Editorial

An update on community based rehabilitation for leprosy practitioners

During recent years we have seen quite a number of developments in the field of leprosy-related disability. Some organisations and programmes have increasingly paid attention to individual physical needs of people affected by leprosy through, for example, prevention of disability (POD) activities included the formation of self-care groups.\(^1\)\(^2\) We see also in some parts of the world that self-care groups gradually evolve into self-help groups with a stronger focus on advocacy and socio-economic rehabilitation.\(^3\) Increasingly we notice developments into multi-disability self-help groups such as the large number of self-help groups that can be found these days in India. Such self-help groups may even form federations and coalitions and become, in fact, disabled people’s organisations (DPO); some specifically focusing on people affected by leprosy while others become multi-disability DPOs, which include people affected by leprosy. The ILEP Guidelines for SER\(^3\) were an expression of new thinking and new direction. The more recent ILEP-WHO Guidelines on CBR provide an even broader framework of thinking and focus on integration of people with a disability and people affected by leprosy in society with equal rights and participation.\(^4\)

Besides a growing awareness among leprosy practitioners that they have an important role to play regarding the rehabilitation of people affected by leprosy (physical, social, economical as well as psychological), it is encouraging to note that within mainstream disability development more attention is given to the position of people affected by leprosy as well.\(^5\)

The year 2008 will mark the launch of a new set of general guidelines for the development and management of Community Based Rehabilitation (CBR). The Disability and Rehabilitation (DAR) unit of the World Health Organization has been working for quite some time with over 150 authors on these new CBR Guidelines.\(^5\) The Guidelines have been field-tested in the second half of 2007 in 25 countries and on the 3rd of December 2008 – International Disability Day – the Guidelines become reality. These Guidelines form the tangible outcome of the International CBR review that took place during 2003 in Helsinki. However, there is another outcome that is certainly of equal importance: the final transformation of CBR from a service delivery model into an inclusive development strategy. For some professionals this still remains a controversial development, while for others it is a logical step forward and a recognition for the work they have been doing for a long time: working in the struggle for human rights and more specifically the rights of disabled people.

While in essence the struggle for equal rights forms the basis of thinking for a growing number of disabled people with regard to rehabilitation, there is also a counter side to it: the so much needed services (e.g. medical or social services) may never be provided as long as policies and guidelines are not put in place and especially not put into practice. Legislation and (new inclusive) policies, though of great importance, are themselves no guarantee for accessible and appropriate services. Similarly guidelines may easily end up on the shelves of
managers. Our organisations and professionals need to ensure that guidelines will be used by front-line CBR workers and will become meaningful for disabled people.

It is a paradox that perhaps the more vocal and politically minded disabled people who are often critical of CBR are also those people who are hardly in need of CBR. People with disabilities and especially people affected by leprosy often form the poorest of the poor. The reality is that those we claim to serve live under extremely poor and dangerous circumstances and may live in parts of the country that are entirely lacking in or excluded from any development. Those who usually benefit are the middle-class new elite of disabled people living in the cities and towns. They already have access to services, transport and employment and may also be in the forefront of national disabled peoples’ organisation.

Those who were and are in the forefront of the struggle for disability rights are disabled activists, who have often already personally benefited from expert rehabilitation knowledge, skills and techniques, to the point where they no longer need them. Perhaps in their fight for rights they are in danger of neglecting the majority of disabled people with no access at all to specialised knowledge and skills. It is for them that CBR can be of great importance as long as it meets their needs, is of good quality and reflects inclusivity and participation principles.6

As professionals we need to closely work together especially with those people who have no access to services; the people who do not know that they have rights and who often need and want clinical, social, vocational and educational services for themselves. If we are able to fulfil such needs we in fact have helped these people to claim their rights. We as professionals need to contribute towards the implementation process of existing legislation – including the new UN Convention of the Rights of People with Disabilities.7 If we do so, ordinary people with disabilities can start benefiting from the conducive environment brought by such legislation.

For the field of disability and rehabilitation in leprosy – traditionally and unfortunately – largely a parallel field from mainstream CBR development, the new CBR developments could represent the ultimate moment to finally ensure that rehabilitation of people affected by leprosy will become an integral part of mainstream CBR. If CBR is an inclusive development strategy it has an obligation to CBR organizations and managers to include also vulnerable groups of people who traditionally have not benefited from CBR such as people with mental health problems and people affected by leprosy.

This special issue on CBR confronts the reader with the need for integration of vertical, special rehabilitation services for people affected by leprosy into the mainstream of CBR development. Within the latter the focus is increasingly – and where possible – on inclusion of people with disabilities in local, national and regional developments as a basic philosophy. However, it should be noted that, where necessary, specific programmes or interventions may need to be continually provided. While this may mean that special programmes and services need to be provided for special groups of people, we need to ensure that current leprosy-specific activities should not be continued as the alternative and exclusive pathway of a twin-track approach.8 On the contrary; it is hoped that policymakers, planners and managers in the field of leprosy realize that Community Based Rehabilitation represents an opportunity to make basic services available, as well as addressing the issues of accessibility and exclusion, discrimination and stigma. Exclusive leprosy-only services may have a role to play for a time, but if we aim at sustainable services we need to follow the track of mainstreaming. The new CBR Guidelines4 as well as the recently adopted Convention on the Rights of People with Disabilities7 may form guides that ensure a more egalitarian society, where barriers are reduced and disabled people have more equal opportunities to live a respectful life.
Finally, this CBR Special of the Leprosy Review painfully demonstrates that we do not have much confirmation that people affected by leprosy are well accepted and integrated in mainstream CBR programmes. Possibly this is a sign that in general rehabilitation programmes for people affected by leprosy are managed as vertical programmes, although the editors are aware of worthwhile initiatives in for instance India, Nepal, Uganda and Sudan. We call for increased research in this area as we believe, based on experiences and the scarce evidence that is described in some of the papers in this special issue, that these experiences of incorporation of people affected by leprosy should be well-documented and researched in order to ensure further integration into mainstream developments.

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References

8. DFID. Disability, Poverty and Development. DFID, UK; February 2000.