Integrating community-based rehabilitation and leprosy rehabilitation services into an inclusive development approach

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Summary Community-based rehabilitation (CBR) has been described as a strategy for leprosy rehabilitation. Developments in CBR and leprosy rehabilitation services, including Socio-economic rehabilitation (SER) show that both approaches aim to become part of a community development process. The basic assumption is that people with disabilities will benefit most from being included in mainstream programmes implemented in their own community, e.g. programmes aiming to improve livelihood.

These developments have a decisive impact on the roles of all people involved in the rehabilitation process. Where the emphasis in the rehabilitation process shifts to the community and becomes part of community development, the rehabilitation workers need different competencies than were required in vertical disability programmes.

This article focuses on the changing roles of mid-level rehabilitation workers and trainers and therapists. In many programmes a mid-level cadre was introduced to work with people with disabilities and their families. Consequently, trainers and therapists have moved away from direct, hands-on interventions and focussed on training this mid-level cadre and offering specialised referral services. This system was primarily developed to provide treatment at all levels, including community level. However, when rehabilitation becomes part of a community development process there is a need for ‘change agents’ and a structure that supports them.

The success of integrating disability specific programmes like CBR and SER, into inclusive development programmes will depend largely on the extent to which rehabilitation workers are able to reinvent themselves as ‘change agents’ and redefine their roles, positions, and competencies.

Introduction

Community-based rehabilitation and leprosy rehabilitation services, i.e. Socio-Economic Rehabilitation, are relative recent developments in the field of rehabilitation. Both concepts...
focus on participation of the persons with a disability in their own community and position the rehabilitation process in the community. By doing so, the rehabilitation process moves away from the structured, continuous and tranquil settings of the rehabilitation centres and hospitals and has instead become part of the dynamics of society and public debate. Forces from outside the professional rehabilitation field very strongly influence the understanding of ‘disability’ and the lay out of the rehabilitation process. In this article we will first discuss developments in CBR and leprosy rehabilitation services and then proceed to a discussion on the changing roles of the different rehabilitation workers involved in this transition.

CBR was introduced by the WHO as a strategy to provide rehabilitation to people with disabilities in developing countries.\textsuperscript{1–6} The concept has been implemented in many countries and rehabilitation workers all over the world have gained plentiful experience by organising support for people with disabilities in their own community. Despite this broad and vast body of experiences, research on CBR is still rare and the evidence base of the concept is fragmented and incoherent.\textsuperscript{7}

The rehabilitation of people affected by leprosy has developed itself alongside rehabilitation services offered in ‘mainstream’ rehabilitation and vocational training centres or in outreach and community-based programmes. This applies to clinical rehabilitation in leprosy hospitals as well as to the Socio-Economic Rehabilitation programmes (SER).\textsuperscript{8} Little integration of these leprosy specific and mainstream clinical or community-based services has been reported. It is suggested that the stigma attached to leprosy as well as the existing leprosy control programmes are the main reasons why CBR programme managers do not include people affected by leprosy in their programmes.\textsuperscript{9} Recently it has been argued quite strongly that for people affected by leprosy and in need of rehabilitation CBR should be the strategy of choice.\textsuperscript{9,10}

Where CBR and leprosy rehabilitation services have a different background and have gone through a different development process they now share a common understanding about supporting people with disabilities. Both CBR and, to a lesser extent, leprosy rehabilitation services, position themselves within a human rights approach and consequently state that rehabilitation services should support people with disabilities to access and exert their rights. The key issue here is ‘inclusive development’ meaning that rehabilitation services should aim at including people with disabilities in mainstream development programmes and strategies.

DEVELOPMENTS IN COMMUNITY BASED REHABILITATION AND LEPROSY REHABILITATION SERVICES

In the development of CBR and leprosy rehabilitation five different but related forces are identified that influence the further conceptualization of ‘rehabilitation in the community’ programmes and its inclusion in community development programmes.

1. From an individual to a social approach

Disability is no longer seen as a personal disadvantage only that requires individual modification in order to allow the person with a disability to take part in all kind of mainstream activities. Instead, society needs to make sure that all members of society can participate. This has often been referred to as a paradigm shift, i.e. moving from a medical model to a social model. Now the social model is reinforced by the human rights approach in which people with disabilities actively claim their human rights like access to public services, education, work, and a decent standard of living. Advocacy movements and
Disabled People’s Organisations argued that people with disabilities would gain much more from exercising their rights than from adjusting themselves, through rehabilitation, to a handicapping environment.

2. **Steering of the process by the person with a disability**

   In the past decades a demand-driven approach has been promoted as opposed to a supply-driven approach. Consequently, people with disabilities are set in charge of their own rehabilitation process and define their own goals and objectives. A demand-driven approach seems to go very well with the underlying ideas of CBR and SER but does not always relate well to the focus of service providers and to the initial competencies of rehabilitation workers, vocational trainers and Leprosy Control Officers. In a demand-driven approach CBR and SER programs need to be designed as open programmes, able to address a variety of needs.

3. **Focus on improving livelihood of people with disabilities**

   The focus of the rehabilitation process has traditionally been on restoring or maximising the individual’s capacity. People with disabilities who needed intensive and continuous treatment and care were often cared for in institutions and in the case of leprosy in settlements or colonies and stayed there often for many years or even life-long. Because of the presumed risk of infecting others and the stigma attached to leprosy this definitely applied to people affected by leprosy. The institution provided different activities like agriculture and tailoring. With the development of all kinds of income generating activities, micro credit schemes and support services at community level, their dependency on institutions could largely be reduced. However, because of their long absence from their community and the stigma attached to certain types of disability and leprosy, they experienced problems in regaining their place in their community and to secure an income. It was also realised that a ‘day-time activity’ is really different from having a job or being self-employed and that this transfer often failed due to lack of customers, lack of capital and competition by others. Whereas in CBR programmes income generating activities have been set up for individuals or small groups of people with disabilities on an ad hoc basis, vocational training programmes have systematically been set up within leprosy rehabilitation services. Over the past 10 years socio-economic rehabilitation programmes (SER) have been introduced alongside leprosy control programmes but somewhat separate from other development programmes.

4. **Need for integral, inclusive development programmes**

   Thomas and Thomas not only argued that CBR is an important strategy in leprosy rehabilitation but also emphasised that the strategy has become a community development process. This is in line with the 2004 definition of CBR where it states: ‘CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities’. With the introduction of the Millennium Development Goals (MDGs) the need to include disability issues in community development became even more significant. Yet in none of the goals, nor in the indicators, is disability mentioned explicitly. However, it can be argued convincingly that the MDGs can only be reached if people with disabilities are included.

5. **Demand for evidence-based practices**

   There is an increasing demand to provide evidence that rehabilitation programmes are indeed effective. Governments in low and middle income countries, and the NGOs working with them, want to make sure that they make informed choices in spending money and allocating manpower. In some cases funds have been earmarked, but otherwise
'rehabilitation in the community' programmes face competition from all kinds of specific and general development programmes and might be at stake if they cannot prove that they change the lives of people with disabilities significantly. So far, only a few attempts have been made to establish the evidence base of these programmes.\textsuperscript{7,18}

In addition to these forces two developments which are more specific for leprosy rehabilitation can be identified. The first is the possibility of exploiting leprosy specific expertise. Particular knowledge (e.g. nerve function assessment and ulcer prevention) gained in leprosy rehabilitation can be used in the rehabilitation of people with disorders that ‘relate’ to leprosy, e.g. peripheral nerve injuries or diabetes.\textsuperscript{19} Also, leprosy-specific instruments developed to assess the disabling effects of the disease and to evaluate the interventions\textsuperscript{20,21} can be modified to assist other groups of people with disabilities. Secondly, with the availability of effective drugs, people affected by leprosy can now stay in their own community without the risk of infecting others. They can use public health care services and rehabilitation can be provided through mainstream rehabilitation services.\textsuperscript{10,22} An alternative strategy (‘reverse integration’) is to open up leprosy hospitals, colonies and rehabilitation services for other people with and without disabilities and transforming themselves into mainstream services.\textsuperscript{23,24} Opening up leprosy rehabilitation services position these in the regional health care system amidst other health and community services.

Noting that these developments in rehabilitation services have taken place in a relatively short time it is disquieting that very little attention has been given to the different rehabilitation workers in the rehabilitation process. Their roles will continue to change when CBR and leprosy rehabilitation services become part and parcel of inclusive development programmes. In the next section we will address the changing positions, roles and competencies of the rehabilitation workers.

\textbf{Implications for the roles of rehabilitation workers}

The changing roles of the rehabilitation workers can best be discussed by looking at the introduction of a mid-level cadre and the shifting roles of trainers and therapists. Reflecting on the first four of the five forces outlined above it can be concluded that there is a definite need for a mid-level cadre that supports people with disabilities at community level. This support should primarily aim at involving people with disabilities in all types of community activities and especially in activities set up to improve the livelihood of the community members. There are a number of reasons why people with disabilities are not fully involved in community development programmes. Traditionally, the type and severity of the impairment has been seen as the limiting factor for participating in community development programmes but there is a growing awareness that there are several exclusion mechanisms that go beyond the impairment. People with disabilities can be excluded by other members, staff or by the design of the project but also because people with disabilities themselves do not share the perception that they can contribute to a programme (self exclusion).\textsuperscript{25}

The need for a mid-level cadre in CBR has been recognised and addressed by the WHO.\textsuperscript{26} The focus of this cadre has been very much on training people with a disability in their own communities and acquiring skills to take part in household duties and contribute to the family income. The introduction of mid-level rehabilitation workers has taken various forms in different countries. In a systematic literature review Finkenflügel\textsuperscript{27} incorporated 33 articles dealing specifically with the different stakeholders of which seven discussed the roles
of therapists and 13 the roles of mid-level rehabilitation workers. To get a better insight into these roles, the characteristics of the different stakeholders and their influence were studied more closely in 10 CBR projects in southern Africa. Both the literature review and the study of the projects showed that the mid-level rehabilitation workers – who go by different names, such as rehabilitation assistants or community rehabilitation facilitators – assess people with disabilities, instruct family members, make referrals, liaise with other organisations in the area, and organise services. They are the most decentralised and community-oriented rehabilitation workers. In fact, CBR projects appear to rely completely on the involvement of this type of rehabilitation worker. Two examples are given here to illustrate these mid-level workers. In Zimbabwe the Ministry of Health started training ‘rehabilitation technicians’ in 1982 well before the Ministry initiated eight pilot CBR projects in 1988. These technicians were initially meant to assist the physiotherapist or the occupational therapist in the district, provincial and national hospitals. When setting up CBR projects the rehabilitation technicians became the backbone of the projects where therapists settled in a management and referral role. A different approach is used in South Africa where CBR facilitators are trained to play a role in community development and social mobilisation as well as in physical rehabilitation. Therefore topics such as advocacy and lobbying, community entry, understanding power relations in communities and the rights of people with disabilities all have a prominent place within the training. One CBR facilitator assisted community leaders in ensuring that new water and sanitation facilities being installed in his community would be accessible to people with disabilities. Other CBR facilitators have worked with local taxi associations to change attitudes of drivers and to try to stop the practice of charging double for wheelchair users. Through such activities CBR facilitators are beginning to address the oppression of people with disabilities in their own communities. As a particularly marginalised group, people affected by leprosy could also benefit from the inclusion of leprosy issues into the mainstream of the work of CBR mid-level workers.

This example shows that this mid-level cadre should and can act as ‘change agents’ and that their competency and influence should go beyond addressing the limitations resulting from the impairment and the obligate measures to create an accessible environment. They should probably refrain from setting up projects for people with disabilities although organisations often follow a ‘twin-track’ approach, meaning that they continue to run disability specific projects and at the same time encourage participation in mainstream programmes. Where the emphasis shifts to bringing about change, advocacy and empowerment there is less need that this mid-level worker has a thorough knowledge of impairments. To address ‘exclusion by design’ problems and issues of ‘self exclusion’ a basic understanding of disability is still required but social skills, networking, and the power to influence processes in the community will be the decisive competencies for this cadre. This opens up this position to people with different educational backgrounds and life experiences, not in the least for people with disabilities themselves. A few last comments need to be made on the position of mid-level workers. A factor of influence is whether the mid-level worker is employed or working as a volunteer. In situations where a mid-level worker is a volunteer, his or her time may be restricted due to having other income-generating employment. In such a case, it is possible that the mid-level worker may concentrate on practical, time-limited interventions, e.g. exercises, during home visits rather than focusing on community development activities which may be more demanding of time and
involvement. Another factor is that the job description of the mid-level worker will be determined by the agency. If this agency is health oriented their role will be so. In situations where the CBR worker is employed by or accountable to a NGO or disabled people’s organisation, the role of the CBR worker may be more related to the spectrum of needs that people with disabilities express.

Having discussed the need for a mid-level cadre and their extended role as a change agent battling the different forms of exclusion of and by people with disabilities there is a need to address the training of this mid-level cadre, their supervision and the availability of back up services. What we see is that the rehabilitation technicians or facilitators are generally trained and supervised by occupational therapists, physiotherapists, vocational trainers, special teachers etc. However, given the new role and expectations of the mid-level workers it is questionable if therapists, trainers and teachers are equipped to do so. Including social workers and professionals trained in community development programmes in the training might solve part of this problem. However, the first thing to do is to develop a new curriculum that defines and addresses the required competencies of this mid level cadre.

Where the role of professional rehabilitation workers in the training of mid-level workers will change significantly there is still a role to play in the referral system, the management of programmes and, finally addressing the fifth force (the need for evidence), in the evaluation of programmes.

In situations where the type or severity of the impairment limits the participation of the person with a disability and the design of the development programme cannot be changed to meet the potential of this person and the necessary changes cannot be made in the community (by training the person with a disability or adapting the environment), a backup service like a referral centre is needed. In a referral centre, highly specialised professionals with expertise and equipment can be made available. In the best situation a referral centre is intimately linked to general health and rehabilitation services and community programmes to provide a care-chain. In an effective care-chain competencies, decision making capacities and information needs of the different rehabilitation workers are interlinked and defined on the basis of an understanding of the needs of the clients.35

Initially, therapists and trainers took a leading role in setting up CBR and SER programmes. These professionals were involved in a number of tasks: screening people with disabilities in the community, providing hands-on therapy, setting up training programmes, training family members and volunteers, discussing the need for rehabilitation with community leaders and organising services at local, district, and provincial levels. When the emphasis moved from an individual and social approach to a human rights approach they became involved in promoting the rights of people with disabilities and forming Disabled People’s Organisations (DPOs).36 Due to the outlined developments in CBR, SER and in the disability field their dominant position has changed. With the training and deployment of mid-level rehabilitation workers, therapists and trainers have taken up more managerial duties and are no longer primarily in direct contact with people with disabilities and their communities. Nicholls and Smith13 point out that where responsibilities are delegated to field assistants, the field managers and social workers monitor the progress of the fieldwork and on working together with other organisations and the communities. The paradigm shift to a human rights approach appears to function well at community level. Going to school, having a paid job, or getting involved in community activities can be approached as human rights issues that steer the objectives of the rehabilitation process and address the changes needed in the community to eliminate barriers against disability. With the emphasis on human rights,
non-medically trained professionals, such as social workers and development workers, have entered the field of rehabilitation, adopted the CBR approach, and in many cases taken over the management of the projects from health-oriented professionals. CBR has earlier been described as a de-mystification of rehabilitation but can also be characterised by de-professionalisation. It is probably unnecessary to comment that the changing roles of the mid-level workers do not always comply with the expectations of the professional rehabilitation workers. Cornielje et al. found that some CBR facilitators who had been trained to work towards the social integration of people with disabilities were in fact not engaging in social rehabilitation because the managers of their employing organisations expected them to play a clinical therapeutic role. Similarly, in the experience of the second author, a mid-level worker was refused permission by his supervisor to participate in an advocacy event for disability rights, because the event was ‘too political’. Such experiences raise the question as to whether professionals, who are often supervisors or managers of a ‘rehabilitation in the community’ project, really understand and accept the multi-skilling of mid-level workers. There is a need for any project to address beforehand how therapists and other professionals will cope with and support the mid-level worker who undertakes activities such as advocacy, which may be outside the range of experience and competence of the therapist or other professional.

The need for evidence should be addressed at programme level. The effectiveness of CBR, SER and inclusive development programmes is not established: it is simply not known whether these programmes address the needs of people with disabilities and their communities in the best possible way and which components are most effective. This is not only dissatisfying for policymakers and funding agencies but also creates worries on what the best scenario would be to further develop the inclusive development concept. Programme implementers, and amongst them trainers and therapists, should involve themselves in research projects and share their findings in publications. They have a responsibility to utilise their professional, and comparatively expensive, expertise in the most effective way, especially in situations where this expertise is scarce and where many people with disabilities have no access to rehabilitation services. Research is an investment in which the progress of the project, the usefulness of the interventions, and the contribution of physical therapists and others can be investigated. This will add to the accountability of the project and subsequently strengthen the positions of the stakeholders involved in the project.

Conclusion

Merging leprosy rehabilitation services and CBR into inclusive development programmes is a valuable and promising exercise but will only succeed if the roles of the mid-level rehabilitation workers and the therapists are assessed and made explicit and a supportive structure is designed. This arrangement includes therapists and trainers supporting mid-level rehabilitation workers and providing feedback and referral services, and mid-level rehabilitation workers being properly embedded in the public services structure. This would provide a good starting point in which the specific expertise available in leprosy rehabilitation services and CBR is secured and will be beneficial to inclusive development programmes. Therapists and trainers will continue to play an important role but they will need to focus on training mid-level rehabilitation workers and making themselves available as resource people. Additionally they are encouraged to get involved in the academic debate on
CBR, SER and inclusive development and contribute to the evidence base of these programmes.

The vitality of inclusive development programmes will increasingly depend on mid-level rehabilitation workers and their competence to work with people with disabilities, organisations of people with disabilities, community members and all other stakeholders. Although not much is written about the role of the mid-level workers, it is apparent that the role they play is not consistent across development programmes. In order to avoid conflict amongst the various stakeholders in a project, it would seem to be most beneficial to clarify the role of the mid-level worker from the beginning of the project.

References


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