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COMMUNITY-BASED REHABILITATION AND LEPROSY: HIDDEN CHALLENGES

Key-note Presentation Session 47

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(Summary)

Introduction: Global strategy for reducing the burden of leprosy recognizes a specific role for Community-based Rehabilitation (CBR) programmes in answering the needs of persons with disabilities due to leprosy.

The CBR Matrix presented in the CBR Guidelines prepared by WHO, UNESCO, UNICEF and international NGOs (IDDC) can be seen as a framework to understand and organise CBR activities. It divides CBR activities in five domains - health, education, livelihood, social and empowerment.

CBR is a strategy for working at the level of communities with active participation of persons with disabilities, their families and their communities.

The basic principles underlying CBR are same as that of the U.N. Convention on Rights of Persons with Disabilities (CRPD) - these include participation (persons with disabilities play an active role and not seen just as users or beneficiaries) and main-streaming (using existing services for other non-disabled persons rather than creating specific services for persons with disabilities). A CBR programme respects these principles and is carried out in the communities where people live.

CBR and Leprosy: The inter-connections and links between CBR and leprosy can be seen in 3 broad groups:

(a) Using CBR programme in existing leprosy projects: This occurs usually in NGO managed projects dealing with different aspects of leprosy, where they use the basic principles of CBR in their activities and promote community-based activities. This means that the leprosy project continues its activities, it does not become a CBR project, but in some activities, it uses the CBR approach. For example, leprosy projects may support setting up of and strengthening of organisations of leprosy affected persons in the communities.

(b) Considering some activities of leprosy projects as CBR activities: This is closely related to point (a) above. Sometimes, leprosy projects implement activities such as self-help groups and credits for income generation, that are also commonly used in CBR, thus they call these activities as CBR. Earlier such activities were called socio-economic rehabilitation. However, a key issue here is do these projects adopt the basic principles of CBR or it is just a change of name?

(c) A third issue is inclusion of persons with leprosy related disabilities in CBR programmes dealing with different groups of disabled persons.

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The past decade has seen gradual closure or at least a diminishing of specific leprosy projects dealing with persons who have leprosy related disabilities, managed by NGOs. On the other hand, most of the government-led national and state level leprosy programmes have never played an active role in Prevention of disabilities and socio-economic rehabilitation programmes.

On the other hand, after the ratification of CRPD and different other initiatives over the past five years, increasingly there is greater attention towards starting or expanding CBR programmes.

Thus, it is increasingly important to ensure that persons with leprosy related disabilities are included in CBR programmes.

Need for research and understanding: Most articles in peer review journals on the leprosy-CBR interface are about adoption of CBR principles and approach in activities carried out by leprosy programmes. There are very few articles

Inclusion of leprosy affected persons in CBR: Members of an international federation active in the field of disability related activities were asked if they have any experiences of inclusion of leprosy affected persons in CBR programmes. There were a few positive answers to this query, however all these experiences seem to be in collaboration with organisations working in specific leprosy programmes and seem to be collaboration between CBR and leprosy programmes rather than inclusion of leprosy affected persons. A closer look at the examples collected in this exercise can clarify.

None of these CBR programmes were able to quote any data about leprosy affected persons who were included in CBR activities.

One organisation involved in training of CBR programme managers with experience from different countries reported that in their field work, they had not noted any example of inclusion of leprosy affected persons in CBR. If we look at articles in peer-reviewed journals, almost all the articles on this theme are from leprosy programmes.

Experience of AIFO/Italy: AIFO is an Italian NGO that is a founding member of both anti-leprosy federation (ILEP) and the federation of NGOs working in the area of disability and rehabilitation (IDDC). AIFO supports cross-disability CBR programmes and promotes inclusion of leprosy affected persons in those CBR programmes.

The 2012 monitoring data from AIFO supported CBR projects showed that together these CBR projects reached 115,442 persons with disabilities, out of which less than 5,000 were leprosy affected persons (about 4%). However, if we limit the analysis to CBR projects that are also involved other leprosy related activities, among their beneficiaries, leprosy affected persons are around 8%.

Considering that normally persons with leprosy related disabilities are less than 1% of all the persons with disabilities in leprosy endemic countries, this shows that their inclusion in CBR projects is feasible. At the same time, it would be interesting to see what percentage of persons with disabilities due to leprosy actually take part in CBR activities, and the different factors that influence their participation.

Some issues related to CBR-Leprosy interface: CBR is a relatively new concept and there are many aspects relative to its implementation and its inclusion of different groups of persons with disabilities that require better understanding and related research. For

example, in terms of CBR and leprosy interface, the following aspects need to be understood better:

(1) How many persons affected with leprosy are benefiting from CBR programme? Persons can "benefit" from or be "involved" in CBR in different ways that can vary from participation in a meeting to being part of a self-help group, to receiving footwear or other orthopaedic appliances to receiving home visits. Thus we may need to clarify better what do we mean by "benefiting" or "involved with", when we ask such questions.

While leprosy programmes work with the diagnosis of leprosy, CBR programmes work with the concept of "body functioning affected by the disabilities". Thus, persons affected with leprosy who have an amputation and blindness, may be considered by CBR programmes as "persons with locomotion disabilities" and "persons with vision disabilities", and not as "persons affected with leprosy". Therefore, it may not be easy to get information about number of leprosy affected persons involved in or benefiting from a CBR programme.

Discussions with persons affected with leprosy involved in some CBR programme have shown that they may prefer to be known as "persons with loco-motor disabilities" or "persons with vision disabilities" and may not like that people look at them as a separate group of "leprosy affected persons". Thus, asking CBR programmes to count or identify how many leprosy affected persons are involved in their activities may not be ethical and may be against the wishes for those persons.

(2) Self-care burden: Often CBR programmes and leprosy programmes ask leprosy affected persons to do regular self-care activities such as - soak the feet in water and then rub them with oil, use specific disability preventive measures during their leisure activities or household work and participate in self-care groups. There is insufficient attention towards the burden/costs of such activities on daily lives of persons.

Increasingly, there is greater attention towards users' participation in community lives at different levels and for different activities. Demands on persons to carry out self-care and participate in specific activities may be even greater on women. A more systematic approach to understanding the impact of such activities on lives of persons and not just on "disability prevention" or "ulcer-improvement" is needed.

In leprosy related disabilities, grade 1 disabilities are very different from other disabilities and very little information exists on this issue in terms of peoples' perceptions about their bodies. Usually "disabilities" are linked to some activity limitations and participation limitations. However, grade 1 disabilities (loss of sensation without other visible disabilities) does not lead to any activity limitation or participation limitation. Rather persons with grade 1 disability in the hands may be able to do additional things that even non-disabled persons cannot do such as picking up hot pots and pans without feeling pain. Usually most persons with grade 1 disabilities end up with visible disabilities. This is another area that requires greater understanding.

(3) Which are the barriers to inclusion of leprosy affected persons in CBR? While discussing it with CBR managers, they usually say that their programme activities are open to all the different groups of persons with disabilities but often we find that unless these project specific steps, persons affected with leprosy do not participate in collective activities such as self-help groups.

What roles is played by self-exclusion and what roles are played by prejudice or discrimination by CBR personnel and other persons with disabilities needs to be understood better.

Conclusions: At international and national levels, a great deal of CBR programmes are being planned and implemented for persons with disabilities. These have received stronger support following the approval of the international convention on rights of persons with disabilities. For example, in May 2013, WHO General assembly approved a resolution that asked countries to ensure that persons with disabilities do not face barriers in accessing health services and to strengthen the CBR programmes. Similarly discussions about the next phase of Millennium Development Goals in 2015, have underlined the importance of ensuring the inclusion of persons with disabilities in all plans and activities.

These are opportunities for persons who have disabilities due to leprosy so that they can also benefit from increased support to CBR and other rehabilitation programmes. Thus, it is important to ensure that persons affected with leprosy are included in CBR programmes. This requires, leprosy experts and leprosy programmes to have greater dialogue with organisations involved in CBR. While it is important to ensure that CBR programmes understand the needs of leprosy affected persons, an effective dialogue cannot take place, unless leprosy programmes take care to understand how do CBR programmes work, and what are their guiding principles.

In the CBR-leprosy interface, there are different operational issues that are poorly studied and understood. Greater research in these areas is needed.