REHABILITATION PROFESSIONALS IN PUBLIC HEALTH SYSTEMS – AN INITIATIVE TO REDUCE VULNERABILITIES FOR DISADVANTAGED COMMUNITIES

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HARD FACTS

- ⇒ 600 million people in the world experience disabilities and an estimated 80% of the world disabled people live in developing countries.
- ⇒ 80% of the total populations (including People with Disability) live in rural areas – whereas most of the hospitals/facilities exist in cities…
- ⇒ Approx. 1 million of new cases of disability are added annually in South Asia…
- ⇒ Average only 5-10% persons with disabilities have access to basic rehabilitation services…
- ⇒ 1% children with disabilities complete schooling – a majority cannot go to school…
- ⇒ Less than 1% of PWD are employed and about 90% of them are paid less than US $1 per day …

References: 2001 census government of India, National Sample Survey Organisation (NSSO) – 58 round (2002), UN statistics department library data for India age classification, UNDP formula for the calculation of disability prevalence, WHO classification for disability analysis, World Development Indicators 2001 and Ministry of Social Justice and Empowerment, India – 2000

EXPERIENCE FROM INDIA…

COMMON PROBLEMS IN INDIA

A) Disability Scenario – Government of India (Census 2001 and National Sample Survey Organisation) estimates approx. **2 percent** of the total population as disabled. Due to differences in the definitions of disability used by the Govrenmnet institutions and use of inadequately trained surveyors, the data reported are not comparable. Organisations working in disability do not consider the census data to be accurate and believe that there are at least, if not more than, 55 million people with disabilities in India i.e. **5 percent** of the population is disabled.

B) Possible causes of Disability (Impairment) - Almost 70%[1] of the causes of disabilities in India are due to communicable diseases, serious illness during childhood, pregnancy related, polio, ear discharge, eye diseases, cataract, accidents, violence and untreated injuries/ diseases. All of which

[1] Department for International Development (DFID) – March 06

have a strong relationship to poverty. Hence, the 360[2] million people in India who live below the poverty line are the most vulnerable to impairments.

C) Women with disabilities - Women with disabilities generally have less access to rehabilitation services than disabled men. In accordance with the traditional social and cultural norms in village societies, many women do not go out of their houses to seek help for health care, especially if the care-provider is a male.

D) Health and Rehabilitation - Rehabilitation services (especially is the most neglected chapter and still not part of health care delivey system. It is difficult to identify whose 'baby' rehabilitation services are … Health or Social Justice.

E) Access to Rehabilitation Services - At present, there are a number of benefits/directives/rules for persons with disabilities in the areas of education, health, labour, rural development, social welfare and other sectors. Despite all these schemes and attempts, still only about 5%[3] of the disabled population of India is reached.

F) Rehabilitation Professionals - The numbers of trained rehabilitation professionals are not sufficient, there is a huge gap between the number of rehabilitation professionals required and the ones that are available.

- The personnel of institutions at the national and state levels are the professionals who can be expected to work in conventional rehabilitation and health services, for example specialized physicians, orthopaedic surgeons, occupational therapists, physiotherapists, speech therapists, and prosthetics & orthotics staff.
- At district level they may be professionals like general physicians, may be physiatrists or orthopaedic surgeons, therapists, and prosthetics & orthotics staff.
- Finally, at *community (Village or Block/Taluka) level*, there are usually no rehabilitation professionals at all. The persons working there - usually called *community health workers* or *community rehabilitation workers* – are often volunteers.

INTRODUCTION AND BACKGROUND

Handicap International is an international organisation specialised in the field of disability. Non-governmental, non-religious, non-political and non-profit making, it works alongside people with disabilities, whatever the context, offering them assistance and supporting them in their efforts to become self-reliant. Handicap International has been working in the South Asian region since the early 1980's and in India since 1988. Handicap International has been working on disability and rehabilitation initiatives following the earthquake (year 2001) in Gujarat state in western India.

PUBLIC HEALTH CARE SYSTEM

[2] National Sample Survey Organisation (NSSO) – 58 round (2002)
[3] Ministry of Social Justice and Empowerment, India - 2001

In India, **Public Health Care System** is the **cornerstone** of **rural healthcare** and is widely utilised **by people especially the poor**. It is a first port of call for the sick and is set up to provide an effective referral system; in addition to being the main focus of social and economic development of the community. It forms the first level of contact and a link between individuals and the national health system, bringing healthcare delivery as close as possible to where people live and work.

The public health care system is responsible for providing promotive, preventive, curative and rehabilitative care.
The public health care system consists of Primary Health Centre, Community Health Centre, Block (Taluka) Hospital, District Civil Hospital and Medical Colleges.

The public health care system functions on a three-tier healthcare framework; the Primary Health Care Centre (at the village level) act as referral centers for the Community Health Centers (5 – 10 bed hospitals), Block *(Taluka)* level hospitals (30 to 50 bed hospitals) and District Civil hospitals (150 – 200 bed hospitals).

Despite having an impressive and relatively better health care delivery system amongst all the Indian states, disability had been largely an ignored issue in Gujarat state. Further, the early identification of disability and appropriate rehabilitation intervention is not the focus area for public health care providers.

NEED OF THE HOUR
Many persons become more and more disabled due to lack of early intervention facilities, untimely/poor referrals and poor accessibility of health and rehabilitation services. As per Department for International Development (DFID) article on Disability, poverty and development (Feb 2000), more than 50% of the impairments that result in people being included in current disability prevalence rates “are preventable and directly linked to poverty”.

Only 15% of the people living in urban areas and 3% of the people living in rural areas can avail rehabilitation services - in India, total coverage according to Ministry of Social Justice & Empowerment (2001) is only 5.7%.
We all need to work together to address the need as a "TEAM".
To reach the masses…

- Disability Organizations / Rehabilitation professionals need to understand the public health system.
- Explore possibilities to work in partnership with the public health system.
- Integrate or liaise[4] rehabilitation services in existing health care delivery system.

AN INITIATIVE …
In the course of the collaboration between Handicap International and the Department of Health and Family Welfare, Government of Gujarat (DoHFW)

[4] Alma Ata Declaration 1978

identified a need to enhance the capacity of the existing government health structure in prevention, early identification, intervention and rehabilitation of people with disabilities (PWD) in the whole state of Gujarat.

As a result, a pilot project was conducted in Ahmedabad district of Gujarat from July 03 to May 04, with an aim to ensure that health service providers undertake prevention and management of disability as an integral part of the health services and in an equitable and sustainable manner. Following the successful completion of the pilot and a follow up project covering 9 districts, the project titled "Public Health Care Initiative to reduce vulnerabilities for disadvantaged communities in Gujarat" is now extended to the whole state of Gujarat. The project is been implemented in a phased manner and will accomplish by 2011.

The mechanism of service delivery in the project district is as follows i.e. Identification of PWDs by PHC and referral to CHC and/or District Civil Hospital for medical needs and Rehabilitation centre for rehabilitation needs. Similarly cross referrals between District Civil hospital and Rehabilitation Centre. Also PHC is involved in follow-up of medical and rehabilitation interventions.

Focus of the intervention of the Project

- Build the capacity of primary level healthcare providers for early identification of disability, prevention of disability, and referral of the person with disability to appropriate rehabilitation services
- Consolidate linkages in between the two separate streams (preventive i.e. PHCs and curative i.e. CHCs and district civil hospitals) of healthcare delivery system
- Form networks of Government and Non Government agencies at district levels, who provide services to the persons with disabilities in isolation
- Increase awareness on disability issues in the community

Apart from building the skills of health providers regarding the topics mentioned earlier, the skill building also aims that health providers integrate the issue of disability in the 16 Health programs they implement through their health centers. Most of the health workers are not able to form the link between the existing health programs and disability services. For instance the awareness level about the link between Polio vaccination and Physical disability is very low. The same applies for anti-natal care that can prevent pregnancy etc.

The preventive and curative streams of the healthcare delivery system are two separate islands and hence the need was identified to better coordinate between the two on the issue of disability. For instance, only a panel of 3 doctors at the Government District hospital or the Government Medical College can issue the certificate of disability however the preventive stream has limited knowledge about the same. Hence, the health workers and the other functionaries at the PHC were made aware of the process of certification of disability, so that they can advise and refer accordingly.

The project therefore forms close linkages with the different stakeholders providing services and assistance to the persons with disability. The project seeks the local resources and builds their capacities, for the reason that local agencies have a wide outreach, and building their capacities aims at providing sustainability to the intervention.

The project has also developed a comprehensive behavior change communication strategy on prevention, early identification, intervention and rehabilitation. As per the communication strategy, the most relevant messages on the issue of disability will be conveyed to the community using appropriate mediums (e.g. radio and television programs, posters, banners etc) by the stakeholders.

Interesting Statistics from the project in 10 districts (Till Oct, 2007)

- ⇒ Number of Health Workers trained – 4,414
- ⇒ Number of Medical Officers trained – 540
- ⇒ Number of Rehabilitation Organizations associated with Health department – 10
- ⇒ Number of PWDs identified and received rehabilitation services – 50, 000

ROLE OF DISABILITY ORGANISATIONS / REHABILITATION PROFESSIONALS

Based on a Twin-Track approach, i.e. by working with the Public Health System on one hand and Medical/Rehabilitation service delivery on the other hand, disability organizations and rehabilitation professionals can play the following roles:

a) Facilitate multidisciplinary team approach
b) Provide and enable access to quality rehabilitation services
c) Provide rehabilitation services to people with disabilities in a rights based manner and facilitate their participation in education, economic, social and political spheres.
d) Network the different rehabilitation service providers in the district to provide comprehensive services
e) Train grass root level health workers on early identification, prevention, intervention and rehabilitation.
f) Orient and sensitize staff at primary health centre and community health centre levels on disability and rehabilitation management
g) Facilitate development of networks and collaboration between Government and Rehabilitation Centers
h) Raise awareness for prevention of disability and bringing disability management initiatives into mainstream development activities.

An Example:

- Health worker identifies during a house to house survey in a village that Lata, a 7 yrs. old girl “cannot walk and has no urine control”
- Lata is referred to a primary health centre from where she goes to a rehabilitation centre
- In the rehabilitation centre Lata is identified as having spina bifida and paraplegia with a loss of bladder and bowel control and on top of all these two big pressure sores due to prolonged sitting

- The rehabilitation centre refers Lata to the district civil hospital for treatment of the pressure sores
- The rehabilitation centre speaks to the parents and explains them her problems and what they have to do to ensure she does not develop secondary infection and deformity
- Lata is taught exercises and positions to strengthen her muscles and avoid pressure sores. She is fitted with an orthosis
- The health worker follows up rehabilitation intervention at home and assists the family to build a pair of parallel bars using bamboos
- Lata is now standing on her feet with the orthosis and a pair of crutches, due to some training
- The health worker arranges an Identity Card and scholarship to ensure she can go to regular school.
- The health worker along with community members takes Lata to the school and speaks to the teacher and other classmates about her problems. After initial hesitation they accept her, and with assistance from the rehabilitation centre, the school modifies the toilet so she can use it without problems
- Lata stood second in the class – credit goes to……..

CONCLUSION

- Working with the government whenever possible is a key in providing rehabilitation services to people with disabilities. It is an undeniable fact that the government system has the widest outreach along with a massive infrastructure and human resources. These facts increase chances for sustainability of changes. Its is a fact that the community relies heavily on the public sector for health care services even though they do not have all the best things to say about it. A vast number of community members looks forward to the public system to avail the health services.
- We at Handicap International have the firm believe that if the existing system (Governmental and Non-Governmental) is strengthened, and once the government machine starts rolling, then there is no looking back.
- Rehabilitation services and rehabilitation professionals need to work with the public healthcare system to reach a maximum number of people with disabilities.

We are confident that working with the health system is a strong way to reach people with disabilities living in far flung and remote areas and enable people to access rehabilitation services and build an inclusive rights-based society.