Many people recognise that it is important for community-based rehabilitation (CBR) and disability services in developing countries to build a stronger evidence base. They realise that better and more evidence will help to improve CBR practices, and that this will lead to better disability services. Most importantly they emphasise that it will lead to better outcomes for people with disability and their families and communities. While we agree this is vital, we also suggest that there are a few ways of thinking about evidence, and there are some things we should keep in mind as we seek to establish a better evidence foundation for CBR. First, we should remember the unique values of CBR and incorporate them into our evidence base and second, we need to include research from a community perspective. These aspects are sometimes forgotten, but we think they’re important.

Incorporating CBR model values
CBR has evolved a lot over the decades (see Kuipers 1998). As a dynamic approach with multiple layers and different strategies, it can and does respond to diverse political, cultural and social contexts and different organisational and financial factors. Therefore the sort of evidence that should inform CBR should also be broad, comprising a mix of principles and values as well as relevant research findings. In light of new understandings of evidence, which include values (Sackett et al 2000) and philosophies, we suggest that decisions about the CBR approach should be informed by values as well as traditional research, and that these values should be acknowledged and actively debated. For example, some CBR values are outlined below.

Originally CBR was an attempt to meet the need for adequate and appropriate rehabilitation and disability services for all people in developing countries. CBR then, like other rehabilitation models, is based on an understanding of the value of rights and worth of all individuals (Helander 1993). Recognising the disadvantage experienced by most people with disability, many CBR initiatives seek to enhance their rights and roles in society. Social empowerment of people with disability, family members and communities is a key value inherent in CBR (Kendall et al 2000). Again, this value is shared to varying degrees by many rehabilitation models.

The CBR model is a bit different from some other models because of its focus on the community. Where possible, the CBR approach seeks to utilise and build on existing resources, and involve people with disability, their families and communities. So, CBR programmes aim to be context-specific, influenced by social and other factors within the community (Kim and Jo 2001). They provide rehabilitation, training and vocational opportunities and seek to improve the integration of people with disability into their local communities. The ideal for effective CBR programmes is that people with disability, their families, the community, community workers and health professionals collaborate to provide services recognising the value of the local community (Mitchell 2001).

Another value that can be seen in the CBR model is community participation. This results in greater involvement of family members and local volunteers in the rehabilitation process (Boyce et al 2002), and less travel and expense for people with disability. When this value influences services, family and community members can see the gains people with disability are making, and they can continue to participate in the social, cultural and work life of their community. The value of community participation is also linked to two other values key to CBR. First, cultural appropriateness — employing local people is more likely to result in culturally appropriate practice (eg. language, religion), and lead to the use of locally-available materials. Second, cost effectiveness — the use of family and community volunteers reduces the dependence on external professionals, which decreases service costs and promotes sustainability.

The focus of CBR programmes is usually to support all people with disability across a community (horizontally), rather than focusing vertically on a specific group or those with a particular disabling condition. This distinction highlights an important values issue that informs choice of model. For example, in the case of working with people with leprosy, practitioners who hold a community-oriented values framework, argue for the integration of leprosy treatments and control programmes into CBR and similar horizontal approaches (Deepak 2003). They express the position that a key to combating social stigma is social and service integration (Frist 2000). Others who emphasise the values of specialised services prefer a traditional vertical service model for the same reason, to prevent the social stigma people may experience (Seddon and Seeley 2006; Arole et al 2002). This highlights our suggestion that at the level of
model, values need to be made explicit and debated and then incorporated (along with research) into the evidence debate and decision making.

**Reflecting these values in research**

We think that a dimension currently under-recognised in the evidence debate, is that of the voice of people with disability, their family members and communities. Given the CBR focus (at the local, community level), maybe we should also seek new forms of research that are responsive to service-users (i.e., listening to people) as a foundation for evidence. The new UN Convention on the Rights of Persons with Disabilities (UN 2006) enshrines people with disability’s ‘full and effective participation and inclusion in society’ as one of its general principles. This should include developing appropriate ways of ensuring that people with disability can participate in research which will shape the evidence base for future services.

Across CBR more broadly, there are increasing efforts to ensure that the voices of people with disability are heard, at both the individual level and at the collective level. At the individual level, CBR is increasingly adopting the ‘social model’ which acknowledges the influence of social factors on people with disability’s functioning and requires their active participation at all levels. At the collective level, an increasingly rights-based approach to CBR is giving disabled people’s organisations (DPOs) a larger role in the initiation, implementation and evaluation of CBR programmes (ILO, UNESCO and WHO 2004). CBR practitioners should therefore collect evidence through participatory methodologies at both of these levels.

In CBR, approaches such as participatory rural appraisal (PRA) are particularly suited to gathering evidence from people with disability and communities in CBR programmes. PRA may be described as a toolbox of research methods which are appropriate for communities with low levels of education and little research experience, (e.g., visual and oral methods and use of local materials which allow everyone in the community to participate). However, more importantly, PRA is a philosophy by which outside researchers learn from communities and encourage them to take control of the research process. In so doing they can provide information from their perspective which informs CBR service delivery. The challenge is to turn this information into evidence for practice.

While PRA is now commonly used in community development, there are added challenges when used in the area of disability and development. First of all, disability is rarely if ever a priority issue for communities, so before collecting evidence from communities on disability there is need for community sensitisation to disability issues. Definitions of ‘disability’ vary across cultures, and hidden and mild disabilities may not be recognised. Communities may only raise a narrow range of disability-related issues, such as loss of income, and not be aware of other issues such as the psychosocial effects of disability, communication problems or problems facing women with disability.

There are also a number of other challenges in carrying out PRA activities with people with disability themselves, since they are often the poorest, most marginalised people in the community. Their marginalisation can exclude them from participatory processes in a number of ways: due to extreme poverty (being unable to participate due to more pressing economic needs); by being ignored or considered unimportant by more powerful people in the community; through communication problems (e.g., for people with hearing or learning difficulties); mobility problems; or by being unaccustomed to forming or expressing their opinions.

At the collective level, evidence on CBR programmes can also be gained from people with disability acting through their DPOs. In some countries, DPOs have informed national policy debates on poverty reduction and debt alleviation (Dube 2005); however this may be a long-term aspiration for many others. In places where DPOs are relatively newly-established and have limited resources and capacity, genuine representation across gender, disability type, children’s issues and rural/urban issues is more limited.

**Developing participatory methodologies to gain evidence**

How then do CBR programmes go about ensuring community and people with disability’s participation in collecting evidence? A CBR organisation in Cambodia, Disability Development Services Pursat, piloted methods of enabling illiterate, inexperienced rural people with disability to lead participatory exercises to plan CBR activities (Harknett et al 2005). The research team of rural people with disability were trained in a range of PRA exercises (mapping, ranking, role play, household surveys, Venn diagrams, etc) and carried out surveys of people with disability and their communities in three villages. Many of the lessons learned on participation in planning CBR are also applicable to gathering evidence during a CBR project to inform practice and service delivery.

The research team identified people with disability across the region, using a set of picture cards depicting types of disability to ask villagers how many people in each category of disability there were in the village, and explore incidence of disability. They also identified people with disability’s main concerns and potential project priorities through focus group discussions and individual ranking (using a number of stones to rank importance). This method could also be used to gather evidence on the effectiveness of CBR interventions, or to compare questions of different methods of service delivery, such as service uptake and service effectiveness.
At the collective level of people with disability's participation, CBR programmers should also make efforts to include DPOs in gathering evidence on CBR. While DPOs are weak in many countries, it should be realised that they have ‘the right and the responsibility to identify the needs of all people with disability, to make their needs known and to promote appropriate measures to address their needs’ (ILO, UNESCO and WHO 2004). This is the sort of evidence that CBR services should seek, to inform service delivery.

Limitations in participatory methods

Clearly there are limitations to participatory research done by village people with disability. Lack of numeracy skills necessitate additional support. Low status and poor self-esteem (especially of women with disability) make leadership of activities problematic, and limited community development skills may inhibit the generation of village-based solutions. Further, some aspects of research such as the measurement of outcomes usually rely on specific rehabilitation skills and understanding, and may be difficult for people with disability and community members without substantial support. Despite these limitations, we suggest that a commitment to ‘hearing’ the voice of people with disability and community members will result in an important source of evidence for CBR.

Similarly, there is considerable scope for bias from data collected by community members (either exaggerating positive effects of a project or intervention to please others, or over-emphasising difficulties in order to persuade the project to continue). While such bias may occur in data collected by organisations and DPOs, it may be particularly evident in any project working with vulnerable and marginalised people.

Due to these potential sources of bias, CBR programmes should always cross-check participatory data gained via people with disability and communities. This cross-checking, or triangulation (Gosling 1995), might take place through: collecting data with a multi-disciplinary team using visual, verbal, group and individual methods, and through using a range of different sources of information (men, women, children, people with different types of disability, with different levels of exposure to the CBR project), with different connections to the CBR project.

Conclusion

After nearly 30 years of experience worldwide, CBR is still struggling to gain recognition as a legitimate model of service provision to people with disability. An important step in this process will be the development of a broad evidence base. We think that using the evidence from rehabilitation services in economically developed countries may be promising for informing CBR rehabilitation techniques. We also think synthesising CBR evaluation reports will give us useful evidence. In this paper we’ve stressed that there is a need to better understand and incorporate CBR’s ‘values base’ into its ‘evidence base’. In keeping with underlying values in CBR, we suggest that CBR needs some creative new methodologies for determining evidence. These methods should emphasise participation at the community level, they should include the service users themselves, their advocates in DPOs, and local community members. Appropriate research methods, drawn from the experience of the wider community development field, should be used to make sure the voice of village people with disability is heard and incorporated into a unique, multifaceted evidence base for the discipline of CBR (also see Wiley and Lowry, this issue).

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