

Monday 23 April 2001

Dr Ala Alwan: Director, WHO, Overview — Rethinking care

This is an important event for us. We have access to a relatively large number of experts and we would like to ensure that we make the best use of the short time we have. Thus, I would like to suggest that we shorten as much as possible our presentations and use the time for structured discussion and objective dialogue.

About 10% of the population are estimated to have impairments; over the century, the principal causes of impairment have changed: some infectious diseases such as polio and leprosy are now less common. Increasing life expectancy has contributed to a growing population of older persons and, as a result of this ageing population, there is an increase in the magnitude of chronic diseases such as heart diseases, stroke, diabetes, arthritis and chronic respiratory diseases and a rise in the number of disabilities. Industrialization has brought with it new problems such as environmental pollution, traffic and industrial accidents. Injuries are also on the rise due to increasing violence and conflicts. Today noncommunicable diseases and injuries are responsible for more than two-thirds of deaths globally and about 57% of the disease burden. The magnitude of chronic conditions and injuries has increased in all regions of the world. But, at the same time, the old problems such as poverty, malnutrition and wars continue to be an important cause of morbidity and mortality.

Persons with disabilities are living longer in all societies and the consequence of this trend has been a rise in the need for rehabilitation services which, until now, has not been able to be met. A vast majority of disabled persons live in rural areas and have no or limited access to any rehabilitation services.

During the last two decades, beginning with the UN *International Year of Disabled People* in 1981, there have been significant changes in the concepts of disability and rehabilitation. The traditional medical model of care has developed to incorporate social aspects. The limited participation in school, work and social activities experienced by disabled people is no longer viewed by some as a result of their impairments but as a result of societal barriers to their participation. The rights of people with disabilities

to the same opportunities as others in their communities are now well recognized.

Every effort should be made to achieve full equal rights and opportunities for all people with disabilities and to improve rehabilitation services. The WHO Disability and Rehabilitation (DAR) programme contributes to these efforts. The DAR Team at WHO has been mainly concerned with promotion of community-based rehabilitation strategies, and strengthening of rehabilitation services at national levels in Member States.

However, with the changing burden and disease patterns and with the new concepts emerging in relation to disability and care, new issues and questions are being raised in terms of future action. These include the need:

- to evaluate the current strategies in DAR;
- to evaluate the progress made in implementing these strategies during the last two decades;
- to assess the effectiveness of these strategies in developing affordable services in low-income countries.

More basic issues include the need to assess the impact of current strategies, which focus on services in improving the quality of life. There is no doubt that addressing these issues requires close involvement of people with disabilities.

Our plan for this year and the coming two years is based on these needs. In addition to evaluating current approaches to develop new strategies, there are new issues that should be addressed:

(1) The first is health as a human rights issue. Disability is defined in the UN Standard Rules:

“The term ‘disability’ summarizes a great number of different functional limitations occurring in any population in any country of the World. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.”

Health is a “*fundamental human right*”. A WHO policy on disability has been drafted and will hopefully be discussed internally this year, and then by governing bodies next year.

(2) The second is bringing together different groups of disabled persons. This conference is bringing together two broad groups of disabled persons:

- There is a group of disabled persons with stable impairments who do not need regular and continuous medical care. This group of disabled persons has formed organizations that do not involve professionals and they have strongly declared their right for independence and the right to make their own decisions; they feel that the medical intervention is strongly prescriptive and attempts to take away the autonomy of disabled persons.
- There is another group of disabled persons who have chronic diseases that tend to get worse with time. This group has formed organizations of which professionals form a part, and they ask for their right to treatment and research to control the causative diseases.

This conference also includes people from developed and developing countries, people from high-income countries with sophisticated and highly specialized services and others from low-income countries with services characterized by very scarce human and financial resources. Although they both share many constraints in relation to care, it is important to recognize that the needs are not homogeneous and there are special priorities in different populations.

Now I would like to return to the objectives of our conference: *Rethinking Care*.

“What do we mean by care?” is one of the questions often raised.

Care may mean different things to different people in this room. To some people, providing care means looking after someone, and many of us have been expressing concern about this way of caring, which does not promote independence and full participation and often leads to isolation and segregation. However, there is another meaning of care, which is to care about something, to be interested in an issue, to address it, to identify constraints and to find solutions. It is important that this way of regarding care is strengthened so that societies, communities, professionals, legislators and others will care about disability and assume responsibility for promoting accessibility, equality and independence.

Services are needed, but there is also a need to assess the relationship between users and providers. We should be able to discuss in the conference how an alliance can be developed between professionals and disabled persons, where professionals are advisors and disabled persons are encouraged to make their choices. Rehabilitation cannot be concerned only with functional recovery — it must look at gaining increased autonomy.

Another issue to consider relates to poverty, disability and care.

Especially in developing and less developed countries, disability is closely linked to poverty, and the care services are extremely limited. The emphasis has traditionally focused on decentralizing services, with greater emphasis on primary health care services, nurses and other professionals. During our working groups we hope to revisit this issue and think in very practical terms of priorities and prerequisites for addressing the needs of disabled people.

Community-based rehabilitation (CBR) programmes, with their strong emphasis on community ownership and involvement of disabled persons and their family members, can play an important role in supporting increased autonomy. These programmes need to be supported locally by primary health care and centrally by specialized services. I hope that we can hear your views on the strengths and weaknesses in implementing CBR in your countries and how these programmes can contribute to a new more effective strategy for care.

This conference is an opportunity for initiating a dialogue between disabled persons, their family members and service providers, as equal partners. We are looking for ideas and recommendations in two main areas:

- What should be the future areas of focus for the health services in relation to disability and rehabilitation? Clearly, health care and social services will always be needed but how can we ensure that these services do not compromise the independence and autonomy of disabled people? How can medical services support disabled persons in their fight against social barriers?

- How can we promote and strengthen this dialogue and understanding between the disabled persons, their families and the service providers?

Finally, it is important that WHO takes into full consideration the views and concerns of disabled people in its strategies and future work. We look at this conference as an important opportunity to ensure your contribution to WHO's future work, particularly in relation to the review of the UN Standard Rules.

Nisha Miller: Schizophrenia Research Foundation, India

Noted here are some of my experiences as a user of the mental health services, mainly in India.

To begin with, in London when I first became mentally ill, I felt that I was not mentally at ease. So I asked my GP to sign me up for psychiatric therapy.

Later on I was admitted to a mental ward in a London hospital. I found my stay there very pleasant. We were not locked in, and this trust meant that we did not go anywhere. I went to my flat once or twice, but only to get a sweater. In fact, even though we were not locked in and needed no permission to go out, I did ask the duty nurse if I could go out, and until she gave me permission I did not leave. Once I reached my flat I hardly stayed two minutes. I went back to the hospital immediately. The other good things about the hospital in London were the classes. The yoga classes in particular were marvellous. They were held in a nice, bright room, and the teacher did the exercises, which we followed.

We had several activities but none were compulsory. Then there was a TV room. Anyone could watch at any time. But no one became an obsessive TV viewer. We watched some nights until late, some nights hardly at all. We each had separate cubicles and, although we did visit each other, we did so rarely. It was understood that we were resting and recuperating; we were not lazy. But we did not take advantage of this chance to rest either. We went out, we went to classes, or we just did something.

In India, I am a patient at the Schizophrenia Research Foundation (SCARF) NGO. Although I am very lucky to be in such a decent place, there is much that could be improved. I must say that, even in India, I have had happy moments in mental hospital. For instance, when I was first admitted to the mental hospital, I occupied a single room, which was very nice. I had privacy and solitude, which I like.

However, when I was moved to the rehabilitation centre, I was very unhappy. We have to share rooms and do all sorts of things. We are locked in and there are many rooms.

The patients here are expected to do exercises on a rough, stony expanse of ground. As there are a lot of kneeling exercises this is very painful. If one of the staff were to lead us in the exercises, then they would feel the pain and know what we are suffering. This would surely make them move us to a room. However, the problem here is the money. They cannot afford different staff for each class, for example. Despite this, I must say that I am very privileged because I have had access to the state-of-the-art facilities that SCARF offers.

There are no other organizations like this in India, perhaps in the world. In other parts of India, people like me are abused by their families, i.e. treated like servants, or left to wander in the streets. Thus, other organizations like SCARF are necessary in the rest of the country, especially for women who have a greater need for protection.

Karen Ling: Experiences of women with disabilities in medical services, China

Women with disabilities are deprived of the rights to motherhood. As the medical profession does not think that women with disabilities should enjoy equal rights with their counterparts, in terms of rights to motherhood, women with disabilities are asked not to bear children when they get married. The medical profession has never considered that women using wheelchairs can get pregnant. There are many occasions where pregnant women using wheelchairs could not have antenatal check-ups. Even when antenatal checks are arranged, there is no suitable equipment. For example, there is no appropriate way to measure the weight of the disabled pregnant woman. During delivery, both the medical doctors and nurses are in a chaotic situation. They do not know what to do. When the child is born, nothing is offered to help the disabled mother. The disabled mother also has great difficulty when she takes the baby to visit the maternal and children's health clinic. Such clinics are not accessible to wheelchair users, and do not offer any realistic assistance or adaptive equipment to help the disabled mother care for the baby at home.

Women with physical disabilities are in a better position to become mothers than women with other types of disabilities. Very often, women with learning disabilities are asked to undergo sterilization when they are young. Their parents are very supportive towards such an act since they fear that strangers could take advantage of their disabled daughters, resulting in unwanted pregnancy. In case these women give birth to disabled children, the medical doctors are always ready to offer 'help'. Women with mental illness suffer the same experience. Sometimes, disabled women themselves initiate sterilization because those they trust (parents or family members) have influenced them.

The situation also applies to women with chronic illness, like me. After I had my first heart operation, my doctor told me that I should not have any children even if I was 'lucky enough' to get married. Later, when I joined the patients' groups for heart disease, other members related to me similar experiences with the medical profession. They said they also had been told not to hope for children, solely because they had such a disease and had to take medication for the rest of their lives. But I told them that we should

make our own choices. The fact is that I am now a mother of two children.

Of course, some medical doctors do advise us with good will. However, sometimes their suggestion may be so forceful that patients' personal rights are violated.

Marjorie January: Experiences and constraints in accessing specialist services, South Africa

For me, the struggle of being disabled and of accessing health care services started in 1990 when I was diagnosed with multiple sclerosis. For three weeks, upon my admission to a tertiary hospital (Grootte Schuur Hospital), medical doctors and specialists had their small conferences about multiple sclerosis not being a disease affecting Africans and asking questions about my family lineage over my head, but not explaining why they were asking the questions. After three weeks of talks without any treatment, they eventually decided to send me for an MRI to determine the exact diagnosis and then I was put on medication and physiotherapy.

At the time I thought that a diagnosis would improve my health status, as the medical staff would then be aware of the appropriate intervention. I did not realize that my nightmare was about to begin. One night I lost control of my bladder and rang a bell for the nurse to come and change the linen. She told me that there was no linen available and I must sleep on the wet sheets, and tell the day nurse to change the linen the next morning; she returned to her station. I knew that was not true, and I was very angry that the nurse read only the frequency of my medication in my folder, and not the complications of my condition that were clearly stated within. My right to basic care and human dignity was violated, and I felt abused and humiliated.

The next day, the day nurse arrived and I explained what had happened, and the fact that I was a trained nursing sister, so I knew what was readily available. Immediately the day nurse apologized for the night nurse's behaviour, and I was moved to a side ward. I was happy about the move, but the change of attitude came as a result of the disclosure that I had been a professional nurse. I could not help wondering about my special treatment and about other patients who would come to this world-renowned hospital to receive specialist care. They might not speak English, or might be afraid to speak up to people who were supposed to care for them during a critical time in their lives.

After three weeks of extensive medical care and physiotherapy, I was transferred to a nearby rehabilitation hospital for further rehabilitation. To be honest, I went there expecting a raw deal from the staff. To the contrary, I found the staff in this hospital more

caring and mature, and there was no rushing around, even when they had nearly finished their shifts. The healing for me started from my talks with the nurses who wanted to know me as a real person. That was motivation enough for me to get up in the morning. Now it was different — the staff cared to know me, and they were not just obsessed with their routine procedures.

However, the caring attitude was limited to pre-discharge. On the day of discharge I was given a wheelchair, which I had never used before, and the rehabilitation staff had difficulty in clearly articulating the progression of my condition. It was difficult for me to comprehend that, reading between the lines of my prognosis, there were no preparations for going home.

The people who had taken care of me for three months were not even able to look me in the eye and tell me what to expect. They did not even ask me about the accessibility of my home and my support systems. They told me that it was time for me to be discharged and that they must carry on with their work, and whether I was ready or not I must manage on my own at home. Arriving at home, I could not cope with the wheelchair, and my family had to carry me everywhere, while arranging for the house to be renovated. I had to cover the renovation costs, as there is no subsidy from the state for provision of access. I still truly do not know how I would have coped without family support during that vulnerable time in my life.

My family had to continue their day-to-day activities, and I was left with my mother who was 75 years old and who was very protective of me. She wanted to do everything, and was hostile to any person who wanted to assist in caring for me. There is an African saying that “umntu ngumntu ngabantu”, in other words, no one should live alone, especially in times of distress. It is basically about being interdependent and the people who wanted to be close to me felt a barrier at that time. Thus, my mother felt that I did not need other care and her hostility alienated any assistance I was offered.

A few years later, she was suddenly taken ill owing to old age, and she had to be taken care of herself. Then I had to look for care beyond my own family, and I found that the Red Cross Society provided this service. The arrangement worked quite well, because I did not require help for the whole day. I needed bathing and my breakfast, and then I headed for my work with the Disabled

Women's Programme, and returned in the afternoon when everybody was home. This arrangement was short-lived as the Red Cross Society dedicates all of their care attendants to AIDS sufferers.

The next challenge for me was hiring care attendants who were untrained and not linked to any agency. The services ranged from people who arrived intoxicated to those who helped themselves to my money without my consent. It was painful for me that I could not lay a complaint against anybody, but just had to ask them not to come any more.

In conclusion, the Integrated National Disability Strategy of South Africa lays a policy framework with a paradigm shift away from a medical model of disability to a development and rights-based approach. Therefore, there is more to disability than medical diagnosis and medication. Health professionals should move away from thinking that people with disabilities are patients or objects that they own, but rather look at us primarily as human beings. No one volunteers for disability. Identification of opportunities should be facilitated so that people with disabilities enjoy equal rights to services like any other citizen. Disability is multifaceted. It requires integration, collaboration and cooperation from all stakeholders involved.

Dra Gabriella Garé Fabila de Zaldo: Mexico

Every day in all the countries of the world, the people with disabilities and their families are suffering some kind of discrimination. This is happening in their societies, their communities, and many times even in their own families.

I learned what discrimination and sub-valorization really were, but not from a degree course at the University. I learned about this from everyday actions that I suffered against my son with multiple disabilities, against my students with cerebral palsy, and against my friends with mental disabilities.

I can feel the pain of many parents of children with disabilities, with health problems and considerable limitations such that “*they simply lower their heads*” when they confront poor education or health services, discriminatory and undervalued attitudes of the doctors, nurses or teachers. I could see many times those mothers accepting everything they were offered because they were afraid that, if they claimed anything, they would be left without the health services or even the schools.

I knew many mothers that returned to their homes from the clinics or schools with more pain, without hope, feeling that they were alone, without the comprehension and support of professionals and their family. They experienced a total lack of self-value and underestimation because their daughter or son had a disability and because the doctors had shown them from their attitudes that their children had “no value at all”. From the environment the child senses she/he is not welcome in the family or in society, and that unhappy atmosphere surrounds the mother and the growing baby.

The mother will cry and be sad. She will not experience the happiness that every baby should bring to the home. She will not have the strength and courage to demand good services or to play, sing, and hug her child because she is depressed.

At this critical moment, it is necessary for the normal well-being of the child and mother to have the stimulation to develop the cerebral plasticity that could be used to advantage to reduce the cerebral injury and the disability, and thus prevent a disability that could grow. Because of the segregation and lack of social integration, this is lacking.

I was one of those mothers 35 years ago, when a doctor told me that my son had encephalitis. He did not care what would happen because the baby may be just “something like a liver with eyes” — he was intending to make a joke with this phrase. Now I know that he tried to hide in these words all the ignorance about humanism, solidarity and knowledge about the effects of early intervention techniques for the baby and family. He strongly recommended putting my son in an institution far away from his family, from the medical institute and from his community, giving no present or future for him. Of course, our son has always lived with us in our home.

My sad experience is happening all over the world, and I would like to know how much longer this will continue and why it is still happening.

Since those terrible years, many things have happened worldwide. Many changes have taken place, especially in rich countries, but we have also experienced changes in the developing countries — many times these changes have been for the better, but not for everyone.

The changes have not wholly benefited:

- the 500 million people with disabilities;
- the 70% of people with disabilities that are living in developing countries;
- the 10 million people with disabilities that are living in my country;
- the people with multiple disabilities;
- the millions of people who are living in poverty in so many developing countries and even in the rich countries.

Real, precise changes were started by groups of people all over the world who were very angry with their reality, and who decided to give their soul, courage, skills and life to promote a better quality of life for themselves, or for their sons and daughters with disabilities. This began in the early years of the 20th century with the people with disabilities, their families and professionals. It occurred too in the public and private health sectors that step by step were improving their services, but that were not covering the entire population.

The associative movement in Mexico began in 1970 with a group of brave parents of children with cerebral palsy and another group of parents of children with mental disabilities who decided to start a small rehabilitation centre and a school. These associative movements grew considerably and now they are the largest in our country.

Part of the success is because these associations have involved the community and the people who live near the schools. They invited the community to be part of the social movement and to be part of the community centres. Now the local people are studying in the art school with people with disabilities, or in the adult school learning to read and write. At the same time, they opened new paths to team with the industrial sectors, professionals, media and, in general, with society in order to support the new cerebral palsy movement. Now they are promoting the movement for all disabilities and integration without discrimination.

In my country, at the same time, many people with disabilities became leaders in cities, big or small. They began to talk in public, to work, to act, to unite.

Together with a group of parents, we founded 'Creceer Community':

- to provide services for people with multiple disabilities, for the children that were the most discriminated against in the educational centres in Mexico City, especially for our own son and many other children that had no present or future;
- to change the mentality of the professionals;
- to demonstrate all the things that can be achieved when they have early intervention services, schools, pre-labour skills;
- to promote activities of social integration with the community;
- to improve the recognition of their rights: the right to belong to their communities with equal opportunities, the right to belong to their families like any other member, without any kind of exclusion.

We cannot imagine a social movement on behalf of people with disabilities where those in most need are excluded, as history has taught us from many experiences all over the world.

In 1994, the General Assembly of the United Nations produced "the most important document on human rights", the *Standard Rules on the Equalization of Opportunities for Persons with*

Disabilities. Its purpose was to provide guidance to Member States concerning policies and measures to achieve the goal of full participation and equality, and to bring about new dimensions to disability policies. It drew attention towards the human rights aspects of disability policies. It promoted the participation of people with disabilities in planning, implementation and monitoring common goals.

The Standard Rules became the basic document that guided the development of a National Plan for the welfare and integration of people with disabilities in Mexico. One organization including the National Coordinating Commission united all the governmental secretariats and the principal organizations of people with disabilities with active participation. We worked in the sub-commissions. One of the sub-commissions was Health, Well-being and Social Security. For 6 years we worked together, the government and NGOs giving important advances and changes to our lives.

Since December 2000 Lic Vicente Fox has been the President of Mexico. He represents a great change in our society, in the advancement of democracy. He has very precise concepts about disability, exclusion and integration. On his first day in government, he announced the creation of a department with the same importance as a secretariat for the promotion and integration of people with disabilities. This head office department comprises people with disabilities and parents of people with disabilities.

This conference on *Rethinking Care* is an opportunity for disabled persons and their families to contribute to the definition of policy issues related to health care and social support. Health care is a priority — it needs a new philosophy based on interdependence, empathy and human rights.

The viewpoints of academics, activists, and professionals involved in caregiving must be considered in order to introduce new ways of living for all members of society. Changes are needed in the environmental support and relations between people with disabilities and their doctors and nurses, who should give all their expertise and empathy to empower the people with disabilities, their families and communities to achieve a better quality of life.

It is a good moment to reflect on the heterogeneity of the world because in some countries the people need water and food to survive, and great support in rehabilitation for the people with disabilities. In contrast, the parents of a child with a disability in another country may be given a training course on how to ask for the latest model of an electronic device for their child because the present model is one year old.

Now is the moment to promote political equity in every country for the compromise and distribution of resources for programmes in big cities, as well as in rural or poor urban areas, because we need sufficient funding to provide better health care in developing countries. We need to know if they are sufficient, how they are working and of course we need to change the attitudes of society, especially in the health sector, to establish better services.

For many years my husband and I have received the biggest support for our son from our neurologist, the paediatrics and one teacher — they were all part of our family.

The beginning for every disabled person or family who has a disabled member is very much the same. It starts with an emotional shock, together with the news about ‘the disability’. The way that this new life starts will affect their future. The notice may be given by an insensitive professional who is very discriminative and who has no respect, information, or knowledge and may make a suggestion to “put away the child or elder grandfather”.

On the other hand, the news may be given by a professional with humanism, friendship, knowledge about the disability and about the resources that the community can give to support those with disabilities and their families. This can be the difference between integration and exclusion, between teamwork and being left alone, between changing our communities to give good services and promoting institutionalization.

Some years ago I was invited to participate in a Project for All America with representatives from every country. We studied the social and cultural barriers that prevent the integration of people with disabilities in Latin America, in order to find the strategies to abolish these problems one by one. We worked for 3 years together and we could detect the barriers that were very similar in

all Latin American countries that were developing common vision, strategies and action plans to promote social change.

The 21st century is beginning and there is still much to do in all countries to improve the quality of life of the people with disabilities. There is no country which can offer a perfect service and in which the conditions of life are ideal for people with disabilities.

Already, persons with disabilities, their families and members of society have brought about a social conscience and a 'vision of the future', which has been the driving force. But we need society to change and support 'a society for all'.

As Jean Vanier said, "Community is the breaking down of barriers to welcome difference".

When I met Dr Pupulin some years ago I knew about his sensibility and the desire of the WHO to change many things. Today we are together with our many experiences to help develop better health services and establish better communities. I would like to finish with a paragraph from the Managua Declaration:

"We want a society, which is based on equality, justice equity and interdependence. Which ensures a better quality of life for all, without discrimination of any type. Which recognizes and accepts diversity as a fundamental aspect of community living. A society where the condition of each member comes first: which guarantees their dignity, their rights, their auto-determination, their contribution to a community life and their full access to social welfare." (Signed in Managua, Nicaragua, on 3 December 1993, UN *International Day of Disabled Persons*)

Let us recall that we have the obligation within societies and governments to ensure the participation of persons with disabilities and their families in the formulation of legislation and coordinated policies in order to achieve this ideal.

Furthermore, we commit ourselves to the development of policies that support social integration according to the characteristics of the community in which the people live, through the provision of information and orientation to the family, as well as making possible the implementation of labour policies and not limiting migration.

The signatories and the institutions represented will work in favour of the particular goals that we have identified in the promotion and defence of rights; to the establishment of associations and ways of cooperation; to the awakening of the public conscience about these issues; to develop information and research systems; and to guarantee the support and necessary services.

Dr Usha S. Nayar: Professor, Tata Institute of Social Sciences, Community-based rehabilitation of disabled in urban slums of Mumbai, India

Acknowledgements

The author acknowledges the support of the WHO, Geneva, and AIFO, Italy, for this project since 1998. She also expresses her deep gratitude to Chandran in initiating and coordinating this project with full commitment until his untimely death in December 2001. The entire team of the TASH Foundation deserves great appreciation for the involvement and commitment made to propel this project forward with hope: their unconditional support, cooperation and trust in improvements for the rehabilitation of the disabled within limited means and notwithstanding severe constraints.

‘Samarth’

“Samarth — to be able to. This word is often used in Hindi to express simple living and movement, a joy in fulfilment. Poetic vinculum makes the word more historic with its ethnic ring. It is quite an honour to bring about a change in thought — to finally realize the capabilities and let loose the handicap, differently abled — is Samarth.”

Background

The slum settlements in Mumbai (Bombay), India, have become an inevitable adjunct to the growth of the metropolis. These slum settlements, which continue to attract migrants from all over the country, are palpable proof that human beings are highly adaptable and it is in such deprived settings that one cannot only observe coping and resilience at its best, but also the approaches to survival. The downside is the appalling living conditions, bereft of basic civic amenities and exploitation by everyone concerned.

The plight of the vulnerable sections, namely the children, the aged, the women and the disabled in particular, deserve serious attention in such settings. Estimates of the disabled population vary widely depending on the definitions used, the approach to the survey itself, the location and the ease of accessibility. The incidence of disability in India is currently estimated to be between

16 and 18 million. One reason for the wide range in estimate is the attitude of the respondents towards the social cost of 'visibility' or 'invisibility' of a disabled person in their family. Thus, a strong case exists to understand the settings (environment), the disabled within these settings and the neighbourhood at large in urban areas. There is a need to evolve systematically a mechanism that would eventually ensure the rehabilitation of the disabled.

Project SAMARTH (meaning 'capable' in Hindi) is an attempt to consider the circumstances, i.e. life in the slums with its attendant implications, in terms of standards, amenities and civic services, and implications for the rehabilitation of the disabled in particular.

The essential objective of the project is to facilitate and document the entire process of community-initiated, community-sustained, and community-based rehabilitation of disabled people living in the slum settlements.

The key factor of the project is the active partnership with the disabled people themselves and their family members living in the slums at all the stages in the project — planning the survey, analyses, action plans, ongoing activities and outlining the guidelines for future directions.

Objectives for project SAMARTH

(1) Development objectives:

- To facilitate and document the process of community-based rehabilitation of disabled people living in the slum by working in partnership with the disabled and their families.

(2) Specific objectives:

- To conduct a rapid survey of the slum to identify the disabled people, their needs, their experiences with the family, the community, the service delivery institutions and other enabling and disabling factors in their lives.
- To identify human resources and others within and around the slum settlements to facilitate the realization of equal opportunities for disabled people.

- To organize awareness campaigns in the slum community for inclusion of disabled people in everyday life.
- To identify the special needs and the management inputs required to rehabilitate the disabled girls and women in the slum community.
- To identify and train volunteers living in the slums to involve them in rehabilitation of disabled people.
- To network with the GOs, NGOs and GROs in initiating activities related to community-based rehabilitation for the disabled living in slums.

Methodology

Various methods have been used in this project. Interviews were conducted with key informants of the community to identify households with disabled people. Detailed interviews were held with 482 disabled persons themselves and/or with their family members to identify their needs and their perceptions to fulfil their needs. Family profiles were prepared to assess the type of support provided or lack of support.

A neighbourhood survey was conducted of 5450 non-disabled persons living next to a disabled person by interviewing the head of the household. Considering that the immediate neighbourhood is of much value to people living in crowded slums about ten neighbouring households were selected on either side of the household having a disabled person. Our committee of disabled people themselves decided that this should be the first line of assistance, since either the assistance or resistance comes from the neighbours first.

Focused group discussions were conducted with members of the community, politicians from the slum community, officials, schoolteachers and health staff operating in these areas to determine their opinion about community-based rehabilitation processes of/for disabled people in the slums.

Case studies were also carried out to obtain a closer and detailed feel for the perceptions and experiences of disabled people living in slums. Clinical psychologists in their premises conducted the

interviews, invariably with the family members peeping in and neighbours taking a glance at the psychologist and the disabled. These sessions were spread over a few days.

Strategies for interventions

Operation of project SAMARTH began with the identification of the three core components:

- the disabled in the slums;
- the slum community;
- the rehabilitation process and mechanisms that would link the disabled, the slum community, the neighbourhood, the intervention agency (TASH) and the support of specialized individuals and institutions.

It was decided that the project should have a long-term perspective and plan of action to make the rehabilitation process relevant, meaningful and sustainable. However, the spirit of the project was flexibility and evolution from the viewpoint of the disabled themselves. Hence, even the pace of the project and regularity were determined by the decisions taken by the Community Action and Advocacy Committee (CAAC). The basis of the rationale associated with approaches to intervention included the following:

- The identification of the disabled should follow a visit by senior field supervisor to assess correctly the type and extent of disability.
- The feasibility of immediate rehabilitation measures should be explored. This should include long-term rehabilitation measures, for example, to prevent further deterioration.
- The role of TASH is to facilitate, organize, sustain, develop and empower local resources to establish mechanisms to handle rehabilitation. It should establish an infrastructure that has trained volunteers sufficiently motivated through regular training sessions, updating information and upgrading their skills related to disability and rehabilitation. A project of this kind does trigger some expectations from the respondents and the community.

Specific interventions

- Facilities and support: the props and the sops
- Training: getting them involved
- Advocacy and awareness-building: the first steps
- Street plays
- Festivals and celebrations
- Medical camps
- Networking with service providing agencies
- Self-help groups' formation
- Volunteers in residence
- Yoga and hobby classes
- Information dissemination: SAMARTH Newsletter
- Actions related to procedures and other matters with government
- Capacity-building of other organizations
- Recreation and retreats

Onward and forward

This project involved over 30 young members from the community itself as fieldworkers to conduct the survey. One fieldworker said that her family members waited anxiously to hear about her experiences of the day. Another said, "I really began to understand that I am not the only one to have problems". These well-trained fieldworkers from the community are now part of the volunteers-in-residence community since their initial exposure to the survey work, orientation and training enabled them not only to identify a disabled person but also to work with them as partners to facilitate their rehabilitation process.

Our ongoing lessons!

Success stories of the rehabilitation of the disabled need to be publicized. This serves more of an inspiration than mere words. Disabled people living in the slums sometimes develop innovative solutions to everyday challenges; there is need for a platform so that they can share these experiences. To disabled people and their families provision of information should be supported by a package of quality services. Counselling and consulting services for the disabled and their families need to be locally available. Decentralization of services enhances their availability by the

disabled and their families. Major civic and other facility providers should be trained in methodologies providing 'disabled friendly' services. Frequent community celebrations (formal and informal) should be arranged to rejuvenate the disabled and their families in their struggles to improve their lives. The visibility of participation and involvement of disabled people in community living should be enhanced. There is a need to build up a pressure group for political action in favour of involvement of disabled people in everyday life that focuses more on equal opportunities than token affirmative actions. Capacity-building of volunteers in residence who live in slums seems a viable approach for the sustainability of disabled people in community-based rehabilitation.

A.K.M. Momin: The experience of working as the Director of the Centre for the Rehabilitation of the Paralysed (CRP) in Bangladesh

The Government of Bangladesh considers that disability is a health problem to be remedied through medical means. Medical rehabilitation is aimed at returning the patient to a maximum state of health, to a former job and to a way of life as normal as possible. However, the services available for treatment and rehabilitation of disabled people are inadequate. There are no specialized hospitals or clinics for treatment and rehabilitation of people with spinal cord lesion (SCL) apart from CRP in Bangladesh. One government hospital has a specialized unit, which provides 40 beds for people with SCL and offers medical treatment and therapeutic services. People with SCL also receive services from other hospitals and clinics, which, however, have little expertise in this area. There is no consultation in these cases between the user and provider. The user is under the full control of medical professionals who provide treatment of this nature on the basis of their professional expertise. Medical domination has caused a great dissatisfaction among the users who have received services from providers other than CRP.

The service offered by CRP is not limited exclusively to medical treatment for people with spinal cord lesion. CRP offers services, which focus on the person's whole life experience rather than treating just the body. Though CRP initially emerged as a unit of a specialized government hospital, over the years its strategy of service provision has changed.

This has been a consequence of user involvement in service design and provision. From CRP's inception, the service users have taken part in the running of the organization and, subsequently, they have become employees of CRP. They also represent user views in the Centre's team meetings. The management of the day-to-day operation is a team approach. The team is composed of heads of different departments and two service user representatives (both of whom are ex-service users of the Centre). They use wheelchairs for mobility. Service users elect user representatives (male and female) for one month. Participation is rotated as CRP's user group changes on a regular basis. User representatives share their experiences directly with team leaders/department heads with regards to provision of

services. This is a user-led approach to service delivery, consistent with a social model approach. My experience of working with disabled people shows that if they are employed as service providers and given the power to control the service, and if those who receive services from the Centre are consulted about the effectiveness of service provision, this has a greater impact on the user's life.

There is no doubt that the Centre benefits directly by employing disabled people and involving users in service provision in a number of ways as listed below:

- A person with SCL feels that they are part of the organization and that they 'own' it. They offer services sincerely and tend to work harder. Many have worked with CRP for 15–20 years.
- The staff turnover rate among disabled people is very low. Furthermore, some of those who have left CRP now work independently. Several individuals have set up a self-help group for disabled people, which is supported by CRP, namely Bangladesh Protibondhi Kallyan Samity. Some work for international organizations such as Oxfam.
- People with SCL feel more comfortable talking with peers than with non-disabled members of staff.
- A user-friendly environment is created where providers and users are on the same level, as opposed to the traditional service provider and recipient approach.
- The effectiveness of the service is much higher than the traditional approach.
- The service is cost-effective. Users feel secure, gain confidence and share expertise with non-disabled providers. This creates a learning environment through which non-disabled providers learn and share experiences.
- Openness between service providers and users reduces the risk of misguided policies and ineffective services.

- The CRP structures, organizational and environmental, have been constructed to facilitate access and minimize obstacles.
- Interaction between users and providers empowers people with SCL and increases their self-reliance.
- Users feel confident to describe their own experiences and limitations, which in turn reduces their depression and feelings of guilt.

All these ways of involving disabled users in service provision increase the effectiveness and sustainability of the organization.

Dr Nadim Karam: Addressing the health related needs of the disabled: concepts, operational concerns and challenges. Background paper for discussion, Lebanon

Introduction

Issues relating to addressing the needs of the disabled continue to face controversy. They present serious challenges to the disabled themselves, their social contacts, their families, their communities and society as a whole.

Related efforts and commitments face conceptual and operational challenges and obstacles, i.e. defining basic terminology, priorities, objectives, and systems of finance and sustainability.

Globally adopted concepts, especially those relating to human rights and discrimination, may be perceived as not easily put into practice by many of the decision-makers and professionals concerned. This may discourage those involved, thus slowing progress, particularly when professional resources, skills and material are limited.

Societies and communities are increasingly frustrated with the alternatives offered by the classical medical model based on high technology that is put forward by powerful service and research industries. Confusing “disability” with “impairment”, the model focuses on reducing or eliminating impairment with limited consideration of the societal and environmental variables that govern the relation between “impairment”, “disability” and “handicap”. This results in excessive expenditure on a small number of “advantaged disabled” individuals who can access the system, with little concern for the “disadvantaged disabled” who cannot access the system. Thus, many individuals with impairments and secondary disabilities are not given enough support.

Despite some progress, many societies still fail to address the needs of the disabled. They fail to learn from the experience of others and fail to adopt appropriate concepts and strategies. Access to cross-cultural experience and research now provides a means of better understanding past failures and the determinants of success.

This paper presents considerations to be taken into account in the planning, implementation, evaluation and upgrading of programmes addressing the health related needs of disabled individuals. In doing so, the paper will contribute to a better understanding of the challenges and obstacles of implementation, the factors influencing impact and efficiency of interventions, and the determinants of success.

The situation

Individuals, families, communities and nations suffer the complex burden of disability and handicap. Affected individuals are many. Actual numbers and related proportions are difficult to estimate because of variations in definitions and the dynamic relation between impairment, disability and handicap.

Those concerned face the challenge of effectively helping the disabled. The challenge is particularly difficult when material and human resources are limited. In this case the disabled often become entrenched in a cycle of disadvantage with increasing socio-economic burden.

There are many issues and related challenges that influence the organization of intervention programmes. A few principles have become permanent guidelines. These include:

- needs are always changing;
- using appropriate interventions, the social burden of disability and handicap can be managed and alleviated significantly with beneficiaries (disabled individuals, families, communities) becoming effective helpers;
- appropriate interventions must be relevant;
- primary and secondary prevention and early identification and intervention are essential and reduce costs;
- involvement of beneficiaries is essential;
- the biomedical approach to the treatment of impairment, disability and handicap is inaccessible to most, is not very effective and does not often reduce costs;
- disability and handicap are related to social role and perceived socio-economic value.

The issues

Impairment, disability and handicap

The interrelation of impairment, disability and handicap has a conceptual framework that is dynamic, context related and to some extent person-specific. All concerned parties should gain in-depth understanding of how time, age and societal variables, including adopted and imposed social roles, may affect this relation. That the disabled cannot be grouped into any single category or profile is an important consideration in planning services and human resources.

Rights

Despite internationally endorsed declarations on rights and opportunities, issues relating to the rights of the disabled continue to be challenged by inappropriate beliefs and practices of those concerned (including the disabled) regarding social value, social role and priority.

Disabled individuals and their families, particularly in communities and societies where resources are limited, often suffer serious disempowerment. This denies them the means to pursue their rights, the outcome being a cycle of continued disempowerment and disadvantage.

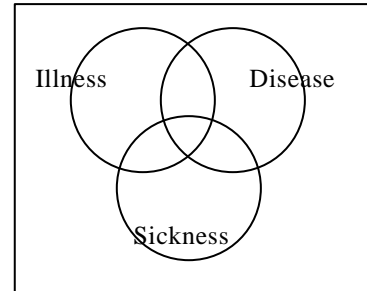
Perceptions of social value and related priorities

The function of the family, community and society should be studied for each intervention programme. Cultural, religious and economic variables that influence perceptions of social value should be identified and discussed. Without these considerations, personal and social responsibility (not necessarily concerning the legal system) will not be taken into account when deciding whether intervention programmes will be viable and sustainable. This is particularly important when discussing actions in relation to social groups such as children, women and the elderly.

Health related needs

Special attention should be directed to the clarification of existing beliefs and concepts that interrelate health, impairment, disability and handicap.

From the concept of Primary Health Care that includes promotion, prevention, care and rehabilitation, it should be realized that the disabled are not necessarily unhealthy. Therefore, a conceptual framework for interaction with the medical care system should include both the disabled and non-disabled population.



This model should relate those who have disease to those who are ill (illness), to those who can assume the sick role (sickness) (see Figure).

As needs are always changing, an appropriate approach would be to clarify what is needed through active discussions with all concerned. A process of empowerment should be integrated into this approach.

Responsibility/accountability/authority frameworks. Who should be involved? Who decides?

Who is responsible for the care of the disabled and should the principle of personal responsibility towards one's own health apply to individuals with serious disadvantage? Who should be held accountable and where does the decision-making authority lie in relation to the health of the disabled? How can those concerned identify with the value of involvement and commitment?

The answers to these questions are important in determining available resources and budget. They deserve wide discussion among the disabled, their families, their communities, caregivers, decision-makers and resource managers.

Provision of direct services: human resources needed, the role of the family and voluntarism

The profile of professionals and service providers involved in the provision of direct and non-direct services to the disabled is of

utmost importance. Manpower and professional models for developed countries are not appropriate for economically and socially underprivileged regions. Therefore, human resource development programmes should relate to actual community needs and resources. This would facilitate the development and training of professionals and service providers recruited from community members. Those trained would be socio-culturally sensitive, affordable, and able to maintain and expand their existing community relations. Such relations are important at every stage of the process of prevention, early identification, appropriate intervention, and commitment.

The role of the family in the provision of direct services is of utmost importance. Family members can be trained to become effective helpers in the caring process. The involvement of family members and proactive service providers would facilitate the development of voluntarism. Serious effort should be directed towards developing organizational frameworks and reward systems to encourage and sustain voluntarism.

Appropriate expectations

False expectations continue to cause serious misunderstanding, resulting in failure and wasted resources. Expectations should be clarified in advance for each case. This would provide a balance between what is needed, what is wanted and what is possible. Such a balance is particularly important in setting rehabilitation objectives and intervention programmes.

Expectations may be inspired by advances in science and technology, or by successful interventions in other communities. However, expectations should not be influenced by outside pressures.

Viability and sustainability

The operational viability of intervention programmes should be extensively discussed in advance and continued during implementation. Factors affecting viability should be identified and given due consideration. Important factors relate primarily to resources and socio-cultural acceptance of interventions. Thus, it is necessary to consider human resources both with and without material and financial issues. Equally important would be to

explore financial reward systems that relate to the level of commitment.

The programme should also be sustainable, i.e. able to be prolonged and still be effective in addressing future needs. All those concerned should consider this concept.

Monitoring and evaluation

Monitoring and evaluation continue to present a serious challenge to efforts of addressing the needs of the disabled. Monitoring and evaluation are essential prerequisites for good management. The disabled are a diverse section of the population. Hence, indicators of progress are difficult to identify and estimate. Indicators relating to effectiveness and outcome are even more difficult.

Monitoring and evaluation need many resources. Where resources are limited, valuable management information systems are difficult to establish, operate and maintain.

Cross-disciplinary contacts

The disabled and handicapped are active members of society. Systems developed to address their health related needs interact with systems concerning all needs of society. It should be noted that the needs of the disabled are not limited to health. Thus, intervention programmes should ensure that there is contact among those trained to work with the disabled and those from other areas of study.

Operational considerations governing interventions

The complex nature of disability and handicap, the related disadvantage and disempowerment suffered by the disabled, and the social burden on the community deserve consideration as social priorities.

Viable, effective and affordable intervention programmes are essential in every society, within every community and at the level of every individual and family in need. It is useful to consider the whole population:

- the healthy need preventive and promotive interventions;

- the person suffering impairment needs early identification and appropriate interventions to limit or remove the impairment;
- the disabled need interventions to reduce disability where possible, and to prevent or limit possible handicap;
- the handicapped need interventions to reduce handicap, and to prevent or limit secondary social burden.

Therefore, intervention programmes should take into consideration the following principles.

Preventive interventions

Such interventions should extend beyond primary prevention to include secondary prevention. Primary prevention is important to prevent injuries and/or diseases that may lead to impairment. Secondary prevention is important to prevent and/or limit the impairment after injury and/or disease. Early detection and intervention are integral to the concept of secondary prevention.

Accessible services

Easily accessible services are very important; they should be affordable, socially and culturally acceptable, and situated near to those in need. Services should be managed so that inappropriate utilization and abuse are avoided.

Proactive approach

The cycle of disability, disadvantage and burden often leads to a state of disempowerment. Disabled individuals, families and even communities may lose hope. Cultural beliefs and practices may be perceived to encourage such despair.

Interventions should have an empowering proactive perspective to create an atmosphere of hope among those in need and to invest in the development of reward systems acceptable to all concerned. Moreover, proactivity is essential to a modular incremental approach to rehabilitation, social integration and inclusion. Such an approach would inspire further action.

Partnership, commitment and involvement

Rehabilitation, involvement of the disabled themselves and prevention of disability need active support. Such involvement would not be effective without a sense of commitment and partnership. Those concerned should feel that their personal interest and welfare are at stake. They should identify with a reward system that goes beyond material reward for services.

In view of this, family and community involvement is a prerequisite for success. With adequate training and appropriate planning and monitoring, interventions can become more effective.

Service providers, professional and scientific training

Appropriately trained service providers should use their acquired skills and knowledge in professional and scientifically sound ways. Service providers should be involved in professional and service contacts that allow:

- exchange of information;
- on-going skills development;
- two-way referrals;
- support to professionals.

Therefore, the involvement of academic institutions, professional bodies and think-tanks is very important.

The issue of appropriate human resources should not only include scientific training but also the development of community members who:

- are willing to learn;
- can identify community needs and activities;
- are adaptable;
- are accepted by the community;
- are affordable to the community;
- can identify long-term commitments within their area of training;
- are interested in team work and involvement in referral and professional contacts;
- can understand and identify their professional limitations.

Research and documentation

Research and related documentation identify professionals working in a particular area of study and facilitate networking. Both are important for sustainable reward systems. Research and documentation also encourage the organization of information that is useful for management, monitoring and evaluation.

Monitoring and evaluation

A dynamic process of monitoring and evaluation is essential for good management because the intervention programme can be made more effective and successful. This would contribute to the provision of reward systems that are viable and sustainable.

The resources needed for effective monitoring and evaluation should be integral to planning and budgeting. The cost of monitoring and evaluation should be seen as an investment and not expenditure.

Monitoring and evaluation should be adapted for each intervention programme. Benchmarks and related indicators should be identified through a consensus involving all concerned. Such a process also supports the building of commitments and of responsibility/accountability/authority frameworks.

Sustainability

Sustainability is primarily a conceptual issue. Sustainability is only possible if related issues are integral to the social and personal ethic of those involved. Therefore, the intervention programme needs a fundamental perspective determined by commitment.

International assistance

As a matter of principle, international assistance should instigate, catalyse and/or support. It should help the target beneficiaries. However, international assistance is given because it furthers the interest of the benefactor. This applies to all forms of assistance including that provided by international nongovernmental organizations and UN agencies and bodies.

In view of this, beneficiaries and benefactors should agree on issues where there is a confluence of interest, need and related reward.

Challenges and alternatives for action

The complex and serious challenges relating to addressing the needs of the disabled are evident. Most have a conceptual perspective and, in view of this, the health related needs of the disabled are best addressed within the framework of a system based on the concept of Primary Health Care, as detailed in the Alma Ata Declaration of 1978. Such a system would address the issues as well as the operational considerations.

Therefore, an appropriate course for any community or society should strongly relate to the concept and principles of Community Based Rehabilitation (CBR). This would provide a framework adaptable to community related needs. It would take into account the planning and implementation of affordable and acceptable interventions that are responsive, appropriate, scientifically sound and effective.

Coupled with a commitment to a dynamic modular incremental approach to address needs through appropriate planning, CBR stands as the alternative.