

Including Disability: Improving Access to Medical & Rehabilitation Services

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Good afternoon.

I work for an Italian NGO, Amici di Raoul Follereau (AIFO) based in Bologna, which is in official relationship with World Health Organization (WHO) and collaborates with Disability and rehabilitation unit (WHO/DAR). AIFO has been collaborating with DAR over the last ten years and over the last three years I have been working as a project manager for a WHO-AIFO joint initiative. I am not speaking today as official spokesman of WHO/DAR but some of my observations related to their strategies have been agreed with their department.

I shall like to start my presentation by talking about the **declaration of Alma Ata** in 1978 when different country members of UN met in Alma Ata and came up with the declaration on primary health care and decided the objective of "Health for all by the year 2000". The first important concept of health as it came up in Alma Ata was that health is not the mere absence of disease but it is seen as a state of physical, social and mental well being.

The second basic concept of health as it was defined in Alma Ata was to recognise that communities have the right to decide their own health priorities. For reaching the goal of health for all, it was decided to propose the concept of primary health care services, which were supposed to provide promotive, preventive, curative and rehabilitative health care services.

For different reasons, this basic concept of health and of primary health care services as envisaged in Alma Ata declaration was never fully realized. The primary health care services, which came up following Alma Ata focused mainly on some specific curative services and a few preventive services, while rehabilitation was often left out of these and communities did not have any role in deciding about their local health services.

Coming to the **role of WHO/DAR** the challenges facing the world are:

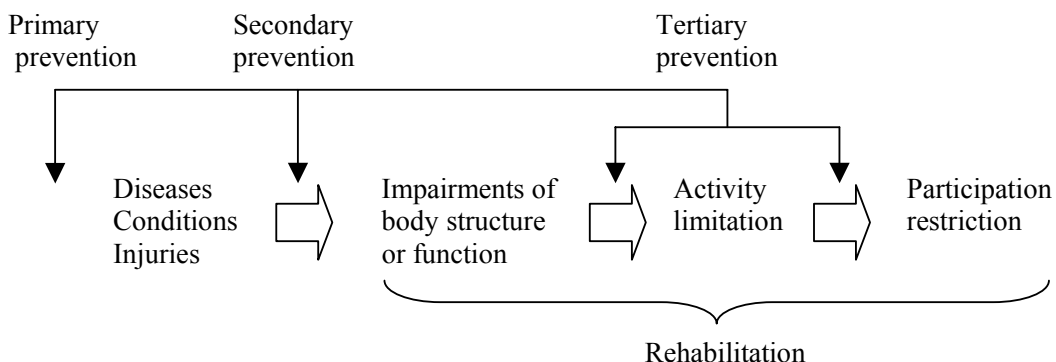
1. Disabled persons make up to 10% of the world population.
2. Not all the persons who are classified as disabled persons require medical services of rehabilitation.
3. Disability is a big issue because it affects the whole families in terms of its economic implications and implications for quality of life of persons. It is estimated that it may affect up to 25% of all families directly or indirectly.
4. Majority of persons with disabilities live in areas far away from the medical services of rehabilitation and most of them have insufficient access to rehabilitation services.
5. There are changing trends in disabilities all over the world as the number of persons with impairments is increasing due to many reasons. Chronic diseases like hypertension, arthritis, diabetes, heart diseases, etc. are also increasing. At the same time, the medical services are organized in a manner, which is more suitable for responding to needs for acute care rather than chronic or long term care. Hospitals and health care services tend to provide acute interventions and are not planned for long term needs.

The **activities of WHO/DAR** focus on three main areas. WHO is a specialized agency of United Nations for giving advice and guidance to member states of United Nations on health issues and health care.

The three areas of focus for DAR are:

1. Helping national governments to develop adequate national policies and guidelines related to disability and medical rehabilitation services.
2. Helping the national governments in strengthening of national rehabilitation services.
3. Reviewing community based rehabilitation strategies and supporting national governments in adopting CBR strategies.

It may be important to clarify the concept of rehabilitation and the level at which it works in terms of medical and rehabilitation services. Promotive and preventive activities work before a disease occurs - thus vaccination of mother and child, antenatal care, health education, etc. are all promotive and preventive activities. Once a disease occurs, early diagnosis and proper treatment are needed to decrease the risk of disability. The role of rehabilitation services covers the part when the impairment has already occurred, which results in limitation of activities and limited participation in the community and family life.



The term “rehabilitation” refers to 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. (From UN Standard Rules)

Medical component of Rehabilitation services can be of three different kinds:

1. **Institutional rehabilitation services** are specialized institutions where persons with specialized expertise are present. Persons with disability need to come to these institutions. These institutions need properly trained staff like doctors in physical medicine, surgeons, orthopaedic surgeons, physiotherapists, speech therapists, etc. and need specialised equipment. Therefore these services have a high cost and in developing countries, these may not have adequately trained personnel or may not always have sufficient resources to maintain and buy equipment. These services are also placed in big cities and may not have sufficient capacity to answer the needs of city dwellers. In any case, these may be in-accessible in terms of cost, transport, and distance to persons coming from rural areas or smaller cities.

2. **Outreach services** are created when specialized personnel from institutions go to community health services to provide their service. As this requires even higher costs, these are usually available to small groups or communities and may not be sustainable even in developed countries.
3. **Community based rehabilitation (CBR)** services are based in the communities and use the existing personnel and resources present in the communities. We shall talk much more about CBR services in a little while.

As far as primary health care services are considered, in many developing countries such services do not cover all the population. Thus in some areas, people may need to walk long distances because there is no health centre nearby or it is there but it does not have any staff.

Even where primary health care services exist, these may not be accessible to persons with disabilities. Disabled persons may face greater problems in reaching the health centres. If they manage to reach the health centres, there may be physical barriers like stairs, so that they can't go inside. If they reach inside the centre, there may not be any person who understands sign language so that a person with hearing disability may still be excluded. When all these problems are solved, still the health centre staff may refuse medical care because they lack knowledge about disability and rehabilitation or feel that rehabilitation services should take care of disabled persons. Thus disabled children may be refused vaccination or treatment for fever and diarrhoea. Even if the primary health care services should also provide basic rehabilitative care, this aspect is not covered under PHC and nurses and para-medical workers do not receive any training on these aspects.

In late seventies, the first ideas of CBR came up at the same time as the Alma Ata declaration. WHO prepared a manual, which focused on basic rehabilitation activities and preparation of simple orthopaedic appliances, which could be used by family members and community volunteers for greater autonomy of persons with disabilities in activities of daily living. During the same time, there were other initiatives using the same idea with some minor variation like David Werner in Mexico, where parents of disabled children came to the Projimo project and were involved in learning basic skills of rehabilitation.

Soon, other specialized agencies of UN like UNESCO and ILO came up with similar approaches for promoting education for disabled children and promoting employment or self-employment of disabled adults. For a long time, there has a debate about these different approaches to CBR known as WHO model, ILO model, Werner model, etc.

Realizing that to be effective rehabilitation has to look after all the different needs of medical care, employment, etc. in 1994 ILO, UNESCO and WHO came up with a joint position paper on CBR saying that all these approaches are complementary. This paper has recently been updated with a new position paper, which has been signed also by UNICEF.

The basic idea of CBR is multi-sectoral - it should involve all the different aspects. CBR should also be responsive to the local needs and thus the basic approach remains the same but it has to be adapted to local social and cultural context and may seem very different from country to country and from project to project.

CBR approach should be based firmly in the community, which needs to look at the priorities and resources. Disabled persons themselves, their families and their organizations together are the first community groups who should take charge of the CBR process. Other community

leaders, religious leaders, local organizations, youth groups, etc. all have a role in the CBR approach and all need to be involved.

The following definition has been taken from the updated Joint Position Paper (draft, 2001) on CBR by WHO, UNESCO, UNICEF and ILO.

CBR is a strategy within general community development for rehabilitation, equalization of opportunities and social inclusion of all children and adults with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families and communities, and the appropriate health, education, vocational and social services.

There are many CBR projects and programmes in a large number of countries. However these still face lot of problems. Most often, CBR activities remain limited to some project areas and answer the needs of limited group of persons. The multi-sectoral approach, which implies activities covering health, education, occupation, sport, recreation, social life, community life, etc. is not very easy and requires lot of effort, especially in terms of collaboration between different governmental ministries and departments.

Bottom-up approach, meaning that initiative starts from persons with disabilities and from communities themselves are considered to be appropriate for community ownership and responsive to local needs. However, these remain limited to small areas. Promoting top-down CBR programmes through national or state governments, which can ensure wider coverage to reach more persons, may ignore local needs and community ownership may be difficult to reach. Thus a more pragmatic approaches which combine the two are probably needed.

Organizations of persons with disabilities (DPOs) and disabled persons don't seem to have much role in many CBR programmes, which become "professionalized". Many countries have national policies advocating CBR but lack resources to implement these programmes. Finally without support from local health centres, it may be difficult to promote CBR.

There is a clear link between **poverty and disability**. The poor population groups are more vulnerable to be disabled while to have a disabled person in the family may mean loss of family income and increased financial burden on the family so that disabled persons face greater risk of poverty. It can be seen as a vicious cycle where poverty aggravates disability, which in turn aggravates disability. Many diseases which produce disability like leprosy, iodine deficiency are specially affect poor families.

The joint WHO-AIFO initiative for studying strategies for promoting **CBR in vulnerable population groups** like slum communities, refugee camps, nomadic populations, etc. is a result of this same understanding that persons with disabilities in poor families and specific groups have more difficulties in accessing health and rehabilitation services. At the same time, this strategy starts by keeping in mind that even the poor and marginalised communities can contribute to the well-being of the poorest and most disadvantaged persons amongst themselves.

The last thirty years have also seen another parallel development, which has links with disability and rehabilitation - that is the development of **social model of disability**. While traditional thinking has been to look at disability as an individual issue where it is person with disability who is considered as "defective" and needs to be repaired or rehabilitated, so that the person can become "as normal as possible". This basic idea of medical view of disability

has been prominent in deciding how different medical, educational and occupation rehabilitation services are organized. The social model of disability is a result of coming together of persons with disabilities to share their experiences, to form their organizations, the DPOs. They present a different view of disability - as a result of barriers created by majority non-disabled society, which does not acknowledge that there are persons with different needs in the society and creates disability. Thus the social model changes the focus from repairing or rehabilitating the individuals to repairing and rehabilitating the society and fighting the barriers. In the developed world, this model has been important in challenging some of the barriers like access to roads and to buildings. The social model also brings forward the view of **disability as a human rights issue**, where disabled persons and DPOs advocate changes in discriminating policies and practices which affect their lives.

People's Charter for Health - Medical Rehabilitation services as part of Right to Primary Health Care: I shall like to briefly touch upon this initiative. Grass-root organizations and NGOs had been behind the adoption of Alma Ata declaration. However the failure of implementation of this declaration, as well as increasing commodification of health services under the guidance of World Bank and International Monetary Fund, which have made access to health service even more difficult for poor population groups, promoted NGOs, grass-root organizations and activists to organize a People's Health Assembly (PHA). The first PHA was held in Bangladesh in December 2000, which resulted in People's Charter for Health. Charter's main appeal lies in its recommendation of answering the basic health needs of all citizens, without regarding their economic status or disabilities etc., by adopting human rights approach. For increasing access to rehabilitation services, it is important that all development programmes keep in mind the needs of disabled persons and make that they are benefit from the activities.

In **conclusion** I shall like to briefly touch the main points of my presentation -

1. There is need to review the medical care paradigm to move from acute care view of services to long term view.
2. Countries need to be helped in reviewing their national policies on disability issues.
3. The civil society institutions, especially organizations of disabled persons need to be strengthened.
4. It is important to make sure that all existing services and programmes, including projects by international development corporations are aware of disability issue and make sure that all interventions, programmes and services are accessible to persons with disabilities.

Thank you for your attention.

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