

## EDITORIAL

### AN OVERVIEW OF DISABILITY ISSUES IN SOUTH ASIA

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#### ABSTRACT

*This paper provides a working knowledge about seven countries in South Asia, namely Afghanistan, Bangladesh, India, Nepal, Pakistan, Sri Lanka and Bhutan, where the authors had followed developments in CBR either directly or indirectly as part of their assignments. This paper analyses the current situation (in 2001), to identify the problems and challenges, and suggests some potential strategies for the future. The information was collected during assignments in these countries or through interviews with people who are familiar with the situation in the countries. However, the paper is by no means a comprehensive document.*

#### INTRODUCTION

In most South Asian countries a range of disability initiatives have already been pursued for the past few decades. These initiatives were developed as a result of local or national interests with little commonality in ideology across the region. While there are many similarities between the programmes from different countries, there are also marked differences between them. This paper offers a brief description of similarities and differences of the situation in community based rehabilitation (CBR) in these countries, for the information of development workers who are familiar with this region.

#### A F G H A N I S T A N

This section describes the situation in Afghanistan before the events of September 11<sup>th</sup> 2001. The authors believe that CBR in the country in the post-Taliban era would have been substantially different. However, it is interesting to note that even before the September 11<sup>th</sup> events, Afghanistan had provided for many years one of the few examples of CBR in a state of chronic and complex emergency. The country had a civil war for about two decades that wrecked its economy, created hyper-inflation, refugees and displaced populations on a large scale. Before September 11<sup>th</sup> about one million people had been internally displaced, migrating to outskirts of cities, hoping to find help from the international community or from Pakistan, and they lived in makeshift camps facing death from dehydration, heat-stroke and hunger. During the Taliban supremacy, even though they controlled most of the country, they did not constitute a recognised government, and Afghanistan had no authority that could develop a national plan. Government services like health and education functioned in a most rudimentary fashion funded by external agencies. There were very few hospitals with necessary facilities and those that were available provided services with the help of visiting foreign medical personnel. The Taliban at the same time was highly ambivalent about the presence of foreigners in Afghanistan.

#### P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y

Records pertaining to health services are either absent or rudimentary in Afghanistan. No national surveys have been done, but local surveys indicate that probably about 3 to 4% of the population of 20 million are disabled persons in need of some rehabilitation interventions. The profile of disability in Afghanistan is weighted in favour of physical disability. Perhaps about half of this population are people with mobility impairments. War injuries, mainly from landmines, have created amputees, blindness and paralysis. Poor preventive and general health care as a result of the prolonged conflict have also resulted in a large number of people with polio and tuberculosis. Survival rate of people with spinal injuries is low and hence their number is low. The other half is composed of people with learning difficulties, cerebral palsy, leprosy in certain areas, speech and hearing problems, visual impairment and multiple impairment. Maternal malnutrition resulting in birth complications, under-age mothers and absence of pre-natal, peri-natal and post-natal care are cited as major causes for mental retardation and cerebral palsy.

#### R e h a b i l i t a t i o n   s e r v i c e s

International agencies and a few national NGOs carry out most of the rehabilitation services in Afghanistan. A planning instrument called the 'Strategic Framework and the Principled Common Programme' that united UN agencies and other NGOs for a common purpose was introduced by the UN. Confluence of groups of service providers in this fashion encourages consensus on major strategic issues on relief and development in the country.

Most of the available services today are for people with physical disabilities. There are few services for people with other disabilities. By far the largest service is the 'Comprehensive Disabled Afghans' Programme', run by the UNOPS as part of the UNDP programme. Other international agencies include International Committee of Red Cross, Swedish Committee, Kuwait Joint Relief Committee and so on. After 20 years of war, Afghanistan has been left with almost no Government infrastructure to provide basic services, and no recognised or elected Government. Traditionally, the families and communities have cared for disabled persons in Afghanistan.

Health care services in the country, including prevention, have been poor in both coverage and quality because of the prolonged conflict. Afghan rural communities are also very scattered and they take many hours of travel on dreadful roads in extreme weather to access available services. In general, the survival rate of disabled Afghans is low because of lack of curative health services. Medical rehabilitation facilities for disabled people are also very limited and restricted to NGO efforts in a few areas for amputees and polio survivors, where they provide physiotherapy interventions and workshops for mobility aids and wheelchairs. There are about 12 orthopaedic workshops that produce prostheses, orthoses, wheel chairs and a variety of other aids and appliances supported by different NGOs. However, their coverage is limited to a few areas. Parts of the country in South West and North West regions have large numbers of amputees and polio survivors without access to any services.

Facilities for treatment of a large number of paraplegics and quadriplegics who are injured due to landmine explosions are limited and mortality rates are high in this group. Teams of visiting foreign surgeons sometimes organise camps for this purpose. Special and integrated education services are promoted by NGOs, mainly for children with visual impairment and hearing impairment, while education services for children with learning difficulties are almost non-existent. Vocational rehabilitation of disabled people has not received much attention till now. Whatever vocational training that is available is through group training at the community level or by one-to-one training, where a local craftsman takes on the disabled person as an apprentice. NGOs and some UN agencies promote vocational training, apprenticeship training, and micro-credit for self-employment, but their coverage and results are limited. Moreover, micro-credit in the Afghan context is problematic because of the Islamic prohibition on charging interest. High rate of inflation of Afghan currency and inability to use dollars or Pakistani currency in Afghanistan also makes it difficult to sustain a revolving fund.

The main focus for prevention is polio eradication and prevention of war injuries from land mines. Polio eradication is led by WHO and UNICEF that rely on other agencies to mobilise local communities on national immunisation days, once in three months. There are a number of specialised agencies that deal with awareness about landmine injuries and rehabilitation. In most countries, landmine damaged limbs are saved as far as possible. However, in Afghanistan the availability of services is so abysmally low, that limbs are amputated to prevent further complications.

## **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

Some NGOs have promoted CBR programmes in a few areas of the country. An example is the 'Comprehensive Disabled Afghan's Programme' (CDAP), promoted by UN in association with other international NGOs. This programme is one of the largest CBR programmes in the world under the auspices of UNDP. It was initiated because many people had been injured by land mines in Afghanistan and needed rehabilitation. Although started initially as a service to mine-injured people, it later became broad-based to include people with other disabilities and also restated its goals to become a development programme. CDAP covered 45 out of 350 districts in Afghanistan prior to the September 11<sup>th</sup> tragedy and was considered by many as a model for the country. It used services of 'Community Rehabilitation and Development Workers' to mobilise local communities around issues of disability and identified disabled people from these groups. They were then referred to appropriate services or given home based training when required with the help of

volunteers. It was also backed by a team of specialists such as physiotherapists, orthopaedic technicians, employment support officers, special education resource personnel and so on. The whole programme employed 400 people and had 2000 volunteers. The success of this programme was primarily attributed to field workers and volunteers recruited from the community, its strong sense of community ownership, dependence on local resources for most of its needs and the low operational costs.

However, in the context of the country's problems and need for development efforts in Afghanistan, CBR is still not seen as a priority. Despite this, there are attempts to widen the scope of rehabilitation by making other organisations dealing with issues other than disability, familiar with CBR. There are also other difficulties associated with working in rural Afghanistan, such as travel through long distances in extreme climatic conditions and cultural restrictions in providing services in homes and community based settings.

Most organisations in Afghanistan use the WHO manual and /or David Werner's 'Disabled Village Children' as background materials for training. There is a well-established staff training facility with CDAP which trains their 'Community Rehabilitation and Development Workers' with three months of classroom and eight months of field training. About 25% of the workers of CDAP are women, a remarkable figure in a country that had banned women from working. They were trained separately from men using women trainers. CDAP also has the capacity to train specialists. International NGOs provide training in physiotherapy and production of mobility aids, and there are efforts to develop a common curriculum in physiotherapy with approval of relevant authorities. The present training programmes have mostly focused on mobility problems. Training to work with sensory and multiple impairments or mental handicap has received less attention. Associations of blind and deaf persons provide some training to personnel who work with these groups. Implementing NGOs usually provide CBR training for their personnel, but most of the training goes on at local levels.

Information and public awareness programmes carried out by NGOs are limited to their operational areas. They are restricted to promoting disabled people's acceptance and participation in the community, reduction in over-protection due to ignorance and misconceptions, and improved awareness about mine injuries and their prevention. Research in the field of disability has been little. Agencies like CDAP carry out some action research on outcomes of interventions, although they are of limited scale.

## **L e g i s l a t i o n**

There is no legislation specific to disability in the country and in the Taliban regime it was not perceived as relevant. Traditionally, the head man in Afghan families decides what the family may do or not do and the tribal head decides what his tribe should do. These roles have been taken away by Taliban. Under Taliban rule Afghanistan was governed by a conservative Islamic influence of eighth century origin.

## **S e l f - h e l p   g r o u p s**

Organisations like CDAP promoted disabled persons' organisations (DPO) for their social integration through community mobilisation. DPOs in the country do not have the means to implement concepts of rights. However, they make themselves more visible and give themselves the experience of managing their own groups. Hearing Impaired Foundation of Afghanistan (HIFA) and Afghan Association of the Blind (AAB) are two national level DPOs.

## **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

Afghanistan under Taliban regime practised an extreme version of tribal values. Under the Taliban edict women could not go out of their homes without a male relative, they could not be trained other than by women or take up an employment. NGOs are however involved in promoting special services and training for women with disabilities in a culturally appropriate manner. They train women community workers to provide home-based services and organise 'women only' CBR committees to discuss issues related to women with disabilities.

## **S e r v i c e s   f o r   p e o p l e   d i s a b l e d   a s a   r e s u l t   o f   c o n f l i c t**

All the agencies involved in disability activities in Afghanistan also provide services for people disabled as a result of violence and conflict, as part of their rehabilitation programmes. In fact, CBR in Afghanistan grew out of the approach called 'Victim Assistance' after the Ottawa Mine Ban Treaty of 1999. This treaty committed that member states would give all possible assistance to victims of land mines. Initially, it was perceived as the provision of prostheses to people who had lost their limbs due to mine blasts. Later, the definition of 'victim' was widened to include all other forms of disabilities and all forms of interventions.

## **BANGLADESH**

Bangladesh has a population density of 867 people per square kilometre and a total population of 125 million people spread over 144,000 square kilometres. It has one of the highest densities of population in the world, with 80% of people living in rural areas. It has a Human Development Index ranking of 146 out of 174 countries, Gender Empowerment Ranking of 67 out of 70 countries and Human Poverty Index ranking of 70 out of 85 developing countries. The per capita income is US\$ 350, life expectancy is 58.6 years, infant mortality is 79 per 1000 live births and adult literacy is 51.1% for males and 28.6% for females.

It is a fertile country prone to frequent floods that causes economic damage and loss of human life. Muslims constitute 86% of the population with all people sharing the same Bengali culture and language. About half of the population is below 15 years of age due to a 2.1% growth in population. It has an unequal distribution of wealth with 10% of the population holding 60% of land. Ground water is poisoned in many places with arsenic. The country has a high rate of corruption, frequent political upheavals and is highly dependent on external debt (37% of the GNP). About 75% of developmental programmes are financed through external aid.

### **P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y**

The WHO figure of 10% prevalence is quoted in most reports on disability in Bangladesh. Surveys by different agencies however, yield figures from 0.5% to 14% due to differences in definition of disability used in methodology. Major causes of disability are communicable diseases and malnutrition. Unsafe birth practices and nutritional deficiencies also contribute to the incidence of disability. Accidents and old age related disabilities are now on the rise. People with speech and hearing problems constitute the major proportion of disabled people in the country, followed by physical disabilities.

### **R e h a b i l i t a t i o n   s e r v i c e s**

Bangladesh has 1200 NGOs that receive funding from other countries out of which 100 are International NGOs. Some of them are very large and employ more than 10,000 people and compete with each other or with the government to form a parallel system. Both government and NGOs provide rehabilitation services with NGOs being more active. However, the government has recently started increasing financial resources for disability initiatives. There are about 100 national NGOs involved in rehabilitation programmes. International NGOs include Actionaid, ADD, Redda Barnen, InterLife, Helen Keller International, CORDAID and Oxfam. Development assistance channels of some embassies such as Norway and UK also support disability-related programmes. Traditionally, members of the family have taken care of their disabled relatives in the community setting.

The government carries out Expanded Programmes of Immunisation (EPI) and distribution of vitamin 'A' supplement. But coverage of prevention programmes in remote rural areas is poor. NGOs and government are involved in awareness building programmes together. Medical rehabilitation facilities of government and NGOs are limited in coverage and are restricted to a few urban areas. Both government and NGOs promote special and integrated education, but coverage is limited to cities and a few district headquarters. Quality is cited as poor, but this is mirrored in the general education system as well. Existing facilities for vocational training and employment generation are limited in both government and NGO sectors, with poor coverage and quality. Trades chosen for vocational training continue to be traditional and outdated. Production facilities for devices to assist disabled people are also inadequate in the country and the ones produced are of poor quality. Many devices are imported and beyond the reach of poor people.

### **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

To date, the government has not initiated any CBR programme though there is now a plan to set up a fund to support NGOs involved in CBR. Some NGOs have promoted CBR programmes in rural areas supported by international donors with a focus on service delivery, but coverage is limited. A network of NGOs involved in CBR has been promoted for information sharing, though it is not very active. Of late, organisations involved in community development activities have also begun to integrate disabled people into their services, particularly credit programmes.

Government and NGOs carry out training programmes in physiotherapy, occupational therapy and special education. There are no training programmes in the area of speech and hearing. Some NGOs are involved in CBR training, but the number of trained personnel is still inadequate to address the needs of all those who require them. The quality of many of the existing training programmes is low, as the availability of training facilities and qualified trainers is limited.

Awareness programmes of both government and NGOs are few and have limited coverage restricted to urban areas. Mass media involvement is also low. There are very few published materials on disability and rehabilitation. Some NGOs bring out a few books and newsletters periodically. Awareness in rural areas is very low and efforts to raise awareness in these areas are minimal. Few NGOs carry out some studies, but on the whole, research is a neglected area.

### **L e g i s l a t i o n**

There is an approved National Policy on disability, and a legislation to protect the rights of people with disabilities was recently passed. Access provisions for people with disabilities are non-existent. Lack of appropriate equipment and absence of attention to planning of infrastructure, compound the problem of access.

### **S e l f - h e l p   g r o u p s**

Of late, some associations of people with disabilities were started in the NGO sector, but not on a national scale. These associations currently include only urban and educated disabled people. Some of them are involved in advocacy work while others are involved in service delivery in education, vocational training and CBR. Some of them are part of a national forum to influence policies of government and to oversee the process of implementation of the national policy.

### **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

There are no special programmes for women with disabilities at the government level. Women form part of the beneficiary group for services provided by NGOs. A forum of women with disabilities has been recently started by an NGO.

### **INDIA**

India is the largest country in the region, with the second largest population in the world and a changing economic system governed by a democracy. Twenty-five percent of the population lives in metropolises while the other 75% lives in rural areas. Rural areas of the country are often inaccessible, have little health and rehabilitation services and the population in these areas are mostly illiterate. Indian society is divided into classes and castes (a system of segregation based on parentage and social roles). Wealth and power are concentrated in the hands of a minority. The closed economy in India has only recently opened out. Most people in India still view government as the only welfare organisation that has the responsibility to safeguard their future. Development in the country is very uneven, with great differences between the different states on indicators of health, education, employment and per capita income.

### **P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y**

Reports on India often quote the 10% figure of prevalence for disabilities. But different surveys with different methodologies have yielded varying prevalence figures. The government has also been conducting national sample surveys once in 10 years, which report that about 3 to 4 percent of the population are comprised of disabled persons who require rehabilitation services. Major causes of disability are

communicable diseases like polio, old age related disabilities, and congenital disabilities. Causes such as iodine deficiency, leprosy and vitamin 'A' deficiency does not contribute highly to incidence, because of the government's prevention and control programmes. Physical disabilities due to polio, constitute the largest group of disabled persons, followed by communication disabilities and visual disabilities.

## **R e h a b i l i t a t i o n   s e r v i c e s**

The government provides the largest services for people with disabilities in India. There are also over 4000 NGOs involved in rehabilitation activities, including NGOs 'for' and 'of' disabled persons. International NGOs supporting disability initiatives are few compared to those involved in poverty alleviation programmes and include Misereor, AIFO, AFD, Actionaid, CBM, Sight-Savers, Caritas, Sense International, The Leprosy Mission, Leonard Cheshire International, CORDAID and SCF-UK. Traditionally, families and communities care for disabled persons amongst themselves, especially in rural areas.

The Ministry of Health has large-scale prevention and immunisation programmes in India, with coverage that is extensive and effective. NGOs carry out awareness, public education and referrals to government programmes. General health services are widely covered through district hospitals and primary health centres, managed by government administration and by private institutions. But facilities for medical rehabilitation are few and still inadequate in coverage. They are usually restricted to urban areas. Even though India has many medical schools, they do not have facilities to train students in physical medicine and rehabilitation.

The government promotes special education and integrated education programmes simultaneously. Many NGOs carry out special and integrated education services. These services are however usually located in urban areas. Quality of education and coverage is abysmally low in rural areas because of insufficient funds and lack of trained teachers. Special schools are utilised by only 1% of the disabled children in India. Both Government and NGOs actively promote vocational rehabilitation. But even in this case, coverage is very poor and quality is low. Trades identified for training are often outdated and based on principles of welfare rather than on productivity and self-reliance. Choices of trades for vocational rehabilitation in most instances do not take into account the fast changing economic and employment scenario in the country. Roughly about 25% of adult population with disability are engaged in 'useful and productive activities'.

While there are a number of production centres for devices that assist disabled people in government and NGO sectors, their products are often outdated, expensive, inaccessible and sometimes inappropriate. Production volumes are low and lack a profitable commercial market for large-scale production. Apart from the example of Jaipur Foot, there is little research and development in this field to promote appropriate technologies.

## **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

The government and NGOs have promoted CBR since fifteen to twenty years. But it has limited coverage restricted to small geographical areas in the country. Recently the government has initiated a national programme to provide services for disabled people in rural areas. Overall outcomes of CBR programmes have been uneven in different areas. Most of them are top-down programmes and lack participation from clients, disabled persons and communities. There is inadequate effort to make the services cost-effective and of optimum quality, or to upgrade small programmes to large national programmes.

Training for required personnel at all levels are available in the country. 'Rehabilitation Council of India', a nodal agency has been set up to standardise and accredit different courses related to rehabilitation. Even though the quality of trained professionals is high, they are not available for work in rural areas. Efforts are now made to standardise training programmes for different cadres of CBR personnel, with a vision that better trained CBR workers will achieve better coverage and quality of services in rural areas.

There were very few publications in the field of disability and rehabilitation in India ten years ago. Gradually, the number of publications and newsletters has grown. They deal with descriptions of events and activities in the field, and experiences of people dealing with rehabilitation. There are few peer reviewed scientific journals. Government and NGOs involve actively in public awareness programmes, and the print media and television have recently started showing an interest in disability issues. NGOs in rural areas act as the main force in awareness building at local levels. Some action research work is carried out on attitudes,

outcomes of interventions, assistive devices, and so on, by different centres. However, research initiatives are low key due to lack of funds and lack of research experience in the field. Growth in rehabilitation is commonly based on experience rather than evidence.

### **L e g i s l a t i o n**

The Government passed a legislation in 1995, to deal with rights of disabled persons. However, its implementation is slow and sporadic. In its present form, the legislation emphasises punitive measures for non-compliance rather than incentives for compliance. Disabled people have poor access to most places in the country due to environmental barriers. Of late, as a result of legislation and some court rulings, there are instances of improving accessibility in city centres and public transport systems. Awareness about barrier free environment and the technology needed to make the environment disabled-friendly, are limited.

### **S e l f - h e l p   g r o u p s**

Associations of people with disabilities have been very active in India for some years. They have been moderately successful in areas of service provision, awareness building, information dissemination and vocational training. Of late, a few groups have become active in promoting rights for disabled persons. They include people with different disabilities. But their impact is still limited. Most of these groups are restricted to urban areas and are formed by disabled persons who have had better education and other opportunities. NGOs have also attempted to form self-help groups with disabled people and their families, at the local levels in rural areas.

### **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

While women with disabilities benefit from all government and NGO activities, there are no special programmes for them. Women-oriented developmental programmes in both government and NGO sectors, have increased over the years and as a result, some of them include women with disabilities also. A few innovative efforts for women with disabilities from the NGO sector include formation of a Disabled Women's Network and establishment of rehabilitation aids workshops by disabled women.

### **NEPAL**

Nepal is one of the poorest countries in the world with a per capita income of US \$ 219 and an infant mortality rate of 104 per 1000 people. Life expectancy is 57 years and the literacy level is 57.6% for men and 20.7% for women. It is a land-locked mountainous country with little available arable land, large areas that are inaccessible, poor transportation, unskilled and uneducated work force and economical and political instability. The 25 million population of the country originates from Mongolian stock in the mountains of the north and from others in the Gangetic plains in the south. The predominant religion is Hinduism, with significant tribal and caste distinctions between groups where Brahmins hold the supreme position. Only 4.9% of the GDP of Nepal is spent on health-care. There are about 2000 doctors, less than 10 speech and language therapists and a few dozen physical and occupational therapists in the country, most of whom are concentrated in Kathmandu, the capital of Nepal. All four main orthopaedic workshops are also in Kathmandu.

### **P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y**

While the figure of 10% is quoted in most reports, other studies show figures ranging from 3% to 20%. The most recent estimate from a survey of 23 districts, showed that about 5.2% of the population consist of people with disabilities in need of intervention. The government and UNICEF have been involved in a national survey. During the last national survey in 1980, prevalence of disability was estimated to be 3%. In 1999, the government of Nepal adopted a new definition of disability, according to which approximately 5% of the population or about 1.25 million people have disability. The major causes of disability are malnutrition, poverty, communicable diseases, consanguinity, and poor pre-natal, ante-natal and post-natal health-care, particularly in remote rural areas. People with visual and communication disabilities constitute the majority of disabled population, followed by those with physical and multiple disabilities.

### **R e h a b i l i t a t i o n   s e r v i c e s**

Less than 3% of people with disabilities receive any kind of formal rehabilitation services. National and international NGOs provide most services, while the government is involved in a smaller way in special education and prevention programmes. International agencies that provide disability services include SCF-UK, Redd Barna, Terres des Hommes, Handicap International, Voluntary Services Overseas, Helen Keller International, UNICEF and DANIDA. Families of disabled persons traditionally take care of their members. If families are absent, other community members also take care of them particularly in rural areas. Ninety percent of the population of Nepal lives in rural areas sparingly served by government or NGO programmes.

The government carries out immunisation programmes that have fairly widespread coverage. But remote mountainous areas remain inaccessible and uncovered. NGOs raise awareness and undertake early detection programmes in some areas. Medical rehabilitation services available at present are poor in quality and coverage and limited to urban areas. However, services for visual impairment are of a higher standard although coverage is limited to urban areas. Access to health services is also very poor. Efforts from a few NGOs in disability and community development has helped to improve the present situation, albeit very slowly. Both government (limited to a few districts) and NGOs promote special education services but the coverage and its quality is poor. Integrated education services are limited. Some NGOs provide vocational training services, mainly through sheltered workshops. But they are not effective in promoting employment opportunities, as availability of jobs is limited. There are few attempts to promote self-employment initiatives. Production facilities for assistive devices are very few, limited to urban areas and their quality is below the desirable level. While some prosthetic and orthotic aids are available in these centres, wheelchairs and other devices are not available easily. Many of the aids are imported and expensive.

### **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

The government, NGOs and a few community development programmes that have included disability issues into their on-going work, promote CBR services. The number of CBR projects is slowly increasing with support from international donors, but there is wide variation in the interpretation of CBR in practice. The National Network promotes co-operation in CBR. However, coverage is still limited and disabled persons from many remote mountainous areas do not have access to any services. At present, there are about 300 organisations in Nepal that either represents people with disability or are related to disability issues.

Training facilities available for rehabilitation personnel in Nepal at present are limited. The government has started a pilot training programme for teachers working with physically disabled children in regular schools. A government sponsored special education service has also been extended to 30 districts in Nepal. However, nearly three-fourths of people with disabilities are yet to be enrolled in any educational programmes. Some NGOs conduct national and local level training programmes in CBR, but their quality is poor and quantity of trained personnel are insufficient to meet the country's needs. The government also carries out campaigns of polio drops and vitamin 'A' distribution, while NGOs promote awareness of these programmes at local levels. The National Network also produces a six-monthly bulletin and they are now planning to develop a national resource centre. Very little research is being done in rehabilitation and present studies are limited to action research projects on programme outcomes.

### **L e g i s l a t i o n**

Nepal has legislation on disability issues, but implementation is almost non-existent. Of late, there have been efforts by the National Network and other NGOs to influence the government to implement the legislation and these efforts have succeeded in stimulating the interest of government in disability issues. The Government now invites the Network and other NGOs for planning and strategy development. The Government has recently formed a 'National co-ordination Committee' to review 'Rehabilitation and the Disability' Act of 1982. It also provides some personal allowances for disabled people within a limited coverage. Limited by geography and terrain, poor availability of appropriate equipment such as wheelchairs and poor planning of infrastructure, accessibility to public places is non-existent.

### **S e l f - h e l p   g r o u p s**

Nepal has some self-help groups that are limited to single disabilities. NGOs have been promoting family groups that are involved in education and vocational training services. Stigma related to disability is very high in Nepal. They believe disability to be caused by bad 'karma', misdeeds of previous birth and so on.

### **S e r v i c e s f o r w o m e n w i t h d i s a b i l i t i e s**

There are only a few programmes for women with disabilities. They are carried out by NGOs based in Kathmandu and are limited to activities such as education and vocational training.

### **PAKISTAN**

Pakistan has a population of 138 million people, and a density of population of 179 persons per square kilometre, spread over 7,96,000 square kilometres. The urban population constitutes about 37% of the total population of the country. Life expectancy is about 62 years, while infant mortality rate is 89.8 per 1000 live births. The adult literacy rate is 59.9 for males and 31.1 for females.

### **P r e v a l e n c e a n d c a u s e s o f d i s a b i l i t y**

The figure of 10% is quoted in most reports from Pakistan also. However, a census conducted in March '98 has elicited the same figure. Factors related to poverty and malnutrition that are common to all developing countries, are also the major causes of disability in Pakistan. In addition, consanguinity and absence of health facilities, particularly immunisation, and road accidents are reported as common causes. Physical disabilities due to polio and cerebral palsy constitute the majority of disabilities followed by learning difficulties.

### **R e h a b i l i t a t i o n s e r v i c e s**

At the federal and provincial levels, the government is a large service provider from 1981 onwards, through the social welfare and education departments. About 200 NGOs in the country are also very active in rehabilitation, providing direct assistance to individual disabled persons. Some international donors such as AFD, Actionaid, CBM, Leonard Cheshire, SCF-UK, OXFAM, Redda Barnen, and TVO support disability programmes. ILO, UNICEF and the Netherlands embassy are other international organisations that are actively supporting disability in Pakistan. Traditional practices include going to religious leaders and other local healers for help, in case of disability. These contacts substitute in many cases the formal rehabilitation services that are often inadequate, especially in rural areas.

The government has a country-wide immunisation programme in place, with centres for 'Expanded Programme of Immunisation' (EPI) in every hospital for women and children, distribution of polio drops and iodised salt, and mobile EPI services for remote areas. NGOs create awareness about existing facilities and collaborate with the Government in EPI programmes. However, coverage of prevention programmes is still restricted and does not reach many rural areas. Both government and NGOs provide medical rehabilitation interventions with NGOs being more active. Government has earmarked a few hospitals in each province to provide medical rehabilitation services for disabled persons, but their coverage is poor.

Government and NGOs promote special education centres with qualified staff. But services are of poor quality. A few NGOs are also promoting integrated education in a very small way. Existing facilities cater to only about 1-2% of those who need education. Government and NGOs are also involved in vocational training and placement of disabled persons. However, this activity is very limited and not market oriented, leading to poor results in most instances. Production facilities for assistive devices are few and limited to wheelchairs and mobility aids. Most of the assistive devices are imported and beyond reach of poor people.

### **C o m m u n i t y b a s e d r e h a b i l i t a t i o n**

Government and NGOs support centre-based activities in rural areas for special education and vocational training. Some NGOs are also involved in CBR. However, the coverage is limited and there are many rural areas that have no access to rehabilitation services. Some teacher training facilities are established by government and by some NGOs for special education. However, they train only small numbers of personnel that are not sufficient to meet the needs those who require interventions. Training facilities for other rehabilitation personnel are limited. Government and NGOs are also involved in awareness building and

information dissemination. Publications in this field are limited to a few newsletters and magazines. There is hardly any research that goes on in disability in Pakistan.

### **L e g i s l a t i o n**

The Government passed an ordinance in 1981 for rehabilitation and employment of disabled persons. There is also a national plan of action that includes programmes for disabled persons. However, it is not adequately implemented. Access provisions for disabled people are grossly inadequate.

### **S e l f - h e l p   g r o u p s**

Of late, a few associations of disabled persons have been formed in Pakistan, but they are very few in number. In general, disabled persons have been recipients of welfare services and have not been active in organising themselves.

### **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

The government provides some special education and vocational training for disabled women and also provides legal aid services, particularly for those in jail. The national plan of action contains a chapter on women's rights. NGO services are limited to providing loans to start businesses for women, and training women workers. Some government departments provide services for people disabled due to violence and conflict. NGOs with other development activities also provide support to this group.

### **SRI LANKA**

The situation in Sri Lanka is considered in the context of it having achieved the highest standard of living in South Asia, according to the 1999 Human Development Index Report by the UNDP. Adult life expectancy in Sri Lanka is 72 years and literacy rate is 90%. Yet 18% of people experience 'deprivation in the dimension of human poverty'. Sri Lanka spends about 5% of its gross domestic product for the war effort. War in northern parts of the country has also given it the distinction of having the highest suicide rate in the world.

### **P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y**

Sample surveys by the Government in 18 out of 25 districts in the country, for the purpose of initiating CBR programmes have shown that about 6% of the country's population have some form of disabilities. Major causes of disability are related to poverty and malnutrition. Due to effective immunisation programmes, incidence of polio has declined, while disability due to accidents and armed conflict is on the rise.

### **R e h a b i l i t a t i o n   s e r v i c e s**

Government is the major service provider for disability rehabilitation. National NGOs are also active in this field. International NGOs supporting disability issues include SCF-UK, CBM, CCF, TDH, Diakonia of Sweden, IT-UK and Cheshire Homes. JICA, NORAD and USAID, are some of the bilateral agencies involved in supporting disability-related work, while UN agencies include ILO, UNDP and UNICEF. Traditionally, family members and communities care for their disabled persons. In some instances, they tend to over-protect disabled people, which make it counter-productive to their interests.

The Government's immunisation programmes have country-wide coverage and are very effective. NGOs carry out awareness programmes regarding prevention and refer clients to these programmes. Coverage of medical rehabilitation is limited to urban areas and some rural areas. However, quality of services in rehabilitation from hospitals is high. People with disabilities who reside in remote rural areas are however, unable to access these services because of transport and logistical problems. Facilities for people with spinal injuries due to accidents and conflict are few, leading to higher mortality rates in this group.

Both government and NGOs promote special and integrated education for children with disabilities. Government also conducts inclusive education with a limited coverage, as a result of inadequate teaching materials and trained teachers. Poor accessibility in schools also hampers integrated education. The government has passed a legislation to allocate 3% of public sector jobs for disabled persons. Both government and NGOs actively promote vocational training and placement of disabled persons, but these

programmes have limited acceptance because of the use of outdated trades for training. Implementation of 3% reservation in government jobs is also not to the desired level. There are schemes of financial assistance for mobility aids and hearing aids. However, production facilities for assistive devices in the country are few and are located in urban areas. To address the needs of disabled persons for recreation and sports, and to promote participation of disabled persons in competitive sports nationally and internationally, the government has established a 'National Federation of Sports for the Disabled'. Government and NGOs also sponsor cultural activities for persons with disabilities.

### **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

The Government promotes the WHO model of CBR through a national programme. Some NGOs also promote CBR with the support of international donors. However, most CBR programmes are top down and follow a medical model. Participation from disabled persons and their families is limited. A number of personnel training programmes are available in government and NGO sector for special education teachers, therapy professionals and CBR personnel. These programmes are of high quality. However, the numbers trained in each of these programmes are too few to meet the demand, particularly from rural areas. Government and NGOs are both involved in awareness programmes and they widely use print and electronic media for awareness programmes. However, information generation and dissemination are still short of requirements and do not reach rural areas. Research in rehabilitation is neglected, but Sri Lanka plans to establish an information and research unit under the National Council.

### **L e g i s l a t i o n**

The government passed legislation to protect rights of disabled persons in 1996, and its implementation process is underway. A National Council has been formed to be responsible for all matters related to disabled persons and a National Secretariat has been established to implement decisions of the Council. People with disabilities are being made aware of their rights through various awareness programmes. The current level of accessibility in the country for people with disabilities is poor. However, due to constant awareness programmes and lobbying, new buildings are being made accessible. There is also a committee under the National Council to oversee modification of existing buildings, transport and other infrastructure.

### **S e l f - h e l p   g r o u p s**

There are active associations of people with different disabilities providing education, training and information services to their members. Self-help groups form part of the National Council. These groups are also active in advocacy, influencing policies of the government, lobbying for accessibility, creating awareness about rights of disabled persons and overseeing some aspects of policy implementation of the government.

### **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

While disabled women are part of all schemes and services of the government, there are no special provisions for them. Some NGOs have been set up by women with disabilities that focus on service provision for disabled women in rural areas.

### **S e r v i c e s   f o r   p e o p l e   d i s a b l e d   a s a   r e s u l t   o f   c o n f l i c t**

Both government and NGOs have special service provisions for people disabled due to conflict, but coverage is insufficient due to lack of financial resources.

## **BHUTAN**

Bhutan is the latest entrant to the group of countries that have initiated CBR services in south Asia. Bhutan initiated its first CBR programme in 1997, after it signed the ESCAP proclamation in 1993. It started a pilot programme in Khaling Geog, Trashigang Dzongkhag in the 8th five-year plan of the country. It was extended to Mewang Geog, Thimphu district from 2000. The infrastructure used to deliver the CBR services was the Primary Health Care system in Bhutan. In the beginning, CBR was supported technically and financially by WHO. From 1999, DANIDA supported these programmes.

Bhutan has a population of about 600,000 people amongst whom 3.5% constituting 21,000 has been identified to have disabilities. However, these statistics may represent only the people who are disabled due to blindness, deafness and some form of paralysis. Lately, a more detailed survey of disabilities is being planned.

At present, Bhutan has no significant services for the disabled people except these two CBR programmes. It has not been a priority in the health plan until now. Recently the government of Bhutan, to co-ordinate different sectors involved in CBR, formed a 'National Co-ordination Committee on Disability'. Bhutan is also in the process of developing a national plan for CBR in its 9th five-year plan. In this five-year plan, Bhutan will include disability prevention and rehabilitation as an integral part of primary health care in all the 20 dzongkhags.

## **A GLOBAL VIEW OF SOUTH ASIA**

The status of disability rehabilitation in south Asia shows many similarities as well as differences between countries. These countries are poor, with very dense populations living mostly in ill developed rural areas, having medical services that are poor in quality and rehabilitation services which are still in infancy. People in these countries also have high morbidity due to communicable diseases and live shorter than their counterparts in more developed countries. They have a larger number of children because of high growth rate. Hence, childhood disabilities are more common than adult versions in these countries. Development takes place slowly because of political instability, corruption, poor gender equality and illiteracy. However, they are also quite different from each other culturally. A vast country like India follows many traditions and attitudes in different regions, according to religion or caste. Similarly, there are many differences in cultural and traditional practices in the region, due to racial or religious differences between them.

## **P r e v a l e n c e   a n d   c a u s e s   o f d i s a b i l i t y**

Most countries in this region quote ten percent as official prevalence statistics in their reports. This figure has entered the official statistics from the WHO estimate of 10%, made a few decades ago. However, a survey of literature will also show that there are some studies in almost all countries in the region, that give national statistics or at least a regional prevalence rate. Prevalence rates reported by these surveys range very widely from 1% to 20% depending on definitions used. Yet, these surveys give enough indications to suggest that at least 5% of the population in these countries will now require some form of rehabilitation.

Many people in these countries are spontaneously rehabilitated in their natural environment without any external assistance. For example, children with mild and moderate retardation are often integrated in normal schools spontaneously without anyone ever knowing that they are retarded. Many other people with disability are assigned socially acceptable roles in the community according to their abilities. Certain groups also traditionally reserve some chores in the community for people with disabilities. At the same time, disability causes great shame for the affected family. As a result, people hide their disabled family members from the eyes of the public. This behaviour artificially reduces prevalence rates. Stigma, however has been less in this region of late, due to efforts from government and NGOs. Most south Asian countries have a large population of children. This is because of high growth rates in these countries. Along with the shorter life span of people, a large population of children skews disability statistics to exaggerate childhood disabilities and to produce lower prevalence rates. People in south Asia often do not live long enough to develop disabilities of old age. Finally, disability statistics reported in most studies from south Asia accounts for only loco-motor, visual and communication disabilities and mental retardation. Hence, these rates are not comparable to western statistics that account for chronic diseases such as cardiac failure and bronchial asthma.

Among the six countries from South Asia, national level surveys have been done in India and Pakistan, while in Sri Lanka, the government has conducted a sample survey. In Nepal, the government and UNICEF are in the process of conducting a national survey. In Bangladesh and Afghanistan, local level surveys have been conducted by different agencies. While all countries quote the WHO figure of 10% as the prevalence figure, there are wide variations in the actual prevalence figures derived from different studies in these countries, probably due to differences in methodology, such as the definition of disability, and the different goals of the surveys. This has led to either over-estimation or under-estimation of disabled persons in the population.

However, for purposes of planning rehabilitation services, it is more important to have an approximate idea of how many disabled persons would require rehabilitation services rather than the absolute numbers of disabled persons. The available surveys in different countries indicate, that approximately about 5-6% of the population in these countries may require interventions to be planned for them.

Prominent causes of disability in south Asia are common to all countries in this region. They are effects of poverty, such as poor health care facilities, unsafe birth practices, malnutrition, communicable diseases and work-place accidents. Road traffic accidents are increasing in these countries. In Afghanistan and Sri Lanka, land mine and other conflict related disabilities are high. Consanguinity is a major factor influencing disability in this region, particularly in Nepal and Pakistan. Polio is another major cause for disability in this region. Over the past few years, with improved health care and immunisation efforts, polio has reduced in incidence, particularly in Sri Lanka. In the next few years, polio and leprosy related disabilities are expected to disappear with improved management of these conditions. Visual and communication disabilities constitute the largest group in Nepal, while in Bangladesh communication disabilities form the largest group. Sri Lanka reports relatively more cases of cerebral palsy and multiple disabilities.

### **R e h a b i l i t a t i o n   s e r v i c e s**

South Asian countries have a tradition of providing services to underprivileged persons through non-governmental organisations. In countries like Afghanistan, even when formal government services were absent, NGOs provided substantial services for disabled people. In Bhutan, on the other hand, government provides all rehabilitation services. In India, Sri Lanka and Pakistan most disability services are under the auspices of the government, but they have a simultaneous strong presence of NGOs. In other countries such as Nepal and Bangladesh where the involvement of government is low, NGOs have largely taken over this role. In all these countries, families and communities have traditionally taken the role of carers for disabled persons.

In most countries in this region, government is the sole player in immunisation, vitamin A and iodised salt distribution. In some countries, UN agencies also take part or initiate these efforts. Due to the absence of a formal government in Afghanistan till now, preventive measures had taken a back seat. In Sri Lanka, India, Pakistan and Bhutan well-established governmental systems are present for preventive measures. In Bangladesh and Nepal, NGOs supplement the efforts of government.

There are well-established medical rehabilitation services in all south Asian countries excepting Afghanistan, where medical services are altogether lacking and in Bhutan where rehabilitation has become a priority only recently. However, availability of medical rehabilitation services is usually restricted to urban centres, while rural people find it difficult to access them. Production of assistive devices lags behind in all countries. There are few production centres and what they produce are often inappropriate in design and of low quality. Mass production and commercialisation is still not feasible because of the low volume of demand. Though countries like India train a large number of rehabilitation personnel, they are concentrated in urban areas. Similarly, availability of special education is also restricted to urban centres in spite of all countries in the region actively promoting special education in both governmental and NGO sectors. These countries are short of sufficient numbers of special education teachers. Lack of funds and training facilities for teachers, are barriers to special education services of high quality. Traditionally, many mild and moderately disabled children are spontaneously included in the educational system. However, quality of education in general is poor and the drop-out rates are high. As a result, drop-out rates among disabled children are also high. Drop-outs affect both special education and inclusive education. South Asian countries have grappled with efforts to establish effective forms of vocational rehabilitation unsuccessfully. In densely populated societies of south Asia, obtaining a job is difficult even for normal people. Hence, different forms of reservation and quota systems for disabled people have not worked well, especially in the background of economic liberalisation. At the same time, adequate efforts are not made to develop skills of disabled people in self-employment or market oriented professions.

### **C o m m u n i t y   b a s e d   r e h a b i l i t a t i o n**

Community based rehabilitation has been a NGO initiated activity in most south Asian countries. Bhutan is an exception with only a government initiated CBR. In India, Sri Lanka, Pakistan and Nepal there are some

government initiated CBRs. Most government-sponsored programmes are top-down and have little community participation. All countries have however, made some efforts to involve people with disabilities and communities to plan and implement their programmes. Most CBRs are rural based, but coverage is uneven. In countries like Pakistan and Afghanistan, CBR practice is modified to suit the local cultural needs. In Bangladesh, India, Nepal and Bhutan, attempts are being made to integrate CBR into community development programmes. Yet, CBR in south Asia lacks sustainable low cost alternatives even now. All countries in the region have at least some facilities to train CBR personnel. But they lack standardised curriculum and quality. India has lately initiated some efforts to standardise CBR curriculum. In the last few years, a large number of newsletters that deal with disability issues have appeared in south Asian countries. Print and audio-visual media have also taken up much more space advocating disability issues recently. These initiatives have been primarily started by NGOs. However, it takes time for illiterate populations to assimilate change. Some south Asian countries have recently established national resource centres that disseminate information on rehabilitation. But, till now few countries in south Asia have carried out any research of significance in this field.

### **Legislation**

In most south Asian countries some form of decisions, orders, acts, statements or legislation related to disability issues already exist. However, they are rarely implemented adequately just as most other forms of legislation. These countries prefer to 'enforce' regulations rather than 'encourage compliance', using incentives. But they are difficult to enforce due to weaknesses of enforcing systems, as well as the different understanding of 'rights' in these countries. Most populations of south Asia interpret rights as an equitable access to resources rather than individual freedom of choice. Over and above these barriers, high density of illiterate populations, lack of knowledge about legal systems, delayed dispensation of justice, poor awareness and communication, political instability and corruption, influence access to rights. Lack of concern in removing environmental barriers for disabled people is also another difficulty in these countries. Lately, some awareness is being created about barrier free environment with the help of NGO advocacy. Until the perception in these countries changes for their populations to accept that high levels of human rights is a mandatory requirement rather than a luxurious option, the disability rights movement will be restricted to only a minority group of well educated urban disabled persons and their supporters.

### **S e l f - h e l p   g r o u p s**

Sri Lanka and India and to a certain extent Bangladesh, have groups with people who have disabilities. They have been active for many years in provision of services, awareness creation and dissemination of information. Of late, these groups play an advocacy role, lobbying for rights and influencing policies of the governments. However, their participants are limited to urban areas and to educated groups of disabled persons. In rural areas, NGOs promote organisations of disabled people and parents, at local levels. In Nepal, and to a lesser extent in Pakistan and Afghanistan, self-help groups and associations of disabled people are still new and their activities are limited to provision of services.

However, the people of these countries, fed on welfare funds till recently, resist attempts to organise themselves and to seek support for their causes. They do not easily recognise their collective bargaining power and are often insecure because of illiteracy, poverty, caste and class systems and so on. In most instances, groups are led by strong charismatic leaders and many such groups finally forfeit their original goals, to follow the leader to fulfil a hidden agenda that is far removed from their requirements.

### **S e r v i c e s   f o r   w o m e n   w i t h d i s a b i l i t i e s**

In most countries, women with disabilities form part of client groups in disability programmes, and they have no special programmes exclusively for themselves. However, in Afghanistan and Pakistan, NGOs organise separate CBR committees for women and train women workers to provide services for other disabled women. In Pakistan, the national plan of action contains a chapter on disabled women's rights, and legal aid services are provided to disabled women, particularly for those in jail. In India and Bangladesh, there are attempts to form national networks of disabled women. India has some examples of disabled women being trained as technicians, to fit mobility aids for other women with disabilities. All these are isolated examples with limited coverage of specialised services.

## CONCLUSION

Despite the socio-cultural differences in this region between countries, development in rehabilitation has followed similar lines in most of them. It has been possible because of frequent exchanges of personnel across these borders. They have now recognised that the best possible way to achieve rehabilitation in the shortest time at maximum coverage, is through CBR programmes. Transferring rehabilitation skills to families and community volunteers will improve coverage at affordable costs especially in rural areas. Yet, to promote effective programmes, attention has to be paid to appropriate planning, training and participation of disabled people and their families. About two-third of children with disabilities under the age of 15 years, live in Asia and few of them receive any rehabilitation services. Hence work in south Asia is likely to be more child focussed and education oriented. Economic rehabilitation will also have to be reoriented to suit south Asian requirements that are in line with its dense population, high competition, large informal trade sector and opportunity for self-employment. Lack of public awareness about the potential of disabled people acts as a barrier to their acceptance and participation in this region. Awareness raising activities need to be higher particularly in rural areas. Legislation to protect rights of disabled people has not been enacted in many countries. Rights groups will need to lobby for legislation. Formation of self-advocacy groups is still at an initial stage and it will have to be hastened. Research in disability and rehabilitation is a neglected area. Developments in rehabilitation, particularly in CBR, have taken place based on experiential accounts rather than scientific evidence. Research is necessary for optimal utilisation of resources. While women with disabilities are considered as a beneficiary group in all countries, there are few programmes that address the special needs of women. Disabled women are particularly handicapped in this region, in fulfilling their traditional roles in the family, such as wife, mother, home maker and so on. Strategies need to be developed to address the unique disadvantages faced by these women.

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