GUEST EDITORIAL

CBR Indicators: Pick and Choose what fits your Purpose

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Indicators in CBR

Indicators are a representation of reality. They are just numbers on a piece of paper or on a computer screen, but they stand for something far greater – the success of your project. Indicators are usually defined in the context of project planning and show something about or give an indication of progress towards realising the project goal, without being complete or comprehensive. Of course, there could be other representations of this reality, such as stories (Dart and Davies, 2003) or drawings (Feuerstein, 1986) or photographs (Tijm et al, 2011). However, indicators are a widely accepted way of representing what is being achieved in a programme or project.

It would help managers, planners and policymakers if people were to use the same indicators when they implement similar types of programmes. For example, EPI vaccination programmes or TB control programmes use the same indicators the world over, and this makes it easy to compare data from different geographical areas within a country or even from different continents. Community Based Rehabilitation (CBR) is very different in that programmes are developed locally, are not based on any blueprint or standard model, and address complex problems through a wide range of interventions. Initially CBR programmes were often small local initiatives that did not involve any formal planning, so that indicators were either not used or were defined without any reference to external standards. Now that CBR is coming of age and programmes are more often developed with the involvement of governments and donor organisations, indicators have become more important and more standardisation is called for.

Indicator Development in the 21st Century

As early as the year 2002, Wirz and Thomas tried to bring some order in the unlimited diversity of indicators being used in evaluations of CBR programmes.

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They presented a helpful summary of the rather scant literature on the use of indicators in CBR in the 1990s, and then outlined three domains that indicators were used to represent:

1. Maximising the potential of the person with disability;
2. Service delivery (management of organisation and resources); and,
3. The environment in which the person with disability lives.

Their paper brings together indicators that were actually used in CBR programmes at the time or that were derived from activities actually implemented in CBR programmes.

Velema and Cornielje (2003) distinguished five domains in which data might be collected in CBR programmes:

1. Outcomes pursued for the person with disability;
2. Provider-client relationship;
3. Commitment to involve others;
4. Services offered (type, coverage, quality); and,
5. The interaction between the CBR programme and the environment in which it operates.

In 2008, the same authors repeated their call for more effective monitoring so as to create the evidence base CBR needs to develop further (Cornielje et al. 2008).

Madden et al (2015) presented a monitoring manual developed through a process of consultation with managers of CBR programmes, as well as an analysis of evaluation reports (Madden 2014). The authors are to be applauded for their perseverance over a period of several years to see this process through to the end. They present a menu of data items from which planners and managers can choose the ones they need to monitor their own programme with its specific characteristics and dynamics. Each indicator falls in one of four domains: 1. Person; 2. Organisation; 3. Activities; 4. Workforce. Besides indicators that represent change in the situation of persons with disability and in the CBR programme, environmental factors and outcomes are included as relevant and appropriate for each domain.

In a satellite meeting to the first World Congress on CBR in Agra (WHO, 2012), WHO convened a workshop with a wide range of stakeholders in order to launch a process of indicator development. A first list of indicators was drafted and some thorny theoretical issues were discussed (Neupert, 2013), such as the difference between a conceptual, not directly observable variable and an operational indicator, and formulating indicators as variables rather than as desired outcomes. It was also discussed where and how these data should be collected, i.e., sources of data for indicators and measurement tools.

This meeting took place two years after the launch of the CBR Guidelines by WHO, which had redefined and restructured thinking about CBR by presenting the CBR Matrix as its conceptual framework (WHO, 2010). The CBR Guidelines reiterated a broader approach to CBR, based on social model thinking rather than the limited scope of medical model thinking. In the process of development of the guidelines, the complexity of CBR became evident because of the diversity of its participants, the wide range of goals it is trying to achieve for the individual and for society, and because of the variety of interventions that are introduced to address the limitations and barriers encountered by people with disabilities. The CBR Matrix moved us away from narrow thinking about medical or social rehabilitation and onto issues of inclusion and facilitating the empowerment of persons with disabilities to claim their human rights (Velema and Cornielje, 2010). Indicators could now be developed for each of the 25 elements of the Matrix, to cover every aspect of CBR.

The process that started in Agra in 2012 has recently resulted in the publication of a new manual by WHO in partnership with IDDC (WHO, 2015), presenting a ready-to-roll methodology for a survey that will capture the experience of persons with disabilities in communities in relation to the life domains defined by the CBR Matrix: health, education, livelihood, social life and empowerment. It also compares the situation of persons with disabilities to that of persons without disabilities in the same community. Thirteen base indicators have been defined, which WHO would like to be used in all monitoring of CBR programmes around the world. Another 27 supplementary indicators have been defined that can be used as relevant in a given programme, to provide more detailed information.

In the new WHO manual (2015), indicators are typically formulated as “the percentage of people with disabilities who…”, where the definition of ‘people with disabilities’ is given in a footnote as: “Disability is an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors).”

Clearly, this definition is not one that can be used by interviewers in the field and some operationalisation is necessary. This operationalisation needs to be simple, sensitive and specific. It is important to note that the interpretation of any data produced by the methodology proposed by WHO will depend on the criteria that were used to classify people as being with or without disability, as well as on other characteristics of the persons interviewed such as, for example, age, gender and education.

Measuring Disability

The International Classification of Functioning, Disability and Health (ICF) widened the definition of disability to better include the consequences of impairment, i.e., activity limitation and participation restriction, while recognising that disability happens in the interaction between the individual and the environment. As such, the ICF is presented as an integration of the medical model, the social model and the human rights model (Mitra, 2006). The ICF attempts to achieve a synthesis, in order to provide a coherent view of the different approaches (Mitra, 2006). Thus, the ICF does not replace the medical model and continues to recognise the impairment and the personal experience of, for instance, pain and discomfort, while at the same time recognising the disabling effects that society can have on people's lives. By contrast, a purist social model focusses almost entirely on society as the source and cause of disability. This model played an important role in the emancipation of people with disability in the United Kingdom but is now considered outdated (Shakespeare and Watson , 2002). In reality, all theoretical models reflect the multifaceted nature of disability and none can explain the full extent of disability.

Various schools of thought exist when it comes to measuring disability

Eide (2005) and Loeb (2006) have argued that the measurement of disability has often been rooted in a medical understanding of disability and a focus on impairment. Their view is that it is preferable to measure Activity Limitation through a series of screening questions as this will more accurately identify those in need of services without asking about the cause of the limitation.

Traditionally, questionnaires were designed to classify disabilities according to different types: Difficulty hearing, difficulty seeing, difficulty moving, etc. (Helander et al. 1989). Such questionnaires are still very widely used today. The quality of the data collected in this way is highly variable given the very limited resources available for staff, for training & supervision etc. in the countries where CBR will make the most difference.

The World Report on Disability (2011) strongly criticised the "types of disability" approach as distracting from a complete picture of disability and functioning. The report gave an overview of all the difficulties involved in measuring disability prevalence and called for increased and improved data collection on disability, suggesting that "as a first step" the six questions of the Washington Group would provide a useful tool (cf. Loeb et al, 2008; Madans et al, 2011). The six questions ask about difficulty in seeing, hearing, communicating, walking, remembering or doing self-care. Since one person can score a level of difficulty for each of these six activities, the situation of persons with multiple disabilities is accommodated.

Alavi et al (2010) made an inventory, commissioned by CBM, of 27 tools measuring Activity Limitation and/or Participation (of which 7 tools were designed for children); 13 tools measuring (aspects of) Quality of Life in adults and 32 for children; 4 tools measuring Health and Well-being in adults and 11 for children. These were all generic tools, i.e., not developed for people with one particular impairment or health condition.

Van Brakel et al (2012) put together a rapid disability assessment (RDA) toolkit for their work in Indonesia, which comprised generic methods and instruments for assessing disability and stigma, compatible with the ICF conceptual framework: the Screening of Activity Limitation and Safety Awareness (SALSA) scale (SALSA, 2007), Participation Scale (Kelders et al, 2012), Jacoby Stigma Scale (Jacoby, 1994), Explanatory Model Interview Catalogue (EMIC) Stigma scale (Weiss et al, 1992) and Discrimination assessment form (Van Brakel et al 2012).

Lukersmith (2013) reviewed methods for the evaluation of CBR programmes and offered a list of assessment scales that were used in evaluations of community-based interventions. Some assess the development of children with cerebral palsy or neurological impairments; some assess social functioning in the context of intellectual disabilities or mental illness; others assess activity limitation.

Van 't Noordende et al (2016) aimed to develop a toolkit to assess and monitor morbidity and disability resulting from neglected tropical diseases (NTDs). NTDs are a diverse group of 17 communicable diseases that affect people who live in poverty, without adequate sanitation and in close contact with infectious vectors and domestic animals and livestock (WHO, 2016). Examples include Chagas disease, Leishmaniasis and Leprosy. The authors identified suitable tools that could assess ICF-related domains, i.e., impairment, activity limitation, participation, personal factors and environmental factors including stigma. Tools were identified that were applicable irrespective of the cause of disability, i.e., of the specific disease by which respondents were affected.

Purpose of Data Collection

What becomes clear from the literature is that different actors collect data for different purposes (Loeb et al, 2008). Some need data to inform decision-making and advocacy campaigns for the equalisation of opportunities (WHO, 2015); others need data to set priorities and allocate funds (Madans et al, 2011); and, CBR workers on the ground will first of all want to assess the rehabilitation needs of an individual or to see which of the interventions on offer are relevant for the person in front of them. Researchers will want to use data to demonstrate the effectiveness of CBR interventions (Velema, 2008; Bowers, 2015).

In the light of this, it is helpful to see that the six questions of the Washington Group were developed to estimate prevalence of disability through a population census. They were never intended to identify individual persons with disability for the purpose of offering services and interventions.

The stated purpose of WHO's new manual on CBR indicators is "to standardise the monitoring of differences made by CBR in the lives of people with disabilities and their families, making it possible to compare the difference CBR makes across areas and countries". This formulation suggests that the purpose is to demonstrate effectiveness. However, elsewhere the manual states that "when the proposed survey is undertaken for research purposes, more advanced methodological criteria need to be fulfilled". Thus it would appear that the primary purpose of the data collection proposed by WHO is to make visible the situation of people with disabilities in a given area, so that advocacy and planning of interventions can be informed. Over time, a repeat survey can show whether the situation has improved.

The manager of a CBR programme needs a lot of detail from the monitoring system. For effective management of the programme, s/he needs to know about the performance of the organisation, coverage, staff qualifications, etc., as well as how clients and participants in the programme are progressing and whether their functioning is improving. This is where the Sydney Manual will prove very useful. It presents a palette of possibilities to the CBR manager from which s/he can choose the indicators most useful to the situation at hand.

Measuring the Impact of CBR

Those who collect data to demonstrate the impact of CBR can go one of two different ways: 1. Demonstrating that the functioning of persons with disabilities has improved, or 2. Showing that attitudes and practices in their communities have become more inclusive.

Improved functioning can be shown by comparing standardised measurements between the initial enrolment of clients in the CBR programme and the status when they exit from the programme. Nevertheless, few CBR programmes collect standardised assessment results at intake or define when participants can be considered to exit the programme. A way forward can be to employ a problem- solving approach at intake – by using, for example, the Rehabilitation Problem Solving (RPS) form. This assessment form with ICF categories will reveal what the person with disability needs and wants, and compare these felt needs with the assessment of rehabilitation staff, followed by analysis and setting of rehabilitation goals, and defining the necessary interventions both at individual and community levels. The RPS is widely used in rehabilitation in the Netherlands. It is now successfully being used in CBR in Burkina Faso and Ethiopia (M. Boersma, personal communication), and forms an intrinsic part of the training of CBR field staff in Timor Leste.

This problem- solving approach permits an informed choice of interventions and will, at the same time, permit definition of what measurements should be used to demonstrate the success of CBR interventions offered and when the participant can be considered to exit the programme, or at least to have completed the intervention. Assessments must be simple and swift. It is to be noted that a standardised assessment at the time of exiting the programme is something totally different from ticking a box that says that the participant has, in the opinion of the service provider, “improved”.

Depending on the choices that have been made, a CBR programme can target individual clients with disabilities or may also very consciously target the families of people with disabilities. This will then necessitate a conceptualisation of the kind of changes one would expect as a result of the interventions, and the collection of corresponding data at baseline and at completion. An example is the research by O’Toole (1988) and by Thorburn (1992), which showed that attitudes of parents of children with disability had changed for the better as a result of CBR interventions.

Changes in functioning will occur even if people do not participate in a CBR programme. It is therefore relevant to ask: would the changes that were observed among participants in a CBR programme also have occurred in the absence of the programme? To answer this question, it is necessary to compare changes in the functioning of programme participants with changes in functioning in a control group of persons with disabilities who did not participate in a programme or who benefitted from only a limited set of interventions.

More inclusive community attitudes will become evident from the kind of survey WHO (2015) has now proposed. One might say that this survey is a way of asking persons with disabilities to what extent they feel included, e.g., in their families, in schools, in employment, in religious communities. By repeated surveys over time changes towards more inclusion can be demonstrated. This kind of listening to people with disabilities can also be done through more qualitative approaches. One example of this is the Participatory Inclusion Evaluation package of tools proposed by a team of Dutch, British and South African researchers (Wickenden et al, 2016). Another example is the 'Roads to Inclusion' tool that follows the categories of the CBR Matrix and specifies levels of inclusion that may be attained through targeted action by CBR teams (Blijkers and Cornielje, 2016).

CONCLUSION

In summary, the types of indicators that are needed for use in a given situation depend to a large extent on the purpose for which data are collected and programmes are monitored. The choice of indicators will depend on the services being offered, the goals that are being set, the people that are targeted, the principles that are being followed and what the data is intended for afterwards. Once this is clear, appropriate quantitative and qualitative indicators can be selected. It is wise to choose indicators that are also being used by others as this will permit tapping of experience already accumulated in their use and facilitate comparison of data between programmes. Interpretation of indicators will depend on the personal characteristics of the people whose data is being collected.

As this overview has shown, there is no consensus regarding the best way to measure disability. There is consensus, however, about the use of ICF as a frame of reference. An abundance of tools is currently available in the literature, with a wide variation in the way they were developed and the degree to which they have been validated. There is a search for a limited set of tools that can be used in widely different settings for people with widely different health problems. This is an area where further research is needed and where ideas will continue to develop.

There appears to be movement towards a situation where, given a defined purpose for collecting data, a set of recommended measurement tools is available at a central forum from which a selection can be made. Meanwhile, the authors suggest a stronger involvement of academic groups who, in synergy with each other, optimally use the scarce resources and experiences to ensure that claims made about the importance and success of CBR will be validated.

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