

**Mainstreaming Gender in  
Disability and Rehabilitation:  
A development perspective**

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## EXECUTIVE SUMMARY

There are an estimated 500 million disabled women, men, girls and boys worldwide. This constitutes roughly 7% to 15% of the world's population, of whom approximately 80% live in the developing countries of Asia, Africa and Latin America. Poverty and disability are inextricably linked. Poverty can lead to disability and disability can lead to deeper poverty. Inadequate diets, dangerous living and working conditions, reduced access to vaccination programmes and to health and maternity care, poor hygiene and ignorance about the causes of impairments, all cause disability.

It is also true that often one is disabled as a result of denial of rights and one's rights are often denied as result of one's disability. Exclusion from employment on the open labour market because of low skills due to inadequate education from unemployment makes it extremely difficult to breakout of the vicious cycle of poverty and disability. Latent discrimination is also manifest at the individual level and at the national level through health policies that fail to give sufficient funding priority to the provision of services for the disabled.

A rights-based approach with an emphasis, inter alia, on a right to opportunities for human development and to social protection for physically impaired women, men and children have been instrumental in bringing about significant shifts in attitudes and intervention strategies during the past two decades. A social model of disability also recognises that people with disabilities are not a homogenous group, and that discrimination within mainstream society is likely to be reflected in the negation of the rights of certain sections of the disabled community. Women and men's reality of disability is context specific and varies greatly according to sex, ethnicity, age, class, the environment and socio-economic status.

In the context of South Asia, strong traditional gender roles and relations serve to restrict women and men from achieving their maximum human potential. In particular, this paper argues that two key factors play a determinant role in sustaining the gender-biased experiences of disabled women and girls. First, traditional patriarchal community and households structures in many South Asian countries that reinforce traditional relations deny women opportunities for human and social development by preventing or limiting access to disability rehabilitation services. For example in Bangladesh, the cultural practice of 'purdah' restricts women's freedom to access appropriate health services.

Second, the paper argues that the provision of preventative and curative health care fails to meet the specific gender needs of physically impaired women and men. A gender blind approach to health care services within governments, NGOs and the private sector prevents the integration of gender concerns within institutional policy and planning framework. For example, staff selection practices that fail to specifically target and facilitate the recruitment, training and development of women technicians result in a high preponderance of male staff employed as rehabilitation technicians that restrict disabled women's access to appropriate rehabilitation services.

Part 1 of the paper asserts the links between disability and human rights by highlighting the relationship between disability, gender and development by examining the ways in which poverty, environmental factors and gender issues determine access to health services by physically impaired women, men and young people in South Asia. It discusses the impact of gender relations on disability and suggest that the social construct of gender roles in society greatly affects the ways in which disabled women and men are perceived by others around them, their ability or otherwise to live with the disability and their access to rehabilitation services. Within the context of good governance, the paper reviews good approaches to rehabilitation service delivery that reflect the realities of life experiences of disabled women and men. The popularity of community based programmes in South Asia is discussed as an effective operational strategy for poor under-resourced countries.

In Part 2 of the paper the case study of a community hospital in Bangladesh specialising in the provision of medical care and rehabilitation services for paralysed women, men and children is used as a basis to examine the extent to which a unique and specialised service was able to meet the gender needs of its patients. It provides a gender analysis of its hospital based medical and rehabilitation services and extends this analysis to identify the strengths and weaknesses of the institution's community based rehabilitation programmes. It uses the framework of the 'web' of institutionalisation to examine the extent to which gender issues were addressed and offers recommendations to mainstream gender concerns as part a comprehensive institutional strengthening strategy.

Overall, the paper recommends that strategies to mainstream disability within a good governance policy objective at the global and national levels is essential if the relationship between disability rights and human rights is to be honoured and respected. State level anti-discriminatory legislation to protect the fundamental rights of disabled people and regulatory frameworks to guarantee equal opportunities must form the backbone of a meaningful holistic strategy to meet the rehabilitation needs of disabled women and men. At the micro level, it is imperative that gender sensitive rehabilitation strategies are mainstreamed effectively and consistently throughout an organisation or service provider in order that disabled women and men have access to and control over resources to enable full productive and social participation.

## **1975 Declaration on the Rights of Disabled People**

- Disabled persons have the inherent right to respect for their human dignity.
- Disabled persons have the right to enjoy a decent life, as normal and full as possible.
- Disabled persons have the same civil and political rights as other human beings.
- They are entitled to the measures designated to enable them to become as self-reliant as possible.
- They have the right to medical, psychological and functional treatment, to economic and social security and to a decent level of living.
- They are entitled to have their special needs taken into consideration at all stages of economic and social planning.
- They must be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.
- They shall be able to avail themselves of qualified legal aid.
- Disabled people's organisations may be usefully consulted in all matters regarding the rights of disabled persons.
- Disabled persons, their families and communities shall be fully informed of the rights contained in this Declaration.

**( United Nations, 1975 ).**

# PART 1

## INTRODUCTION

*'In matters of health, everyone should be treated equally. Yet, people with disabilities have been discriminated against throughout history. Their participation in life and social activities has been restricted. This has to change' (Dr. Gro Harlem Brundtland, Director- General, WHO, 2000).*

The World Health Organisation (WHO) estimates that between 7% and 10% of the world's population lives with disabilities, an estimated 500 million people. The vast majority of them, about 80%, live in developing countries, where only 1% to 2% have access to the necessary rehabilitation services (WHO, December 2000).

A 1993 WHO survey of member states revealed that 95% of respondents (104 out of 191) claim to offer medical care to disabled people, with some 30% having no rehabilitation services at all. Forty-six out of ninety-five member states fail to follow WHO guidelines and do not cater for disabled people in primary health care services. The failure to include relevant training curricula for health professionals working with disabled people (such as nurses and doctors, social workers and paediatricians) was another neglected area identified by a third of the respondents.

The experience of disability varies according to culture, ethnicity, race, class, age and gender. It is argued that like gender, disability is also a social construct, that is, that women and men's experience of disability is determined by society's attitudes and perceptions of disability itself. Thus gender and disability combine to create a situation of double jeopardy where physical impairment can have a profound impact on women and men's ability to carry out traditional or non-traditional gender roles. Underlying gender inequalities between women and men in societies in the North and South have resulted in the experiences of disabled men being prioritised in research and rehabilitation service delivery. For both disabled women and men living in developing countries, where the majority of disabled men and women live, their situation is further compounded by poverty. Women are doubly disadvantaged as a result of gender relations.

Latent discrimination against people with disabilities is manifest at an individual level and at a national level through health policies that fail to give sufficient funding priority to the provision of services for the disabled. In many countries, both 1<sup>st</sup> and 3<sup>rd</sup> world, the NGO sector plays a disproportionately large and significant role in providing direct medical care and rehabilitation services to the disabled. However, many NGOs, often operating with limited funds, are unable to develop work patterns that would enable them to work more strategically toward the development of services that are not only responsive to the needs of men, women, girls and boys but also are more sustainable.

This paper argues that two key factors play a pivotal role in sustaining the gender biases encountered by disabled women seeking supportive health and rehabilitation services in South Asia. First, traditional patriarchal community and household structures within many South Asian countries which reinforce traditional gender

relations, prevents disabled women from accessing preventative and/or curative health care. Second, that provision of preventative and curative health care fails to meet the specific and unique needs of disabled women.

This paper draws attention to the fact that disability concerns are still largely viewed as an issue limited to those immediately affected i.e. the disabled and friends and relations of people with disabilities rather than a social issue concerning the whole society. In doing so, the paper suggests that a 'bi-focal' perspective is necessary if women and men with disabilities are to be empowered to participate fully in productive and social activities. That is, a rights-based approach to disability rehabilitation is essential in recognising the links between disability and human rights of physically impaired women, men, girls and boys. Within this, a parallel perspective must address the specific needs of marginalized groups because of gender, ethnicity class or age.

Part 1 of the paper is divided into three focus areas. The first section considers the links between disability, gender and development by examining the ways in which poverty, environmental factors and gender issues determine access to health services by women and men with physical impairments, with special reference to South Asia. The second section discusses the impact of gender relations on disability and suggests that the social construct of gender roles in society greatly affects the ways in which disabled women and men are perceived by others around them, their ability or otherwise to live with the disability and their access to rehabilitation services. The last section explores the rehabilitation strategies developed by institutions and the extent to which policy and practice in service delivery are sensitive to the specific needs of disabled women and men, girls and boys. In particular, this section discusses community-based rehabilitation programmes as an effective operational strategy for poor under-resourced countries.

In 1999, the author conducted a social impact assessment of a community hospital in Bangladesh specialising in the provision of medical care and rehabilitation services for paralysed men, women and children. In Part 2 of the paper, this assessment is used as a basis to assess the extent to which a unique and specialised service was able to meet the gender needs of its patients. It provides a gender analysis of its hospital based medical and rehabilitation services and extends this analysis to identify the strengths and weaknesses of the institution's community based rehabilitation programmes. It uses the framework of the 'web' of institutionalisation<sup>1</sup> to examine the extent to which gender issues were addressed corporately. In doing so the paper argues that in view of the specific gender needs of disabled women, a strategic approach to the institutionalisation of gender is essential. The case study concludes by offering recommendations to mainstream gender concerns as part a comprehensive institutional strengthening strategy.

The paper ends with a section that brings together Parts 1 and 2 by highlighting concluding remarks and lessons learnt.

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<sup>1</sup> The 'web' of institutionalisation (Levy, 1986) provides a diagnostic framework for mainstreaming gender in policy and planning.

## DISABILITY, GENDER<sup>2</sup> AND DEVELOPMENT

Definitions of the terms and concepts surrounding disability vary along a spectrum beginning with one's medical condition to including one's social status. Disability affects an individual life on both grounds: it has consequences for one's health and body, as well as on one's position within community and one's social relations.

In the introduction to the United Nations (UN) Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, a distinction is made between the terms disability and handicap.

*"The term 'disability' summarises a great number of functional limitations occurring in any population in all countries of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness<sup>3</sup>. Such impairments, conditions or illnesses may be permanent or transitory in nature. 'Handicap' is the loss or limitation of opportunities to take part in life of the community on an equal level with others. The term 'handicap' describes the encounter between the person with a disability and the environment". (United Nations, 1993/19).*

Whilst the UN definition acknowledges both aspects of disablement, the World Health Organisation's (WHO)ICIDH-2 (International Classification of Impairments, Disabilities and Handicaps) devised in 1980, takes this latter point further. For WHO, disablement is a combination of three factors: impairments, disabilities and handicaps:

- Impairments: 'losses or *abnormalities* of bodily function and structure'
- Disabilities: 'limitations of activities'
- Handicaps: 'restrictions in participation'

The disability movement adds to the above definition by emphasising disability as a loss which has an effect on function. It identifies disadvantage or restriction of activity caused by social factors which take little or no account of people who have impairments and thus impose a complex system of social restrictions on people with disabilities.

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<sup>2</sup> Gender refers to both the relations between women and men and the roles ascribed to them by society in a given socio-economic context. The social construct of gender includes a consideration of the gender division of labour and gender relations. The latter refers to the different tasks performed by women and men as well as the value attached to those tasks. This in turn affects the status of women and men within the households, the community and the wider society and its impact on their access to and control over resources such as money, land or decision-making power (Beall, J., 1993).

<sup>3</sup> A consideration of the disabling nature of mental illness is not within the remit of this paper. However, the paper acknowledges the extent to which psychiatric illnesses impose a heavy burden in terms of human suffering, stigmatisation of the mentally ill and their families is acknowledged and the direct and indirect economic costs on the 1500 million people worldwide estimated to be suffering at any time from some form of neurological or psychological disorder, including mental and behavioural disorders (WHO, 2000).

It is clear from the above definitions that disability must be defined in a human development and rights context: there should be a focus on an individual's ability to function like other individuals, to engage in productive labour and participate in social activities. It is also true that often one is disabled as a result of a denial of rights, and one's rights are often denied as a result of one's disability.

Reaching a consensus regarding the occurrence of disability, as well as agreement on exact figures is extremely difficult. Disability is not a well-defined condition and there is a distinct lack of available data. Moreover, international comparisons are made more difficult because of the use of widely varying surveys systems. However, notwithstanding these constraints, suggested figures often range between 5% and 15% of the total world population having a disability. The WHO and the UN normally refer to the figure of 10% (WHO, December 2000).

It is estimated that eighty five percent of the estimated 500 million people with disabilities live in a developing country and 98% of these have no rehabilitation opportunities. As a result of this lack of rehabilitation, the WHO believes that 297 million persons with a disability have no possibility of living a dignified life, with full participation in society and equal opportunity. The UN Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities adds that 25% of the entire population is adversely affected by the presence of disabilities (this takes into account the direct effect on families, carers and communities of persons with disabilities). Finally, it is believed that the occurrence of disability will increase with population ageing (Despouy, 1993).

### **Poverty and disability: a gender perspective**

There are many different causes of disability, such as war, malnutrition, unsanitary living conditions and environmental factors. Poverty often plays a significant role; it can either be the cause of disability or further exacerbate the experience of disability. Chambers argues that powerlessness, vulnerability, physical weakness, poverty and isolation operate as a vicious cycle to create interlocking '*clusters of disadvantage*' (1984:111). Caught within the poverty trap, the poor become weak because of insufficient food, malnutrition further depresses the immune systems making the body vulnerable to infections. Poverty and isolation prevents the ill and the infirm to get to or pay for health care, continued ill-health prevents physical labour, and lost income-earning opportunities plummets the households into further debt and sustained poverty (ibid).

In examining the impact of cultural differences on people with disabilities Whyte and Ingstad (1998) argue that sensitivity to cultural factors should not deflect attention from the different social and economic circumstances of families to provide care and rehabilitation to infirm family members. They suggest that whilst most families with disabled members provide care and support to the best of their ability, a combination of superstition, ignorance **and** limited household resources in many poorer countries may lead to neglect and abuse (ibid).

***It is in situations of dire poverty that households are subjected to neglect, and people with disabilities are particularly vulnerable (Reynolds Whyte & Ingstad, 1998:43).***

A combination of economic hardship and gender inequalities may either increase exposure to disabling environments or exacerbate the situation of disabled women and girls. Studies of poverty at the household level have disputed a common assumption that household resources are equally shared, and that unequal distribution of household resources may yet be another determinant in women's accessibility to appropriate and affordable healthcare interventions including rehabilitation care services.

***In fact, some members of households (typically men) are getting larger shares of the total, whilst others (typically girls or women) get less, so that the overall number of people in poverty, or the depth of poverty, may be underestimated (Kabeer1992, in Baden et al, 1995:4).***

Pregnant or nursing women and older women may be particularly prone to poverty and vulnerable to disabling conditions. Currently, more than half of the world's women aged 60 years and over are living in the developing world: 198 million compared with 135 million in the developed regions. The WHO argues that *'longer lives are not necessarily healthy lives'* since the likelihood of disability increases with age (WHO, 2000). Among the types of disability, mobility disability, in particular walking disability, is currently acknowledged as one of the most important quality of life and public health concerns of older women. Poverty is also linked to access to food and nutrition and health of older women and often reflects the cumulative impact of low nutrition levels. For example, years of child bearing and sacrificing her own nutrition to that of the family can leave the older woman with chronic anaemia (ibid).

Pregnancy and childbirth involves considerable additional risks for women within urban and rural contexts. Pregnant women in a poor urban environment are 100 times more likely to die during pregnancy or childbirth than their middle-class counterparts who have access to high-quality ante-natal and post-natal healthcare (Satterthwaite, 1999).

***Pregnant women are more vulnerable because the reproductive system is particularly sensitive to adverse environmental conditions. Every stage of the multi-step process of reproduction can be disrupted by external environment agents and this may lead to increased risk of abortion, birth defects foetal growth retardation and peri-natal death (WHO, 1996 cited in Satterthwaite, 1999:162).***

The economic costs and consequences of disability can be far reaching for the community as whole. For example, the economic costs of victims injured and disabled by landmines further burdens health care services in countries where emergency medical services are already stretched as a result of war and conflict. An estimated half of northern Iraq's medical resources and a quarter of Mozambique's are spent on treating landmine victims (Save the Children, 1994).

Whatever the cause, the consequences of disability are often similar: rights and opportunities are diminished. Disabled people are usually excluded from society; they are less likely to receive an education, or employment. The WHO highlights the relationship between poverty, disability and exclusion and suggests that morbidity and disability among the poor and disadvantaged groups lead to a vicious spiral of marginalisation, to their remaining in poverty and to increased ill-health. The

following section provides further discussion of the relationship between poverty and disability in terms of cause and effect from a gender perspective.

### **Environmental hazards in the home and at work**

It is estimated that approximately two-fifths of the population of Africa, Asia and Latin America live in urban areas with around one-sixth living in cities of one million or more inhabitants (UNCHS 1996, cited in Satterthwaite, 1999). The urbanisation of societies is an increasing phenomenon in most countries as is the increasing size of the urban poor. Bangladesh provides a stark example: despite an overall reduction in population growth, the urban population has grown unrelentingly with almost half the country's entire population living in its 4 major cities, with Dhaka having an estimated half of the total population –9 to10 million (Oxfam, 1995).

Satterthwaite (1999) argues that within an urban context almost all environmental problems are located within social, economic or political factors.

***...it is social, economic or political factors which strongly influence who is most at risk and who cannot obtain the needed treatment and support when illness or injury occurs (Satterthwaite, 1999:15).***

Three key factors contribute to the incidence of increased illnesses and diseases within an urban environment. First, by concentrating people, cities increase the possibilities for transmitting infectious diseases. Second, the emergence of new, more resistant strains of infectious diseases and the resurgence of other infectious diseases makes achieving and sustaining a healthy population more difficult (WHO, 1998). Third, increased urbanisation also impacts on the city's air quality: many countries are failing to meet the WHO guidelines or national air quality standards with the result that more than 1.5 billion urban dwellers are exposed to levels of ambient air pollution which are well above the recommended maximum levels. (WHO, June 1996).

More than a third of the urban population in Africa, Asia and Latin America live in housing of such poor quality with inadequate provision of water, sanitation, drainage, garbage collection and health care that their lives and their health are constantly under threat (Satterthwaite, 1999). Children in such circumstances face particular risks: it is common for one child in three to die before the age of five and for infants, children and adults who survive to have disease burdens many times higher. For example, the incidence of tuberculosis and acute respiratory infections are generally higher because of overcrowding. Many accidental injuries happen where there are three or more persons living in each small room in shelters made of inflammable materials where protection from open fires or stoves is reduced, especially for children (ibid).

Street children are exposed to specific health hazards during their work that lead to illnesses, accidents or injuries. For example, traffic accidents, especially for those selling goods to passing motorists on roads or highways, children for whom the street is their home, often sleeping in the open or in public places. Street children are also more vulnerable to exploitation and physical or sexual abuse.

***Children are more susceptible than adults to accidents, injury and industrial disease. Small, weak and inexperienced workers are more at risk from dangerous machinery and materials, heavy weights and the heat of industrial processes; and more prone to chemical poisoning and respiratory complaints caused by the many air-borne hazards (Lee-Wright, 1990 in Satterthwaite, 1999:160).***

In Bangladesh many women are employed in the informal sector within the garments industry, often in hazardous and life-threatening conditions.<sup>4</sup> Increasingly, the work done by poor women enables them to support their families to survive, and the poorer the family, the more it depends on the economic production of women. Since most women cannot secure employment in the formal sector, responsibility for their families forces women to accept almost any kind of work for cash – street traders, sweatshops, domestic servants, on building sites, as road sweepers or sex workers, and many other low-paid high risk occupations in the informal sector. High poverty levels among women headed households force them to resort to dangerous income-earning opportunities that operate within 'coercive structures' (Satterthwaite, 2000).

Table 1 shows gender-specific, work-related risks faced by women.

**Table 1: Work related health risks for women**

<b>Health problems</b>	<b>Gender specific/related cause</b>
Burns	Female responsibility for meal preparation on open stoves or fires
Sore and painful, legs, hips, shoulders/fatigue	Carrying heavy loads e.g. water and fuel wood
Prolapsed uterus, miscarriage, stillbirth	Carrying heavy loads e.g. water and fuel wood
Smoke pollution: cough dyspnea, respiratory abnormalities, detrimental effects on foetal, growth	Cooking in poorly ventilated structures using biomass fuel sources
Chronic back pain and leg problem	Work in small farms subsistence agriculture: weeding, transplanting, threshing, post-harvest processing
Exposure to toxic pesticides (with effects on unborn and breastfed infants)	Cash crop production: prolonged exposure through hand labour e.g. weeding, picking, sorting, in sprayed fields without protective clothing
Various hazards to health and safety and exposure to carcinogens, acids, solvents, gases	Assembly line production: long shifts, fast paced and intensive monotonous, repetitive work
Byssinosis ('brown lung')	Working in clothing industry
Eye problems, eye-sight deterioration	Electronic assembly line work

Source: Paolisso and Leslie, 1995 cited in Oxaal et al, 1998

Poverty and inappropriate and/or ineffective health services make women more vulnerable than men in the urban environment. A combination of low-nutrition, poverty and gender inequality has knock-on effects on women's health (Oxaal, et al,

<sup>4</sup> On 26.11.00 the news media reported a fire in a garment factory in Dhaka in which 37 women workers died and another 200 were injured, The women could not escape because the factory doors were locked.

1998). This is a particular problem for women living in severely crowded conditions within an urban environment. Poverty denies women access to necessary health care and poor nutrition makes women more susceptible to water related, airborne or food borne diseases associated with poor quality housing. For example, in Dhaka, squatter settlements are developed on land that is topographically unsuitable for housing in that they tend to be near low-lying areas near or next to ditches, lakes railway tracks, sewage canals and embankments. Such areas are more likely to be adversely affected by monsoon and flooding (UNDP-World Bank et al, 1999).

## **Violence and injury**

Injuries<sup>5</sup> have become a major worldwide public health concern. It is estimated that 16,000 deaths occur daily as a result of injuries. Moreover, for every person that dies, several thousands more are injured, many of them sustaining permanent disabling injuries (WHO, 1999). Although, injuries occur in all countries and in all regions, the magnitude of the problems will vary significantly according to age, sex, region, and socio-economic status. For example in the Western Pacific the main injury-related causes of death are road traffic injuries, drowning and suicide, while in Africa they are war, interpersonal violence and traffic injuries (ibid). In high-income countries of the Americas, traffic injuries figure prominently as a leading cause of injury or death, while in the low and middle-income countries of the Americas it is interpersonal violence.

Gender patterns may exist in the incidence of deaths or injuries as a result of homicidal acts in different regional or country contexts. Problems of crime and violence have become increasingly serious in most cities in the North and the South. According to Satterthwaite (1999) more than half the world's population living in cities with 100,000 or more inhabitants are victims of a crime of some kind at least once every five years (UNICRI, 1995 cited in ibid). Crime rates are particularly high in Africa, and North and South America (ibid). While men make up the majority of deaths as a result of homicide, in other countries gender-based violence such as burning, poisoning or drowning may include more women than men (WHO, 1999).

***...violence is among the biggest health threats in the United States. Interpersonal violence has invaded homes, schools, and streets everywhere, reaching what public health experts now conclude is epidemic proportions (UNCHS (Habitat), 1996 cited in Satterthwaite, 1999:168).***

Violence against women contributes directly and indirectly to the incidence of disability among women. Exploitation, physical violence or rape against women or young girls employed as domestic staff may go unchecked behind close doors, particularly within an urban city context, and may leave women with a permanent physical or mental impairment. Gender-based violence such as 'acid-throwing' in Bangladesh may lead to permanent disfigurement with totally life debilitating consequences (Wesson, 1999). Socio-cultural practices related to gender, such as female genital mutilation (FGM), can also have a considerable impact on the physical and psychological well being of women and girls. FGM carried out by inexperienced

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<sup>5</sup> The WHO classifies injuries as either intentional or unintentional. The former includes homicides, suicide and war, while the latter includes most traffic accidents, fire-related injuries, falls, drowning and poisonings (WHO, 1999).

persons, or under unhygienic or medically unsafe conditions incurs significant risks that may be potentially life threatening or disabling (Oxaal, 1998).

Certain cultural practices may directly lead to disabilities. Both intermarriage and FGM entail an element risk in terms of physical or genetic disability (Oxaal, 1998). Whilst such practices are largely restricted to developing country contexts, it has been found that, in some immigrant receiving countries in the West, both practices have been transposed to the new country of settlement. For example, in the UK the practice of intermarriage between first cousins in the Pakistani Muslim community and the practice of FGM among settled immigrant Somali communities and their implications for health policy intervention have been well known for decades. However, a number of statutory services (medical, teachers, social work and psychiatric services) have, until very recently, been slow in responding effectively for fear of allegations of cultural insensitivity (author's observations).

Wars and other armed conflict situation may make women and men more vulnerable to situations leading to disablement. During wars or civil unrest women and girls may face systematic rape or other war crimes, such as those committed in Rwanda or Bosnia. In post-conflict situations, peacekeeping forces may put local women and girls at increased risk as they barter or sell sex for survival (UNDAW, 2000).

Whilst factors such as widowhood in Asia and civil unrest and internal migration for work in Africa has meant that women often have to bear the brunt of responsibility for supporting families, such situations may also entail particular risks for men. For example, men engaged in military activity or in armed conflict are exposed to potentially disabling occupations through combat and/or through exposure to landmines. Every week more than 150 people are killed by land mines in over 60 countries across the world, with an estimated 250,00 landmine-disabled people living in the world today (Warchild, 2001).

Children are particularly vulnerable to injury or disablement from landmines by virtue of their behaviour, curiosity and the jobs they perform. Grazing and herding livestock can take unaware children into minefields. Young girls are at risk when they collect water. Children are also driven, through economic necessity, to scavenging among wreckage of war bits of scrap metal they can sell. Cambodia has an estimated seven million land mines, reputed to kill or injure some 300 people a month. The country has more than 35,000 amputees, one in every 230 people - the highest disablement percentage in the world (Save the Children, 1994).

***'Chyeng was fetching the cow from our field when he stepped on a mine' explained his father, Nyeng, in hospital with him. 'We did not know that there was any danger there. I ran into the field to rescue him, but then I stepped on a second mine and lost my leg. I am widower and with eight other children. I am very fearful for all my children as I have no money and now I cannot work the land' (Save the Children Website, July 2001).***

For children who survive mine accidents, the physical injuries are usually far greater, the emotional trauma much deeper, and the economic prospects notably bleaker than for adult victims. The majority of child mine victims have few prospects of attending school, of receiving counselling, of learning skills which could help them adapt to their new conditions or of marriage in later life. Accessing healthcare for poorer mine victims living in isolated rural areas may be more difficult and costly resulting in long-term poverty through loss of livelihood. For example, surviving victims may need limbs amputated and specialist prosthetic treatment, together with

support to overcome the psychological trauma. Where such specialist treatment is available, the cost of it will add significant strain on the country's health budget. The impact of laying landmines goes beyond the physical injury or death occurred by individuals. It affects nations' economies, destabilises communities and endangers people's livelihoods (ibid).

### **Disability and equal opportunities**

Disabled people face numerous barriers in realising equal opportunities. These include environmental barriers that make access to buildings difficult, legal and institutional barriers that deny fundamental human rights, and, perhaps the most difficult to overcome, attitudinal barriers which lead to exclusion from participation in social and community activities. The UN Special Rapportuer identified the following areas where disabled women and men experience distinct disadvantages (1993):

Education	Lack of access, prejudice and in many cases no admission
Employment	Lack of access, prejudice (from both employers and fellow workers)
Transport	Lack of access which presents an important obstacle to an independent life
Housing	Lack of access
Buildings/Environment	Lack of access and prejudice (access to public places may be limited)
Cultural Barriers	Traditional attitudes that may expose some disabled people (and/or their families) to feelings of shame, superstitious fear and rejection. These barriers are usually the main obstacles to the integration and full participation of disabled persons in all aspects of life.

The economic cost of excluding an estimated 500 million disabled people from taking an active part in the communities is high and has to be borne by society. Excluding disabled people implies a loss in productivity through reduced collective human potential.

As discussed earlier, disabled women can be doubly disadvantaged through exclusion from productive activity because of disability as well as traditional expectation of gender roles. Women commonly form the great majority of carers of disabled children, and caring for severely disabled children further increases the workload of women living in extreme poverty and takes away valuable time from income earning opportunities. Women with disabilities generally have less access to medical or rehabilitation services than men because of cultural restrictions such as 'purdah' practiced in many communities in South Asia. The exclusion of disabled women and men because of attitudes and perceptions of their gender roles is discussed in detail in the following section.

## **IMPACT OF DISABILITY ON GENDER RELATIONS**

Disability or incapacity has a profound impact on women and men's ability to carry out their ascribed gender roles. Until relatively recently disability research and debate has tended to focus almost exclusively on the experience of disabled men. However, this situation is slowly changing with both disabled women's and men's experiences being explored and represented (Morris, 1997). In the West, there is a growing movement of disabled women and carers asserting their needs and interests, whilst in developing countries, particularly in South Asia, there is an increasing recognition of the particular needs of disabled women by NGOs working in disability issues. This section focuses on the gender roles and gender-related needs of disabled women and men. Much of the data cited in this section has been collected and collated by Northern countries and it is possible that in the interpretation and translation of different cultural perceptions the reality of the life experiences of disabled women and men living in Southern countries may not have been fully or accurately reflected.

Like gender, disability can also be viewed as a social construct in that society's perceptions of and attitudes to disability will influence women and men's experience of disability. Although the nature of the physical disability will greatly determine its impact on his or her life chances, it is society's response to the disability that will determine the consequences of his or her experience as a woman or man. Just as poverty may affect the incidence of **exposure** to hazardous employment environments for poor women and men, the **experience** of physical disability will also differ according to poverty, gender, age, ethnicity, class or geographical location (ibid).

***'I have horrible scars on my face. What I mean by that is that people react to them with horror. Forty-years ago, when I was in my twenties, and also when I was a child, I so hated the way that I looked. I tried not to think about it but every time I went out in the street I would be reminded about how I looked because of the way people reacted to me. As I walked down the street and someone was coming towards me, they would look and then drop their eyes or move their head, as if the horror was too much. But they could never, ever resist looking again' (Morris, 1997: 104).***

Morris argues that it is the '*individualisation of disability*' (ibid: 86) that equates incapacity with personal tragedy, and that it is the apparent connection with individual psychological problems that prevents a more focused examination of the experience of disability within a social context. A study of society's interpretation and perception of what is appropriate behaviour for women (and men) is, it is argued, likely to be more revealing than a study of the disabled individual (ibid).

The relationship between masculinity and disability provides an insight into the way that mainstream society defines physical incapacity. For men, disability often means that they are unable to fulfil society's expectation of masculinity in terms of strength, physical ability, status and authority. Disability may affect their ability to meet their gender expectation as the head of household or see to more 'masculine' type of household tasks traditionally ascribed to male gender roles e.g. mowing the lawn in Western societies or shopping in many conservative societies in South Asia. For example, the American president Franklin D. Roosevelt was paralysed from the waist down and in a wheelchair, and yet this was hidden from the American and international public and he was never seen in a wheelchair, lest it detract from his perceived leadership qualities (Gallagher, 1985 cited in Morris, 1997).

The relationship between femininity and disability is arguably more complex than between masculinity and disability: an essential aspect of being a woman in any society involves an element of passivity and dependency. And yet, these constitute a common social experience for disabled women. Women, therefore, receive conflicting messages about their traditional reproductive role as homemakers, mothers, wives and partners: they are unable to fulfil these roles but neither do they conform to society's expectations of femininity and beauty.

## **Women and disability in South Asia**

According to UNDP women with disabilities in developing countries are twice as prone to divorce, separation and violence as able-bodied women because of perceptions of dependency, an inability to contribute to household chores or to the household economy (1995). The situation for disabled women and men in many developing countries in South Asia can be particularly restrictive because of strong traditional gender roles: disability may exacerbate women's traditional position of subordination and powerlessness in many socio-cultural contexts. It may become more difficult for women to assert their needs within their domestic situations as well as in the context of medical and/or rehabilitation care professionals.

In cultures where childbearing is synonymous with womanhood, ignorance about the physical capabilities of disabled women and men to bear children or to have healthy children may adversely affect their life chances to marry and have children. In cultures where children are a socio-economic necessity, particularly within a rural farming environment, and where status is accrued from having boy-children, the impact of such exclusion can be profound. Additionally, misconceptions that perceive the disability to be 'contagious' or 'inherited' may serve to further exclude disabled women further from participating in community or social activities.

In many South Asian countries, the subordinate status of women is reflected, for example, by practices such as infanticide or differential allocation of foods that demonstrate a preference for male children (Saith et al, 1999). Given this biased cultural setting, and given limited resources at the national, community and household level in a developing country, the education and rehabilitation of a girl child (or adolescent girls or women) is often considered to be a poor investment. In many developing cultures, including those in the SA region, there is a common belief that having a child with a disability, particularly a girl child, is the result of a curse or an act of retribution from god.

***In Botswana, severe mental retardation is sometimes perceived as being caused by the breaking of sexual taboos by the parents during pregnancy. Families are often stigmatised for moral laxity (Reynolds Whyte & Ingstad, 1998:43).***

In cultures where arranged marriages are the norm, families may find it difficult to find a suitable partner for a disabled woman and may succumb to financial pressures to marry at any cost. Families of prospective disabled brides may also incur higher dowries because of their disabled status (Oxfam, 1995; UNDP, 1997, Baden et al, 1994, author's observations). Additionally, physical impairment may result in greater physical and economic dependency on family and friends and/or make them more vulnerable to physical or sexual abuse by non-disabled individuals. Conflicting

emotions of 'shame' and protectiveness on the part of families and friends lead many disabled women to live in almost total isolation and anonymity.

### **Disabled women and social exclusion**

Such mixed emotions impact negatively on the disabled woman by further restricting her ability to participate in community life activities, and where behind closed doors, the potential for physical and emotional abuse may be high. For instance, a survey conducted in India revealed that disabled women are subject to discrimination three times as much as others because of their gender, their disability and the deprived conditions in which they are forced to live. They are also more likely to live segregated lives with little opportunity for social interactions or participation in mainstream community activities (CBR Frontline Digest, 1995).

Women's participation within health programmes has been demonstrated to bring direct tangible benefit (Oxaal, 1998). Well-designed participative initiatives have been shown to be valuable in helping to identify the reality of women's and men's experiences and to highlight the ways in which poverty and gender interact in relation to access to health services. However, traditional perceptions of women's roles, over-protectiveness, a family's sense of shame or negative attitudes to disability generally may all be inhibiting factors towards the participation of disabled women in community level activities that promote their interests and needs.

Unequal gender relations combined with the absence of availability of suitable and affordable formalised care in many societies result in women having to shoulder a disproportionate share of caring responsibility for disabled family members. Traditional perceptions of gender roles enable men to have greater access to formal support services than women for whom a caring role is viewed as being consistent with their reproductive role as mothers and wives. The role of principle provider of informal care, isolation and overwork has a negative impact on the economic, social and emotional lives of all carers, but this situation may be further exacerbated because of poverty and gender concerns. Moreover, mothers as carers of disabled children are often ostracised by their communities for having a disabled child, and considered to be responsible for the disability suffered by their child.

***Difficulties associated with rearing a disabled child should not be secluded within the family circle. Rather they should be shared with others; not only with those in the same situation but also with those who are unaware (Selli-Serna, 1991, cited in Mcglade and Aquino, 1995:187).***

Walmsley argues that women's second class citizenship is reinforced by disability since the burden of caring for disabled or infirm family members further prevents women from participating as full citizens in that a caring role often confines women to the private world of the family and thus restricts participation in the community because of opportunity constraints, i.e. lack of time, information, transport (Walmsley, 1997).

Different cultural contexts will have a differing impact on those involved in the provision of home and community care. In the West, where the availability of formal care is greater, people may choose to be cared for at home or in the community and be supported to do so. However, within many developing countries inadequate government health service provision has shifted the responsibility on to individual

families that leave families with no alternative to home based care. Although, care at home is often a preferable option, it can nevertheless divert attention from income earning opportunities and add a substantial financial burden on already meagre financial resources.

The exclusion of disabled women and men from participation within local community or political decision-making processes runs the risk of rehabilitative services that are inappropriate and/or inaccessible, and therefore fail to reflect their practical and strategic needs. The exclusion of disabled women and men from community level politics will further limit their potential to influence long-term strategic change within the disability rights and advocacy movement.

## **DISABILITY, GENDER AND GOOD GOVERNANCE: Good practice in rehabilitation strategies**

The provision of rehabilitation services for people with disabilities has traditionally been perceived as the sole responsibility of the health sector (see Appendix 1 for a brief history of the development of the health sector). However, recent shifts in rights based approaches has resulted in the movement of an holistic approach to meeting the rehabilitation needs of people with disabilities. This section explores the role of good governance in the implementation of rehabilitation strategies within an equal opportunities framework.

## **From exclusion to inclusion**

Traditional categorisation as 'special' or 'different' has marginalized the needs of disabled people. A medical approach that perceives disability as an individual health 'problem' has emphasised changing the individual to mould her or him to society's demands rather than promoting social change through empowerment. Thus a medical approach has tended to focus on identifying specialised solutions that emphasise difference rather than promote integration (Coleridge, 1993).

However, two significant developments during the last two decades have shifted the debate surrounding responses to people with disabilities. First, a dramatic change in attitude has occurred during this period that identifies disability as a social construct and advocates a social model of disability as opposed to a medical one. Coleridge argues that the introduction of the concept of 'barrier removal' i.e. the task of communities and rehabilitation services to remove the barriers that disabled women, men and children face as a result of their impairment has provided a progressive perception of disability rehabilitation (1995).

***Thus the role of the physio or occupational therapist is not to make a paralysed person walk, but to enable them to become mobile. This may include providing mobility devices; it will also certainly include lobbying to get ramps installed in public buildings (Coleridge, 1995:20).***

Second, an increasing emphasis on a rights-based approach to development has led to a recognition that disabled people have a right to health, to a livelihood and opportunities for human development, to social protection, and the right of some groups to extra attention to ensure that they get the same rights as everyone else, including disabled people. This movement has been further strengthened by the connection between disability and Human Rights afforded by several international legal frameworks including those proposed by the International Labour Organisation, UN, CEDAW and the Beijing Platform for Action (1995) to name a few (Coleridge, 1993).

A rights based approach argues that if all individuals are rights-holding citizens, then the right to participate and to equality of care are all part of this approach. In working towards an inclusive society, the disability policy objective should be to enhance the dignity, well being and empowerment of disabled women and men, by enabling them to achieve the essentials of life, equality and participation, independence and self-determination. This may be achieved through ensuring that basic rights are recognised, through prevention and rehabilitation, universal access and support services.

Equally importantly the special and specific needs of disabled women and girls must occupy a central position within a rights-based approach. The targeting of disabled

women and of women as carers must include a policy objective on women's *well-being* through a recognition of their *entitlement* to live as full a life as possible, politically, economically and socially (Sen, 1999).

## **Community Based Rehabilitation: opportunities and constraints**

Community based rehabilitation (CBR) is often claimed to be the best approach to inclusion and social integration. Most CBR programmes aim to prevent, rehabilitate, integrate and provide services through the community in general and disabled people in particular. Community learning and consciousness raising are integral activities of the CBR model. Citing the widely accepted fact that the rehabilitation needs of 80% of disabled people can be met at the community level, supporters of CBR argue that independent, supported living in the community is more cost-effective and better for the health of disabled people (CBR Network, South Asian Region, 1993).

A CBR strategy is popular in many developing countries. In for many working in the disability movement in South Asia, CBR is not a matter of choice but a necessity. In countries with poorly resourced health service provisions, CBR enables a wider geographical impact by placing rehabilitation within the community, with people becoming the most important resource (ibid). Increased people participation within disability focussed development strategies can harness local expertise by working with communities to unlock existing community interests, to adapt and sensitively apply external technical and medical expertise. CBR has, therefore, the potential to release and validate existing indigenous knowledge and information systems whilst facilitating access to relevant information and ideas from outside the community.

***CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health education, vocational and social services (CBR Network, South Asia Region, 1995:42).***

As previously discussed, many of the unique disadvantages that disabled men and women face are often anchored in traditional social and cultural perceptions and belief systems. Working at the household and community level the CBR approach, in principle, lends itself to working towards limiting restrictive and complex cultural, economic and social factors that impact on traditional gender relations. Although gender issues have until recently been marginalized within CBR programmes in South Asia, NGOs have begun to identify the linkages between the generally subordinate position of women in the region and their access to medical and rehabilitation services (Mobility India, 2001, McGlade and Aquino, 1995, CBR Frontline Digest).

Although the CBR model draws strong support from a broad spectrum of those involved in disability advocacy, many disability rights activists have identified several limiting factors in the design and implementation of CBR programmes:

- The difficulties of recruiting and retaining committed and experienced CBR workers is widely acknowledged, as is the 'exploitation' of CBR workers who are underpaid or sometimes not paid at all (McGlade and Aquino, 1995). Obvious dangers exist where CBR programmes attempt to deal with a recruitment and retention problem by prioritising the employment of women carers as CBR workers. In such instances, CBR programmes run the risk of perpetuating

women's traditional role of women as carers without appropriate remuneration or engaging in awareness raising work with male family members (McGlade and Aquino, 1995).

***By receiving little or no salary, is CBR guilty of giving women and disabled people yet another raw deal? These issues are integral to the CBR value system and hence, its long terms sustainability (McGlade and Aquino, 1995:187).***

- Although CBR is considered to be a valuable improvement to traditional, and inadequate health services for people with disabilities, it is important to recognise that CBR programmes, by their very nature, tend to operate on a small geographical scale, and may not address macro level problems.
- The disability movement of many developing countries have commented on the decentralised nature of CBR activities and expressed concern that negative institutional practices and attitudes have, in some cases, been relocated at the community level where supervision and monitoring is more difficult. Additionally, NGOs have cited local community power dynamics as being an inhibiting factor on the successful implementation of CBR projects (CBR Frontline Digest, April, 1993).
- Improved educational and employment opportunities will have a natural 'knock-on' effect on increasing awareness of the impact of gender relations on women's and men's experience of disability. Public education and awareness raising efforts must challenge negative perceptions and attitudes to disabled women and men by identifying positive role models that explode narrow conservative myths and misconceptions about the capabilities of people with disabilities. In particular, gender-sensitive CBR programmes need to address the following (Coleridge, 1993, 1995, CBR Frontline Digest 1999, 1995, 1993, McGlade and Aquino, 1995):
  - Promote training of young disabled women through home based training or through peer support groups to develop functional skills, provide technical aids and adaptation to the home and surrounding environment such as low-level trolleys to facilitate completion of household tasks and support greater social participation;
  - The fitment of orthotics or prosthetics by men has been identified as a particular problem for disabled women from cultures where contact between the sexes is severely restricted. Increasing the cadre of women CBR workers or community development workers will have a significant impact on improving access to fitment services for disabled women.
  - Increased education and employment opportunities for disabled women will reduce dependency on family, boost self-confidence and improve marriage prospects.
  - The promotion of self-help groups for disabled women and men will help reduce isolation, provide mutual support and improve participation in social and community life. Peer support provides greater potential to reduce exploitation or abusive family environments by raising awareness of rights and opportunities;
  - CBR activities also need to work with partner organisations working in disability issues to increase awareness of gender issues as a key aspect of disability rights and advocacy.

***The success of CBR efforts will remain contingent on maximum integration with other community development efforts. (CBR Frontline Digest, 1995)***

Despite the suitability and popularity of CBR programmes in developing countries, many NGOs are voicing an air of caution against the dangers of viewing CBR as the single panacea to meet all the needs of disabled women and men. Implementers of CBR programmes in SA warn that CBR programmes alone will be insufficient to address the holistic needs of women and men with disabilities, and emphasise that the integration of CBR within a wider social and community development programme is essential (CBR Frontline Digest, 1995, Coleridge, 1995, McGlade and Aquino, 1995).

## **Mainstreaming disability and gender**

The close relationship between disability and human rights recognises the extensive and severe violations of the human rights of persons with disabilities (Despouy, 1993). State level anti-discriminatory legislation to protect the fundamental rights of disabled people and regulatory frameworks to guarantee equal opportunities must form the backbone of a meaningful holistic strategy to meet the rehabilitation needs of disabled women and men.

If it is accepted that the objective of good governance is a valid and desirable objective in itself then it follows that disability rights must be fully integrated or mainstreamed within the state's legislative and regulatory frameworks as part of a strategy of good governance<sup>6</sup>. In arguing for gender rights within the development paradigm, O'Connell (1996) argues that the assimilation of a respect for human rights as a policy objective of good governance, as incorporated, for example, by the UK government and the European Union, must involve the application of institutional legislative and regulatory framework that respect and honour the rights of those who are excluded and/or marginalized. O'Connell also suggests that nations wishing to strengthen and improve governance could be 'supported' (author's emphasis) to do so as a necessary condition of effective use of aid.

***...a good government is surely one which protects the most marginalized, which manages the country's resources in such ways as to ensure all citizens have access to the means of livelihood and basic services...(O'Connell, 1996:109)***

Disability and poverty and, as a result, exclusion from participation in productive and social activities is an issue of good governance since the capacity of disabled women and men to perform as political actors is severely limited by their daily struggle to survive. Good governance is essential if the human rights of marginalized women and men, including those who are disabled, in Southern countries are to be protected (ibid). However, the use of aid as a means to demand change will not necessarily guarantee accountability to respect or promote the rights of disabled women and men equitably. A good government will need also to ensure that

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<sup>6</sup> The UK governments attempt to clarify the practical implications of an agenda for good governance includes inter alia, a respect for human rights and the rule of law guaranteeing individual and group rights and security, to provide framework for economic and social activity and to allow and encourage all individuals to participate (ODA, 1993 cited in O'Connell, 1996).

strategies that promote women's agency are mainstreamed at all levels of social and economic development (Sen, 1999).

***...encouraging Southern governments to become more accountable.... Does not necessarily ensure they are better at respecting and promoting women's rights (O'Connell, 1996:107)***

A strategy of mainstreaming disability rights will help to strengthen the impact of the role that civil society plays within the disability movement. NGOs in South Asia have a history of playing a vital leading advocacy role on behalf of the poor, marginalized and excluded, and their work with disabled women, men, girls and boys is not insignificant. In some cases they provide national and regional leadership in promoting equal opportunities for disabled men and women. In the SA region the last two decades have seen the work and impact of several large disability rights NGOs expand with international donor support including an active network to promote intra-regional collaboration.

Mainstreaming has been widely adopted as a strategy for institutionalisation of gender concerns within development organisations. It involves complex technical, political and administrative processes that require major shifts in organisational cultures and ways of thinking, as well as organisational goals, structures and resource allocations of international agencies, governments and NGOs (Levy, 1996).

It is argued that strategies designed to increase gender equity must rest on a sound analysis of the gendered dynamics of decisions-making and organisational functioning (Goetz, 1995). This entails an examination of the ways in which organisational structures, and practices lead to gender discriminatory practices: structures that include rules and regulations that act as social constraints, either informally or formally, practices that are manifest in everyday behaviours and processes that support and reinforce the structures, and the individuals, whatever their sex, who bring their own ideologies and value systems that impact on the institutional structures (ibid). Levy's concept of a 'web of institutionalisation' (1996) provides a valuable diagnostic tool for mainstreaming gender perspectives within institutional policy and planning mechanisms (see Appendix 2A for the diagrammatic framework).

***Institutionalisation is 'the process whereby social practices become sufficiently regular and continuous to be described as institutions, that is social practices that are regularly and continuously repeated, are sanctioned and maintained by social norms, and have a major significance in the social structures' (Abercrombie et al, 1988 in Levy, 1996).***

## **Concluding Remarks**

It has been argued that disability must be defined in a human rights context: often one is disabled as a result of a denial of rights and one's rights are often denied as a result of one's disability. Moreover, the fact that the majority of the world's disabled population live in the developing world makes it imperative that rehabilitation strategies constitute a central part the development agenda for Northern and Southern countries. The exclusion of disabled people implies a loss of productivity in general, and of human potential. The economic impact of excluding an estimated

500 million disabled women and men from taking an active part in productive activity is potentially very high.

The relationship between poverty and disability is inextricably linked for many communities in the developing world. Malnutrition, war and conflict, exposure to hazardous environments exacerbates the vulnerability of poorer households to accidents and illnesses leading to permanently disabling conditions. Whilst, culture, ethnicity class and age is an important factor in determining the reality of disability for disabled women, men and children, gender relations also plays a significant role in women's and men's experience of disability.

It has been argued that like gender, disability is also a social construct in that society's perceptions of and attitudes to disability will influence women and men's experience of disability. However, in many developing country contexts, where women occupy a subordinate position because of entrenched traditional expectations and attitudes of gender roles, the agency of disabled women is severely undermined as disabled women, as parents and as carers of disabled family members.

The integration of disability as a development issue must, whilst being anchored in a rights-based model, adopt a holistic approach to rehabilitation strategies. A multi-disciplinary approaches involving several key sectors such as health, housing, education and anti-discriminatory legal frameworks designed to empower disabled women and men are also essential. The adoption of a gender perspective in the development of a health and disability policy and planning framework is essential if the needs of disabled women and men are to be addressed effectively.

Using a case study from Bangladesh, PART 2 of the paper provides an analysis of the efforts of a large specialist community hospital to mainstream gender concerns within its hospital-based medical and rehabilitation services including a large CBR programme. The framework provided by the 'web of institutionalisation' (ibid) is employed as a diagnostic tool to identify strengths and weaknesses of the organisational approach and, where appropriate, opportunities are identified and recommendations offered. The following key questions forms the basis of analysis (ibid, see Appendix 2B):

#### Political Sphere

- What is the corporate policy objective and to what extent is a gender-inclusive approach integrated into the organisational mission and values?
- What is the nature of political commitment in the organisation to integrate gender into medical and rehabilitation activities?
- Is there a willingness to allocate adequate resources to address gender issues at the organisational and service delivery levels?

#### Organisational Sphere

- What is the underlying policy approach to gender mainstreaming and how is it realised i.e. to what extent are programme resources allocated to gender issues in mainstream policies, programmes and projects?
- What procedures (programme and administrative) are in place to ensure that gender concerns of target groups are fully incorporated into all levels of service delivery throughout the organisation?

- Where and with whom does the responsibility for gender issues rest? To what extent are they acting in the appropriate roles and what support structures exist to enable them to carry out their responsibilities effectively and appropriately?
- How does the organisation address gender mainstreaming in its human resources management and development e.g. training and staff development, recruitment and promotion?

#### Delivery Sphere

- What is the underlying policy framework for service provision?
- Taking into account existing gender roles of the target group, what impact has the intervention had on these gender roles, either planned or unplanned? Also, what has been the impact of the intervention on women and men's access to and control over resources to carry out these roles?
- To what extent have the strategic and practical gender needs of disabled women and men and of their carers been addressed?
- In what ways are representatives from the public, private and community sectors involved in the design and delivery of services?
- To what extent are gender issues reflected in current methodologies used in the design, implementation, monitoring and evaluation of policies and programmes?
- To what extent do the relevant research initiatives and/or secondary research use methodologies and reflect knowledge on gender roles, access to and control over resources and gender needs of women and men?
- What organisational learning structures exist to support internal and external theory building on disability, gender and development issues?

#### Citizen's Sphere

- Which political constituencies are involved or could be involved in the design, implementation and evaluation of policies, programmes and projects?
- Do they represent different gender interests across class, age, ethnicity, and religion? Are these reflected in practical and strategic gender interests?
- To what extent do political structures involved in the design, implementation and evaluation represent gender interests? Who are they and what is the membership breakdown in terms of gender?
- Is there an underlying policy approach in the way in which some groups in the political structures are operating? Are issues of access to and control over resources and practical and strategic gender needs being addressed?
- Which are the groups affected by the intervention? Are issues of access to and control over resources addressed for both women and men target group? Does the intervention meet the strategic and practical gender needs of women and men?

## PART 2

# **MAINSTREAMING GENDER IN DISABILITY AND REHABILITATION IN BANGLADESH: A CASE STUDY OF THE ORGANISATION OF FOR PEOPLE WITH DISABILITIES.<sup>7</sup>**

## **Introduction**

In September 1999 the author was a member of a two-person team of independent consultants commissioned to conduct a social impact assessment of the Organisation for People with Disabilities (OPD) on behalf of a major bilateral-donor. The terms of reference required the team, inter alia, to identify opportunities and constraints to addressing quality and equity concerns throughout the work of OPD, with particular reference to gender and CBR.

The methodology included a documentation review and collection of gender disaggregated data of OPD's in-patient and outpatient services according to previously determined criteria. Information was gathered through unstructured interviews with disabled women and men and staff at the main hospital site, and during field visits to discharged clients and to CBR implementation areas.

## **Background**

Bangladesh has one of the world's highest infant mortality rates at seventy-seven per thousand live births and life expectancy is only 59 years (UNDP, 1995). Antiquated equipment, unhygienic hospitals and wards, and in some health centres, absence of even the most basic of medication such as aspirins provide a partial explanation for the sick state of the country's health service. Lack of transparency in management and little or no accountability also play a significant part in a generally poor national health care service. Despite being adequately serviced by well-qualified doctors with one doctor for every five thousand patients, there is an apparent shortage of doctors because they simply fail to turn up for work. A 1996 survey of *Thana* Health Complexes found that doctors were working as little as 15% of their designated hours (ibid).

The Ministry of Health and Welfare has concluded that only 50% of the population have access to basic health care, whilst donors and concerned healthcare professionals express wider concerns regarding the marginal role of healthcare within broader development issues (Government of Bangladesh Fifth-Five Year Plan cited in ibid).

An ineffective and inefficient health service will have a direct impact on the incidence of disabilities, provision of curative care and its ability to develop prevention strategies. It is estimated between 8%-10% of the population in Bangladesh are disabled (CBR Frontline Digest, 1996). Although services for people with disabilities are reported to have begun in the 1950's, such services have tended to be largely school or institutional based (ibid).

A combination of environmental, geographical, economical and social factors contributes to the challenge of ensuring that the rights of disabled people are met. A

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<sup>7</sup> This is not the real name of the organisation. A fictitious name has been used to afford a degree of anonymity to the organisation.

population of nearly 120 million people, of whom, it is estimated, 80% live in isolated rural areas over a geographical mass of nearly 144 square kilometres poses a daunting task for a country so poor, once famously described as a 'basket case' of the developing world (Oxfam, 1995).

A politically and administratively weak leadership has ensured that Bangladesh lags behind regionally in the disability rights and advocacy movement. Although, responsibility for leadership at the national level services for disabled people lies primarily with the ministries of health and social welfare, in practice, an ineffectual and ineffective civil administration is reflected in a confused and directionless strategy that fails to meet the needs of physically impaired women and men.

Bangladesh provides a stark example of the relationship between poverty, malnutrition and disability. Studies carried out by NGOs show that approximately 90% of disabilities are the result of nutritional disorders: physical ailments such as goitre, rickets, and blindness are commonly caused by vitamin deficiency (ibid). Spinal injuries are also widespread in Bangladesh, where many paraplegics and tetraplegics are the result of carrying heavy 'head loads' or falling from great heights whilst picking fruits or coconuts (ibid).

During the past two decades a combination of factors has worked together to bring about modest but significant improvements to services provided for those fortunate to access rehabilitation services. The injection of foreign aid during the period following the War of Liberation in 1971 and a growth of a strong and prolific NGO sector has helped to fill the vacuum left by the state's inability to provide a comprehensive national health care system including services for the disabled population. However, whilst pockets of quality professional services to people with disabilities exist in Dhaka, medical and rehabilitation services for disabled people living in isolated rural areas remains largely nonexistent (CBR Frontline Digest,1996).

The recent growth of CBR programmes in the South Asia region has given people with physical impairments in Bangladesh a valuable lifeline. It is reported that currently many of the 63 NGOs working with people with disabilities are involved in CBR activities as well as over 20 government sponsored projects (ibid). The creation of a national CBR Working Group in 1995 has helped to raise the profile of the needs of disabled people within a right/advocacy framework. It has also enabled greater co-ordination and networking between NGOs working with the physically and mentally impaired through information dissemination and training and skills development (ibid).

The situation of disabled women in Bangladesh is comparable to that of women in other South Asian countries, as discussed in the preceding section. However, high poverty levels and a strongly patriarchal family structure means that most women in Bangladesh suffer deep discrimination, which restrict their access to rehabilitation services. Gender inequality that begins from an early age as girl babies through to adolescents and adulthood means that women have access to fewer rights and fewer opportunities<sup>8</sup>.

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<sup>8</sup> Young children girls have less access to medical care: of children under five suffering from respiratory infections, for example, 37% of boys receive medical treatment compared to 29% of girls. Women are less educated: the literacy rate for men is 48%, but for women it is 35%.

At the household level and through local decision-making structures men exercise control over most areas of a woman's life: men act as mediators in almost all aspects of a woman's life and control women's access to social, economic, political and legal institutions. Although the constitution of Bangladesh affirms sex equality in principle, its legal frameworks and institutions reinforce gender subordination and dependence (Baden, 1994). Men's authority over women is strengthened by pervasive gender-based violence. Bangladesh is reported to be the only country where the practice of acid violence<sup>9</sup> is perpetrated by men against women (Wesson, 1999).

## **Mainstreaming Gender in Organisation for People with Disabilities: A Diagnosis**

The following section reviews OPD's attempts to address gender concerns within its policy and planning framework and programme delivery. The four spheres of the 'web of institutionalisation' (Levy, 1996) i.e. the political, the organisational, the citizens and the delivery spheres are employed to assess the strengths and identify the weaker elements of each component.

### **The Political Sphere**

The growing awareness of the failure of mainstream national health services to meet the special needs of people with disabilities led to the creation of OPD in 1979. Operating as a national NGO, OPD is committed to improving the quality of life of persons with disabilities and working to ensure their integration into society through provision of direct medical and rehabilitative care. It is nationally and regionally recognised as providing a unique and high quality support and rehabilitation services for paralysed people. By mid-1999 OPD had supported approximately 2,500 paralysed women, men, girls and boys to return to independent lives in their homes all over Bangladesh. OPD's long-term vision is to replicate central services in other regions of the country through training and education in partnership with governmental departments and other agencies providing support and rehabilitation services to people with disabilities.

At its headquarters, some 10 miles north of Dhaka, OPD has a 100-bed in-patient facility. Specifically, its in-patient care is directed at paraplegics and tetraplegics, injured primarily as a result of traumatic spinal injuries but also through orthopaedic surgery and infectious diseases such as TB. Post-operative medical and/or orthopaedic care includes physiotherapy and occupational therapy, vocational training, counselling and social welfare support to facilitate rehabilitation.

Since 1994 OPD has operationalised a CBR programme in 42 neighbouring districts. The programme focuses on prevention of disability, awareness raising, improving the

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In the economic arena women earn less: the daily wage rate averages 46 taka for men and 26 for women (UNDP, 1997).

<sup>9</sup> Acid violence describes an attack in which sulphuric, hydrochloric or nitric acid is used as a weapon to inflict severe burns. The impact of the attack is permanent disfigurement, often blindness and sometimes hearing loss. Acid continues to burn after the attack is over as it continues to eat into the skin and tissue, often revealing bone. In Bangladesh where 80% of the population is estimated to live in rural areas, accessing timely medical treatment is severely limited.

physical environment of people with disabilities, referral services, vocational training and rehabilitation. It is estimated that OPD's CBR programmes reaches some 2,000 people each month. OPD's other satellite services includes a vocational training and job-creation centre for disabled women, a centre for children with cerebral palsy and stroke cases and a physiotherapy and occupational therapy clinic.

As well as the above unique services, OPD fulfils an important function in the training of physiotherapists and occupational therapists and rehabilitation nursing care. OPD's purpose built Training Institute is affiliated with Dhaka University and delivers undergraduate courses in physiotherapy and occupational therapy. Their nursing courses include a number of courses leading to certificates and diplomas in rehabilitation and special needs care.

OPD has grown tremendously over the last few last years in terms of number and type of services provided, increased utilisation of services, size and complexity of the organisation, and number of collaborations. Throughout this period of rapid expansion OPD has been heavily dependent on donor funding. However, in recognition of the importance of long-term sustainability it implements a large and diverse income-generating programme through fish and poultry farming and production and sale of handicrafts. It also designs and manufactures locally produced durable wheelchairs and other mobility aids.

There is, overall, little evidence to suggest that OPD has strategically planned to address gender issues at the political and/or organisational level. A prioritisation of direct service delivery over the development of sound organisational infrastructure, however legitimate, has, unsurprisingly, imposed limitations on its ability to develop strong management and administrative institutional capacity. For example, the organisation does not have a long-term strategic plan nor a policy framework covering any aspect of its work, technical, management or administrative. A policy framework for mainstreaming gender is non-existent.

The activity-focussed nature of its organisational goal (Annual Report 1997-98) identifies its mission statement as *'improving the lives of people with disabilities in Bangladesh with particular reference to spinal cord injuries (SCI)*. Despite the gender-neutral nature of its mission statement, gender concerns are highlighted in other institutional documents. For example, OPD's funding proposal<sup>10</sup> to the commissioning donor refers in several instances to an increased focus on the needs of women and girls as a particularly vulnerable group in its medical and rehabilitative services and through the activities of its Training Institute. Its Annual Report also notes, inter alia, that it would place gender awareness in all its undertakings as one aspect of its Strategic Plan (OPD, 1997/98). However, despite a professed theoretical commitment to gender equality, there is little commitment or capacity to translate intent into practice at the corporate level.

The absence of a political and institutional commitment to integrate a gender-perspective within a policy framework has impacted on OPD's failure to consider the budgetary implications of implementing a gender mainstreaming strategy. In light of the continuous financial fiscal constraints under which OPD operates, the fiscal implications of a systematic and effective policy and planning framework to

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<sup>10</sup> All subsequent references to the funding proposal will relate to that submitted to the commissioning donor.

mainstream gender concerns is likely to pose a particular challenge to OPD management. Allocation of sufficient resources will be a crucial factor in the demonstration of OPD's commitment to working towards a gender-inclusive approach throughout the organisation.

## **The Organisational Sphere**

CRP has a complex, and at times confusing, hierarchical organisational structure with mid and senior level staff having both line-management and functional responsibilities.

The staff position with special responsibility for gender is a case in point. In addition to having duties and responsibilities as Administrative Officer, she is responsible for:

- Providing rehabilitative support and counselling to individual women/girls, both as in-patients and out-patients;
- Overseeing responsibility for the Women's Hostel;
- Co-ordinating an informal advice and support network for women staff and wives/daughters of male staff in areas such as financial affairs, counselling and/or intervening in marital disputes;
- Act as a link with the Training Institute on gender issues;
- Participate in interview panels to ensure a gender balance;
- Undertakes certain duties on behalf of the Director in his absence.

The role and work of the Administrative Officer and her tri-partite role in rehabilitation services, administration and training is considered by senior management to be a key mechanism for reinforcing gender concerns throughout the organisation. The level of gender related authority associated with this position is not included in the job description, nor is the extent to which these responsibilities have been formally incorporated into the institutional structure of OPD. The Administrative Officer is an ex-patient of OPD and is a wheelchair user.

The role and function of the Administrative Officer raises two important concerns. First, the levels of authority of the respective duties of this postholder differ greatly. They range from administrative duties to the management of a hostel and onto the strategic and policy demands of gender equity. Second, as previously stated, a commitment to gender equity demands considerations of policy, planning management, monitoring and evaluation and the 'add-on' approach employed by OPD to address gender issues demonstrates an absence of strategic thinking to integrate gender concerns in a comprehensive and effective manner.

At the service delivery level, discussions with OPD senior management confirmed an awareness of the special needs of women and girls and the social, cultural and environmental factors that often prevent them from accessing medical and rehabilitative care. Within an overall targeted response, informal policies exist which prioritise the special needs of women/girl patients and women students at the Training Institute. For example:

- Women/girl patients will not be turned away for reasons of lack of bedspace alone.
- Women SCI patients are encouraged to stay as long as possible to facilitate recovery.

- The Training Institute is proactive in encouraging registration of women students. For example, between 1997/99 the proportion of women students increased from 18% to 45%;
- The establishment of a special needs hostel for abandoned and/or neglected disabled women, where vocational training is provided so that women may 'earn while they learn' towards eventual reintegration into the community.

Staff records show that OPD has made good progress in the employment of women. The yearly statistics for the last 3 years demonstrate an increasing percentage of women employed. Women staff in the focus group discussion indicated that OPD has a policy of affirmative action in its recruitment and selection procedures although a formal written policy does not exist. The focus group suggested that OPD could further encourage women applicants by adding a statement to that effect in all its future job advertisements.

Focus group discussions with mid and senior level staff and information gleaned from disaggregated staffing data indicate that OPD management has made a concerted effort to reach a gender balance in its employee recruitment and appointment. Tables 1 and 2 provide a breakdown of women and men staff within OPD.

**Table 1: Gender pattern of OPD staff 1997-99**

1997		1998		1999	
Men	Women	Men	Women	Men	Women
92	42	103	55	121	81
69%	31%	65%	35%	60%	40%

**Table 2: Gender pattern of OPD Management August 1999**

	Trustees	Team Leaders	Senior Staff
Men	4 (67%)	6 (60%)	10 (50%)
Women	2 (33%)	4 (40%)	10 (10%)

As a result of the overlap between line management and functional roles and responsibilities, individuals appear more than once in Table 2. For example all of the team leaders will also be senior staff and one of the trustees is also a team leader.

Table 3 shows the distribution of men and women at the top and middle levels on the one hand, and the lower levels on the other hand, are comparable.

**Table 3: Gender Distribution in OPD Hierarchy**

Level	Men	Women
Top	10 (8%)	10 (16%)
Middle	50 (40%)	16 (24%)
Lower	65 (52%)	38 (60%)
Total	125	64

OPD has demonstrated a willingness to appoint women to non- traditional positions normally dominated by men. For example, it employs women guards and has recently appointed two women as ward assistants to the male wards. Both sets of

appointments have been successful in terms of acceptance within the organisation and in challenging gender stereotyping.

However, a staffing gender imbalance unable to fully meet the needs of women patients was noted in several specific contexts:

- In confirming the absence of a women doctor in the senior medical team, the Consultant Orthopaedic Surgeon acknowledged that a woman doctor or more women in other senior medical positions would significantly strengthen the quality of service currently provided to women patients. OPD is aware of this need and despite a concerted efforts to fill this position they have been unable to identify suitable candidates, OPD is committed to continuing their efforts in this respect.
- A preponderance of male technicians is likely to affect OPD's capacity to fully meet the mobility needs of women and girl patients.
- A shortage of women staff in the Social Welfare Department indicated that the counselling needs of women in-patients and/or follow-up visits to discharged women patients could not be fully met.
- There was a notable gender imbalance within the CBR programme areas visited. For example, in one area women CBR workers constituted roughly a quarter of those present whilst in another areas there were twice as many women as men present. CBR workers who are single women highlighted particular concerns regarding the safety and security issues as well as community 'pressures' on them as single women going out to work.

The majority of OPD staff either live on the compound or live nearby within easy travelling distance. OPD has made a concerted effort to increase the numbers of women students registered at the Training Institute. It has done this by taking additional measures to provide safe and secure accommodation, provide kitchen facilities and women-only library schedules. However, recreational facilities appear to be limited for women students confined to the OPD compound. OPD will need to explore innovative ways of balancing the needs of existing women students for improved recreational facilities whilst encouraging registration of women students by satisfying the expressed safety and security concerns of their families.

Although gender awareness training reportedly takes place formally and informally, there is a need for this component to be formally structured within an overall organisational staff training and development strategy, which currently does not exist.

A focussed approach to methodological issues throughout OPD's work organisationally and programmatically was notably absent throughout the evaluation process. The organic and speedy growth of OPD over a relatively short period has impacted on an absence of a clearly thought out strategic approach to identifying appropriate rationales and techniques that underpin its organisational functioning.

## **The Citizen's Sphere and the Delivery Sphere**

OPD's out-patient clinics provide advice, support, medical and rehabilitative care to men, women and children with a range of disabilities including people paralysed by a

stroke, children with cerebral palsy or others requiring orthopaedic or neurological therapy. On average 500 patients attend OPD's outpatient clinics per month. Other facilities at OPD include physiotherapy, occupational therapy, a special needs school for children with cerebral palsy and a residential mother and child unit for parents with children with cerebral palsy.

OPD's current 100 in-patient bed space capacity is distributed as noted below:

Male beds	48
Female beds	16
Cerebral Palsy Unit (mixed)	8
Operating Theatre	4
Isolation Ward	4
Transit Hostel	20 (12 men, 8 women)

The bed-occupancy capacity according to gender varies significantly with male bed-occupancy rates running at 69% in contrast to 31% for female bed-occupancy. OPD's formal gender differential bed-allocations policy is underpinned by an informal but a widespread common understanding among all staff that a women/girl patient in need of in-patient care will never be turned away. Table 4 to 6 (Annexe 3) provide gender-disaggregated data of OPD's in-patient and outpatient services between 1997-1999.

OPD believes that its differential bed-allocations policy between women and men reflects the respective gender needs of SCI patients in the community. Although the absence of reliable data within Bangladesh makes it difficult to accept this as a reliable indicator, there is, however, a global consensus that SCI is more prevalent amongst men than women. It is suggested that this is because men are more likely to be engaged in hazardous activities such as manual labour and fruit picking. Additionally, and this may be relevant factors particularly in societies where women's movement outside the home is restricted, men are more likely to be the victims of SCI as a result of road traffic accidents.<sup>11</sup>

In contrast, however, it is believed that the cause of SCI among women is more likely to be other non-traumatic cases arising from illnesses or infectious diseases such as TB. OPD's experience appears to confirm this view where the incidence of SCI among women patients as a result of non-traumatic causes such as viral infection, tumours or muscular degenerative diseases is more common. The unequal status of women and girls in Bangladesh, where women and girls are often unable to access medical care early or are malnourished resulting in low immune systems, is considered to be an important factor in the high incidence of non-traumatic SCI amongst women and girls. OPD believes that an earlier detection of SCI among women and girls may have resulted in a full recovery in many more cases.

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<sup>11</sup> Recent comparative studies examining the causes of SCI between developed and developing countries further endorse this fact. For example, a 1996 study (Spinal Cord, 1996) conducted in urban and rural Thailand showed a ratio of 5.6:1 (urban) and 5:1 (rural) of men and women with the causes being equally divided between road traffic accidents involving cars and motorcycles. Similar studies conducted in Turkey (Spinal Cord, 1997) and Jordan (ibid) also indicate that SCI is six times more common amongst men than women because of socio-economic and cultural patterns relating to gender roles.

Despite OPD's formal differential bed allocations policy for women and men, almost all staff confirmed its policy of never turning a women/girl patient away. In such instances extra bed-space will always be secured and made available. Staff willingly acknowledged that a lack of awareness about OPD's services is likely to be a significant constraint in accessing services by poorer households including women.

Interviews with patients at the Transit Hostel and with discharged patients living back in the community raised a number of issues relating to the needs of women and girls both as carers and as clients. Despite the smallness of the sample, the evaluation team considered the following issues important to note:

- The pressure on disabled women to continue supporting the family, either at home or going out to work, whilst the able-bodied husband remains unemployed;
- In the case of disabled women, pressure from the husband's family for him to remarry;
- The increased burden on women, e.g. wives, mothers and other female members members of the family as carers;
- The increased burden on the children with a disabled mother or father, particularly girls which impacts on their schooling;
- Vocational training needs of women carers to enable them to engage in income earning opportunities;
- In some cases, the lack of initiative and motivation on the part of the disabled man with regard to their physical care and household tasks, adds to the burden of women carers.

The Women's Hostel provides temporary accommodation for 20 disabled women who have either been abandoned by their families or cannot be supported at home. The length of stay at the hostel ranged from 3 months to 5 years. Two of the residents are students while the rest have received vocational training and are receiving income either through self-employment or piece work from the local industrial export processing zone. Whilst recognising that the hostel provides valuable opportunities for disabled women to access to income-generating activities and control over resources to lead independent lives, the management and overall policy direction of the hostel had to some extent been 'lost'. For example, the geographical location of the hostel some distance from OPD (with no resident staff support) warranted closer supervision and management including structured counselling support. The evaluation team found that effective support structures for the residents appeared to be minimal.

OPD's currently operates a CBR programme in 42 *thanas* or districts in neighbouring areas. It was initiated in 1994 as a direct response to an increase in the numbers of clients being refereed from different parts of the country as well as an increased referral rate of people with disabilities other than those associated with spinal cord injuries. It is evident that the CBR programme has led to an increased awareness, acceptance and social integration of disabled persons as well increased opportunities for education and income generation. However, extreme poverty, the resultant illiteracy and superstitions and remote locations continue to present barriers to identify and access rehabilitation services.

Despite the unequivocal success of the CBR programme, the evaluation team concluded that the quality and relevance of individual directed services provided by

the CBR programme, and the outcomes for disabled persons and families, are uneven, depending on the degree of disability, the availability or referral support, and the motivation and skills of the concerned CBR worker. More people with mild disabilities have benefited, while people with severe disabilities are likely to have remained isolated within the CBR areas.

Limited opportunities for staff training and skills development, an ad hoc and unstructured approach to training and skills development of CBR workers with little provision for on-going or refresher training and specialist training for staff working with persons with severe disabilities were all identified as particular gaps.

The CBR activities of 4 (out of a total of 42 districts) were assessed by the evaluation team including 24 clients and 97 CBR staff members. The team identified the following gender issues:

- An uneven gender distribution among the CBR workers in some areas reflected an absence of a structured approach to the recruitment and selection. For example, 0% in 2 areas to 50% in one area. Such gender disparity will inevitably have some degree of access and user impact for those women and men who prefer to be seen by a worker of the same-sex.
- Single women CBR workers expressed safety and security concerns especially when required to travel further a field by public transport – in the absence of guidance from OPD, women workers had decided to travel in pairs to make home visits. A few women workers also referred to community 'pressures' as single women going out to work.
- In some cases where there was a need for emotional and sexual counselling, staff had been unable to provide adequately support. Lack of appropriate training and a shortage of women staff who may have been more suited to supporting and responding empathetically to concerns expressed by women patients were identified as being the main reasons for this gap in service provision.

OPD's ability to collect and analyse quantitative data as a service provider and employer was noted. However, systematic monitoring and evaluation tools with measurable indicators and mechanisms for programme reviews remain operationally weak. The absence of a sound policy and planning framework and inter-departmental communication was deemed to be an area of particular weakness. OPD's focus in this area requires strengthening with identification of relevant research areas including incidence and relevance of SCI in the general population and among women and men.

OPD's CBR programme is ideally placed to further highlight the rights of people with disabilities at a local community and political level. OPD's work with local grassroots NGOs and CBOs is minimal at present, although it recognises that a number of opportunities exist to expand collaborative work with others engaged in rehabilitation service provision. By working with local grassroots organisations, OPD occupies a pivotal position to work towards the expansion and delivery of CBR activities that reflect the reality of lives for disabled women, men and children. Moreover, collaborative partnerships with large national NGOs such as BRAC and Proshika will support the long-term sustainability of OPD's CBR programme.

## **Recommendations**

1. A lack of services for disabled people, particularly for those from poorer households and from remote rural areas has been and continues to be a major problem in Bangladesh. Consequently, most of OPD's efforts have been largely preoccupied with improving coverage and quality of services in rehabilitation. An advocacy and rights based approach for persons with disabilities and large-scale partnerships have been limited. OPD's skills and expertise in working with people with disabilities places on it a particular responsibility to scale-up its work as a model of good practice nationally and regionally.

OPD has grown tremendously over the last decade in terms of numbers and type of services provided, increased utilisation of services, size, and complexity of the organisation and number of collaborations. It is imperative that OPD take 'time out' to review and consolidate before embarking on further expansion. Future growth and long-term sustainability of its mission depends greatly on establishing clear and viable policy planning framework that articulates the organisational values that underpin its programmes.

2. The pioneering nature of OPD's work in the treatment and rehabilitation of SCI patients is widely acknowledged. Its professional and technical credentials as the provider of high quality medical care places it in a strong position to influence greater understanding of this specialist field through appropriate training and research, both areas that could benefit from being strengthened. Equally, the formulation of a comprehensive methodology of programme monitoring and evaluation with built in reviews to aid organisational learning must be addressed systematically and comprehensively. Documentation and dissemination of action research to all stakeholders and partners will assist in the scaling-up of OPD's work nationally and regionally.

A programme to strengthen organisational management and administrative capacity will need to address the question of integrating gender within these processes. A comprehensive gender analysis will need to be incorporated into any organisation-wide strategic planning. The needs of women and men, girls and boys with different levels of disability alongside gender sensitive employment practices will need to be integrated into such a strategic plan.

3. The creation of a gender sensitive planning and policy mechanism that includes procedures for technical accountability that incorporate a comprehensive monitoring and evaluation (M & E) are recommended. Within this framework gender sensitive indicators will need to be developed to support the programme 'auditing' processes. Such an M & E system will, in turn by identifying deviances or weaknesses in OPD's efforts to mainstream gender feed into research activities and assist the continuous process of organisational learning. It is noted that as OPD's role in spearheading a more professional and technical approach to SCI patients nationally lends itself to OPD playing a leadership role in research projects that directly reflect the experiences of disabled women and men.

4. Effective gender mainstreaming will entail budgetary implications. The resource implications, for example, of a comprehensive staff training and development strategy and special recruitment packages to attract senior women medical staff will need to be considered. It is suggested that OPD could explore new funding opportunities to support the development of an institutional wide gender mainstreaming strategy through external technical assistance. OPD would also

benefit by developing collaborative partnerships with local women's NGOs or others working at the national level with experience of implementing institutional mechanisms with a gender perspective.

5. At the level of programme delivery activities may benefit from an assessment of the underlying policy framework for rehabilitation service provision. A comprehensive M & E system must be able to assess the impact of OPD's services to meet the strategic and practical gender needs of disabled women and men and of their carers. Impact assessments will also need to focus on training and employment opportunities for ex-patients and their carers as an integral aspect of rehabilitation services that enable disabled women and men to access and control over resources to live independent and full lives.

OPD's specialist skills and expertise in the area of disability and its standing within CBR areas provides the ideal foundation for the development of a participatory approach to consolidating its CBR programme. OPD already provides a unique positive role model in working to emancipate and empower people with disabilities through the employment of disabled women and men, girls and boys and their families. Although collaborative work with other NGOs and sister organisations working in the area of disability has been largely minimal, the CBR programme lends itself to effective collaborative initiatives since many other NGOs are already involved in CBR activities in the same or nearby localities. Joint projects will contribute towards streamlining and improving referral procedures as well as being cost effective use of resources.

It is suggested that OPD needs to revisit the policy rationale for the Women's Hostel provision to ensure that the hostel retains its original objective of providing temporary accommodation only. This would not only minimise the risk of women residents becoming 'institutionalised' but also increase the turnover of residents and thereby provide more women with disabilities to benefit from the services provided by the hostel. To those women who are unable to return to their families other opportunities to establish group-living environments, group employment and micro-credit schemes could be explored. Whilst acknowledging the internal and external cultural pressures against women living alone and/or to find marriage partners, awareness raising activities should form an integral aspect of the hostels' rehabilitation programme to highlight the risk of exploitation by families and/or others as a result of their increased economic status

6. OPD is uniquely placed to adopt a more proactive stance in identifying and developing awareness-raising strategies that fully address the special gender needs of disabled women and men. Lack of awareness about OPD may be a constraint in accessibility by poorer households. OPD is uniquely placed to highlight the incidence of non-traumatic SCI among women and girls, its causes and the affects of no or late intervention and the benefits of early detection and intervention.

A need exists to strengthen existing awareness-raising programmes and develop new initiatives to target poorer households using a variety of different methods including use of mass media and increasing impact through collaborative ventures with specialist and generalist CBOs and NGOs.

7. It is suggested that OPD could explore collaborative ventures with, in particular women's NGOs. Generally, OPD may also wish to review its educational and

awareness-raising programmes among the general public and mainstream medical and paramedical personnel, especially regarding prevention, early detection and 'best practice' issues during the critical hours following injury.

Working strategically with other NGOs can also provide valuable support to strengthen the disability rights movement nationally. By adopting a rights and advocacy approach to working with other NGOs, OPD is in a strong position to mobilise through collective action and raise the profile of people with disabilities. Such partnerships should ensure that it is women' and men's own realities and not that of health planners or decision-makers that determine gender appropriate interventions that distinguish between practical and strategic gender needs.

Opportunities also exist whereby OPD could extend its influence disability advocacy within the political arena. OPD is ideally placed to play a leadership role in seeking out strong and knowledgeable women activists who have a sympathetic understanding of gender issues (ideally within a disability context but not necessarily) to make maximum use of the quota system for political appointments to the local district council. An increased awareness of gender issues alongside equal numbers of democratically appointed women and men within local political structures will provide valuable support to community level collective action towards ensuring that disability is placed high on the national development agenda.

8. OPD provides a valuable example of where donor led priorities for gender-sensitive programming have been imposed and accepted by the aid-receiving agency without a full consideration by both partners of its implications for institutional functioning. In view of the fact that the budgetary implications for the above recommendations are likely to be significant, it is suggested that OPD should actively explore seeking additional funding support to facilitate capacity building in this area. For many donor agencies the integration of gender-sensitive and pro-poor programme methodologies continue to be a priority for joint programme funding.

## **CONCLUSIONS**

Poverty and disability are inextricably linked. Poverty can lead to disability and disability can lead to deeper poverty. It is also true that often one is disabled as a result of denial of rights and one's rights are often denied as result of ones' disability.

The fact that eighty percent of the world's disabled people live in poor countries and that lower-socio-economic status is directly associated with higher numbers of disabled people demonstrate the symbiotic relationship between poverty and disability. Inadequate diets, dangerous living and working conditions, reduced access to vaccination programmes and to health and maternity care, poor hygiene and ignorance about the causes of impairments, all cause disability. In turn, disability exacerbates poverty, by increasing isolation and economic strain, not just for the individual but also for the family. Disabled people are excluded from employment on the open labour market because of low skills due to inadequate education from unemployment. It becomes extremely difficult to breakout of the vicious cycle of poverty and disability.

Changes in development thinking that recognises the impact of exclusion from mainstream community activities for certain marginalized groups has changed society's attitude to disability, emphasising a social model of disability as opposed to a medical one. Additionally, a shift from a 'welfare' and 'needs' based approach to a rights based approach with an emphasis, inter alia, to a right to opportunities for human development and to social protection have been instrumental in bringing about significant shifts in attitudes and intervention strategies.

Some also argue that disability, like gender, is mostly culturally and socially determined in that society's attitudes and perceptions of disability itself determines experiences of women and men of disability. Thus a social construction of disability that sees disability as a medical 'problem' has tended to focus on strategies to change or 'mould' the individual to fit in with society's demands. In many contexts this is manifested through latent discrimination at the individual level and at a national level through health policies that fail to prioritise rehabilitation services for people with disabilities within a policy and practice framework.

A social model of disability also recognises that people with disabilities are not a homogenous group, and that discrimination within mainstream social, cultural or economic spheres will be reflected in the negation of the rights of certain sections of the disabled community. Women and men's reality of disability is context specific and varies greatly according to sex, ethnicity, the environment and socio-economic status.

In many countries in the South Asia region gender inequality and social exclusion go hand in hand to deny disabled women and girls access to opportunities for human and social development. Cultural practices such as 'purdah' which restrict the freedom to access appropriate health services and a high preponderance of male staff employed as rehabilitation technicians serve to restrict disabled women's access to timely and appropriate rehabilitation services. Strong traditional gender roles and relations can also serve to restrict women and men from achieving their maximum human potential. A combination of poverty and gender inequality has been shown to be a strong determinant in the susceptibility of women and girls to disabling illnesses such as TB, polio and blindness because of malnourishment or limited access to health services.

Rehabilitation strategies have sought to reinforce the fundamental message that integration of disabled people must ultimately be about the removal of barriers rather than an emphasis on 'normalisation' or cure or care. The popularity of the CBR model with an emphasis on inclusion and social integration through supported living

in the community is more cost effective, and thus lends itself to implementation at a local level in developing countries with poorly resourced national and local health services.

However, despite the popularity of the CBR approach, its future development must address two key challenges. Firstly, CBR activities must be viewed as one aspect of a national strategy towards a rights based rehabilitation strategy that addresses problems of poverty, marginalisation and exclusion. The needs and rights of disabled people in the South cannot be fully addressed unless the underlying causes of poverty are tackled. Poverty does not only mean inadequate income but also being deprived of influence, power and opportunities to participate in the decision-making processes, and being denied information and access to basic necessities. Secondly, gender inequality and powerlessness are widely recognised as being a factor in the incidence of ill health leading to disability. Gender concerns must be integrated within CBR programmes to ensure that women's practical and strategic gender needs are comprehensively addressed into all aspects of programme activities.

The concept of human development recognises the fundamental rights of physically impaired women, men, girls and boys to function like other individuals, to engage in productive labour and to participate in social activities. For a society to be fully inclusive, government policy and practice, the legal framework, civil society and all services and facility providers must adopt an approach of equal access for all within the community. The mainstreaming of disability within an equal opportunities framework where inclusion, advocacy and agency regardless of gender, age, vulnerability, ethnicity must be central to the development agenda of national machineries.

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## APPENDIX 1

### The Development of the Health Sector: a brief history

The 1970s witnessed a dramatic shift in the development paradigm that advocated a broader definition of development that included economic growth as well as progress in social sectors such as education and health. Within this shift, rapid population growth was initially considered to be primary cause of poverty, or at least, an obstacle to effective strategies. The recognition that the majority of the population was not benefiting from a development model that prioritised economic growth alone, led to an acceptance that greater redistributive strategies were needed to sustain economic growth and a concern for meeting basic needs.

The 1978 Alma Ata conference which acknowledged the *"failure of existing hierarchical, vertical, curative and high-tech health care models to serve the health needs of the majority of people"* and proposed an alternative model of universal primary health care (PHC), to be achieved by the year 2000. Accepting the equation proffered by major donors such as the World Bank, that a healthier nation was more likely to increase productivity and economic growth, many national governments have accepted the concept of PHC as a basic human right and have included progress in PHC services as a overarching goal in national development strategies (Beall, J., 1993, Oxaal, Z., et al, 1998).

Adopting a preventative rather than a curative approach, the PHC system was developed to provide a decentralised health care service with the notion that decentralisation would bring about greater community participation and control (Kabeer & Raikes, 1992 in Oxaal, 1998). However, the over-ambition of a comprehensive provision of basic healthcare services soon was realised, and by the mid-1980s highlighted several weaknesses of the PHC approach. Inattention to the pivotal role of the community, the notion of the 'community' itself, lack of sustainability and management problems at the local level were all identified as weaknesses that contributed to the failure of the PHC (Akin et al, 1986 in Oxaal, 1998).

A disenchantment with the PHC approach coincided with the economic crises and the structural adjustment policies of the 1980's. Cutbacks in public expenditure and social sector budgets affected the status of certain sections of the population. In many developing countries health sector budgets were the hardest hit which meant that the poor and vulnerable felt the brunt of the economic recessions.

Until relatively recently, the relationship between poverty and health care provision has largely been limited to a concern over the delivery of appropriate and affordable health care services to the poor or near-poor. Within this, a targeted approach has led to specific public health interventions such as immunisation campaigns directly benefiting the poor but indirectly benefiting the wider society. Similarly, and more significantly, a targeted strategy has focused almost exclusively on women's health needs through provision of mother and child health and reproductive-related services (Oxaal, 1998).

More recently, recognising the obvious limitations of an approach that neglected women's non-productive health problems and care needs, a shift in focus has taken place to address issues of *gender equality* within the health sector. This approach seeks to assess the impact of gender relations in the creation of vulnerability to ill health or disadvantage within the healthcare system, and the different ways in which women and men are adversely affected in terms of utilisation and access to services (Oxaal, 1998). A change in emphasis from 'safe motherhood' to 'safe womanhood' (Lewis & Kieffer, 1994, cited in Oxaal, 1998) has enabled a movement away from the narrow interpretation of women's reproductive health needs to the adoption of a wider perspective on women's health needs.

Although development goals acknowledge that improved health is a critical factor towards the achievement of broader development goals, it is now commonly accepted that a focus on non-health interventions is equally important in improving the well-being of the poor and for alleviating poverty. Thus, for example, there exists strong evidence that links an investment in women's and girl's education with improved health status, particularly that of children. Similarly, it is argued that poverty alleviating strategies designed to increase household wealth are more cost effective mechanism for improving health status as poorer households are more likely to utilise household expenditure in ways that improve their health (World Bank, 1993 in Oxaal, 1998).

The impact of the economic recession of the 1980s on social sectors generally, resulted in cutbacks in the health sector which in turn led to an overhaul of the health sector commonly known as 'health sector reforms'<sup>12</sup> outlined in the World Development Report 1993 (Oxaal, 1998). Thus, while adhering to the fundamental principle of universal coverage, a dramatic shift took place, which emphasised a more cost-effective approach to the use of available resources through the introduction of user-fees, increased participation of the private in health care provision and institutional reforms of the public sector. The impact of the introduction of user-fees is discussed in more detail in the following section.

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<sup>12</sup> Health sector reform includes a set of policies to finance provision of services. It emphasises cost-effectiveness by providing low-cost, high impact health interventions, such as large scale public health programmes (e.g. immunisation). It includes a strong focus on maximising efficiency through competition between providers and greater private sector involvement, and the introduction of cost-recovery mechanisms such as user-fees, pre-payment and insurance (World Bank, 1993 in Oxaal, 1998).

## **APPENDIX 2**

### **The 'Web' of Insitutionalisation**

## APPENDIX 3

### Gender Patterns of OPD Hospital Services

**Table 1: gender patterns of in-patients and out-patients at OPD**

	1997		1998		1999 (8 months)	
	women	men	Women	Men	women	men
<b>In-patient</b>	45 (19%)	190 (81%)	<b>52</b> <b>(18%)</b>	230 (82%)	22 (28%)	57 (72%)
<b>Out-patient</b>	748 (33%)	1517 (77%)	2284 (33%)	4569 (77%)	1672 (40%)	2480 (60%)

Table 1 shows a gradual increase in the percentage of women accessing OPD's services between 1997-99. OPD believes that this may be due to an increased awareness amongst women about its services as a result of the CBR programme.

**Table 2: Gender patterns at Transit Hostel and Mother & Child (Cerebral Palsy) Clinic, July 1998-June 1999**

	Women	Men	Girls	Boys
<b>Transit Hostel</b>	54 (29%)	131 (71%)		
<b>Mother &amp; Child Clinic</b>			61 (42%)	83 (58)

The residents of the Transit Hostel are transferred from the in-patient awards, and will, therefore, reflect in-patient gender patterns. The Mother & Child Clinic is designed to provide in-patient treatment, support and health education for a 2-week period to mothers and carers of children with disabilities.

**Table 3: Gender patterns of OPD services**

<b>Follow-up forms received (July '98-June '99)</b>	121 (17%)	574 (83%)
<b>Pathological tests (Jan-June '99)</b>	392 (25%)	1180 (75%)
<b>X-rays undertaken (Jan-June '99)</b>	397 (29%)	868 (64%)
<b>Operations undertaken (Jan-June '99)</b>	17 (26%)	48 (74%)

Again, follow-up services to discharged patients reflect in-patient gender patterns. The number of X-rays and operations undertaken reflect the gender patterns of those seeking treatment at OPD initially as outpatients.