

# Hidden Sisters: Women and Girls with Disabilities in the Asian and Pacific Region

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## The Problems of Discrimination

Despite their significant numbers, women and girls with disabilities, especially in the developing countries of the ESCAP region, remain hidden and silent, their concerns unknown and their rights overlooked. Throughout the region, in urban and rural communities alike, they have to face the major problem of triple discrimination by society in general: not only because of their disabilities, but also because they are female and poor. Prejudice prevails even within each of the three categories.

Among women, the woman with a disability is seen as inferior, and even among other people with disabilities she is not their equal. In fact, women with disabilities find themselves in a "Catch 22" situation, in which they are forced into being among the most isolated and marginalized. Thus they become the poorest of people, leaving them at increased risk of ill-health.

Women in poorer communities, and particularly those in the developing countries, appear to be more vulnerable to disability. A study, carried out in 1989 by the International Labour Organisation (ILO) in six Asian and Pacific countries, showed a relatively higher incidence of disability among women between the ages of 15 and 44 when compared to men.<sup>1</sup> Yet, overall, there are more disabled men than women. This could be explained by the fact that women in that particular age group suffer more from ill-health caused by too many pregnancies, inadequate post-natal health and medical care, and poor nutrition, all of which put them at greater risk of disability. That there are fewer women than men with disabilities, despite the fact that women generally live longer than men, may indicate that girls and women with disabilities simply receive less care and support than men, leading to earlier death.

Disabled women face discrimination from birth. It is not unknown for children born with congenital disabilities to be killed or left to die. This is far more likely to happen in the case of a girl-child. If allowed to survive, the girl-child is likely to continue to face discrimination within the family, receive less care and food, and be left out of family interactions and activities. She will have less access to health care and rehabilitation services, fewer education and employment opportunities, and little hope of marriage. She will also be more vulnerable to physical and mental abuse.

Disability creates and exacerbates poverty, because of economic strain and isolation, not just among individual men or women but for the disabled person's entire family. However, because

far fewer opportunities for productive work or gainful employment exist for the disabled woman than for the disabled man, she is perceived as posing a greater burden for the family.

The problems that confront women with disabilities are even more severe in rural areas. The inadequate or total lack of access to information, health care and rehabilitation services is further compounded by much higher illiteracy rates, longer distances to services and facilities, if they exist at all, and more severe conditions of poverty than in the urban areas. In addition, traditions and prejudices that force women into a low status are likely to be widely practised in the rural areas. One study on women with disabilities in rural areas of the Philippines, for example, found that more than 80 per cent had no independent means of livelihood and were, in fact, totally dependent on others for their very existence. The few who had jobs were grossly underpaid.<sup>2</sup>

Understanding the extent of the problems faced by women with disabilities is hampered by the lack of relevant statistics – not only just how many affected women there are, but also their social and economic status. The number of disabled women in the ESCAP region can be roughly estimated from existing overall disability prevalence figures. The mostly frequently cited figure is the 1976 World Health Organization (WHO) estimate that about one in ten people has a disability. However, this estimate has been the subject of much debate because of the lack of standard definitions of disability, and the different survey methodologies used in the various studies from which this figure was derived. Current thinking is that the prevalence of disability is probably lower than the WHO estimate. One more recent estimate of moderately to extensively disabled people in developing countries puts the figure at around five per cent.<sup>3</sup> Using this lower disability prevalence rate, the number of women with disabilities in Asia and the Pacific may therefore be estimated at around 80 million.

It is important to understand that this number is growing daily, not only because of the rising population but also because of the growing number of elderly persons and the rapid rate of urbanization which the region is experiencing. Evidence suggests that there are now more disabled people in urban areas, caused in part by the greater risk of injuries resulting from road and industrial accidents.<sup>4</sup> One study estimates that some 8.5 million disabled persons are added annually to the global figure or 23,200 a day.<sup>5</sup> Based on this estimate, the daily increase in the number of disabled persons in the ESCAP region which contains about three-fifths of the world population can be put at around 14,000, about half of whom are women.

Despite the existence of this significant number of disabled women in the ESCAP region, little attention has been devoted to their concerns or their rights. The global growth of two social movements in the last 20 years the women's movement and the self-help movement of persons with disabilities and the significant attention to the rights of these two social groups at the international and national levels, should have meant improvement in the status of women with disabilities. Instead, disabled women's concerns and problems have so far been inadequately addressed or supported by either movement.

### **Hope for the future**

However, there are several regional initiatives within Asia and the Pacific which have significance for women with disabilities. The Manila Declaration on the Agenda for Action on Social Development in the ESCAP Region was adopted by the Governments of the region in October 1994, thus affirming their commitment to the alleviation of poverty, the expansion of employment and the promotion of social integration.

The region's people with disabilities, having long been subjected to systematic discrimination, and denied equal status and opportunities as citizens, workers and consumers, are among the disadvantaged and vulnerable groups identified for special attention in the implementation of the Agenda for Action on Social Development. The Agenda's plan of action outlines affirmative actions aimed at creating conditions and mechanisms which will enable people with disabilities, including women and girls, to participate in, and benefit from, the social development process.<sup>6</sup>

One such affirmative action is the Asian and Pacific Decade of Disabled Persons, 1993-2002, which was launched at the end of 1992,<sup>7</sup> as a regional follow-up to the global United Nations Decade of Disabled Persons (1983-1992). The central aim of the Asian and Pacific Decade is to catalyse initiatives in the ESCAP region towards full participation and equality, and thereby provide a better quality of life for the millions of people with disabilities in the region.

The Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region, and the Agenda for Action for the Asian and Pacific Decade of Disabled Persons, 1993-2002, (referred to below as the Proclamation and the Agenda for Action for the Decade), were adopted by ESCAP at its forty-ninth session in 1993.<sup>8</sup> To date, 31 Governments have signed the Proclamation. The Agenda for Action for the Decade (annex I) serves as a guide to policy formulation and action by Governments, non-governmental organizations (NGOs) and United Nations and its bodies and agencies as well as individuals, for fulfilling the goals of the Decade.

However, not every action to improve the status of disabled persons benefits disabled women equally, and there is a real danger that women with disabilities may be further marginalized by the end of the Decade. If the Asian and Pacific Decade of Disabled Persons is to make a difference for women with disabilities in the region, greater attention must be given to the issues faced by them and to increasing their capacity to participate in the implementation of the Agenda for Action for the Decade at the local, national and regional levels.

At the Meeting to Review the Progress of the Asian and Pacific Decade of Disabled Persons, 1993-2002, held in Bangkok from 26 to 30 June 1995, a working group composed largely of women with disabilities from the ESCAP region, discussed the gender dimension in the implementation of the Agenda for Action for the Decade. The recommendations that emanated from the discussions of that working group were subsequently adopted by the Meeting and are reproduced in annex II.

Women with disabilities have been specifically included in the Plan of Action for the Advancement of Women in Asia and the Pacific, adopted by the Second Asian and Pacific Ministerial Conference on Women in Development held at Jakarta in June 1994. The Jakarta Plan of Action, as it is popularly known, will provide further impetus to efforts to improve the situation of women and girls with disabilities.

This publication highlights the main issues concerning women and girls with disabilities and makes recommendations for their advancement within the framework of existing instruments, especially the Agenda for Action for the Decade. Information has been drawn from many different sources, including replies to questionnaires sent out by ESCAP to the national focal points for women-in-development issues and self-help organizations of disabled persons in the region. The term "women with disabilities" is used interchangeably with "disabled women" and refers to the gender without differentiation of age, while "girls with disabilities" or "disabled girls" is used when girl-children or young women are referred to.

## **The Main Issues**

### **Attitudes and Images**

A central reason why many women with disabilities are unable to do more to improve their own situation is their lack of self-esteem. Shown from birth, either through neglect or through over-protection, that they have little value or are unable to do much, girls with disabilities grow up with the burden of that stigma and expect little of themselves. Even a woman who becomes disabled later in life will have her own sense of self-worth eroded by the prevailing attitude that she has become a useless dependant.

While women the world over are striving for equality with men, women with disabilities struggle to be recognized first as persons and then as being female. There is a tendency for care-givers, whether at home or in institutions, to treat disabled persons as objects without

feelings or the right to decide on matters concerning them. This is particularly the case with those who are extensively disabled and fully dependent on others for their daily activities. In the case of women, the gender bias in society imposes a subordinate status on them, and increases the likelihood that disabled women will have their individuality and rights ignored.

Despite rapid social, cultural and economic changes in the developing countries of the ESCAP region, the traditional role of the woman as the nurturer remains the norm. Throughout her life, a woman is to a large extent defined by her capacity as a daughter, wife or mother and, increasingly so, by the work she does and the position she holds outside the home. The disabled woman is not considered "marriageable" because her disability is seen as a "defect" and there is fear that her disability could be passed on to her children. There is doubt, too, whether she would be able to fully look after the home and family.

Universally, the incidence of marriage for disabled women is lower than that for disabled men. In Nepal, a society where marriage is the norm for women, 80 per cent of women with disabilities are reported to be unmarried.<sup>9</sup> In China, the situation is comparatively better; 52 per cent of disabled women over the age of 18 are unmarried.<sup>10</sup> Since women with disabilities are largely denied access to labour force participation, they are unable to acquire either the status or the social identity of being wives, mothers or workers.

Sexuality for women with disabilities is as much a part of their identity, and as important to their well-being, as it is for non-disabled women. Yet society at large is, more often than not, surprised when women with disabilities express their sexuality. Disabled girls and young women are seldom included in programmes on reproductive health education. In fact, they are commonly encouraged to repress their sexuality.

Family shame, limited mobility or lack of ability to communicate all serve to discourage a disabled woman from making contact with others outside the immediate family. Loneliness compounds the resulting sense of isolation and helplessness. In a survey of the needs of disabled men and women between the ages of 15 and 45, related to a project in Viet Nam, the most commonly felt needs – expressed by more than 80 per cent of those interviewed – were for information (about their disability), for schooling as well as for participation in family and community activities.<sup>11</sup>

Their low self-esteem has not been helped by the mass media. Positive images of women with disabilities – in roles such as exerting their rights, and contributing to the wealth and well-being of society – are rare in the mass media of ESCAP developing countries. Whenever there are reports, they usually feature the disabled woman as a victim and an object of pity, in need of help. Because the mass media plays such a powerful role in the formation of public opinion, it can be destructive when it reinforces the public's tendency to equate disability with helplessness on the part of the disabled woman and perpetuates the denial of opportunities for her to develop her capabilities. However, journalists write and project the situation of women with disabilities to the extent of their understanding. Their failure is therefore as much the failure of those promoting the interests of disabled persons to raise the awareness and understanding of journalists and others in the media.

It is obvious that the disabled woman is trapped in a vicious circle – her low self-esteem, cultivated from birth by her immediate family or care-givers and reinforced by her wider community and the media, results in her having very low aspirations. She therefore makes few demands, or none at all, of those around her and of society for her rights and opportunities to break out of this vicious circle. There is a critical need for the creation of an enabling psychological and physical environment that is supportive of the ability of the woman with a disability to function, within the limits caused by the disability itself, as an equal member of society. The main areas in which policy and practice can produce such an enabling environment are highlighted in the following sections.

## **Violence**

Disabled girls and women are at high risk of being regularly abused physically and mentally, most commonly by those around them – family members and care-givers – at home or in institutions for disabled persons. The abuse ranges from beatings to rape. Few victims ever talk or complain, let alone press charges. Many lack confidence that they will be taken seriously, and fear of reprisals is common. In fact, most victims simply do not know where or to whom to turn for help. There is an urgent need to investigate the extent of violence against women and girls with disabilities. Public attention can then be mobilized to address the problem, and protective steps taken to assist the victims and punish the perpetrators.

## **Health Care and Rehabilitation**

Disability implies, for a significant proportion of disabled women, the need for regular medical treatment and care. In those ESCAP developing countries and areas where public health facilities are overloaded and lack adequate resources, a disabled woman has to compete for services even if she overcomes the difficulties which are often involved in reaching the facilities. Resources allocated either by the family or the State for her health care reflect the value they place on her. To the extent that families and society believe that a disabled woman has little or no economic value, they are less likely to invest scarce resources in her. Even in countries where health care is free, either for all or for persons with disabilities, expenses are incurred for transport, food and accommodation.

Rehabilitation, as defined by the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities,<sup>12</sup> "is a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence". Rehabilitation is a time-bound activity. It may include measures such as the provision of appropriate assistive devices and the necessary training in how to use them. It may also include training in self-care and independent living. As with health care, the disabled woman's access to rehabilitation is limited by her low status.

In general, despite progress made during the United Nations Decade of Disabled Persons, rehabilitation services in the developing countries of the region are still inadequate and poorly coordinated. In order to use rehabilitation facilities, disabled women and girls must commute regularly to rehabilitation centres, normally located in the cities, or stay at residential facilities for a specific period of time. Commuting into the cities poses serious difficulties for women and girls with disabilities. It is also expensive for their families, in terms of money, time and effort. The United Nations Children's Fund (UNICEF) has reported that women and children receive less than 20 per cent of rehabilitation services, such as the provision of prosthetic and orthotic devices.<sup>13</sup>

Often, where residential facilities are available, they do not cater to women. Even if they do, for cultural and religious reasons, or simply because of over-protection by their families, disabled women are less likely than men to make use of such facilities.

As long as rehabilitation services are largely provided by institutions and centres, they will remain out of reach of the vast majority of disabled persons, particularly women. Although concern had been expressed by experts as early as the 1960s about the effectiveness of the conventional system of institutionalized rehabilitation services, leading to the introduction of community-based rehabilitation (CBR) as an alternative, the situation has been slow to improve. For most women with disabilities, their only hope for some degree of rehabilitation lies in CBR reaching them where they are, with the active involvement and support of their families and communities. While certain rehabilitation services requiring specific technology or skills will still need to be based in the cities, this is not the case for many essential types of assistance. For example, training in basic skills such as self-care (eating, drinking, dressing and personal hygiene) and mobility for visually-impaired women is better done in the

environment of the home. Such assistance can make a highly significant contribution to the development of the self-reliance and dignity of a woman with a disability.

## **Education and Vocational Training**

Throughout the Asian and Pacific region, public attitudes are changing regarding the value of educating and training women. The situation concerning women's education is improving within much of the region, and illiteracy rates among women have declined.<sup>14</sup> However, little has changed in this respect for women with disabilities. The prejudice surrounding their ability and value continues to perpetuate the view that educating them is futile. Opportunities for girls with disabilities to receive an education or to attend training courses are available to only a few.

For example, the then International Council on Education of the Visually Handicapped estimated that only two per cent of visually-impaired children in developing countries receive any formal schooling.<sup>15</sup> In China, where there are some 5 million disabled children aged between 7 and 15 years, only 6 per cent are enrolled in schools.<sup>16</sup> It is reasonable to expect that the number of girls included in those estimates is significantly less than half. One report on women with disabilities in the Raichur district of Karnataka State, India, indicated that the literacy rate of such women was 7 per cent compared to a general literacy rate for the State of 46 per cent.<sup>17</sup>

Traditionally, schools for disabled children tend to be segregated institutions, most commonly for those with visual, hearing and intellectual impairments. Girls who have extensive physical disabilities therefore have even less opportunity for schooling. The few special schools that exist are concentrated in large cities. Although they usually have residential facilities, the residential system – as has been previously seen in the case of rehabilitation centres – discriminates against access by girls.

So long as education for people with disabilities is largely confined to a segregated system, few disabled girls and women will benefit. There is an urgent need to consider policies and programmes that will place greater emphasis on the participation of persons with disabilities in the mainstream education system. Certainly the challenges are great. Existing school buildings are usually not designed for easy access by those with physical disabilities. At the same time, there is an acute shortage of trained teachers, suitable teaching materials and text books in appropriate formats, and educational devices which meet the specific learning needs of persons with disabilities.

Evidence indicates that a predominantly segregated school system for disabled children is unlikely to be adequate and accessible for this group of children, and that it is also educationally inferior. A study of disabled girls, both in special (usually residential) schools and in regular schools, found that those in special schools were less proficient in basic literacy and numeracy skills, had lower expectations about their own capabilities and lacked confidence in social settings.<sup>18</sup> Thus it is obvious that mainstreaming girls with disabilities into society must begin at school.

Education is the key to the advancement of women and girls with disabilities; it provides access to information, enables them to communicate their needs, interests and experiences, brings them into contact with other students, increases their confidence and encourages them to assert their rights. Without a basic education, their chances for employment are almost nil.

While the global trend is for greater gender equality in education and vocational training, boys and girls with the same disability often receive different kinds of education, with disabled girls often confined to the most traditional female occupations. One study suggests that girls with disabilities, as a consequence of sex-role stereotyping, develop limited, conventional views of what constitutes careers for men and women. This is a clear indication of their lack of awareness and understanding of the changes in perception brought about by the women's movement.

## **Employment**

Women in general face discrimination in employment. For women with disabilities, this discrimination is far greater. In situations where there is high unemployment, opportunities for remunerative work tend to be severely limited. When disabled women do find jobs, they receive considerably lower wages. For example, even for an industrialized country, studies have shown that a disabled woman working full-time earns only 56 per cent of the salary of a full-time employed disabled man.<sup>19</sup> In fact, disabled women earn the lowest wages compared to disabled men or non-disabled women.

Furthermore, in addition to the prejudice and discrimination barrier, the inaccessibility of the physical environment (e.g., buildings, roads, transport and toilet facilities) is a serious obstacle to disabled women working outside their homes. Since the lack of mobility limits disabled women from obtaining raw materials and marketing their products themselves, engaging in piece-work is the most common form of income-generation available to them. Examples of piece-work by disabled women and girls include labour-intensive and poorly paid activities such as weaving, sewing, basket-making, the assembling of toys and production of handicraft items. The materials are delivered to their homes and the finished products are collected by agents. There is no legal or social protection. Disabled women and girls may be exposed to unsafe materials and subjected to excessive hours of work under harsh conditions. Even where disabled women have jobs, their rights as workers may be overlooked. Faced with discrimination, little job mobility and few skills, disabled women workers may be forced to endure oppressive working conditions.

Despite the most optimistic outlook for change in employment opportunities for women with disabilities, the present reality is that the best hope for productive work may lie in self-employment, probably on a cooperative basis with others. While numerous projects exist which provide skills training for disabled women, they frequently fall short of meeting the ultimate goal of providing a means of adequate income.

A critical need remains for programmes such as credit schemes, entrepreneurial skills training and advisory services to include disabled women in the ESCAP region and to develop a niche in the market for the goods and services they can offer. For women with disabilities in rural communities, little attention has so far been given to developing options for productive and remunerative work, or the requisite training that would be appropriate for them.

Apart from economic independence, work is an essential means of enabling a person to develop a sense of identity and self-esteem. Thus gainful employment is an important means of promoting the social integration of disabled women. From the perspective of the State, investing in the education and training of women with disabilities, and promoting opportunities for their employment, is sound economic and social policy. Gainfully employed women with disabilities contribute actively to the economy.

## **Participation in Development**

The potential contribution of disabled women to the economy and to society has not been given sufficient attention by policy-makers in the ESCAP region. While the specific nature of their contribution might be influenced by the nature of the disability, it has been suggested that coping with disability produces certain strengths in individuals. It may lead to the development of inner resilience, patience, perseverance and an ability to deal in a positive way with the vicissitudes of everyday life, thus shaping individuals who can benefit society.<sup>20</sup> The fact is, however, that most women with disabilities have not had equal access to the opportunities they need to help them contribute to, and benefit from, development.

The two social movements – the women's movement and the self-help movement of people with disabilities – have so far had a limited impact on improving the quality of life of women with disabilities in the ESCAP region. For instance, although the Nairobi Forward-looking Strategies for the Advancement of Women to the Year 2000 have been instrumental in an

overall improvement of the status of women, their impact has been insignificant for women with disabilities. The Forward-looking Strategies had identified disabled women as requiring "special concern".<sup>21</sup> However, 10 years on, it is clear that insufficient attention has been given to their situation. An examination of 12 country reports from Asia and the Pacific on the status of women, which is to be submitted to the Fourth World Conference on Women to be held in September 1995, reveals that only one report makes any direct mention of women with disabilities. That one report admitted that "specific programmes for...disabled women...are not available at the moment. However, interventions in such areas are under active consideration."

In responses to a survey conducted by ESCAP for this publication, only one out of 16 replies from national focal points for women-in-development indicated that the concerns of women and girls with disabilities had been integrated into the overall policy for women in development. Policies and programmes for disabled women and girls are still too often thought of in terms of providing welfare services for them. There continues to be little recognition that they can be partners in development.

As for the self-help movement of people with disabilities in developing countries of the ESCAP region, its efforts to incorporate women's concerns into its agenda thus far have been too few and generally ineffective. Apart from a lack of resources for sustained action, there is also an apparent lack of strategic focus in the activities organized to promote the advancement of women with disabilities. Activities are frequently carried out for women with disabilities, without parallel efforts to increase their participation in decision-making related to those activities.

Greater efforts are needed to raise awareness among members of self-help organizations regarding the gender issue. In particular, disabled women members need to understand the gender perspectives of the problems they face, and to work towards their right to equal participation in the policy-making and management activities of such organizations.

The responses of self-help organizations in the region to the ESCAP questionnaire indicated that, in all cases where membership comprised both men and women with disabilities, women were significantly under-represented in the highest decision-making body of each of those organizations. Yet, in more than 70 per cent of the self-help organizations, a special committee existed for promoting the advancement of its women members and disabled women at large.

The end-result may be that women's concerns become marginalized, and not integrated into the central policy-making mechanism of the organization. This situation may be indicative of the poor awareness of gender issues among the male policy-makers who predominate in these organizations.

## **Strategy for Action**

### **Overall strategy**

Women with disabilities in the ESCAP region are left out of the development process because of two distinct but interlinked fundamental barriers:

The stigma surrounding their disability, resulting in a lack of measures at all levels of society which take into account their particular needs and aspirations;

Their subordinate position as women in society. The combined effect of both barriers is the extreme deprivation and marginalization of women with disabilities.

Any strategy to mainstream their concerns and participation in the development process must take into account these barriers. Therefore, to overcome these barriers, a two-pronged strategy is proposed which will:

Meet their practical needs, particularly for health care, rehabilitation, education, training and employment, and social integration;

Empower them to actively seek more opportunities, greater access to resources and more equal participation in decision-making with: (a) disabled men; and (b) non-disabled women.

Programmes developed with the above -mentioned overall strategy in mind should enable women and girls with disabilities to participate in the:

- Implementation of the Agenda for Action for the Decade;
- Self-help movement of people with disabilities in the ESCAP region;
- Women's movement in the ESCAP region.

The Agenda for Action for the Decade identifies under 12 major policy categories for implementation by Governments, NGOs, and the United Nations agencies and bodies during the Decade. Several forums are at present in place for generating broad support for the Agenda for Action for the Decade. One is the Regional Interagency Committee for Asia and the Pacific Subcommittee on Disability-related Concerns (referred to below as the Task Force) which meets once a year. The Task force is composed of United Nations agencies and bodies, as well as regional non-governmental organizations and networks concerned with disability issues. Governments of the ESCAP region also participate in the Task force meetings. Another forum is a series of biennial regional meetings to review the progress of the Decade. It involves the participation of Governments, and members and affiliates of the Task Force.

The Task Force and the biennial regional meetings are convened by the ESCAP secretariat. The regional NGO Network for the Promotion of the Asian and Pacific Decade, including information exchange among NGOs, annual public awareness campaigns and annual conferences in different countries of the ESCAP region. While women with disabilities participate in all these forums, there is a need to strengthen their effectiveness in promoting the interests of disabled women and girls.

Self-help organizations of people with disabilities exists in many countries of the Asia and Pacific region at various levels: community national and regional. In many cases, mechanisms have been established for involving those organizations in policy-making and other activities at the different levels. But there remains the need for more effective representation of the concerns of disabled women, and for the consistent effort to incorporate those concerns into policy formulation for the advancement of marginalized groups, particularly programmes on poverty alleviation, employment expansion and social integration.

The extensive network of women's organization in the ESCAP region offers a potentially important partnership opportunity. However , women and girls with disabilities are not yet adequately linked up with this network and there is a glaring lack of collaborative effort between the self-help movement of people with disabilities and the women's movement.

The underlying principle for all such effort is the direct involvement of disabled women. It should be emphasized that, for long-term gains, they must be given every opportunity to promote their own cause. They must also be empowered to influence decision making, and allowed to participate in the implementation of activities aimed at improving their social and economic status.

### **Women on the Move**

- A Family of My Own
- Setting the Trail in Bhutan
- APH and N S Hema
- Making a Living

## **A Family of My Own**

Carmen Reyes-Zubiaga is the Manager for Public Relations, Development and Planning of Tahanang Walang Hagdanan (House with No Steps), Philippines.

I was not quite two when I had polio. I grew up under the care of my five older brothers. I remember how much fun I had with them. Although from an early age my mother sought to convince me that I would not marry but would be taken care of by my brothers for the rest of my life, I never accepted the destiny that she had in mind for me.

As with most girls, my adolescent years were critical to the development of my social relationships outside the family. I could not always join friends and was often depressed when I thought of the fun they might be having out on the beach, at parties, or elsewhere. I had crushes on boys just like other girls but my friends were not encouraging because they doubted if men would date me. However, I did have a number of boyfriends. They made me feel attractive and showered me with affection. My mother was wary of my relationships with boys and wanted to protect me from being hurt.

When I met Dennis, I knew right from the start that he really liked me. He was not the picture of my ideal man but he had qualities that are hard to find: sincerity, simplicity, principles and a sense of purpose in life. When he asked me to marry him, I asked if he would accept what his family would say about me. It was his determination to stand by me which helped me make up my mind.

Initially, my family was not happy with our decision to marry. When Dennis asked my mother for permission to marry me, she tearfully pleaded with me to change my mind. I told her that I wanted somebody to take care of me and have children of my own. I was capable of having my own family and I would work hard to have a happy home. My mother eventually gave her blessings when she saw how determined we both were.

We were married five months after we had first met. Our wedding was held in a big church in my home town on 27 August 1988. It was the first time people in our town saw a bride in a wheelchair. A prime-time television talkshow covered our wedding and broadcast it throughout the country. Even now, I am still surprised by strangers who recognize me from that television talkshow. Our wedding has been an inspiration to many.

With our small savings we built a house beside my parents home. The house was designed to suit my needs and I had no problems carrying out my tasks as a housewife.

After seven years, I can proudly say that I am happy and content. We have two children, both boys. Jolly (Jose Ronaldo), our eldest, aged 6, is now in the first grade. Mogo (Moses Gregorio), aged 4, is in kindergarten. Both of them are happy, healthy and active children. Our hope is to give them the best education possible and prepare them for a better future.

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## **Kesang Choden: Setting the Trail in Bhutan**

Kesang Choden, 23, is a first year trainee teacher at the National Institute of Education, Bhutan. She is the first blind woman to be admitted to the Institute. This is her story of her struggles and aspirations.

I was born in a remote area in central Bhutan. My village is about two days walk from the nearest road accessible to motor vehicles. My parents told me that I lost my sight when I was two. I do not remember how it happened; it seems my life has always been engulfed by darkness.

Despite their poverty and isolation, my parents were able to put me in a school for the blind. I was a boarder in the school and was separated from my family for long periods. For the first couple of weeks in school, I learned the alphabet and simple words only. Then I started to read

and write. At first, I found reading and writing very difficult. But gradually, it became easier and I managed to complete class eight without much difficulty. Since I could go no further with my education at the school for the blind, I was sent to a high school. I continued to live in the dormitory of the school for the blind and walked daily to the high school which was about 15 minutes walk away. There, I had a tough time as I was the only blind student. It was very hard for me to cope with my studies. I also found it difficult to take part in social activities. With much suffering, I completed class ten and so completed high school.

I wanted to become a teacher, so I decided to enrol in the National Institute of Education (NIE) which is in Samtse, in the southern part of the country. I chose the profession because it is an honourable one and will allow me to serve my country meaningfully. But it has been a struggle. There are no facilities for blind trainees like me; there are no references in Braille. I am fully dependent on friends. I ask them to read the reference books and materials to me and I take notes. This is how I manage to do my assignments. It takes me many more hours than others. I have completed my first year. I had felt, at times, that the demands were too great, but I am not willing to give up. I am the first visually impaired woman trainee, and I want to set a good example to other disabled women in Bhutan.

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### **APH and N S Hema**

At the age of 18, N S Hema, together with two others, co-founded the Association of the Physically Handicapped in the city of Bangalore, southern India. Little was she to know then that the organization would remain the centre of her dreams and work for over 35 years.

Hema was four when she caught polio. It was so severe that initially it left her with little mobility below the neck. It was during World War II and few in India knew about the disease at that time. It was a year and a half later, after a desperate search by her parents for a cure, before they were told that there was no known cure. She never went to school. Tutors and her parents taught her at home. Hema remembers growing into a young girl who wanted to keep to a world of her own and who, at the same time, constantly asked what the future held for her.

Her family moved to Bombay for a year and there two events occurred which opened up her world and shaped her future. For the first time, Hema met other disabled girls of her age at the hospital in Bombay where she had gone for treatment, and where she also found friendship and understanding. She learned the importance of meeting others with disabilities. Her father had also arranged for her to be fitted with a wheelchair at an army centre. There she met Mr Devan, who lived in a home for disabled veterans. He became her mentor and subsequently her partner in the work of APH.

Back in Bangalore, together with another social worker, Hema and Mr Devan organized meetings of persons with disabilities. At first, the meetings were solely for providing opportunities for them to meet socially. Later, discussions turned to the plight of people with disabilities and what could be done to create opportunities for improving their lives. It was felt that the most useful thing that could be done was to provide training which would prepare disabled persons for jobs which would give them a regular wage. Hema's father's garage was converted into a training centre and APH came into existence. The year was 1959.

Although jobs were found for them in the factories in and around Bangalore, the trainees found it difficult to fit because of lack of support from the other workers, and they pleaded to be taken back by the centre. The situation shaped the next phase in the development of APH – while it continued to provide skills training, it competed for contracts to produce various parts and products for the industries in the area. The trainees stayed for at least two years and were paid a stipend. Hema's family connections with local industrialists were helpful in obtaining contracts and the centre grew to a medium-sized industry.

By 1970, the number of trainees had grown to 450 when a crisis erupted. The trainees went on strike, demanding recognition as regular employees with pay and benefits. The strike lasted over a year and the dispute went to the courts. Work came to a complete halt, contracts were lost, equipment and materials were removed. It appeared to Hema and Mr Devan that the centre which had taken more than a decade to build up was being demolished before their very eyes. For a while they could not understand how the trainees could have turned against the centre which had with all sincerity wanted to help them. Acceptance came when they realised that the trainees had aspirations too and were prepared to fight for them, and as such, were to be respected and valued. APH learned its lessons and restructured into two separate entities – an industry and a training centre. The industry generated income to run the training centre, which in turn provided skilled labour.

In the meantime, new work with disabled children was started. Coaxed by Mr Devan, who was convinced that if children with disabilities were reached early enough, the intervention would make a very significant difference to their future, Hema started a school in 1973 with ten children. The number was kept deliberately small "in case we failed," she explained. "I embarked on this project with great trepidation. I had never gone to school, so what did I know about schools?" Today, the school has 200 students with classes from kindergarten to middle secondary level. Through the school, the students receive medical assessments and rehabilitation services. The students and their families in turn have led APH to reach others. Currently, APH's education and community rehabilitation work involves some 800 children. Because the school has gained recognition for its high standards, parents vie for places in the school for their non-disabled children. Now, a fifth of the students in the school are non-disabled children and the integration creates a positive environment for interaction between disabled and non-disabled children and their families.

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### **Yodying Khajitmanee: Making a Living**

It was the rainy season in Thailand and the downpour started soon after Yodying Khajitmanee had set up her stall for women's clothing on the sidewalk of Silom Road, in the commercial heart of Bangkok. Three hours later, it was still raining and the clothes remained covered by plastic sheets. "As you can see, it's not a good day for business," she grinned as she signed the words. Yodying has been deaf from birth and is one of some 30 hearing-impaired sidewalk traders in the area.

She was introduced into this business by a deaf friend eight years ago. "It was a much smaller stall then. I had 5,000 baht (about US\$200) from my savings for capital." Promise of better money prompted her to leave her job as a seamstress in a tailor's shop. With two children to bring up on her own, the daily wages of 60 baht (about US\$2.40) were simply not enough.

Everyday, except Wednesdays – which is her day off – Yodying sets up her stall at about half past four in the afternoon. If the weather is good, she stays until about 11 at night. As her stall is located in a main tourist shopping area in Bangkok, most of her customers are foreigners. Although earnings vary from day to day, the business has provided her with a reasonable income of at least 5,000 baht a month. Overheads are few: rent for storage of the goods at a nearby warehouse and monthly "goodwill" money to keep her spot on the street. Her stall is flanked by other stalls, run also by deaf persons selling much the same merchandise as hers. Whereas in other circumstances, the competition might have caused uneasy relationships, here their common disability seems to have created an atmosphere of mutual support and camaraderie.

Yodying's two children are both studying at the university with the help of scholarships. However, she does not expect them to support her in her old age. She reckons she will stop operating her sidewalk stall when she reaches 50 (she's 43 now) and expects that the interest from her savings in the bank will provide her with sufficient income to live on.

## **Gender Dimensions of the Implementation of the Agenda for Action**

Adopted by the Meeting to Review the Progress of the Asian and Pacific Decade of Disabled Persons, 1993-2002, Bangkok, 26 – 30 June 1995.

### Critical issues

Women and girls with disabilities in every community, whether urban or rural, whether in a developed or a developing country or territory in the ESCAP region, experience triple discrimination: from being female, disabled and poor. Discrimination and prejudice prevail even within each of those groups. Among women, the disabled woman is seen as inferior; among people with disabilities, she is not their equal. Thus women with disabilities are among the most isolated, marginalized and poorest of people.

They are likely to receive less care and food and be left out of family interactions, and community activities. They also have less access to health care and rehabilitation services, fewer opportunities to be educated and employed and little hope of marriage. They will be more vulnerable to physical and psychological abuse.

All actions to improve the status of disabled persons do not always benefit women and girls with disabilities equally. If the Asian and Pacific Decade of Disabled Persons, 1993-2002, is to make a difference for women and girls with disabilities in the region, greater attention must be given to the issues faced by them and to increasing their capacity to participate in the local-, national- and international-level implementation of the Agenda for Action.

### Recommendations

#### 1. National coordination

Strategic objective:

To enable representatives of women with disabilities to be involved in policy - and decision-making on issues that relate to them at the national level.

Action to be taken:

1.1 Include women with disabilities as members of the national coordination committee, their number to be equal to the number of men with disabilities in the committee.

Action by: National coordination committees for disability concerns.

1.2 Provide the means for them to develop the skills required for effective functioning in the committee.

Action by: Self-help organizations of people with disabilities, organizations concerned with human resources development and empowerment among women.

#### 2. Legislation

Strategic objective:

To protect and promote the rights of disabled women.

Action to be taken:

2.1 Identify, examine and amend existing legal and policy provisions which may discriminate against women with disabilities and restrict their access to public services and participation in society.

Action by: Governments, self-help organizations of people with disabilities.

2.2 Initiate and strengthen activities to inform and educate women and girls with disabilities as well as the public (including women and men with disabilities), regarding their rights.

Action by: Governments, self-help organizations of people with disabilities, women's organizations, particularly those engaged in the promotion of legal literacy.

2.3 Provide free legal service to women with disabilities.

Action by: Governments and legal aid organizations.

### 3. Information

Strategic objective:

To generate, collate and disseminate information on the situation of women with disabilities to provide a sound basis for policy formulation and action, and to increase public awareness.

Action to be taken:

3.1 Incorporate the collection of gender-specific data in surveys on the disability situation at national level and by the United Nations system.

Action by: Governments, UNICEF, UNIFEM.

3.2 Undertake studies on the actual living conditions of disabled women in urban and rural areas, particularly those in the poorest and most disadvantaged communities, with a view to identifying ways to improving their status and living conditions.

Action by: Governments, self-help organizations of people with disabilities, women's organizations, organizations working on urban management and housing rights and on rural poverty alleviation.

3.3 Record and document the experiences of women with disabilities in ESCAP developing and least developed countries.

Action by: Self-help organizations of people with disabilities, women's organizations and media organizations.

3.4 Investigate and report on the extent and nature of violence against disabled women and girls, with a view to formulating measures for their protection and redress.

Action by: Governments, self-help organizations of people with disabilities, women's organizations and regional networks involved in campaigning on violence against women.

### 4. Public Awareness

Strategic objective

To generate, collate and disseminate information on the situation of women with disabilities to provide a sound basis for policy formulation and action, and to increase public awareness.

Action to be taken

4.1 Raise awareness among media persons in the ESCAP region on issues relating to women and girls with disabilities and encourage their support for promoting positive public attitudes regarding women and girls with disabilities.

Action by: Self-help organizations of people with disabilities, organizations working on social mobilization of marginalized groups, UNICEF, UNESCO, the Asian Cultural Centre for UNESCO.

4.2 Include women and girls with disabilities in all activities (e.g., sports and the arts) and materials (e.g., posters, commemorative stamps, first day covers and training packages) aimed at public information, education and social mobilization on disability issues.

Action by: Governments, self-help organizations of people with disabilities, media organizations.

#### 5. Accessibility and Communication

No additional recommendations for women and girls with disabilities.

#### 6. Education

Strategic objective:

To ensure that all girls and women with disabilities be given the fullest possible opportunity for education.

Action to be taken:

6.1 Study the reasons for the low enrolment of girls and women with disabilities in schools, higher learning institutions, functional literacy and other non-formal education programmes, with a view to evolving and implementing a comprehensive plan to eliminate barriers to their enrolment.

Action by: Governments and UNICEF.

6.2 Incorporate measures to address the education needs of disabled women and girls in all policies and programmes to achieve the UNESCO goal of Education for All.

Action by: Governments, UNESCO, UNICEF and UNDP, NGOs concerned with the enhancement and promotion of functional literacy.

6.3 Set targets for girls and women with disabilities for all education and literacy programmes, particularly those that focus on girls and women in general.

Action by: Governments and NGOs working on the promotion of education and functional literacy among marginalized groups.

6.4 Integrate the education and functional literacy needs of women and girls with disabilities in all UNESCO s activities to promote education of girls.

Action by: UNESCO and NGOs supporting UNESCO s objectives.

6.5 Support exchanges on models of integrated education for disabled children.

Action by: Governments, UNESCO and UNICEF.

6.6 Request relevant international agencies and bodies through their existing advisory services to governments in the ESCAP region, to provide technical advice to governments in the formulation of comprehensive plans for the education of children with disabilities, with attention to equal access for disabled girls.

Action by: UNESCO, UNICEF.

#### 7. Training and employment

Strategic objective:

To provide equal opportunities for vocational training and employment for women and girls with disabilities.

Action to be taken:

7.1 Establish a system to identify and provide jobs in all sectors which are suited to the abilities, potential and aspirations of women with disabilities.

Action by: Governments, organizations involved in community development, vocational training and other human resource development activities.

7.2 Increase the intake of women and girls with disabilities in vocational training and integrate them with the requisite support services, into existing vocational training facilities.

Action by: Governments, NGOs involved in vocational training for persons with disabilities.

7.3 Provide opportunity for promotion of women with disabilities by upgrading their skills.

Action by: Governments, NGOs involved in vocational training for persons with disabilities.

7.4 Protect the rights of women with disabilities in the workplace.

Action by: Labour unions, organizations concerned with the rights of women workers

7.5 Protect the health and safety of women with disabilities in the workplace.

Action by: Labour unions, organizations concerned with the rights of women workers.

7.6 Educate employers and fellow employees to ensure the rights of women with disabilities to work free from psychological and/or sexual harassment.

Action by: Labour unions, organizations concerned with the rights of women workers.

7.7 Strengthen training in business development, product quality control, marketing and distribution of products and services by women with disabilities who are self-employed either as individuals or as a group.

Action by: Governments, UN agencies, NGOs working on small business development

7.8 Specify the inclusion of women with disabilities as target beneficiaries of credit schemes directed at poverty alleviation among women.

Action by: Governments, organizations concerned with provision of credit in urban and rural development projects.

8. Prevention of causes of disabilities

No additional recommendations for women and girls with disabilities.

9. Rehabilitation services (health and social development)

Strategic objective:

To ensure that women and girls with disabilities have equal access to health care and rehabilitation services.

Action to be taken:

9.1 Strengthen community health care and community-based rehabilitation services, and make available information about them; so that women and girls with disabilities will be able to have greater access to them.

Action by: Governments and NGOs involved in community-based rehabilitation

9.2 Increase the training of women with disabilities as community-based rehabilitation workers to enhance service delivery to more women and girls with disabilities.

Action by: Governments and NGOs involved in community-based rehabilitation.

## 10. Assistive devices

Strategic objective:

To increase the availability of assistive devices for women and girls with disabilities.

Action to be taken:

10.1 Promote the production and distribution of assistive devices which are appropriate for women and girls with disabilities and ensure that they have equal access to existing subsidies and concessions.

Action by: Governments and NGOs involved in the production and distribution of assistive devices.

## 11. Self-help organizations

Strategic objective:

To strengthen the capacity of women with disabilities to include their concerns into the agenda of self-help organizations and to provide them with equal opportunities to influence policy and decision-making in those organizations.

Action to be taken:

Self-help organizations of people with disabilities should:

11.1 Take special action to recruit more women and girls with disabilities as members so as to improve the gender balance in the organizations and better represent the interests of women and girls with disabilities.

11.2 Aim towards equal representation of women members in their policy- and decision-making bodies.

11.3 Form committees elected by the women members to promote the advancement of women and girls with disabilities.

11.4 Raise the awareness of women and girls with disabilities regarding gender issues, with a view to increasing their ability to analyse the barriers caused by gender bias and to develop the skills to deal with those barriers in everyday life.

11.5 Include equal numbers of women in leadership and management training activities.

11.6 Strengthen cooperation with women's organizations through joint projects on issues faced by women and girls with disabilities.

11.7 Approach, in collaboration with the national focal points on disability, all multilateral, bilateral and national funding agencies to ensure that women and girls with disabilities are

explicitly cited as target beneficiaries of development programmes which are intended to be gender-sensitive.

## 12. Regional cooperation

Strategic objective:

To enhance the sharing of information and experience on the advancement of women and girls with disabilities and to strengthen their effectiveness in advocacy at relevant regional forums.

Action to be taken:

12.1 Encourage and support networking among women with disabilities, and \between women with disabilities and mainstream women s organizations as well as other NGOs.

Action by: Self-help organizations of people with disabilities, women's' organizations and NGOs.

12.2 Ensure equal representation of men and women in bilateral exchange programmes in the field of disability.

Action by: Governments and NGOs.

12.3 Discussion on the progress of efforts to promote the implementation of the recommendations regarding women and girls with disabilities should be included in the agenda of the meetings of the Asia-Pacific Inter-organizational Task Force on Disability-related Concerns and the biennial regional meetings to review the progress of the Decade.

Action by: All members of the Inter-organizational Task-Force on Disability-related Concerns.

12.4 Country reports and reports by NGOs for future biennial regional reviews should include gender-segregated data and information on women and girls with disabilities with respect to implementation of all areas of the Agenda for Action.

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