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Global trends in disability rehabilitation and their implications for leprosy programmes

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Introduction

Globally, the disability rehabilitation scenario today is at an exciting stage. After many years of effort, the International Convention on Rights of Persons with Disability is in sight, a major step forward, and binding on governments to protect the rights of their disabled citizens.

At the regional level, the Asian and Pacific Decade of Disabled Persons (1993–2002) is extended from 2003 to 2012, and the Biwako Millennium Framework promoted by the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) is being followed in the Asian region for programmes for people with disability. The period 2000–2009 was formally proclaimed the African Decade of Disabled Persons in June 2002. The African Decade seeks to replicate the practices of the Asian and Pacific Decade. The Arab Decade of Disabled People was launched in 2004. The Decade of Disabled Persons in the Americas was launched in 2006.

All these international statements focus on rights and inclusion of people with disabilities. To gain a better understanding of the current scenario and their implications for leprosy rehabilitation programmes, a brief summary of the Biwako Millennium Framework of the Asian and Pacific Decade¹ is given below.

THE BIWAKO MILLENIUM FRAMEWORK

‘The Biwako Millennium Framework – Towards an inclusive, barrier-free and rights based society for people in the Asian and Pacific region’ outlines issues, action plans and strategies towards an inclusive, barrier-free and rights-based society for persons with disabilities. The new decade (2003–2012) seeks to promote a paradigm shift from a charity-based approach to a rights-based approach to protect the civil, cultural, economic, political, and social rights of persons with disabilities. The framework identifies seven priority areas for action:

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1. Self-help organisations of persons with disabilities and related family and parent associations

Persons with disabilities and their self-help organisations are recognised as the most equipped and best informed to speak on their behalf, who can contribute to solutions on issues that concern them. Self-help organisations should include marginalised persons with disabilities such as women and girls with disabilities, persons with intellectual disabilities and persons with psychiatric disabilities. The Framework recommends that Governments, international funding agencies and non-governmental organisations establish policy to support and develop self-help organisations; that governments take steps to ensure the formation of parent associations and that governments and civil society organisations include self-help organisations in decision-making processes.

2. Women with disabilities

Women with disabilities are multiply disadvantaged through their status as women, as persons with disabilities, and the likelihood of living in poverty. The Framework recommends that governments ensure anti-discrimination measures, where appropriate, to protect women with disabilities; that self-help organisations adopt policies to promote full representation of women with disabilities; and that women with disabilities be included in the membership of national mainstream women's associations.

3. Early detection, early intervention and education

Less than 10% of children and youths with disabilities have access to any form of education compared with an enrolment rate of over 70% for non-disabled children and youths in primary education in the Asian and Pacific region. This exclusion from education of children and youths with disabilities results in exclusion from opportunity for further personal, social and vocational development. The Framework recommends that governments ensure the detection of childhood disabilities at a very early age and that all infants and young children have access to community-based early intervention services. Another key target is that children with disabilities will be an integral part of the population targeted by the Millennium Development Goal Target 3, which is to ensure that, by 2015, children everywhere, boys and girls alike, will be able to complete a full course of primary schooling.

4. Training and employment, including self-employment

Persons with disabilities remain disproportionately under-educated, untrained, unemployed, under-employed and poor. They have insufficient access to the mainstream labour market partially due to social exclusion. The Framework recommends that member states ratify ILO Convention 159 concerning Vocational Rehabilitation and Employment (Disabled Persons) and develop reliable data on the employment and self-employment rates of persons with disabilities.

5. Access to the built environment and public transport

Inaccessibility to the built environment, including public transport systems, is still a major barrier for persons with disabilities. This problem will only be exacerbated, as the number

of older people with disabilities increases in the region. Universal design approaches benefit all people in society, including older persons, pregnant women and parents with young children. Its economic benefits have been legitimised, yet substantive initiatives at policy level have not been taken. The Framework recommends that governments adopt and enforce accessibility standards for planning of public facilities, infrastructure and transport, including those in rural/agricultural contexts; that existing public transport systems and all new and renovated public transport systems be made accessible as soon as practicable; and that all international and regional funding agencies for infrastructure development include universal and inclusive design concepts in their loan/grant award criteria.

6. Access to information and communication technology

In the past 10 years, there has been much progress in information and communication technology (ICT) development, and it opens up many opportunities for people with disabilities in networking, solidarity, employment and independent living. But it has also widened the gap between persons with disabilities and the non-disabled. The digital divide includes inaccessibility to infrastructure for ICT, Internet, and ICT skills. These problems are acute in rural areas. The multi-media environment is creating barriers for people with visual disabilities. The Framework recommends many measures to improve access to technology and accessibility standards.

7. Poverty alleviation through social security and livelihood programmes

Persons with disabilities are the poorest of the poor. It is estimated that 160 million persons with disabilities (over 40% of the total) are living in poverty, unable to benefit from their socio-economic rights. Poverty and disability are mutually reinforcing as persons with disabilities are socially excluded and adequate social services are not provided. The Framework recommends that governments should halve the proportion of persons with disabilities whose income/consumption is less than one dollar a day. Actions call for Governments to integrate disability dimensions into Millennium Development Goals baseline data collection and analysis, and to allocate a certain percentage of the total rural development /poverty alleviation funds towards persons with disabilities.

IMPLICATION FOR LEPROSY REHABILITATION PROGRAMMES

With the use of 'Multiple Drug Therapy' (MDT), leprosy-affected persons now develop less disfiguring disabilities compared to a decade earlier² and as a result, stigma attached to leprosy, especially enacted stigma, has begun to diminish. The integration of leprosy services into general health services has initiated a transformation in leprosy programmes from being a vertical, stand-alone service, based on a single etiological factor, to a service integrated into general health services.³ Leprosy rehabilitation programmes are also using decentralised and community-based strategies such as those adopted by other health and development services.

These shifts have in turn led to changes in rehabilitation philosophy and practice, moving from a medical model where prevention and reversal of deformities were the prime focus of interventions, to a psychosocial model with emphasis on inclusion, economic rehabilitation, and access to services and human rights. Interventions in leprosy

rehabilitation, particularly in the Asian region, are beginning to shift beyond traditional prevention, treatment and surgical reconstruction to others such as community-based rehabilitation, socio-economic rehabilitation and formation of self-help groups for affected persons and families. Thus, leprosy rehabilitation is changing its emphasis from a purely 'client-centred programme' to a 'client and community centred programme'.⁴

COMMUNITY BASED REHABILITATION

The major change in strategy in rehabilitation for people with disabilities over the past 25 years has been the expansion of services into the community. This has slowly gathered momentum and has developed into a differentiated programme called 'Community Based Rehabilitation' (CBR). Among the recent strategies adopted for rehabilitation of leprosy-affected persons, 'community based rehabilitation' is of special interest because this strategy has been found to be a viable alternative for large populations of persons with disability from rural areas, who are unable to access currently available services. The following section provides a brief history of CBR.

The World Health Organisation and other UN agencies promoted CBR in the early 1980s to provide services at affordable costs for people with disabilities in developing countries. Implementation of this method involved shifting rehabilitation interventions to the homes of people with disabilities and their communities, to be carried out by minimally qualified volunteers, including families and other community members. In the early 1980s, CBR was conceptualised and evolved primarily as a service delivery method with a medical focus, since WHO had recommended that it be integrated into the primary health care system that was already well established by then. Subsequently CBR changed its focus from a medical to a comprehensive approach, including interventions such as education, vocational training, social rehabilitation, prevention and so on. Another simultaneous change was the shift in focus from restoration of functional ability in an individual, to modifying community attitudes and contextual factors. It was felt that mere change in an individual to 'fit' him into his community was not enough but that it was equally important to change contextual factors around the individual as well. Changes in contextual factors involved changing attitudes of others to accept people with disabilities and promote their social integration. It also meant provision of equal opportunities in education, employment, protection of rights etc.

In 1994, the joint position paper of WHO, ILO and UNESCO, which was updated in 2002, further changed the focus of CBR from a service delivery approach to a community development process, by defining it thus: 'Community-based rehabilitation is a strategy within community development, for rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through combined efforts of disabled people themselves, their families and communities, and with appropriate health, education, vocational and social services'. This moves away from the view that CBR is merely a form of 'therapy in community', to an approach that promotes inclusion, community participation and community ownership of programmes. It also recognises that disabled people should have access to all services that are available to others in the community, such as community health services, child health services, social welfare, education etc. More recent changes in the field of CBR are the planners' emphasis on inclusion, equal opportunities, protection of rights of persons with disabilities and the rapid growth of organisations of persons with disabilities to advocate for themselves. The common goals of CBR today can be enumerated as: 1) enhancement of functional ability of persons with disability to the extent

possible; 2) achievement of barrier-free environments, information and communication methods in order to create an inclusive society in which people with disabilities have equal opportunities and enjoy full participation; and 3) empowerment of people with disabilities and their families as decision-makers at all levels, and creation of public awareness in order to ensure that people with disabilities have full access to all aspects of community life.

While these goals may be common across different contexts, the way they are translated into activities depend on the local situation, needs and resources.

Programmes and projects at various levels have formulated different strategies to achieve these goals. These include interventions for individuals with disabilities, for families and for the wider communities, utilising resources available within the communities to the extent possible.

There is greater emphasis now on information sharing and networking in the field, sometimes facilitated by donor agencies through their partner networks. More published literature is also available in journals and newsletters on CBR practice and results. Many more training programmes are available in different countries for different levels of CBR personnel.

Advocacy is actively promoted by different agencies, often through self-help groups of people with disabilities or their families. In particular, self-help groups have become a significant tool to promote self-advocacy, inclusion, equal opportunities and rights.

ISSUES TO BE ADDRESSED IN CBR FOR PERSONS AFFECTED BY LEPROSY

Who needs rehabilitation?

Different writers have indicated that there will continue to be demands for care by persons affected by leprosy. However, what is not yet clear is who will need rehabilitation and which services are best suited for different groups of affected persons. In an analysis of studies on leprosy, Srinivasan reported that 21% to 45% of all persons affected by the disease deteriorated economically.⁵ A high proportion of this group had deformities. Yet, not all persons with deformities deteriorated economically. Conversely, some persons without deformities deteriorated economically. The dilemma is to identify 'who amongst leprosy-affected persons will need community level rehabilitation to address the economic and other psychosocial impact of the illness'. Are they persons with deformities? Or are they persons who will require to be classified according to other parameters that are not yet identified? Likewise, it is yet unclear what kind of rehabilitation is most acceptable to leprosy-affected people. For example, only a very small number of people with deformities may be finally eligible and willing to undergo reconstruction surgery. Similarly, a substantial number of economically deteriorated leprosy-affected people may show no interest in seeking available rehabilitation schemes. Objective evidence on acceptance and appropriateness of rehabilitation services in leprosy is scanty.

Shift in philosophy and approach

The transition of leprosy rehabilitation from medical to psychosocial, and from institutional to community-based processes, in line with the move towards promoting rights and inclusion, would need to be accompanied by certain changes.⁶ Traditionally, health care institutions used a 'top-down' approach in service delivery and governance. In some cases

the systems became so autocratic that the 'needs' of clients were ignored and they never became empowered enough to choose their goals. In contrast, 'community-based organisations' do not have highly differentiated structures or systems of communication that are imposed on clients. They use a 'bottom-up' approach that allows client participation in strategy development. Leprosy rehabilitation programmes until recently, tended to be more institution-based and top-down. However of late, some of these programmes have started adopting 'bottom-up' approaches, using 'participatory needs analysis', 'participatory decision making' etc. They have started moving from a charity based rehabilitation philosophy to an enabling, developmental one, focusing on inclusion, self help and so on. There may be a need for training to build capacity of programme personnel to adopt these approaches.

Expanding services to other disability groups

Many of the leprosy hospitals are in an advantageous position to develop services for other disability groups through expanded CBR programmes, as the evaluation of the Karigiri centre in southern India⁷ has shown. Some hospitals in India have built a good foundation for a CBR programme in a relatively short period of time. These programmes can be strengthened and expanded in terms of scope of interventions and groups served. The CBR programmes can cover persons with different disabilities – cerebral palsy, polio, mental retardation, elderly persons with physical or visual disabilities, persons disabled due to trauma, cases of epilepsy that need to be followed up; in short, all groups that require interventions who hitherto may not have had access to them.

The hospitals are in an advantageous position to do this, as they have many departments to play a referral and training support role. At the field level, the workers and volunteers would form the first-level contact with the community, for detection, referral and follow-up. For the referral and follow-up system to function efficiently, mechanisms of co-ordination need to be established between a nodal, coordinating department like a community health department, and other departments. The resource implications would need to be examined, in terms of funds, additional staff, and capacity-building of staff. Links would also need to be established with other players in the disability field at local, regional, national and international levels.

Some hospitals with a CBR programme, with the institutional back up and other resources available within the organisation, are in an advantageous position to grow into centres for training of CBR personnel, at different levels. Along with training, the potential to develop research projects in CBR is also good, as CBR is still in a developing stage, and there are increasing moves towards evidence-based practices and operations research in this field.

Conclusion

Although the available body of literature supporting CBR today is largely from unpublished sources such as annual reports, internal evaluation reports and so on, many published and unpublished reports of evaluation of CBR in different countries have clearly demonstrated the utility and benefits of CBR in addressing the needs of persons with disability, and in empowering them in different ways.

The path-breaking developments in the disability sector today, including the International Convention of Rights of Persons with Disability, can be seen in a way, to have been influenced by the growth of CBR in different countries, along with the efforts made by CBR practitioners to reach, inform and empower people with disabilities and their families on the one hand, and to influence and inform policy makers on the other.

In the light of the above, it is clear that CBR has a major role to play in leprosy rehabilitation. The move from an institution-based medical model of rehabilitation would be more than justified by the empowerment and inclusion that accompany successful community-based rehabilitation.

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