

WORKSHOP REPORT

Inclusion of persons affected by leprosy in CBR

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Accepted for publication 8 February 2008

Introduction

A group of professionals in Community-Based Rehabilitation (CBR) met during a workshop immediately prior to the 17th International Leprosy Congress in Hyderabad, India, on 29 and 30 January 2008. Many of them worked for ILEP member organisations. They reflected on the need to make their rehabilitation programmes, often focussed on serving the needs of persons affected by leprosy, more inclusive for other marginalised groups, in particular persons disabled through non-leprosy causes. They also reflected on the need to promote the self-organisation of people affected by leprosy and their inclusion of them also in general Disabled People's Organisations (DPOs) either individually or through their organisations.

This workshop marked the launch of the new set of guidelines issued by ILEP and endorsed by the World Health Organisation,¹ announced elsewhere in this special issue of *Leprosy Review*. The group agreed on the following statement.

Theme 1: From a leprosy focus to inclusive CBR

CONSIDERATIONS

1. The way for the future of existing leprosy rehabilitation programmes is to go beyond the medical model and opt for a holistic approach such as is found in CBR.
2. Inclusive CBR (i.e. a CBR which includes people with all kinds of disabilities) is an essential element in current and post-elimination leprosy control strategies.

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3. It is important to take a broad-based approach to CBR as defined by WHO/ILO/UNESCO,² and following CBR guidelines which are currently being developed.³
4. Key strategic approaches include a needs-based programme approach, networking, resource sharing, multi-sectoral co-operation within government and, in the case of NGOs, with government. This is necessary because the magnitude of the need is simply too great for one actor to meet it on its own.
5. Leprosy rehabilitation programmes have an added value of leprosy-related skills and resources for mainstream programmes (e.g. wound care, self-care, footwear etc.) while the more general CBR programmes can enrich the experience of leprosy programmes.
6. Empowerment of clients to be active and equal partners (if not more) in the process of rehabilitation is essential, given the importance of client choice and of recognising the diversity of needs and necessary resources required for effective CBR. This demands an *intentional* approach to empowerment, inclusion, and participation of clients in decision making.
7. Once empowered, the members of self-help groups become role models for other members in the community.

RECOMMENDATIONS

8. The group recommends a twin-track approach⁴ to CBR in which on the one hand, people affected by all kinds of disabilities receive mainstream services and are involved in mainstream development, while on the other hand special programmes are developed for people with particular types of disability where special needs are identified.
9. 'Best practices in CBR', including stories of both successes and failures, should be collected from accumulated experience of widening from a leprosy-only approach to inclusion of people affected by non-leprosy disabilities and to community development.⁵
10. Rather than imposing pre-determined interventions, a participatory analysis should identify resources available both within and outside the community through networking so that these may be tapped and shared. Resources include the experience of other emancipation movements and expertise in social marketing strategies.
11. From a perspective of equal rights and responsibilities, it makes sense to encourage people affected by leprosy to participate financially in the cost of treatment and other amenities, according to their socio-economic status.

Capacity building

12. Available resources for CBR should be particularly focused on building capacity of all stakeholders to enable them to move towards an inclusive CBR approach. Stakeholders here include clients, donors, business & other community stakeholders, government staff and staff of rehabilitation programmes.
13. Where existing leprosy rehabilitation programmes embrace CBR, capacity building through need-based training and follow up will empower stakeholders at all levels.
14. Capacity building can be based on the materials now available globally^{1,3} and will result in the development of materials that are locally relevant and appropriate.

Advocacy/research

15. The group recommends communication and advocacy of this approach to stakeholders at all levels. Communication may need to be aware of the barriers created by organisational terminology, image, and culture.
16. Donor agencies will need to have the vision to support leprosy rehabilitation programmes to allow them time to explore ways of transitioning to a participatory and integrated CBR.
17. Tools for the monitoring & evaluation of CBR⁶⁻¹⁰ should be used to document its impact and the findings should feed into advocacy for and promotion of an approach in which persons affected by non-leprosy disabilities are integrated into leprosy programmes (or *vice versa*).
18. Research should be undertaken to compare vertical leprosy rehabilitation programmes and integrated CBR programmes and their impact on quality of life.

Theme 2: Are DPO's inclusive of All?

CONSIDERATIONS

1. DPO's* can be a means for disabled people to speak out for their own rights. Through DPO's empowerment can be supported by raising awareness and providing them with instruments/tools to overcome discrimination and stigma. Conversely, organisations of disabled people may themselves become more aware of their rights and start lobbying and advocating for rights and be enabled to use existing tools (e.g. legislation) to ensure that rights will be implemented.
2. The following barriers were identified which prevent people affected by leprosy from joining DPO's:
 - a. Lack of awareness on the part of non-leprosy disabled people
 - b. DPO's may not welcome leprosy-affected members (stigma)
 - c. Fear on the part of leprosy-affected people of losing (economic) benefits which are available specifically for them
 - d. Donor-organisations whose policies are not (yet) supportive of the formation of multi-disability DPOs
 - e. Fixed mind-set of professionals and lack of skill to engage with clients in participatory processes. All too often beneficiaries are not involved in the identification of needs, priority setting, planning and monitoring and evaluation of programmes that were designed for them.
 - f. Self-stigma of people affected by leprosy may result in reluctance to join DPO's.
3. Geographical limitations of access (urban-rural).
4. It appears that organisations of people affected by leprosy are more likely to engage with DPO's if they are well-established and in control of their own functioning. Thus people affected by leprosy sometimes prefer to form a strong(er) movement themselves before engaging with mainstream DPOs. Leprosy-specific DPOs or self-help groups may be necessary – in an initial phase – in order to ensure emancipation and empowerment of people affected by leprosy.
5. Of course, for leprosy-affected people to be members of a DPO is not the same as fully participating in all aspects of the DPO organisational functioning. Integration should go beyond mere membership.

*Disabled People's Organisation – here used in the sense of an organisation which comprises persons with various kinds of disabilities.

6. There are obvious benefits of integration of leprosy-affected clients into general DPO's. However, it should also be recognised that people affected by leprosy have experiences which can benefit those affected by non-leprosy disabilities.

RECOMMENDATIONS

7. Professionals working in CBR, such as managers and therapists should reflect on their own attitude with regard to allowing beneficiaries to have more control within programmes that are designed to serve their needs.
8. ILEP organisations should reflect on their own policies, philosophies and organisational culture to see how these might hinder the formation of DPO's which include people with non-leprosy disabilities and modify accordingly.
9. Staff of leprosy rehabilitation programmes should create awareness among leprosy-affected clients of the benefits of joining general DPO's, such as the fact that larger networks can fight for bigger issues.
10. Managers and professionals working in CBR, should see the facilitation of DPO's at all levels as an important task.
11. Where grassroot groups/organisations have spontaneously formed, emphasis should be on supporting these rather than on developing new groups. This acknowledges local historical, political and social linkages.
12. Where there is under-representation of specific types of disabilities in a DPO, advocacy for inclusion should be made.
13. Where this is feasible, facilitate the integration of organisations of people affected by leprosy into general DPO's.
14. CBR managers should strengthen the capacity of leadership within organisations of leprosy-affected people to engage meaningfully with DPO's. Where appropriate, they can also build the capacity of leaders in DPO's to engage with leprosy organisations.
15. Acknowledge that the process of empowering DPO's involves the handing over of power by other stakeholders and organisations.
16. DPO's should, as much as possible, play a key role in the identification, development, facilitation and evaluation of projects and programmes.

Final remarks

During the final discussion, workshop participants considered how they could support their organisations working for the rehabilitation of people affected by leprosy to make the step towards inclusion of other marginalised groups. Of course, what is presented here is a vision. The details of how this can be achieved will vary from one context to another. However, the following common themes can be specified:

- Communication/advocacy with policy/decision makers to foster their commitment towards an inclusive CBR approach. The World Health Organisation and ILEP should work together and act as change agents for the promotion of inclusive CBR. The new CBR guidelines³ that will be published within the next year will provide an instrument for this.
- Recognition of the needs of other marginalised groups in the community such as, for example, people disabled due to other causes, people living with HIV/AIDS, destitute people will come about through reflection within the organisation. Such reflection can be the

result of a programme review or evaluation which includes detailed community interactions and participatory needs assessment¹¹ or may come from demands made by marginalised groups themselves.

- Capacity building within the organisation, through programmes of repeated training and supervision.
- Sharing resources and expertise through networking and building partnerships with governments, NGOs, donor agencies to move together towards an inclusive CBR approach.

Effective change does not come if we take an either/or approach. In each situation we need to look at partnerships and capitalising on each others' strengths. Rigid application of principles will not facilitate a steady movement in the desired direction. Thus we should not be dogmatic, for example, that DPOs should be involved at all levels of project activity but at every occasion look for opportunities to take small but concrete steps towards this goal.

Leprosy programmes moving towards CBR – that is the future of leprosy rehabilitation programmes. In doing this, we should not disparage or deprecate the importance of the experience we have accumulated in the area of medical, surgical and physical rehabilitation. Such interventions are of vital importance in most developing countries today and instrumental in the empowerment and inclusion of disabled people and people affected by leprosy.

There is a danger that once managers have 'seen the light' of empowerment they put too much pressure on their staff to perform accordingly, without taking sufficient time to help them discover these ideas and make them their own. Investing in staff was identified as an important need in many general CBR projects around the world.¹² Working according to participation principles implies changes in the internal processes and relationships within the programme. Staff need to be empowered to empower the target group.

Measuring the impact of CBR programmes can be facilitated by the introduction of a simple information system consisting of individual files holding assessments done at entry into and exit from the roster of active CBR clients as well as one year after exit.⁷ Another impact question we must periodically ask is how the CBR programme has contributed to alleviating poverty, the root cause of leprosy.¹³

The president of IDEA India, Dr. P.K. Gopal, attended the workshop for a few hours and answered questions. He said that IDEA is aware of the importance of mainstreaming and being involved with other disability groups. However, the first step is 'to look within our own organisation (IDEA) what we want, where we should go, what the benefits are. Do we want to be part of Disabled People International, or a separate group, or with other groups? A lot of thinking has to be done within IDEA first; then IDEA leadership with the support of others can engage in dialogue with other DPOs and disability groups, to consider the cost/benefits of any alliance.'

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