100(32)</b>	<b>100(64)</b>

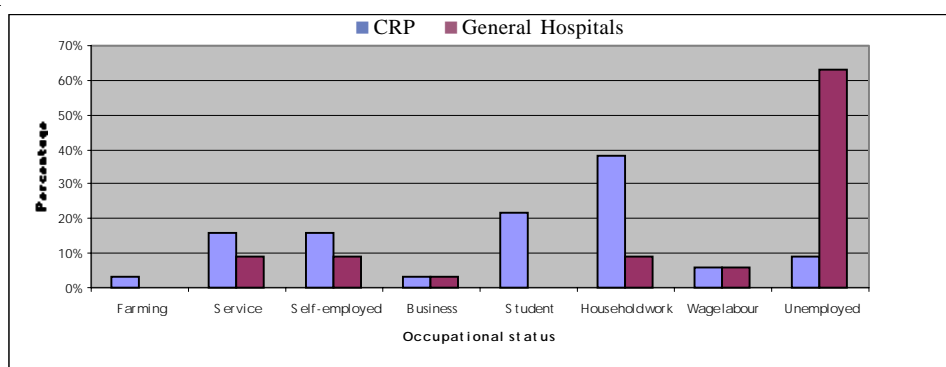
**Figure1: Participation in economic activities before injury**





Before injury more respondents from CRP did farming (13%) or were students (22%). But more respondents from general hospitals were in business (13 %) and worked as waged labours (9 %). None of the participants from CRP or general hospitals were unemployed/inactive before impairment. They were involved either in formal (paid) work or informal (domestic) work or were students.

**Figure 2: Participation in economic activities after injury**



Sixty-three percent of respondents from general hospitals were unemployed/inactive whereas only 9 percent of participants from CRP were in this category. Only 9 percent of the general hospital sample were involved in service as against 16 percent of CRP sample. There was a sudden drop of 22 percent of general hospitals sample from services in contrast to only 6 percent drop from CRP sample after injury. Sixteen percent of CRP sample was involved in self-employment in contrast to only 9 percent of general hospitals sample. Thirty eight percent from CRP sample were involved in household work, in contrast to only 9 percent of general hospitals sample. After injury a higher number of CRP sample were involved in household work in contrast to before their injury, whereas from general hospitals involvement in household work dropped from 25 percent to 9 percent. Twenty two percent from CRP were students, whereas there were no students among respondents from general hospitals. None were withdrawn from education after injury amongst CRP respondents whereas none continued in education from general hospitals after their injury. Three percent were in business both in CRP and general hospitals. There was a drop of 10 percent from general hospital sample for business category compared to only 3 percent drop in CRP sample. There was no difference in wage earning labour between samples from CRP and general hospitals.

More CRP respondents were able to participate in service, self-employment, household and educational activities than respondents from general hospitals. It was possibly because of the provision of mobility aids, vocational training and micro-credit support. CRP's therapeutic support and health education also could have helped respondents continue their activities

without having to depend on others. For general hospitals groups there was a higher dependency on others (2).

### **BANGLADESH GOVERNMENT POLICIES FOR PARTICIPATION OF DISABLED PEOPLE IN ECONOMIC ACTIVITIES**

At the end of 1992, the Economic and Social Commission for Asia and the Pacific (ESCAP) re-designated 1993-2002 as a second decade of disabled persons for Asia and the Pacific region (16). Disability was officially recognised by the government of Bangladesh with signing of the proclamation of ESCAP on 22<sup>nd</sup> August 1993 (17). In the early 1990s NGOs working with disabled people in Bangladesh formed a National Forum of Organisations Working for Disabled (NFOWD) (18). Since then groups for 'equal opportunity' and 'full participation' of disabled people have been lobbying with the Government (12, 17, 19, 20, 21).

The Government of Bangladesh passed the National Policy for Disabled People in November 9, 1995 (12). In the Disability Policy, sections 15, 17, 20 and 29 of the Bangladesh's constitution emphasise 'equal opportunity and full participation' of disabled people. These sections describe access to 'basic rights' such as food, clothing, shelter, education and health care. They also have assurance of equal opportunities in employment. In the policy, the government has acknowledged the International Declaration of Human Rights for Disabled People (1975) and the ESCAP declaration (1993) for 'equal opportunity and full participation' of disabled people (16). The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (22) were also included in the National Disability policy.

However, the implementation of these Government commitments is very slow, to the extent that they remain largely theoretical and are not in practice (17). For example, after adaptation of the National Policy for Disabled People, there have been few changes in terms of development of any services for disabled people or in areas of institutional discrimination such as education and employment (17, 19, 21). The government has also adopted the policy of a 10 percent quota for employment of disabled people (12). But less than one percent disabled people are involved in paid employment (23). The situation of disabled women in Bangladesh is even worse because fewer women present for interventions.

Among participants in this study, 75 percent were not aware of the government job-quota for disabled people. Those who were aware of it felt it would not bring about any changes in the job market for disabled people because there is no legal penalty if they fail to comply (11). In addition, there are no measures to promote employment of disabled people, such as making available vocational training, mobility aids, education, accessible work environment or information about job vacancies. As a result, the quota remains only as a commitment on paper. Little is done in practice to help disabled people take up opportunities in the job market

(2, 11). So far the government has provided vocational training for only two organisations in Bangladesh on trades such as basket making, carpentry, weaving etc (24). However, these trades are not in demand and does not help in improved 'productivity and self-reliance' (25). These training organisations are also under-utilised.

Some clients from CRP who had received services over 20 years could not find re-employment in occupations that they had prior to their injury. They were employed in the formal sectors of employment, agriculture or were students. Many people with SCL were however self-employed after their injury (26). This is due to CRP providing support to them through vocational training that encouraged involvement in self-employment. To obtain a formal job or to continue education requires support from government and private employers. To undertake paid employment attitudinal barriers as well environmental barriers need to be changed (11, 23). Opportunities for disabled people to gain and retain employment could be enhanced if changes in employers' perception of disability are made, barriers to employment in terms of information, physical access and adaptations are removed, employment is subsidised and created (27). Generally disabled people need support through micro-credit programmes also to be able to become economically active or continue their education.

### **SERVICES FOR PEOPLE WITH SCL IN BANGLADESH**

There are no specialised hospitals for comprehensive rehabilitation of people with SCL in Bangladesh apart from one non-governmental organisation, CRP (28). Other service providers for people with SCL as well as other impairments adopt a medical model of disability (9). They offer services only in their hospitals or at their clinics. There is little opportunity for dialogue between users and service providers. When people with SCL are discharged, there is little, if any, follow-up (2). They become dependent on family members and are unable to participate in community activities. Mobility aids are not often available, which further restricts the person's ability to be an active member of his/her community (18).

In contrast, CRP offers services focussed on the person's whole life rather than treating him as a person with impairment (10). Though initially CRP was started as a specialised unit in a government orthopaedic hospital, over the years the types of services provided have changed, through user involvement in service design and provision. Support is also extended once the person goes back to living in the community. Families are encouraged to become active participants in the rehabilitation process. CRP (1, 2) facilitates community awareness activities as well as education and involvement of community members in support networks.

## **BARRIERS EXPERIENCED BY PEOPLE WITH SCL IN ECONOMIC PARTICIPATION**

Given below are themes that emerged from the interview and focus group sessions.

### **Barriers of access for employment or economic activities**

Misconceptions of many people that disabled people have limited abilities affect their opportunity to enter the job market. Employers focus on the physical impairment and assume that wheelchair users cannot work. They do not consider work environment for accessibility for wheelchair users (11). This issue is not unique to Bangladesh. For example, in the UK disabled people might be discriminated against in terms of appearance, as they may not have a 'conventional body shape' (29). A third of the 26 health authorities in the UK sampled in a study chose not to employ disabled people because of misconceptions about their abilities (30).

### **Barriers in retaining work**

Disabled people generally had negative experiences of attempting to keep or find employment. Many were employed before their impairment but found that after their impairment they were often considered 'unemployable' (31). In the UK, one in six people who were or had been economically active experienced discrimination in a work related context (32). Of these, 42 percent report that they have been discriminated against by an employer or a potential employer. The employment situation of Bangladesh is not directly comparable with UK because few disabled people continue working in mainstream job market after their impairment. However, the comparison confirms that disabled people are discriminated against in the job market across the world.

### **Barriers to obtain appropriate work**

Some respondents who had higher secondary level education and were previously employed looked for some jobs related to their previous skills. They had difficulty in getting a job in which they had previously worked. Employers focus on the physical impairment. They seldom make adjustments to the environment for the disabled person to work. Employers put more importance on work output and long hours of work. Many employers do not see a value for disabled people in jobs that they can do perfectly well even after their impairment.

### **Barriers in career prospects**

Attitudes of seniors and colleagues towards disabled people limited their career development opportunities. It also acted as a threat to job retention. No participant reported good career prospects in their current jobs. They felt that employers ignore their career prospect due to

their physical impairment although disabled people have the right to promotion, further education and professional development training.

### **Barriers to receive appropriate wages**

Respondents who were employed for pay found that some of their employers perceived them as 'sick', and 'less productive'. Some respondents were asked to receive less remuneration because of their impairments. Centre for Services and Information on Disability (CSID) (31) also reported similar findings. However, there were mixed responses about discrimination in salary structures. Some respondents did not experience any discrimination in salary structure. There was a report of harassment from supervisors and delay in receiving salary. The same person did not also get any other privileges provided by the government. Yet another respondent had good experiences from her employer and found that the systems were equal for all employees. These reports suggest that misconception about ability of disabled people vary from people to people in the Government or private sector, and sometimes cause discrimination in salaries.

### **Barriers due to discriminating attitude of employers and colleagues**

Another respondent, who worked in a government hospital, found that her annual increment was denied after acquiring her injury. Before her injury she was awarded an annual increment, which was added to her monthly salary on a regular basis. Her salary was halved because she could not move without a wheelchair. Some respondents experienced negative attitudes from senior officers rather than their colleagues. They did not view them as 'worthy', even though they do not have any problems working. Some respondents experienced lack of support from their colleagues in their work place. These reflect the public attitude towards disabled people. Able-bodied employees felt disabled people are less worthy to be employed. There were also reports of disrespect and teasing of disabled women and girls (31).

### **Medical barriers in job market**

In the current job market employers often expect applicants to have certain physical attributes. Respondents who had physical limitations felt that the expectations concerning physical attributes restricted their opportunities to get paid employment; even though they met the other criteria for the jobs they had applied for. Employers focussed on physical characteristics rather than on actual requirements for the job when considering a disabled person for employment. They also had the problems of mandatory requirement of medical certificates to enter into formal job market (6, 11).

### **Barriers due to lack of appropriate skills**

Some respondents said that there were limited training opportunities they could access for paid employment or self-employment. Available opportunities for jobs include traditional trades such as weaving, sewing, and carpentry. Even though the goal is to rehabilitate disabled people with useful job skills, there was no assessment to see if training would be of any use for economical solvency. On many occasions these training programmes were found unproductive (33).

### **Barriers due to lack of educational qualification**

Education is the key to take advantage of new technologies both at home and work. International Labour Organisation (ILO) reports that new technology has reduced the demand for unskilled and semi-skilled labour and it has gradually reduced the opportunities for disabled people (34). Some respondents pointed out that they do not qualify for the present job market, as they are illiterate and do not have any appropriate skills (11). Almost all jobs need some basic education as well as skills and experience, which they lack. In addition, disabled people have no access to jobs that are advertised, due to poor accessibility to information or employers' choice of able-bodied people. Disabled women particularly experience greater difficulties gaining paid employment. This is also because girls are less likely to attend primary or secondary school, or undergo any training. Disabled girls are also limited in their range of education probably because people have lower educational expectations of them (31).

### **Barriers due to inaccessible work environment**

Many participants who had jobs expressed concern that their work environment was inaccessible for them as wheelchair users and/or that the 'production process' was inaccessible. It was worse for those who used any kind of mobility aid. They also reported that employers are not interested in making the environment accessible for disabled people because they think that disabled employees are less important than non-disabled employees. There are no laws in Bangladesh that require buildings and other facilities to be accessible. Employment opportunities are restricted because of inaccessible physical and social environments. Many people with SCL cannot take part in paid employment because of inaccessible work environment.

### **Barriers due to inaccessible transport systems**

Many respondents reported on inappropriate transport system. When no provision is made for accommodation near the work place for disabled people, the majority become homebound. The Bangladesh transport policy ignores disabled people altogether.

## **FACTORS THAT ENHANCE ECONOMIC PARTICIPATION**

### **Job based training**

CRP offered job based training to disabled people and found that both employers and employees were satisfied with the outcome. Many trainees got jobs after completion of the training and their employers also were happy with their performance.

### **Market led training**

Participants who were clients of CRP received vocational training of their choice. They underwent training in the area that interested them and some found jobs based on the skills they had learned. When disabled participants gained appropriate skills they were more confident in their ability to work. Ironically, some disabled people reported that prejudice and discrimination actually drove them to greater achievements.

### **Accessible work environment**

Most participants view inaccessible work environment as a major barrier to participate in the job market. Those who continue their job after spinal injury experience great stress due to structural barriers. In contrast some participants' workplace were made accessible for wheelchair users.

### **Financial support through micro-credit**

Participants who received support through micro-credit were generally happy about being given this opportunity.

## **CONCLUSIONS AND RECOMMENDATIONS**

Disabled people experience multi-sectoral barriers to participate in paid work. One of the main barriers is because the employer adopts a medical interpretation of disability. They perceive disabled people as inactive, useless and unworthy, hence excluding disabled people from the job market. However, disabled people view disability as a social problem, as listed below:

- Attitudinal barriers that prevent access to employment, retention of work, obtaining appropriate work, career prospects, discriminatory attitude of employers, supervisors and peer groups.
- Institutional barriers that include mandatory requirements of medical fitness certificate for employment, lack of inappropriate training and lack of education opportunities.

- Structural barriers include inaccessible work environment and inaccessible transport systems.

Beyond their physical impairment these barriers perpetuate a disabling society in which disabled people are discriminated against and often excluded from economic participation. On the other hand some positive measures such as job based training, market related training, accessible work environment and support through micro-credit, promote effective participation of disabled people in paid work. Government and developmental organisations must promote an inclusive policy that ensures disabled people obtain access to the mainstream job market and compete with non-disabled people. The following recommendations would be of help to combat barriers for disabled people:

- Adoption of inclusionary policies and practices that foster inclusion of disabled people in mainstream economic participation (35).
- Legislation promoting equality and full participation implemented through enforceable laws.
- Medical or physical fitness for employment should be replaced with the individual's capacity to work when given the access they need.
- Government should provide subsidies available to help employers make work environments accessible.
- Employers should prioritise making work environment accessible, provide accommodation for disabled employees near the workplace and accessible transport for easy access to workplace.
- There should be mechanisms to prevent discriminatory remuneration practices.
- Information regarding job vacancies, training etc. should be accessible to all disabled people.
- A recruitment allowance should be paid to cover travelling expenses and cost of lodgings to facilitate participation in the recruitment.
- Employers should include a disabled representative in the recruitment process.
- Peer support should be provided to disabled people to enhance their self-esteem and give them confidence to enter the job market.
- All disabled people should have equal opportunities to gain promotion based on their education, training, skills, experience and merit.
- The government should provide subsidised training and education for all disabled people, in an environment where job-based training is available.



- Disabled employees should be provided with allowances to cover the cost of aids, adaptations and assistance.
- Employers should offer flexible working hours to disabled employees and other employees if appropriate.
- Employers should educate and train the staff about understanding of disability.

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## LANGUAGE MIXING AND SWITCHING IN MALAYALAM - ENGLISH BILINGUAL APHASICS

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### ABSTRACT

*Language mixing defined as inappropriate switching from one language to another, is a frequently observed recovery pattern among bilingual aphasics. In spite of the fact that a significant amount of population in India is bilingual, language mixing is one of the least researched areas. Also, the distinction between language mixing exhibited by bilingual aphasics and the normal process of code switching employed by neurologically normal bilingual speakers is not very marked. Hence, the present study was taken up with the purpose of investigating the similarities and differences in the code switching behaviors of aphasics and neurologically normal Malayalam-English bilingual speakers. There was an increase in code switching behavior but the quality of switches did not differ when compared with those in normal subjects. These results could be a reflection of increased reliance on two languages as a compensatory strategy in this set of subjects.*

### INTRODUCTION

Code switching is the alternative use by bilinguals of two or more languages in the same conversation (1). The ability to switch linguistic codes, particularly within single utterances requires a great deal of linguistic competence (2).

Code switching is a linguistic practice constrained by grammatical principles and shaped by environmental, social and personal influences including age, length of time in a country, educational background and social networks (3). Aphasic impairments in bilinguals or multilinguals virtually affect all the languages an aphasic knows. Languages have been shown to behave differently or equally with equal or unequal extent of interference and substitution. Bilingual aphasic speakers, like all speakers of multiple languages are required to identify and use the language or languages appropriate to communicative interactions. Aphasic speakers have reduced linguistic competence and face potential disruption in their ability to alternate linguistic codes (4).

Perecman (4) investigated language mixing in a trilingual male with a history of brain trauma who demonstrated language mixing and unsolicited spontaneous translation in conversational speech. Perecman observed that these behaviors were atypical of neurologically intact multilinguals and indicative of a language deficit.

Grosjean (5) commenting on Perecman (4) argued that both language mixing (including utterance level mixing) and spontaneous translation are also found in normal polyglots, and thus may not always reflect language deficits in aphasics. Only a good assessment of the patient's language and speech before and after the injury will determine if these behaviors do indeed reflect deficits.

Language mixing is a frequently observed recovery pattern among bilingual aphasics characterized by alternating language use at the word or sentence level, spontaneous translation, unexpected language switches, and / or linguistic interference (6). Munoz, Marquardt and Copeland (7) compared the code switching patterns of aphasics and neurologically normal bilingual speakers of English and Spanish using the Matrix Language Frame (MLF) model (8). Results showed that aphasic subjects use a greater amount of code switching. This suggests an increased dependence on both languages for communication following neurological impairments.

In the present study, the term code switching will be used to describe the alternative use of two languages in a conversational discourse, by both normals and aphasics. Bilingualism is one of the less researched areas but has become an area of interest for present aphasiologists. According to de Bot (9), 50% of the world's population is bilingual. According to Mahapatra (10), 80% of India's population is bilingual / multilingual. In spite of such figures bilingualism is still one of the least researched areas in India. Bilingualism as it exists in India, cannot be confused with the situation generally existing in the western world. As noticed by Mahapatra (10), the bilingualism in the western world is not at a grass root level as in India. Hence, it is difficult to generalise results obtained from western studies, especially in terms of code switching, into the Indian context.

Aphasia in bilinguals is also least researched upon, especially in Indian context. It is important that language variables be studied for intervention purposes. Hence, it is very important to investigate the language switching in bilingual aphasics in comparison with normals. So this study puts a foot forward in investigating and explaining the bilingual phenomena of language mixing in aphasics as well as normals.

## **METHOD**

**Subjects:** Two groups of subjects were taken; control group consisting of neurologically normal individuals and experimental group consisting of aphasic subjects.

Both the experimental and control group consisted of six Malayalam - English bilingual adults. They were matched in terms of age, gender, handedness, social and educational level and language proficiency in both Malayalam and English. Language proficiency in two languages was matched based on responses to Part-A of bilingual aphasia test (BAT, 11).

All the individuals in the experimental group were diagnosed as having Broca's aphasia in both Malayalam and English using the Western Aphasia Battery (12). All the six subjects had a history of left hemisphere cerebro-vascular accident confirmed by neurological examination and computerized tomography.

### **TEST MATERIALS**

- Western Aphasic Battery (WAB, 12) was used to identify the Broca's aphasic population.
- The presence of code switching was studied using Paradis' Bilingual Aphasia Test (BAT, 11)
- The various sections in BAT were thus used to find out the instances of code switches exhibited by subjects.

During the test administration, the communicative partners were strictly instructed to speak only the assigned language in the monolingual conditions.

Analysis: The collected data was analyzed for code switching in terms of the language choice, lexical semantic, syntactic, morphological and phonological levels of switching and spontaneous translation. The relation between language history and code switching behaviour was also studied.

### **RESULTS**

In the present study, the data obtained from the administration of Bilingual Aphasia Test (English-Malayalam) was analyzed to study and compare the code switching patterns exhibited by aphasics and neurologically normal individuals.

Analysis was done in terms of the language choice, lexical- semantic, syntactic, morphological and phonological levels of switches (4). The relation between language history and code switching behaviour as well as spontaneous translations were also studied.

### **LANGUAGE CHOICE**

It was found that all controls and three of the aphasic subjects responded in the language established by the interlocutor. The other three aphasics preferred Malayalam, the dominant language to converse in, even in monolingual English context.

The normals and other aphasic subjects occasionally used some Malayalam utterances in the monolingual English condition, though they were instructed to speak only in English. This use of Malayalam in English context may be a deliberate choice to establish shared group identity regardless of the language skills of the conversational partner. This notion is supported by other authors (5,7).

It was also noticed that, in five of the six aphasics and two of the normals, the latency of the utterances were more in English than in Malayalam that is, the reaction time, though not formally measured, was found to be longer in monolingual English context. This could be because these subjects were less fluent in English than in Malayalam.

On the task of confrontation naming in monolingual Malayalam context, many utterances were made in English by both normal and aphasic subjects, which cannot be explained as borrowed forms. But these words are judged as being used very commonly by Malayalam-English bilingual speakers in daily utterances as they are lexically integrated into the language  
Eg : /pen/ /book/ /key/.

### **Lexical - Semantic level switching**

This can be analyzed in terms of word level switching or phrase level switching. Word level mixing was produced by four normals and six aphasic subjects in monolingual Malayalam context and by three aphasics in monolingual English context.

e.g : Malayalam Context

# nan samsaritʃa ailə entə teacher a:nə

The person with whom I spoke is my teacher.

# a: manuʃ anə utʃakkə exam ka:num

That person may have exams in the afternoon

# vi: til randə brother undə

I have two brothers at home.

English Context

# Bus vanilla

Bus has not come

# The branch odinu man and birds ta:rə vi:nu

The branch broke and the man and the birds fell down.

# One boy and girl standing under the tree, appam crow is sitting on the tree.

One boy and girl are standing under the tree. Then a crow is sitting on the tree.

Phrase level mixing was produced by both aphasics and normals. Both the groups were observed to begin an utterance in one language without forming a complete constituent in the first language. This phrase level mixing was noticed in both monolingual Malayalam and monolingual English contexts.

Eg : # randə pilla : rə pinnə wife is there

Two children then wife is there

# The and .... of the box ..... send of the ..... sarija : vunilla anottə

The and ... of the box ..... send of the ..... It is not coming.

Phrase level mixing was also reported by Schwartz (13) in a 49-year-old hexaglot Indian woman whose paroxysmal aphasia was manifested as the intrusion of totally irrelevant phrases and sentences in a language other than the one currently spoken.

### **Syntactic Switching**

It is the use of the grammar of one language with the lexical items of the other language. Two of the normals and four of the aphasics, while translating from Malayalam to English used the syntactic structure of Malayalam, though the lexical items were in English.

eg:

# Yesterday you saw a boy that was my brother.

Malayalam equivalent : innale ni: kanda a:nkutti enteə saho:daranaṇḁ

Correct translation : The boy whom you saw yesterday is my brother.

# One who eating salt, he will drink water.

Malayalam equivalent : uppu tinnunnaven vellam kudikkum

Correct translation : One who eats salt shall drink water.

# I was going the house that is in this way.

Malayalam equivalent : na:n pə:ja vidə e: varijila:nḁ

Correct translation : The house where I went to is in this way.

In Malayalam, the word order is not as rigid as it is in English. From the examples given above, it is evident that when doing a translation task, the subjects formed the English sentences in the syntactic framework of Malayalam.

Perecman (4) reported syntactic level mixing in aphasics and described it as an abnormal phenomenon. But in the present study, the syntactic level mixing was found in normals also, drawing support from Grosjean (5) who argued that both language mixing and spontaneous translations are also found in normal polyglots, and they may not therefore always be reflecting language deficits in aphasics.



### **Morphological Switching**

It was observed mostly in terms of the mixing of free morpheme in one language and the bound inflectional morpheme in the other language. This was seen mainly in the monolingual Malayalam context. This was produced by two normals and four aphasic subjects.

Eg :

# na : n eight ninth tenth classil patippikkunnu

I am teaching in eight ninth and tenth classes

# Father mother ellam sixthil patikumbol maritu po:ji

Both father and mother passed away while (I) was studying in sixth.

# antintə se: Jam hospitalilekə kondu po:ji

After that (I) was taken to the hospital

### **Phonological Switching**

This was noticed in only one of the aphasics. None of the other aphasics or normals exhibited phonological level mixing.

Eg: bala for vala which means bangle.

Phonological level switching has been reported by Perecman (4) also.

### **Translations**

Spontaneous translations were mostly observed in confrontation naming tasks. Four of the six aphasics and two of the normals labeled the target in both English and Malayalam.

Eg: # pen ..... pe : na. (pen..... pen)

# book ..... pustakam (book ..... book)

# vala ..... bangle (bangle ..... bangle)

another example is

# vipari : tam oh opposite

opposite oh opposite

In literature, translations are reported by Lin (14) and Perecman (4).

Two of the aphasic subjects were able to produce the target word after being given a phonemic cue, indicating a difficulty in accessing the word rather than a lack of knowledge of the word in a particular language. Eg : One of the aphasic subjects when asked to say the days of the week in monolingual Malayalam context started saying Sunday, Monday etc., but on cueing was able to say the Malayalam translational equivalent of the days of the week.

On the other hand, all the subjects except one aphasic recited the names of the months in English though the question was asked in monolingual Malayalam context. On phonemic cueing two more aphasics and one normal subject were able to recite the Malayalam months. But the others were not able to do it indicating that the English months have become a borrowed form in Malayalam. All subjects exhibited circumlocutions, a pattern typical to aphasics and second language learners.

## **DISCUSSION**

A consensus is yet to be reached as to whether this language mixing exhibited by bilingual aphasics is a pathological phenomenon or just a natural phenomenon exhibited by even neurologically normal bilingual individuals. While authors like Perecman (4) argue that language mixing (and especially utterance level mixing) reflects a linguistic deficit and that spontaneous translation indicates a paralinguistic processing deficit, others (5,7) opine that language mixing and spontaneous translations are behaviors that are also found among normal polyglots, and that they may not therefore always reflect deficit in aphasics.

The code switches and spontaneous translations in the speech of polyglot aphasics can have many causes. Some reflect the language and conceptual deficits mentioned by Perecman (4), but others are the results of conscious, deliberate communicative strategies on the part of the patients. This results in increased frequency of occurrence of code switching

The results of this study reveal similarities and differences in how neurologically normal and aphasic bilingual speakers code switch or alternatively use two languages in an interaction. Many of these were considered indicative of a language disorder by previous researchers (4).

Individual differences in the frequency and type of constituents produced and the contexts in which they were produced were evident in the code switching patterns of bilingual aphasics. These similarities and differences may indicate that aphasic speakers are adopting normally occurring code switching patterns to enhance communicative effectiveness.

Individuals in both groups also exhibited the use of a second language in monolingual contexts and spontaneous translation, behaviors considered inappropriate and thus characteristic of language mixing (5). However, since both patterns were observed in the speech of the normal and aphasic subjects, they are clearly acceptable in the local speech community. The code switching exhibited by aphasics thus, may not be an inappropriate behavior, but rather an atypical and disruptive increase in the frequency of use of normally occurring code-switching patterns (7).

Code switching may be a conscious or unconscious strategy used by the bilingual aphasics to access the correct word in either language. A word in one language may function as a "paraphasia" in the second language but does not affect communication as a paraphasia

because it is semantically accurate (6). Hence a bilingual aphasic may benefit from learning strategies, which develop code switching into a means of enhancing functional communication, particularly for a patient who resides in a bilingual community.

As stated earlier it was noticed that in monolingual Malayalam contexts two of the aphasic subjects started reciting the days of the week in English but reverted to Malayalam on giving a phonemic cue. This indicates a difficulty in lexical retrieval rather than lack of knowledge of the word in Malayalam, a conclusion supported by their language history. It appears that aphasia can selectively disrupt access to a lexical item in one language while sparing access to the item in the other language resulting in an inability to match the language of the context. Hence, aphasic subjects may be "forced" to code switch in view of the effects of the linguistic impairment (7).

The code switches which are seen during the testing can simply be the reflection of the patient's normal interference behaviour before injury since language knowledge and language behaviour of the aphasic subject before injury also plays a significant role in the pattern of code switching exhibited by the aphasic patients. This is evident from the fact that both normal and aphasic subjects who were less proficient in English than Malayalam exhibited similar kinds of code switches.

This comparison of code switching patterns in normals and aphasic subjects thus reveals a pattern that reflects similar types of code switching abilities in both the groups. However, the aphasic patients code switch, borrow and translate more after the injury than before, and this increase in mixing of the languages may be shown as a deficit. Such a notion is supported by Grosjean (5) and Munoz, Marquardt and Copeland (7) who stated that disruption in the code switching of bilingual aphasics is not limited to language mixing and is more complex than a dichotomous decisions regarding appropriateness. Thus, the behaviour of code switching itself is not abnormal but the increased frequency of the behaviour makes it appear abnormal. In fact, code switching may actually be a compensatory mechanism in lexical accessing in the deficient language.

It is only by means of careful assessment that we will better understand, and therefore better treat, polyglot aphasia. This in turn, will improve our understanding of normal polyglots; their language competencies, their language use, and the mechanisms that allow them to maintain their languages separate in a monolingual speech mode but let them interact in a bilingual speech mode. This in turn would have far reaching implications for language rehabilitation of polyglot aphasics.

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### **SOURCE - INTERNATIONAL INFORMATION SUPPORT CENTRE**

Source is an international information support centre focusing on disability and health issues within a developing country context. It is a joint venture of Handicap International, Healthlink Worldwide, the Centre for International Child Health, and Exchange.

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The growing use of electronic communication technologies offers great potential for DPOs and NGOs, but access to online resources is limited in many developing countries. To help meet diverse information needs, the project “Improving Access to Disability Information” was launched in December 2003, under the Disability Knowledge and Research Programme. This project aims to make relevant information accessible for people with disabilities and to raise awareness of disability-related information. So far, Source has conducted a survey to assess the needs of individuals and organisations in developing countries, and is producing relevant quick lists, practical ‘how to’ manuals, printed resource lists and CD-ROMs. The project will also facilitate improving accessibility to the Source website for disabled users.

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## BRIEF REPORTS

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### PROVIDING INTERVENTION SERVICES FOR COMMUNICATION DEFICITS ASSOCIATED WITH CLEFT LIP AND / OR PALATE - A RETROSPECTIVE ANALYSIS

Sunitha Raman,\* Monica Jacob, Manju Sara Jacob, Roopa Nagarajan

#### ABSTRACT

*The incidence of cleft lip and palate in India is enormous: one in 781 live births. Early identification and early intervention programmes are the most effective tools to counter the long-term detrimental effects on speech and language in this population. The current institutional based rehabilitation programmes follow a 3-tier strategy of regular therapy, demonstration therapy and parent guidance programmes. The efficacy of this programme is greatly hampered by factors such as socio economic status, distance travelled to avail of services and other health considerations. To overcome these setbacks and evolve more effective intervention plans, the focus needs to be directed towards outreach and community based rehabilitation.*

#### INTRODUCTION

The management of cleft lip and /or palate is a complex and life long issue. The staggering magnitude of the need for intervention is indicated by the results of a recent study conducted by the Tata Institute of Sciences (1).

The salient features are:

- The incidence of cleft lip/palate in India is estimated at one in 781 live births, with a male to female ratio of 2:1.
- An estimated 35,000 children are born with cleft lip/palate every year.
- Most report a family income of Rs.1, 000/- a month.
- Approximately 46% had made no effort to correct the defect. Others reported that they may have consulted a doctor, but no surgery was done due to economic reasons, ill health of the child or fear of surgery.
- Care takers / individuals with cleft lip/palate reported problems ranging from speech defects to social acceptance and feeding.

These results focused on the fact that, early identification and early intervention is the need of the hour. Early identification of the cleft is not an imposing problem as very often, it is a visible deformity. In India early forms of surgical intervention are also becoming a reality, consequent to the efforts by non-profit organisations such as the Smile Train.

Ever since their partnership with agencies in India, around 3,500 surgeries were performed in 2000 approximately 640 surgeries were performed at Sri Ramachandra Hospital during 2003.

As an integral part of the team dedicated to improve the quality of life of individuals with cleft lip/palate, the speech pathologists were called upon to provide the following services:

- Assist in decision-making regarding surgical / prosthodontic / orthodontic management.
- Evaluate and provide diagnostic therapy pre-operatively.
- Deliver speech therapeutic services post operatively.
- Heighten awareness of speech defects and rehabilitation measures among families and professionals.
- Train allied health workers to provide greater assistance in speech services covering cleft care.

To achieve these objectives, the data reviewed revealed the necessity to address various concerns such as the need to draw a profile of the average patient at the cleft clinic, evaluation of current models of service delivery and inclusion of necessary modifications and to develop additional / alternative methods of rehabilitation.

The present study attempted to address these concerns.

## **METHODOLOGY**

### **Data Collection**

Sample size: 488 individuals.

Criteria for subject selection:

- All individuals with oral cleft (unilateral/bilateral, complete/incomplete, lip and /or palate, repaired/un repaired).
- All subjects who reported at the Sri Ramachandra Cleft Care Centre and were registered under the Smile Train Programme between 13th November 2000 to 15th December 2001 (2).
- All subjects included under the study were evaluated at least once, by a speech pathologist from the Department of Speech, Language and Hearing Sciences, SRMC and RI (DU).

**Procedure**

The parameters considered for data collection were: type of cleft, gender distribution, age at first consultation, distance travelled to avail of services, economic status and type of intervention procedure.

Each sample was slotted into different categories under each parameter, in accordance with the data enlisted in the case records that were compiled at the time of the patient's first visit. The collected data were then statistically analysed.

One hundred children in the age group between 0 and 3 years, were also analysed for their language levels using the Language Assessment Tool.

**Data Analysis**

Frequency distribution (in percentage) according to the pre-determined class intervals was calculated. The mean and the standard deviation were calculated for "age of first consultation", "economic status" and "distance traveled to avail of the services". Test of significance (two sample mean tests) was applied to statistically determine the significance of the relationship between intervention procedures and the enlisted parameters as stated earlier.

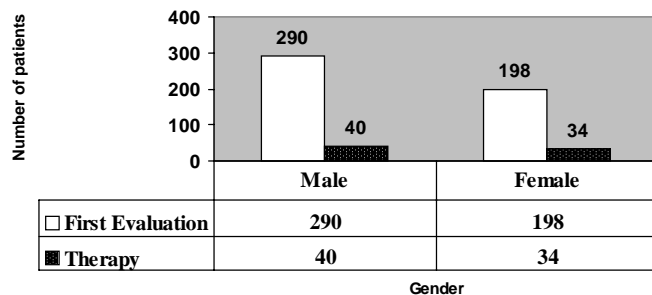
**RESULTS AND DISCUSSION**

A typical profile of the average client who visits the Sri Ramachandra Cleft Care Centre was drawn out on the basis of the statistical analysis.

**Gender Distribution**

At first consultation, the male to female percentage ratio was found to be 3:2, with the distribution of 290 males (59.53%) and 198 females (40.57%). At the therapy clinic, Department of Speech, Language and Hearing Sciences, Sri Ramachandra Hospital, the gender distribution was 40 males (54.05%) and 34 females (45.95%) with the percentage ratio of 1.2:1.

**Figure 1. Gender distribution at first evaluation**

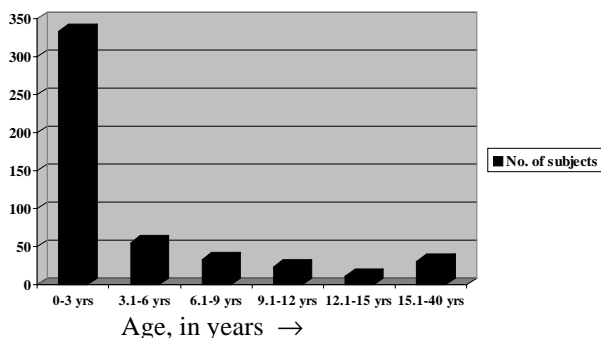




### Age of First Consultation

Most subjects (56.11%) were found to have a cleft of lip and palate as against 19.24% reporting with a cleft palate alone and 24.65% reporting only with a cleft of lip. The earliest age of first consultation (mean) is 4 years with 333 (68.23%) children receiving medical help within the first 3 years of birth. 56 children (11.48%) between the ages of 3.1 and 6 years and 33 children (6.76%) between the ages of 6.1 and 9 years, reported for medical consultation for the first time. 4.93% of the total subjects (24 children) in the age group of 9.1 to 12 years and 2.25% (11 children) in the age group of 12.1 to 15 years, had had their first evaluation for medical services. 6.35% (31 individuals) over the age of 15 years sought medical assistance for the first time.

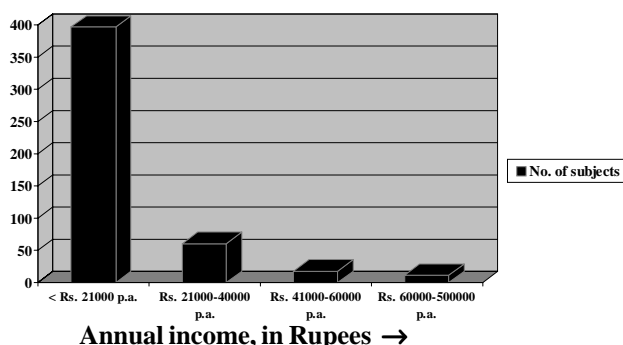
**Figure 2. Age of first consultation (in years)**



### Economic Status

The results showed that the vast majority of patients (81.35%) who reported at the clinic numbering 397 subjects, lived below the poverty line (less than Rs.1750 per month). 61 subjects (12.50%) reported of annual incomes between Rs.21,000 and Rs.40,000 per annum. While 18 individuals (3.69%) indicated an annual income between Rs.41,000 and Rs.60,000, 2.46% of the subjects reported an income greater than Rs.60,000 (up to Rs.5 lakhs per year).

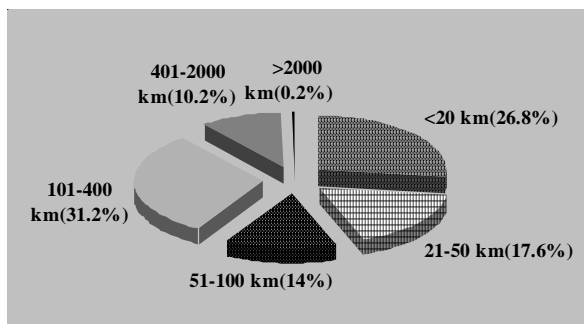
**Figure 3. Economic status (Annual Income in Rupees)**



### Distance traveled to avail of services

About 26.8% of the subjects reported having travelled 20 km to avail of the services. 17.6% reported having travelled distances between 21 and 50 km, while 14% reported traveling between 51 to 100 km. Hometowns of 31.2% of the individuals were located at distances between 101 and 400 km, while hometowns of 10.2% were located at distances between 401 to 2000 km. Only 0.2% reported traveling more than 2000 km to receive the necessary medical attention.

Figure 4. Distance travelled to avail of services



Results of the analysis show that most patients (55.6%) travel distances upto 50 km to avail of the services. Significantly, a large majority (81.35%) fall below the poverty line and hence, can neither afford extensive travel, nor the services. Tests of significance (two sample mean tests) applied between type of intervention procedure and "distance travelled to avail of services", "age of first consultation" and economic status" showed statistical significance of each of these factors.

Due to these limitations imposed by the socio economic status, extensive distances and other health considerations, most patients are unable to access the benefits of a regular intensive speech and language therapy programme.

The current intervention programmes at the Sri Ramachandra Hospital Speech Clinic include a three-tier strategy:

### Regular therapy

Intensive language, articulation (phoneme specific goal), voice and prosodic therapy are offered at the Speech clinic of Sri Ramachandra Hospital at schedules of one, two, three or five sessions per week as per the patient's convenience. However, even this extent of flexibility is unable to accommodate the constraints of school / office timings of most clients. This thereby limits the choice to one, or a maximum of two sessions per week.

### **Demonstration therapy**

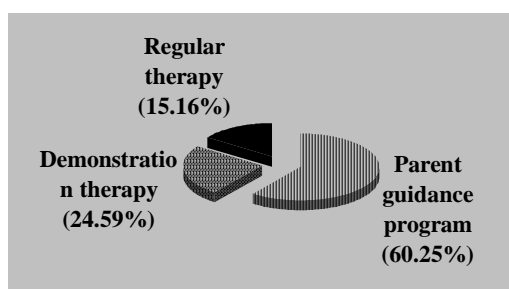
This plan was developed to accommodate the needs of the large majority who can neither afford the time nor money for a regular therapy schedule. Lasting between one week and one month, it includes a complete demonstration of all techniques and activities included in the home plan. This programme is individually tailored to suit the needs and responses of the client with a suggested review and follow up after two to three months.

A review of the current trend of the age of first consultation revealed that the figure was shifting towards the age range of 0 to 1.6 years. Subsequently, an analysis of the language deficits of 100 toddlers between the ages of 0 and 3, indicated that 68% had delayed / inadequate expressive language and 32% had speech and language within normal limits. However, even this number of 32% of children were considered to be at a high risk for developing further communication deficits. A probe into the speech disorders among older children (who were intervened later in life) revealed developmental errors of articulation (including compensatory patterns), hyper nasality, reduced intelligibility and errors in prosody. To prevent / minimise these detrimental long-term effects, an effective early intervention plan, that can be implemented even prior to demonstration therapy, needs to be developed. Therefore there arises a need for parent guidance programmes.

### **Parent - guidance programmes**

This package includes (i) measures to sensitise the family to the communication deficits in the child, (ii) hand-outs to monitor the child's developmental milestones and (iii) activities to promote speech and language development. This individually tailored plan is given to the caregiver after a detailed explanation of its contents. This briefing is done during the ward visits, post surgically. The efficacy of this measure is yet to be validated.

**Figure 5. Distribution of intervention procedures**



To monitor the progress of the client and increase efficiency in services, alternative methods of rehabilitation are also suggested. The benefits of home training programmes and

demonstration therapy, need to be augmented to match the greater benefits of regular therapy. Models of out-reach and community based rehabilitation, would serve to bridge the chasm between the need of the community and the services provided.

- **Out reach programmes** include camps, screening and counselling and the SLP's visits to the community for periodic follow up.
- **CBR** can be a powerful service delivery model, to directly provide services at the community level. It involves skill transfer and systematic monitoring of progress of the child / client. Sensitising surgeons and other medical professionals at primary health centres and rehabilitation centres, also forms a core objective. CBR also necessitates development of training material / curriculum / programmes to empower local authorities and health workers. This is the ideal solution to counter the stumbling blocks of non-availability of adequate number of professionals and requirement of working with individuals who are illiterate and monolingual.

## **CONCLUSION**

The results of the present study indicate that the homogeneous model of institutional based rehabilitation currently followed, does not fully meet the therapeutic needs of persons with cleft lip/and or palate. Early intervention programmes incorporating out-reach and community based rehabilitation schemes, would ensure a higher success criterion. Therefore, it can be concluded, that despite the great diversity of needs which is reflective of the nation's population at large, it is the most unified efforts of the community, with the service providing institutions. that will bring about sustainable efficiency in intervention measures.

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## **A REPORT ON DISABILITY IN THE WESTERN REGION OF NEPAL**

Chhabi Goudel\*

### **ABSTRACT**

*NDUP Nepal has recently successfully carried out a research to investigate the underlying reasons for disability. The research focuses solely on the causes of disability problems but not on disability itself. Similarly, NDUP focuses its study on responsible parties for problems and possible solutions. The main objective of the study was to find out underlying reasons of disability in Nepal. A total of 97 non-disabled and 35 disabled members, plus two different focus groups were included in 8 Village Development Councils of (VDCs) Kaski, Tanahun, Syanja, and Parbat districts. Qualitative data were collected by interviewing the two different focus groups in each VDC and individual interviews. The findings of this study encourage further development of rehabilitation plans of people with disability in Nepal.*

### **INTRODUCTION**

The main purpose of the study was to identify the causes of disability in Western Nepal and to assess how the community and individuals viewed rehabilitation of disabled people in their society. The study also identified attitudes of disabled people and their participation in their society.

### **METHODS**

The study was carried out in eight VDCs of four districts, namely Kaski, Syanja, Tanahun and Parbat in Western Nepal. There were two VDCs selected for the research, Dhikurpokhari and Kaskikot VDCs in Kaski, Ward No. 1 and 2 of Putalibazaar municipality in Syanja, Jamune and Khairenitar VDCs in Tanahun, and Tilahar and Pipaltari VDCs in Parbat. Interviews were conducted to extract a range of attitudes, opinions and behaviours from 97 non-disabled individuals and 35 disabled people in the eight VDCs of the selected four districts. Of the 35 people with disabilities included in the study, about 50 % were physically impaired and others had hearing difficulties or visual impairment. Focus group discussions were conducted with two different focus groups, namely disabled people and key family members, and community leaders selected from

each VDC. About 7-10 people were invited for focus group discussions in each group. The former VDC chairperson and other executives, teachers, women leaders, and Community Based Organizations (CBOs) existing in that particular VDC were also invited for focus group discussions. One in every ten households was selected for the focus group discussion and the members for discussion were selected randomly. Consent was obtained from each member/household included in the study. It was clearly communicated that participation in the study did not carry any material benefits or any promises of further rehabilitation. Names of informants and communities were kept confidential. The period of study was from April 2003 to October 2003.

## RESULTS

**Table 1. Summary of opinions during individual interviews**

<b>Questions</b>	<b>Response of the key community leaders, parents, health workers, teachers and volunteers</b>
What do you think about disabled people, since they are part of your community?	Disabled people are different in physical appearance as compared to non-disabled people. They are unable to walk, speak, see and eat. They have difficulties in daily activities, have paralysis, deafness, dumbness and mental retardation. It is pitiful, filled with suffering and complicated. It could be due to sin, dependency, lack of appropriate health services, impairment, hereditary, accidents, being proud, lack of money, leprosy, nature's gift or mental weakness. Their condition may also be due to previous life, poor confidence or frustration.
In your opinion, what are the causes of disability?	<ul style="list-style-type: none"><li>• Lack of self-confidence, shyness, being teased.</li><li>• Lack of educational opportunities, encouragement, and co-operation.</li><li>• Lack of appropriate health services, socialisation, social work and hatred.</li><li>• Negligence of doctor, family and government.</li><li>• Poverty, unemployment and lack of opportunities for economic development.</li><li>• Lack of assistive devices/equipment, unfavourable environment, and physical infrastructure.</li></ul>

	<ul style="list-style-type: none"> <li>• Poor policy and legislation.</li> <li>• Problem of accessible market, unable to learn skills and no opportunities to learn skills.</li> <li>• Poor education, attitude, forgiveness and social beliefs.</li> <li>• A stage of weakness, hesitation and poor treatment.</li> </ul>
In your opinion, who are affected by disability?	People with disabilities themselves, families, community, parents, children, poor and illiterate families, country, world, everybody, friends, teachers, Institutions, poor and unemployed.
In your opinion, who is responsible for the problem of disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community and others.</li> <li>• VDC, District Development Council (DDC) country, institutions, teachers and mothers.</li> <li>• Policy makers, parents, neighbours, doctors, lawyers, hospitals, political parties and government.</li> <li>• Poverty, illiteracy and lack of awareness.</li> </ul>
In your opinion, who is responsible to resolve the problem of disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community and institutions.</li> <li>• VDC, DDC country, international communities, political leaders and social workers.</li> <li>• Policy makers, parents, neighbours, doctors, lawyers, NGOs, CBOs and INGOs.</li> </ul>
What is the root/cause of the disability?	<ul style="list-style-type: none"> <li>• Carelessness, ignorance and lack of knowledge.</li> <li>• By birth, accident, diseases, natural disaster, hereditary, negligence of mother during pregnancy and after birth, negligence of doctor, lack of doctor, unsafe delivery and use of drugs during pregnancy.</li> <li>• Marriage with a close family member, early marriage and premature delivery, poverty, lack of health, education, social circumstances and lack of physical infrastructure.</li> <li>• Abortion.</li> <li>• Lack of nutritious food, immunisation, awareness, and lack of health services.</li> </ul>



In your opinion, especially in the context of rural communities, what are the main needs of people with disabilities?	<ul style="list-style-type: none"> <li>• Education, employment, salary and allowance, skills training and awareness about activities.</li> <li>• Affection, counselling, encouragement, human rights and dignity.</li> <li>• Economic support, referral, treatment, and concessions.</li> <li>• Business opportunities such as animal keeping, shops and skill training.</li> <li>• Opportunities according to one's age, sex, and disability.</li> <li>• Development of physical infrastructure that is barrier free.</li> <li>• Assistive devices and equipment.</li> <li>• Accessible roads, schools and hospitals</li> </ul>
Do you know of any other people with disabilities in your community? If yes, what do you think of them?	<ul style="list-style-type: none"> <li>• Yes = 89, No = 8.</li> <li>• Services provided by government are not enough, local support is essential for their development.</li> <li>• Help them when there are difficulties, needs psychosocial counselling, encourage them for confidence building.</li> <li>• Treat equally; include them in all social activities.</li> </ul>
Do you know any children with disabilities in your community who are school- going?	Only one-third of the people know that children with disabilities go to schools. It means the either the physical infrastructure in villages has severe barriers, or awareness levels about schools is low.

**Table 2: Views of persons with disabilities about their situation in comparison with their peers**

Description of the situation	How severe is the problem?	How serious is the problem for you?
A. Mobility	11	24
B. Self care	25	10
C. Learning and applying	23	12
D. General tasks and demands	24	11
E. Communication	13	22
F. Domestic life	9	26
G. Major life areas	21	14
H. Community social and civic life	21	14
I. Interpersonal interactions and relationships	23	12
J. Attitudes and concerns	18	17

Out of 35 people with disabilities, the majority have difficulties in mobility, communication and domestic life. Mobility is a major problem because the roads are not accessible for wheel chair users. Sometimes, the community does not accept disabled children and the parents stated that it was a big problem. They did not know how the disabled children would spend their life after the parent's death. They felt that other family members needed to support them.

**Table 3: Focus group discussion results**

<b>Questions</b>	<b>Response of the key community leaders, parents, health workers, teachers and volunteers</b>
As a community member what do you think of disability?	<ul style="list-style-type: none"> <li>• Disability is: hereditary, due to accidents, being proud, poverty, natural gift, being different in physical structure compared to other non-disabled people, mental weakness, lack of support from others, leprosy, difficulty to walk, speak, see and eat, return to previous life, poor confidence and frustration.</li> <li>• Disabled people do have to develop their confidence. They still need to do more about it.</li> <li>• We do know that there are some disabled people in our area, we do not know in depth what is their real situation. We also hear that they have difficulties in working in the groups.</li> </ul>
In your opinion, what are the causes of disability?	<ul style="list-style-type: none"> <li>• Poverty, unemployment, lack of opportunities for economic development.</li> <li>• Lack of assistive devices/equipment, unfavourable environment.</li> <li>• Problem of accessible market, unable to learn skills, no opportunities to learn skills.</li> <li>• Poor education, negative attitude, lack of forgiveness, social beliefs.</li> <li>• Stage of weakness, hesitation, and no treatment.</li> <li>• Poor policy and legislation.</li> </ul>
In your opinion, who are affected by disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community, parents, children, poor and illiterate families and country.</li> </ul>
In your opinion, who are responsible for problems due to disability?	<ul style="list-style-type: none"> <li>• People with disabilities themselves, families, community.</li> <li>• VDC, DDC, country.</li> <li>• Policy makers, parents, neighbours, doctors and lawyers.</li> <li>• Poverty, illiteracy and lack of awareness.</li> </ul>

In your opinion, who are responsible to solve the disability problems?	<ul style="list-style-type: none"><li>• People with disabilities themselves, families, community.</li><li>• VDC, DDC, Country, International communities.</li><li>• Policy makers, parents, neighbours, doctors, lawyers, NGOs, CBOs and INGOs.</li></ul>
Are you aware about the root cause of disability?	<ul style="list-style-type: none"><li>• By birth, accident, diseases, natural calamities, hereditary, negligence of mother during pregnancy and after birth and negligence by doctor.</li><li>• Lack of nutritious food, awareness, lack of health services.</li><li>• Poverty, lack of health education, biological differences, social circumstances, lack of physical infrastructure.</li><li>• Marriage with the nearest family relative.</li></ul>
As part of community, what do you think about the needs of the disabled people in remote villages in Nepal?	<ul style="list-style-type: none"><li>• Education, employment, skills training, awareness activities.</li><li>• Opportunities according to their age, sex, and disabilities.</li><li>• Development of physical infrastructure as per their disability.</li><li>• Assistive devices and equipment.</li><li>• Accessible roads, schools, hospitals.</li><li>• Establishment of revolving fund fixed deposit, economic development.</li><li>• Formulation of policies and their implementation for welfare of the disabled people, and inclusion into the mainstream society.</li><li>• Establishment of organisations to work for people with disabilities.</li></ul>
what are the recommendations for programmes on disability?	<ul style="list-style-type: none"><li>• There is a big problem of getting clean drinking water in our village and so even more for the disabled people.</li><li>• It would be very nice to establish a skill-training centre for the disabled people.</li><li>• Disabled people know the problem of the disabled people better.</li><li>• All the disabled people who live in the community should be encouraged to be included into the mainstream development of the society.</li><li>• Disabled members should not be sidelined in any opportunities available to them.</li><li>• Awareness-rising programmes about disability and rehabilitation must regularly be organised by the concerned organisations/offices.</li></ul>

- Some families still hide their disabled members in their houses for fear of loosing their prestige. Therefore it is necessary to arrange a comprehensive awareness-raising programme in the community. Unless community attitudes are changed to favour disability, there will not be any holistic development in the community.
- Education, employment, skills training, awareness programmes are needed.
- Opportunities according to their age, sex, and disabilities need to be provided.
- Development of physical infrastructure as per their disability is required.
- Assistive devices and equipment are needed.
- Accessible roads, schools and hospitals are needed
- Establishment of revolving fund, fixed deposit and economic development are required.
- Formulation of policies and their implementation for the welfare of the disabled people, and inclusion into the mainstream society are required.
- Establishment of organisations to work for people with disabilities is required.

## **CONCLUSION AND SUGGESTIONS**

Supporting people with disabilities is a great concern of every individual and organisation. Hence, NDUP-Nepal initiated this research for identification of reasons of disability. Even though there are many reasons for disability, this study identified some of them that are useful for planning and inclusion of people with disabilities into the mainstream development of the society. The findings of this study can be a useful resource to planners concerned with Nepal.

Some suggestions arising from the study are:

- Physical infrastructure must be accessible for disabled people so that all disabled people can use public utilities.
- Training packages should be developed according to the age of the people. People should also be categorised according to the severity of their disability.
- Effective awareness raising programmes should be conducted for disabled people, family and community about disability and development issues before and after implementing any rehabilitation activities.

- Disabled people should be encouraged to be involved in all community development activities according to their potential.
- All disabled and non-disabled members are equally responsible to establish a discussion forum about disability.
- Community attitudes need to be changed to favour disability issues, there should be an effective awareness raising programme in the community, for existing groups, schools, volunteers, elected officials, mass meeting etc.
- Family members should be trained on how to communicate with their deaf members, how to cure wounds of disabled members, how to orient blind members and how to teach their mentally retarded members etc.
- Primary rehabilitation interventions should be available in the community. It is the responsibility of the government, NGO, NGO and the community.
- Families should be encouraged to send their disabled children to schools, community events, cultural events etc. that they can enjoy, learn and share their views.
- All the disabled members are equally responsible and have equal rights to take decisions.
- Families and communities must be informed what the real needs of disabled people are because they are the key people to help disabled people to mobilise local resources.
- Non-formal education classes should be started in the community.
- Families should be encouraged not to hide their disabled members in their houses.
- VDC, DDC and government should be made aware that solving disability issues are also part of community development. Therefore they should consider this issue as any other component of community development.
- Existing laws, acts, policies and legislation about disability and disabled people must be amended by the government and implemented. INGO/NGO should be requested to implement rehabilitation activities in the community.
- There should be an opportunity to attend schools for those who cannot pay monthly expenses of schooling.
- INGO/NGO should be transparent in all the activities and should establish a good positive relationship with the community.

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## IN REFLECTION : MAKING SENSE OF ACHIEVEMENTS AND FAILURES OF A CBR INITIATIVE

Namita Pande,\* Ajit K. Dalal

### ABSTRACT

*This paper presents lessons that were learnt while carrying out a CBR project for rehabilitation of physically disabled members of a village community. The outcomes of this project are narrated in a reflective manner without categorising them as either achievements or failures. The purpose of this paper, therefore, is to share our understanding of the performance of a CBR programme.*

“The modest amount published about CBR continues to be mostly on ‘What A great Job we Did’, i.e. the heroic struggle to get things going, urgent pleas for funds to expand, anecdotes from grateful clients, etc. No doubt this literature has its place, but the genre seldom contains any serious, critical thinking” (1).

For over five years during the early nineties we were committed to setting up a Community Based Rehabilitation (CBR) project at Sirathu (a village district bordering western Uttar Pradesh, India), a region which was till then unexposed to voluntary initiatives by any formal agency. We came across many opinions in matters related to CBR, which communicated to us the merits and viability of community based approaches in meeting challenges of disability. There were many written reports documenting success of such initiatives. For us, who were stepping out of an academic department into the “real” world for the first time, such informed opinions and narratives of success had a great inspirational import. Driven by the zeal to align psychological knowledge to needs and aspirations of people, we ventured out, made commitments, formalised plans and strategies, made efforts to enter into the community, solicited support and carried out many activities in the name of CBR. We were elated when the programme moved along predicted lines but most of the times remained confused for it would digress in unforeseen trajectories. All through, the programme oscillated between achievements and failures as did our “sense-making” of its outcomes. It is only after the programme has caved in for reasons that this paper would enumerate after a while, that we feel the need to reflect and narrate the story of the programme performance. We are doing it at a cost; there are apprehensions of being seen as initiators of a social action programme who were more enthusiastic than informed, those who made mistakes but did not pause to correct them and now are indulging in the luxury of reflection when threats of either losing face or cessation of funds have become matters of distant past. Yet, the need to tell the story is more compelling than threats associated with misperceptions.

It seems to us that categorizing outcomes of any change effort as either achievement or failure casts outcomes in an evaluative mould and renders any alternative interpretation of the meaning of an outcome, almost impossible. Depending upon how efficiently and at times, strategically, the conflicts and crises inherent in human endeavours are appropriated, outcomes appear to be either achievements or failures. What is deemed as an achievement may have failed in the sense that it may have met the expectations of a select few at the cost of ignoring the aspirations of a large number of stakeholders. Similarly what gets dismissed as a failure may indeed be an achievement for it may affirm the dignity of human effort and furnish insights for improvement. Therefore, while narrating the story of this CBR initiative, it would be our task to critique limits of what we did achieve and present possibilities hidden in our failures. Incidentally, the story that we are about to tell does not have a consistent story line. During the course of this paper readers might experience many shifts, some of which they may not anticipate; the narrative and the sense making will proceed side by side and in no definite order. In reflection, this perhaps is inevitable.

Recently, it has been suggested that among psychologists, the understanding of disability has remained confined to addressing psychological issues which an individual with physical disability might present and therefore psychologists need to “..... demonstrate competency to develop clinically valid intervention strategies and address concerns that fall outside of the realm of psychological issues” (2). No doubt, the core of the disability concept is the individual but the term ‘disability experience’ that has gained currency, implies that disability is not inherent but is experienced at the intersection of person and environment (3). Besides, it is the contention of the first author that only psychologising issues of vital concerns - those that affect human lives and determine the quality of human condition- and not taking any initiative to bring about a positive change, is an act of irresponsibility. Therefore in order that psychologists speak and act responsibly vis-a-vis disability, there is an urgency to grow out of the disciplinary confines and carry forward the task of integration of persons with disability into the societal mainstream by at least recognizing issues which may fall outside the psychological realm. While it may be conceded that psychologists are not trained to address issues at the systemic level, yet there are visible signs to suggest that they would continue to visualise possible utopias and will sustain efforts to realise them (4).

Irrespective of who initiates social action programmes and with what kind of training, the core of almost all such programmes which aspire to intervene in processes with discriminative socio-political underpinnings, is animated with an idealistic vision of creating a better tomorrow for those who are discriminated against. A natural fall-out of this vision is to understand the reality in clear dichotomies such as the perpetrator and the victim, the haves and the have-nots, the deprived and the privileged. Interventions that are designed to bring the underprivileged at par with their privileged counterparts, clearly share this vision. Although noble in their



intent, they seldom address the question of discrimination at a systemic level. Their schemes of evaluation define programme success in terms of the number of underserved who eventually get served through the programme. For example, most CBR programmes subscribe to this 'victim-service' model of intervention because they ascertain the effectiveness of the programme by counting the number of persons who were given aids and appliances, compensatory education, skills or physiotherapy. Even when such remedial projects are undertaken with the help of community's initiatives or expertise, they still reflect the institutional model of rehabilitation which considers compensation for the losses due to physical disability as the only method of restoring independence and freedom.

We recognised right from the beginning that disability is more a socio-political issue than an issue arising out of physical limitation or impairment, and that no CBR programme can ignore the socio - political fabric of the community. We also realised that the means to access and reinforce the lost sense of power and autonomy lies in political action and not in treating persons with disability as a special category of people in need of help and assistance, because such compensatory initiatives only accentuate the dichotomies that must be done away with. What confused us was discovering appropriate strategies that would begin and sustain the political action of this variety.

Why not focus on abilities rather than disabilities? We raised this question hoping that the answer might help us explore capabilities of Persons with Disability for their development and integration into the community's mainstream. This question could also change the reference point : what becomes more important is not what able-bodied are doing or are capable of doing but the unexplored potentials of persons with disability themselves. Implicit in this approach lies the assumption that like any one else, persons with disability too have their unexploited reservoir of creative energies which can be released and utilised for the community's development. In that sense they become equal partners in realising the dreams and aspirations of the community. Related to this, was the possibility of viewing CBR as a project of community development because a CBR programme could sustain if it contributed to the development of the entire community. If persons with disability become more resourceful, then resourcefulness of the entire community is enhanced. Needless to say that placing the enterprise of CBR within the power dynamics and developmental processes of the community can render programme implementation more difficult. What may appear to be a sound ideology may not lend itself easily to concrete action plans. As was true in our case, the problem got further complicated by our lack of expertise in handling such vexed issues.

It may be best to begin with a brief description of the site, the programme ideology and its objectives. This CBR initiative was undertaken in five villages of Sirathu tehsil (an administrative division) of Kaushambi district. These villages had a total population of about sixteen thousand

people. Barring a few high caste families, most inhabitants belonged to scheduled and backward castes and worked either as underpaid agricultural labourers or petty businessmen. There were around three hundred persons with physical disability (we had a list and detailed information of two hundred and twenty persons but we estimated that the list was not exhaustive) due to post-polio residual paralysis (PPRP), tuberculosis, malunion/nonunion of fractures and traumatic amputations due to accidents. Out of these 220 persons 180 belonged to scheduled and backward castes and the rest were either high caste Hindus or Muslims. The number of children with disability was fairly large. The adults had disability since childhood or early adulthood and had not undergone any medical treatment or physiotherapy. Some were educated upto the primary level but the rest were either illiterate or semiliterate. A large number of children with disability did not go to school and the disabled adults usually stayed at home. There were at least one primary school and one adult education centre in each village but the attendance was poor. There was just one Primary Health Centre (PHC) for all the villages of the tehsil. Except for a few government sponsored campaigns for birth control and immunisation, this region was not exposed to any kind of voluntary social action.

Given that the overarching philosophy of CBR is integration of persons with disability in all spheres of community's life, this programme addressed the question of integration within the framework of empowerment of persons with disability and of the community. In that case, perhaps, integration becomes both, the means as well as the indicator of empowerment.

Many community psychologists in the West have used the term empowerment as an individual's sense of mastery and efficiency, without focusing much on the context in which empowerment takes place. Experience tells us that in the world of action where individuals, groups and organisations struggle to control resources to fulfill their competing goals, empowerment for one is loss of power for another and the powerful do not always give up power so easily. One may get embroiled in such debates as long as the implicit linkage between individual empowerment and the empowerment of the community are not appreciated.

Integration of persons with disability into the community's mainstream both as a means and as an indicator of empowerment requires conceptualising empowerment at the levels of a person with disability, a group of persons with disability and at the level of community. At the individual level, the driving force behind empowerment is the critical consciousness of powerlessness due to external forces which are not under personal control. From this vantage point, psychological variables such as personal inefficacy, lack of personal control and learned helplessness come handy in understanding the subjective experience of powerlessness and forwarding strategies that can help the individual become more efficacious and resourceful. This conceptualisation of empowerment dissociates the individual's psyche from his social conditions and ignores the intricate mechanisms through which individual and social environment interact. This conceptual lacunae is overcome when persons with disability are

seen as a pressure group striving to access and create resources and control their allocation. To be able to engage in political activity of this variety, cognitions regarding personal control and self efficacy are perhaps necessary and here in lies the delicate link between the two perspectives. At the level of community however, the notion of empowerment needs to extend beyond its restrictive definitions and popular images. Community empowerment, as we see it, not only refers to the community's greater control over the resources for its development vis-a-vis other communities or the state but also refers to its increased resources which are available by integrating persons with disability into its mainstream. The power struggle between persons with disability and the larger community is at least theoretically resolved when both are seen as the sources and beneficiaries of empowerment. If persons with disability acquire greater power from utilising community's resources, and in the process discover additional sources of power, the community too becomes more powerful by utilising the resources of persons with disability who have now been integrated into its mainstream for its development. Idealistic and to some extent unreal though it may sound, this broadening of the notion of empowerment is necessary for conceiving CBR as a community development project.

This very brief description of the programme ideology can now render the rationale for laying out certain objectives and carrying out certain action plans, more comprehensible. The main thrust of the programme was to integrate persons with disability into the community's mainstream and improve the quality of life of the community as a whole. More specifically, the objectives of the programme were to :

- (a) evaluate the health and rehabilitation needs of the village community and mobilise persons with disability, their families and the community so that they are able to access institutional resources and create new resources to fulfill their health and rehabilitation needs.
- (b) sensitise the community towards special needs and abilities of persons with disability so that it maximally utilises them for its development and
- (c) mobilise the institutional and local resources for promoting economic self reliance among persons with disability.

A significant feature of this programme was that it attempted to anchor attitudes (of persons with disability their families and the larger community) towards disability within the matrix of empowerment and integration. The purpose was to add a psychological perspective to the programme and test the extent to which attitudes (a micro level concept) help in understanding the dynamics of these essentially macro level processes. Intuitively, it appeared to us that the hopes and possibilities which are nurtured despite serious physical limitations are psychological resources to strengthen political actions directed towards securing the desired end states. If

the current psychological state is that of resignation, apathy and withdrawal, initiatives for regaining the lost sense of independence and freedom would be less likely. For such initiatives to surface a more favorable self-perception was perhaps necessary. Positive attitudes towards disability which, from community's perspective refer to a belief that persons with disability can become productive members of the community, could make their special abilities and skills, more evident. The community would get empowered to the extent that it utilises those abilities for its development. Putting it differently, the kind of attitudes which persons with disability and the community hold towards disability would determine the efficacy of political mobilisation, status of persons with disability, their level of integration, and the seriousness with which community would take on the responsibility of their rehabilitation and create necessary conditions for equal participation.

Having said that, now the stage is set to review the CBR activities which we undertook and to critically evaluate their outcomes. Rather than listing the activities which we were able to either initiate or complete, our choice is to consider them as components of various action plans. Looking at the nature of these activities, the action plans which were carried out were creating awareness within the community about community's needs of health and rehabilitation and about the general philosophy of CBR, mobilising the community and persons with disability to get access to rehabilitation facilities which existed but were denied to them, and changing the community's negative attitudes (the data which we collected around that time on disability attitudes, beliefs and behaviour clearly showed that attitudes towards disability and disabled persons were extremely negative) by helping some persons with disability become models of success in terms of being economically self reliant.

The programme took off in early May 92 with a couple of informal meetings at the villages. These meetings were attended by the opinion leaders such as the Gram Pradhans (village heads), Block Development Officers, doctors from PHC, teachers of primary schools and also by persons with disability and their families. In these meetings, issues relating to causes of disability and its prevention, nature of disability in that region and the resources for rehabilitation were discussed. During these meetings, our focus as initiators was to highlight the merits of the CBR approach in addressing these issues. The initial response of the community was very positive. The area for programme implementation was earmarked, people offered their services voluntarily and even suggested concrete steps that could be taken in these directions. Some volunteers took up the responsibility of identifying persons with disability in five villages, the nature of impairment, their needs and special abilities and their expectations from the programme. This survey yielded a detailed record of 220 persons with disability residing in that region.

Building awareness is perhaps the most important and at the same time, most challenging task. Especially when a programme carries a definite ideology, there is an urgent need to arrive at a shared understanding of its essential components. Often in this urgency, the

alternative understanding of the components is silenced and needs other than those which the programme purports to address are marginalised. We still remember an old disabled lady walking up to us and asking what the legitimacy of promoting rehabilitation was when even safe drinking water was a scarce resource. Another young disabled person alleged that CBR was yet another instrument used for denying the benefits of technological expertise in the field of rehabilitation to those who need them the most but cannot afford them.

We did not have ready answers to these questions. These and many more such instances have suggested to us that community's understanding about what is desirable and what the programme should be achieving was at variance from our understanding but, nevertheless, it is this variance which was of critical significance. The act of inflicting a programme on the community with 'stated' goals and objectives closes all avenues for a meaningful dialogue to arrive at a shared understanding about the goals and objectives of the programme. This definitiveness with which a programme is launched militates against the very spirit of empowerment because in this entire exercise, community has no role to play. The goals and objectives if stated as though they are sacrosanct, only reflect the vision of the initiators and not that of the community. Attempts should be made so that they may come to be 'shared' and should remain open to modifications and adjustments as and when required. This we learnt the hard way and tried to recast the programme objectives in the light of community's understanding of CBR. It is another matter that this understanding eluded us because the village community that had competing factions and conflicting interest groups, interpreted CBR in more than one way that were often irreconcilable.

Awareness also increases needs and expectations and when they grow beyond what the programme can afford to fulfil, it becomes difficult to sustain people's motivation. Despite our repeated submissions that it was neither our intent, nor did we have necessary resources to distribute money or other things, people in general and persons with disability in particular perceived the programme as a source that could fulfil their long pending demands for financial help and assistance. We had in our files, a number of such applications and it became increasingly difficult for us to wean people away from those expectations.

These unfulfilled expectations were then manifested at different levels. The promise which the project showed started waning and the enthusiasm with which the programme began started fading at an amazingly rapid pace. The office bearers of the project started abstaining from meetings and other activities. At that stage we came to realise that people were dissatisfied because by then they knew that the programme had no backup of external funding which they could have utilised to strengthen their political base. At the same time, they also saw that the participation of persons with disability and their families in the programme had increased. Since a majority of persons with disability belonged to the scheduled and backward castes,

their increased participation was perhaps being perceived as a threat to the existing socio-political order.

We feel that as long as any social action programme remains at a 'show case stage' in performing essentially a decorative display function such as highlighting the credentials of the initiators and the participants, it evokes great enthusiasm. But when it gets underway and starts striking at the vested interests, threatens to disturb the existing pipeline of resource flow and unsettles political structures, it meets with resistance. Therefore we are tempted to interpret the dissatisfaction of the office bearers of the project both as an achievement and a failure. If some such people were dissatisfied, may be the programme was doing well. The activities directed towards creating awareness had a 'ripple effect' in the sense that many persons with disability belonging to villages other than the selected five, came in large numbers and shared their problems with the group. They even made suggestions about what they could do with or even without external help. We considered it as an achievement because persons with disability and their families who should ultimately own the programme were taking more interest and initiative and the political heavyweights were distancing themselves. It was also a failure because these politically powerful people who could have provided a major impetus to programme planning and implementation were dissatisfied and angry. We made desperate attempts to discover what had led them to feel dissatisfied. Despite our concerted efforts, that remained unknown till the end and we could not devise methods which could have harnessed their political ambitions to use their resources for programme augmentation.

Somewhere during the middle of programme implementation we collected some data from the PHC about the number of inhabitants of the chosen villages who went for immunisation prior to May 93 and between May 93 and December 94. The number had significantly increased both for high caste people, as well as for the scheduled and backward castes though the increase was much higher in case of scheduled and backward castes. It may be unfair to suggest that this was entirely due to the awareness which the programme had brought about. All that can be said is that the programme could have been one of many factors which led to this difference.

Another set of activities that we carried out consisted of mobilising the community to get access to the resources for rehabilitation. The Government of India had instituted many welfare schemes for the rehabilitation of persons with disability, such as loans for self-employment, vocational skills training, concessions in travel and fellowships for education. As our visits became more frequent, we realised that people were either ignorant of such schemes or were unable to avail them for various reasons. This knowledge gave us the first opportunity to take a small step in the direction of community mobilisation for increasing the responsiveness of the bureaucracy towards community's needs. This we thought was not a difficult task and with little effort, the strength of collective action could be readily demonstrated.

In order to avail such facilities, a certification of disability from the Chief Medical Officer or from the head of the orthopaedic department of the local medical college was needed. The community took a major initiative in this direction and organised three such camps where doctors from the city visited the site, made disability assessments and issued disability certificates to more than a hundred persons with disability who were eligible. These certificates were used for various purposes and the local doctors and other officials who were previously denying help came forward to help the persons with disability complete various formalities for obtaining certification. Many persons with disability and their families also contacted the Government and non-government agencies in the nearest city.

However, getting access to community's own resources for rehabilitation continued to remain a distant goal. This happened because many local resources such as surplus land of the villages were managed by people who were politically powerful. They were reluctant to distribute the land to persons with disability because that could have brought about power imbalance and disturbed the existing social structures and relationships. If a village chief extracts political mileage by extending the favour of giving surplus land of Gram Samaj (village community) to one of his allies, would, he give the same land to a person with disability or his family? Therefore as far as using local resources for rehabilitation was concerned, the distancing of the powerful groups from the programme constituted a major set back.

The programme attempted many other activities but they were not followed up very systematically. For example, one volunteer was attached to the orthopaedic department of the medical college for fifteen days to learn physiotherapy but he could not start giving this service at the village level. Similarly, a three-day bee keeping training programme was organised at the PHC of Sirathu with the help of the government's garden at Allahabad city but there was no follow up because it required financial investments in the beginning. With the help of a local NGO, working for the rehabilitation of blind children in the city, we provided small loans to two persons with disability to start pavement shops. Whether or not it created success models is a matter of debate but that definitely created more pressure on us to extend such activities to others.

It was around that time that we thought that the programme was in need of a major change. Instead of feeling desperate and making sporadic attempts to give the programme a new lease of life, we decided to implement plans for the vocational rehabilitation of persons with disability. To achieve this, we arranged to start an integrated school where disabled and able-bodied children could learn together, and a bakery that was to be owned and managed primarily by the disabled members of the village. Little did we realise that attempts at vocational and educational rehabilitation are no magic wands to resurrect a programme that was already sailing in troubled waters.

Within a couple of months of commencement of the integrated school at least two such schools sprang up nearby. This was a great surprise as this was least expected. We were later told that since one of us belonged to a family of erstwhile landlords who had still managed to remain influential in that region, these initiatives were perceived as yet another strategy adopted by the family to increase its power base. The bakery was hijacked by others, marginalising the disabled members of the community. The programme suffered because of yet another reason. In order to ensure a smooth entry into the village community we relied heavily on a couple of key persons. Although it may be a good way to begin with, yet the process of entering into the community must be carried forward, a task we did not engage in. All programme activities centred around these key persons and predictably enough, the programme came to be identified as their programme and not that of the community. Later those key persons got involved in other activities and lost interest. One such key person suffered a major health problem and as a result many ideologically driven activities came to a grinding halt.

Now, in reflection, many images and insights related to programme performance - what we did and what we could not, where we erred and where we succeeded, what could have been done and how - keep coming to us, some of which compel us to ruminate over our success and failures. In retrospect, we find it extremely difficult to flag 'success' or 'failure' as the outcome of our initiative. What seems possible at this stage is to share with the readers, some sense which we have been able to arrive at from this very exciting but unfinished project.

We have come to realise that CBR is a relatively difficult concept to communicate and even more difficult to generate a consensus about what it means. It has been our experience that trying to arrive at a consensus regarding the meaning of CBR, while interacting with diverse groups with varied interests, motivations, background and commitment, is not an easy task. Moreover, the idyllic image which the term 'community' evokes in our minds is more a myth than a reality. It is not as though a vibrant community consisting of people eager to extend help and cooperation to one another already exists and all that is needed is to just plug in the task of rehabilitation. In fact, the community spirit has to be consciously cultivated, maintained and reinforced from time to time. How efficiently this task is handled, determines how smooth becomes the entry and subsequent success of a CBR initiative.

It has often been suggested that in India, most community development programmes did not yield desired results because the programme did not modify the psychological structures of people (5). Our contention is that before one intends to modify the psychological structures of others through any programme, examining one's own motivations is perhaps imperative. If the motivations are only to drive home the point that 'I am holier than thou' or 'I have had a feel of the soil' or to 'add another feather in one's already colourful cap', then one most



likely will become what Miles (1) calls 'a flying expert'. In this case one is not aiming for sustainability of a programme and therefore one will not get it. But if the motivation originates from a deep rooted conviction to change an unjust social order by mobilising people to fulfil their dreams and aspirations, then any intervention to bring about change is not a part-time engagement. Building capacities through social interventions requires fusing of expert knowledge with local knowledge, that which is available in the form of beliefs and perceptions (6). This can happen only when the initiator is willing to become a part of the community and is ready to put other concerns at bay. A successful intervention, after all, is not so much a matter of expertise as it is a matter of commitment.

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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.
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