REVIEWS

Disability Data Collection in Community-based Rehabilitation

Sunil Deepak[1*], Francesca Ortali[2], Geraldine Mason Halls[3], Tulgamaa Damdinsuren[4], Enhbuyant Lhagvajav[5], Steven Msowoya[6], Malek Qutteina[7], Jayanth Kumar[8]

1. Independent Consultant on disability & rehabilitation, collaborating with AIFO (Bologna, Italy)
2. Head, International Projects Office, AIFO, Bologna, Italy
3. National Adviser GCBR & Coordinator, Rehabilitation Assistant Training Programme, Ministry of Health, Guyana
4. AIFO Representative, Ulaanbaatar, Mongolia
5. Project Officer, AIFO office, Ulaanbaatar, Mongolia
6. Research and Documentation Officer, NAD, CBR programme in Malawi, Uganda and Zambia
7. Consultant and Evaluator, Palestine CBR Programme of NAD-Diakonia, Palestine
8. Head of Programmes, Amici India Trust, Bangalore, India

ABSTRACT

Today there are Community-based Rehabilitation (CBR) programmes in a large number of countries. In many countries, the CBR approach is a part of the national rehabilitation services. However, there is a lack of reliable data about persons with disabilities who benefit from CBR and the kind of benefits they receive.

This article reviews the disability data collection systems and presents some case studies to understand the influence of operational factors on data collection in the CBR programmes.

The review shows that most CBR programmes use a variable number of broad functional categories to collect information about persons with disabilities, combined occasionally with more specific diagnostic categories. This categorisation is influenced by local contexts and operational factors, including the limitations of human and material resources available for its implementation, making it difficult to have comparable CBR data.

Therefore, any strategies to strengthen the data collection in CBR programmes must take these operational factors into account.

Key words: *CBR, classification, case studies, data collection, disabilities, ICF*

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* **Corresponding Author:** Dr Sunil Deepak, Independent Consultant on disability & rehabilitation, collaborating with AIFO (Bologna, Italy). Email: sunil.deepak@gmail.com

INTRODUCTION

CBR strategy was proposed by the World Health Organisation (WHO) when the Primary Health Care (PHC) Strategy was launched in 1978 (Helander, 2010). CBR is a strategy within general community development for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disability (WHO, ILO, UNESCO, 2004).

Though CBR programmes are being implemented in a large number of countries, there is limited information about persons with disabilities who are involved. For example, a survey on disability and rehabilitation in 29 countries of Africa (WHO/DAR, 2004) had reported ongoing CBR programmes in 13 countries, including 8 which were national CBR programmes. However, none of the surveyed countries was able to provide information about the persons who benefit from CBR.

Article 31 of the UN Convention on the Rights of the Persons with Disabilities (CRPD) asked the States for collection of *"appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention"* (United Nations, 2006).

The first World Disability Report (WHO & World Bank, 2011) had also recommended that international methodologies for collecting comparable data on people with disabilities need to be developed.

It has been suggested that the International Classification of Functioning, Disability and Health (ICF) can be used alongside the CBR Guidelines at each stage of this cycle, as a tool to help think about disability and the environment, plan related interventions, and gather information about disability in a common framework (Madden et al, 2013).

There have been recent calls to expand the CBR programmes to make them more inclusive of persons with chronic conditions and elderly persons as well. For example, the Disability Action Plan 2014-2021 of WHO (DAP, 2014) proposes widening the scope of rehabilitation services to reach *"the wider group of persons who experience difficulties in functioning due to a wide range of conditions such as non-communicable diseases, infectious diseases, neurological disorders, injuries, and conditions that result from the ageing process."*

In 2015, the first Global Report on Ageing and Health was published by the WHO. This report notes that the percentage of elderly population is destined to increase all over the world, creating new challenges for countries. It also asks for the expansion of rehabilitation services and access to assistive technology to promote independence and participation of elderly persons (WHO, 2015).

Thus, to strengthen and expand CBR programmes, it is important to understand which group of persons with disabilities benefit from them and how existing programmes collect information about different groups of persons with disabilities.

Objective of the review

This review aimed to look at the different systems of disability data collection used by CBR programmes and to understand the operational factors influencing these systems. This review is based on systematic online searching (using search terms to identify CBR data, beneficiaries, training, monitoring and evaluation reports) together with hand-searching of books, programme reports and manuals from different archives and documentation centres.

It is not a systematic review and therefore cannot claim replicability or comprehensiveness. It focussed on collecting information through a number of CBR practitioners in different countries and continents, some of whom are represented among its authors. It is supported by selected case studies to understand and illustrate specific issues.

CBR Disability Data Collection Systems

WHO developed a draft version of a CBR manual in 1979. In 1989, an updated version of this manual, "Training in the Community for People with Disabilities" (TCPD) was published (Helander et al, 1989). It included a CBR data collection form and proposed dividing the persons with disabilities into 8 functional groups - seeing, hearing and speech, movement, loss of body sensations, difficulty in learning, strange behaviour, convulsions and other/multiple disabilities.

Except for TCPD, other CBR-related international manuals such as Disabled Village Children (Werner, 1987), WHO guidelines on monitoring and self-assessment (WHO & IDC, 1996) and, more recently, a manual on CBR indicators (WHO & IDDC, 2015), do not provide any template for collecting disability data in the CBR programmes.

Helander (1999) reviewed the evaluations of some CBR programmes carried out between 1984 and 1992, showing that during that period countries were using very different criteria for CBR data collection, though many of them shared some common elements with the format proposed in TCPD.

More recently, some systematic reviews of CBR evaluation methodologies have been carried out but they do not mention the specific data collection systems used by the programmes (Kuipers et al, 2008; Iemmi, 2015; Grandisson, 2015).

CBR Data Collection Systems at National or Sub-National Levels: Most CBR programmes use some of the functional categories proposed in TCPD. Table 1 provides a summary of categories used for classifying disabilities in national or sub-national CBR programmes in a few countries, showing that categories differ widely.

Table 1: Disability Categories used in some National & Sub-national Level CBR Programmes

Regions/ Countries	Source of Information	Disability Categories
Africa (13 countries)	Workshop report (Schneider M. et al, 2002, pp. 177-178)	7 (seeing, hearing, speaking, moving around, learning/comprehending, movement including reaching, gripping & holding, and others)
Caribbean (Childhood disabilities)	Book article (Thorburn M. J., 1990, p. 8)	6 (fits, visual, hearing-speech, physical, learning & strange behaviour)
Caribbean (Childhood disabilities)	Book article (Durkin M. et al, 1990, pp. 191-194)	10 (sitting-standing, walking, seeing, hearing, understanding, fits, learning, speaking, if speech is understandable & naming objects)
India	CBR manual of Ministry of Welfare (Pahwa A., 1990, p. 65)	4 (locomotor, speech & hearing, visual & mental retardation)
Indonesia	CBR Training manual (Handoyo S., 1995, p. 18)	6 (visual, hearing, speech, moving/ walking, thinking/learning & multiple)
Indonesia (Childhood disabilities)	CBR Training manual (Handoyo S., 1995, p. 44)	13 (hearing, speaking, hearing-speaking, low vision/blind, mild mental handicap, moderate-severe mental handicap, severe physical without learning problems, severe physical with learning problems, minor physical with mental handicap and minor physical without mental handicap)

Mauritius	U.N. report (UN, 1996, p. 28)	6 (mobility, hearing/speaking, mental illness, seeing, mental retardation/ epilepsy and multiple disabilities)
Philippines	Philippine CBR Manual (McGlade B. & Mendoza V. E., 2009, p. 163)	9 (psychosocial disability, chronic illness, learning disability, mental disability, visual disability, orthopaedic (musculoskeletal) disability, hearing disability, speech impairment and multiple disabilities)

Operational Factors Influencing Data Collection in CBR

There are different operational factors that influence data collection in CBR.

There can be differences between communities in how they decide which groups of persons are to be considered as persons with disability. For example, when a CBR programme in Nepal asked self-help groups to decide the criteria for defining persons with disabilities, they decided not to consider persons with epilepsy and mental illness as persons with disabilities (Shrestha et al, 2009).

Some CBR programmes periodically compile information about the persons involved in their activities. However, "involvement in activities" can be defined very differently in different programmes.

There are some disabilities for which specific interventions exist, such as cleft lips and palate (reconstructive surgery), club foot (Ponsetti technique) and children with deafness (cochlear transplants). Depending upon the availability of specific interventions, CBR programmes collect information about such disabilities.

Persons responsible for data collection - A key issue here is about the persons who collect data in the CBR programmes. The need for a new cadre of worker in the rehabilitation field, namely the community rehabilitation worker (CRW), was advocated by WHO in 1981 (Helander et al, 1989).

However, except for a few countries like Mongolia that have adopted CBR as a national programme, most countries continue to have "pilot programmes" covering limited geographical areas and are often dependent on international aid for their functioning. These CBR programmes work through community-level workers, who may be paid workers (like a community health agent or a specific CBR worker) or an unpaid community volunteer, many of them with limited educational backgrounds. The training provided to these community-level workers varies substantially (Deepak et al, 2011).

Most CBR workers are supposed to receive formal training for 10 - 21 days but because of the high turnover they may sometimes receive only on-the-job training. Sometimes CBR workers are expected to cover big geographical areas with limited or no public transport and a large number of persons with disabilities, while support from referral services is limited (Deepak and Pupulin, 2013). Thus, along with limited training, they also face problems of heavy workloads.

CBR Data Collection Case Studies – A few case studies are presented here, to illustrate some of the operational issues affecting CBR data collection.

Case Study 1-AIFO CBR monitoring experience: The Italian non-governmental organisation Amici di Raoul Follereau (AIFO) started supporting CBR programmes in 1988. In 1992, AIFO began to use a standardised monitoring form to collect CBR information from different countries. It was based on Form 1 of the TCPD and included the same 8 categories of persons with disabilities.

One of the objectives of this monitoring system was to collect comparable information from different programmes and countries. It was found that knowledge about local contexts and operational factors is necessary while comparing data from different programmes. For example, an analysis of 2012 data from different CBR programmes supported by AIFO showed that persons with convulsions were: 39% of all the persons with disabilities in 5 counties in Liberia, 2.5% in 3 districts of South Sulawezi province in Indonesia, and 8.1% at country level in Mongolia, while there was no mention of persons with convulsions in Bellary district of India.

The high number of persons with convulsions recorded in Liberia was possibly due to the distribution of anti-convulsion medicines through the CBR programme, while the absence of such persons in Bellary district was because the Indian Disability Law does not consider persons with convulsions as persons with disabilities.

Thus, even while using uniform disability categories, the CBR data may not be completely comparable across different countries.

Case Study 2 - Categories used by a CBR programme and the functional difficulties according to the Washington Group: In a research about violence against persons with disabilities carried out in Bidar district (India), 146 persons with disabilities were interviewed. All of them were classified by CBR workers in 8 groups as suggested in TCPD (Deepak et al, 2014). All the 146 persons were also asked the 6 questions suggested by the Washington Group (WG, 2010), pertaining to : difficulty in seeing (even if wearing glasses), difficulty in hearing (even if wearing a hearing aid), difficulty in communicating, difficulty in walking or climbing steps, difficulty in remembering or concentrating, and difficulty in self-care such as washing properly or dressing.

This gave an opportunity to compare the data collected by the CBR programme with the answers to the Washington Group Questions (WGQ) about functioning.

Persons with different impairments according to the CBR programme classification: The 146 participants belonged to the following groups: vision disabilities - 12 persons (8.7%); hearing and speech disabilities - 8 persons (5.8%); physical/locomotor disabilities - 92 persons (66.7%); loss of feeling in hand/feet - 7 persons (5.1%); multiple disabilities - 18 persons (12.3%); and others - 7 persons (5.1%).

There was no one with convulsion-related disabilities in the sample, while persons with mental illness and persons with intellectual disabilities were 1 each (together 1.4%).

Number of functional difficulties experienced by these persons in terms of WGQ: An analysis of data showed there were: difficulties in no area of functioning - 20 persons (13.7%); difficulties in one area of functioning - 34 persons (23.3%); difficulties in two areas of functioning - 33 persons (22.6%); difficulties in three or more areas of functioning - 59 persons (40.4%).

Among the 20 persons who had no difficulties in any area of functioning, 55% were persons classified as "physical disabilities" by the CBR programme. They usually had a mild disability in one leg or in one arm or hand, or the spine, which did not significantly affect any specific area of their functioning. However most of them reported that they faced serious social barriers.

Comparing CBR classification and the functional difficulties of WGQ: Table 2 presents the functioning difficulties reported by 6 groups of persons classified by the CBR programme.

Thus persons put under a specific category by the CBR programme had different functional difficulties. For example, 25% of persons with hearing and speech disabilities, 10% of persons with physical disabilities and 57% of persons with loss of feeling, also had difficulties in seeing.

Table 2: Comparing CBR classification with Washington Group classification

Functional Difficulties	CBR Classification					
(Washington Group)	Visual (N=12)	Hearing-Speech (N=8)	Movement (N=92)	Loss of Feeling (N=7)	Mental Illness (N=1)	Intellectual (N=1)
Difficulty seeing	12	2	11	4	0	0
Difficulty hearing	2	4	3	4	0	0
Difficulty communicating	1	4	1	0	1	1
Difficulty walking	4	3	71	6	0	0
Difficulty remembering	3	1	21	4	1	1
Difficulty self-care	2	0	23	4	0	1

In this respect, compared to the TCPD system WGQs provide a much better assessment of people's rehabilitation needs. At the same time, by using only WGQs the CBR programme would have missed some persons who did not have a significant functional difficulty but who were considered to be persons with disability in the local context and had faced different barriers.

Case Study 3: Classification of persons with disabilities in Malawi – The Malawi CBR programme, supported jointly by Norwegian Association of the Disabled (NAD) and Christoffel Blindenmission International (CBMI), covers 13 out of 28 (46%) districts of the country. In the programme, identification of persons with disabilities is a two-step process. First, persons with disabilities are identified by Community Rehabilitation Volunteers (CRVs). As a second step, these persons are seen by better-trained Community Rehabilitation Workers (CRWs).

Initial identification of persons with disabilities is guided by the ICF model. A form with a list of 10 disabilities (difficulty in seeing; difficulty in hearing; difficulty in speaking; difficulty in moving; difficulty in self-care; difficulty in learning new things and solving problems; slow development; fits; albinism; and any other difficulties) is used by CRVs to identify "persons with difficulties". CRVs usually have 5 - 8 years of school education.

Once CRVs identify persons with difficulties, a CRW visits each identified person for verification. CRWs are recruited from high school graduates and receive more comprehensive training on various aspects of CBR. From the information collected by CRWs, a list of persons with disabilities is compiled and fed into a "CBR Management Information System" run by the Malawi Council for the Handicapped (MACOHA), a government agency coordinating CBR implementation at national level (MACOHA, 2015).

A CRV is responsible for a village (300-500 persons). There is a high turnover of CRVs and the duration of their training is not long enough. Training is supposed to be for 15 days but rarely exceeds 5 days.

A CRW covers 20 villages spread over an area of around 25 km. As this is a large area, the quality of data collection is affected.

Data entry, analysis and key outcomes are uploaded onto a web-based CBR management information system (CMIS) by MACOHA. This system currently covers data only for 9 of the 13 districts (69%) that implement CBR. There is also a need to harmonise CMIS with disability databases of other key service providers to persons with disabilities.

In 2008, the Malawi National Statistical Office (MNSO) for the first time included 3 questions to identify persons with disabilities. Tools used were restricted to identifying persons with a range of physical, seeing and hearing challenges. The census report documents that 3.8% of the population of Malawi comprises persons with disabilities (MNSO, 2010).

Case Study 4 - CBR Programme in Palestine: The Palestine CBR Programme was initiated in 1990. It was expanded gradually to cover all the regions in the country. Supported jointly by the Swedish organisation Diakonia and NAD, it is implemented by local partners cooperating through regional rehabilitation committees.

CBR Workers (CBRWs): Initially CBRWs were selected from the communities they were expected to serve. Almost all of them were young women who had either partially or fully completed their secondary education. They usually receive 3 months of training on the TCPD and other related skills.

When starting out in a new community, they begin with a house-to-house survey to identify persons with disabilities, using the TCPD Form 1. Identified persons are assessed for rehabilitation needs, and personal work plans are prepared. At present the programme covers around 65% of the total population. On average, each CBRW looks after a population of 15,000.

CBR Data Collection: The disability data is collected as suggested in the TCPD manual. These categories are identified at two levels: single disability and multiple disabilities.

Since the programme is implemented by different local NGO partners in different districts, some variations exist in the way they operationalise this classification. For example, some partners add autism as a separate group while others include autism within the "strange behaviour" category, and others do not report it (Qutteina, 2010).

Although all NGO partners in the programme employ the same tools to identify and assess persons with disabilities, wide variations exist in their statistics. This relates to the classification of types of disabilities they work with, as well as to their modes of intervention.

National surveys conducted by national statistical bodies or academic/research institutes use different criteria and tools unlike those used by CBR workers. Therefore, such national surveys or studies are sometimes unable to assess the coverage and achievements/gaps in the work of the CBR programmes.

In 2011 the Palestinian Central Bureau of Statistics (PCBS, 2011), the national statistics body, published the first national disability survey, using the Washington Group classification of functional difficulties. The report provided a different categorisation (seeing, hearing, mobility, remembering and concentrating, communication, learning and mental) than that used by the CBR programme.

Thus, when data collection is action-oriented, the outcomes may vary according to the differences in the intervention mode and the focus of each organisation. Data collectors will be more interested in informing their planning and action rather than in getting results that are comparable with those of others, even when best intentions for coordination exist.

Case Study 5 - Classifying disabilities in Mongolia CBR Programme: The CBR programme in Mongolia was initiated in 1992 with support from AIFO/Italy, in technical collaboration with WHO. It is now a national programme covering all the 21 *aimags* (provinces) and the 9 urban districts of the national capital, Ulaanbaatar. With a vast geographical area and a tiny population, Mongolia presents a distinct challenge to the implementation of the CBR programme.

Each province and all urban districts have a CBR committee and local CBR coordinator. The role of CBR workers is played by the family doctors and somon (district) doctors as well as by the *"bag feldshers"* (community health workers - CHWs). The CBR programme is implemented through the existing health-system structures in order to reach all the people, especially the nomads living in the remote areas.

The Mongolia CBR programme has been using TCPD, translated into Mongolian, as its principle CBR reference guide since 1996. Till 2001, the duration of the CBR training was 14 days for family and district doctors and 21 days for CHWs. After 2001, the duration of training for different groups of personnel was reduced to 10 days.

Since 2010, the CBR programme also collaborates with the National University of Medical Science in Mongolia to prepare general practitioners and paramedical staff at the national level. Undergraduate students of the School of Public Health are taught 16 hours of theory and 32 hours of practice on CBR. A 2014, a working group was established to develop core CBR curriculum for under-graduate and post-graduate students, and is under development.

Disability statistics in Mongolia: Apart from the CBR programme data, the only other surveys of disability in Mongolia were made in 2004 (a project of Asian Development Bank and the National Statistics Office) and in 2010 (as part of the national census).

In 2004 the survey was conducted using the ICF classification. It included the following 11 disability groups: blind, low vision, deaf, low hearing, no speech, speaking difficulty, mental illness (severe/chronic, light), intellectual disability (severe, mild), brain damage (severe, mild), physical (hand, leg, spinal cord), and internal diseases. The National Census (2010) included the following 6 disability groups: seeing, hearing, speaking, moving, mental and others.

CBR uses Form 1 of the TCPD manual with 8 categories. Every year CBR workers collect the data and send their reports to the National Rehabilitation Centre. In July 2011, the Ministry of Health made CBR a national programme. It has since been collaborating with the Ministry of Health to revise the data collection form. Since 2014, CBR data is published officially in the annual Health Statistics of the Government of Mongolia.

Case Study 6 - Classifying disabilities in Guyana CBR Programme: The Guyana CBR Programme (GCBR) began in 1986. It was introduced in 8 of the 10 administrative regions of Guyana in a phased manner. CBR is implemented by trained community volunteers, many of whom are family members of persons with disabilities. They are also responsible for the data collection through Form 1 of TCPD. However, based on the need for specific data, adjustments were made by the GCBR Programme, from time to time in relation to the categories used on the form.

Over the past decades, different international organisations supporting GCBR have influenced the data collection. Some partners were more interested in data related to their area of focus or support. For example, information about children was often a major area of interest and consequently the collection of data was a mixture of impairments, functioning and medical diagnosis. The data form included functional disabilities such as difficulty in seeing, difficulty in hearing, etc., as well as some specific impairments such as club foot, cerebral palsy and spina bifida.

One of the challenges the CBR programme faces is the difficulty in getting volunteers to be consistent in collecting data. Initially volunteers received training over a period of 12 months. However, over the years, considering the turnover of volunteers, their training was changed.

It was also a challenge to get the CBR collected data integrated into the national disability data management system.

In 2012, GCBR and the Rehabilitation Services of the Ministry of Health of Guyana developed a Joint Rehabilitation Initiative to promote CBR as a national strategy. As one component of the strategy, the two entities have identified data collection as being critical to the project for programming.

A new CBR/Rehabilitation Data Collection Form has been developed and although both entities would still continue to collect data that would be relevant to their respective programmes, this new Form will be tested over the next two years. It will be reviewed after two years to identify strengths and weaknesses and to consider amendments before the final version is completed. In this Form, data will be collected for the following 7 categories of persons with disabilities: visual, hearing, physical, speech, learning, multiple and others.

Apart from the GCBR volunteers, another category of rehabilitation workers is active in Guyana – the Rehabilitation Therapy Assistants (RTAs). The CBR volunteers have been collecting information more related to social needs and interventions, while the RTAs who work in the Ministry of Health have been focussing more on medical interventions.

DISCUSSION

CBR programmes involving persons with different kinds of disabilities need to categorise them so as to plan their activities and ensure that all the different groups can access these activities.

Most CBR programmes use functional categories, also used in the TCPD manual of WHO, to collect disability data. Many of them also collect information about some specific disabilities. However, while the basic approach to data collection is similar, there are many variations in this process.

Classifications based on functioning, such as "can the person see?" allow programmes to identify persons with different degrees of difficulties, from mild to severe. Classifications based on specific disabling conditions such as "partially sighted" have definitions that may vary between programmes and countries. Specific disabling conditions also carry the risk that other specific conditions are missed, so usually a mix of general and specific categories is used at the same time.

Thus, to have comparable intra- and inter-country data about persons with disabilities, a core group of ICF-based functional categories can be identified. At the same time, each programme can continue to collect additional information about specific groups.

A monitoring manual for CBR and disability inclusive development programmes (Madden et al, 2014) suggests such an approach by proposing a "Monitoring Menu" that can allow programmes to pick and choose between different items linked to persons, organisations, activities and workforce. The manual recommends a participatory approach to monitoring by including all stakeholders, especially people with disabilities and their families, and their representative organisations. It also recommends that efforts be made to include a range of potentially marginalised people in order to ensure diversity is recognised (e.g., people with intellectual or psychiatric disability, women, older people, youth representatives or people who belong to a cultural minority group).

As pointed out in the Guyana case study, consistency in categorising may be a problem. Sometimes, even in the same CBR programme, different CBR workers and supervisors may use different criteria to classify disabilities. Therefore clear guidance is needed about the definitions of the core functional categories.

For comparing the data between programmes, additional information about the specific local context will be necessary.

There are certain issues related to the specific functional categories that require more information and understanding. For example:

- Lack of feeling (sensation) and leprosy - One of the categories used in TCPD is “lack of feeling in hands or feet or eyes”. In the CBR programmes, this category is usually perceived as exclusively for persons who have leprosy-related disabilities. Hence programmes that do not cover persons affected by leprosy, usually do not report any persons under this category. However, lack of feeling can be due to many other conditions including diabetes.
- Additional information is needed for persons placed under “multiple and other disabilities” to plan specific interventions.
- Persons with similar disabling conditions who can be placed under different categories can also pose a problem. For example, persons with cerebral palsy can be placed in different disability categories depending upon their dominant conditions – physical disabilities, speech disabilities, convulsions or even, learning disabilities.
- Functional categories may not be sensitive enough to identify children with disabilities in the younger age group (0 - 5 years). This has implications for early identification and early intervention programmes.

Today, while there are discussions around strengthening and expanding CBR programmes to make them more inclusive of persons with chronic conditions and elderly persons, there are also opportunities to critically review the disability data collection. This would however require the involvement of all the different CBR stakeholders and addressing of the operational factors.

Limitations of the Review

Most documents related to CBR - including annual progress reports, monitoring forms, evaluations - are part of grey literature kept locally and difficult to access. This review attempted to overcome the difficulty by involving persons from different CBR programmes through the case studies.

Language used for categorising persons with disabilities is another issue which has not been explored so far in CBR research. All the reports and discussions about categories of persons with disabilities are usually in a European language, especially in English, while most CBR workers use other local languages in their daily lives. Consequently there may not be an exact overlap between the way in which the CBR data is grouped for the reports prepared in English, and the way the community workers organise it for their daily work.

CONCLUSION

CBR programmes in different parts of the world have been using very different data collection systems, though most use a mix of functional categories and some specific conditions. Depending upon the selected system, sometimes some specific groups may not be counted as persons with disabilities while some specific health conditions are counted separately.

Even when similar categories of persons with disabilities are used, there can be other factors which influence the data collection, such as community perceptions, training of CBR workers, and problems of categorising persons with difficulties in multiple functional areas. In many countries and organisations, the criteria used to collect information about disability among adults are different from those used for children. Finally, even when everything else is similar, specific operational factors may still create difficulties for comparison of CBR data.

Form 1 described in TCPD and developed by WHO in 1989, including some of its variations, seems to be the most common data collection instrument in CBR programmes. However, there is no consensus about the most appropriate system of CBR data collection, and programmes use very different systems.

This review of disability data collection also shows that though over the past decade there has been some agreement about the importance of ICF-based approaches focussing on functioning, this can be a starting point to identify core functional areas for CBR data collection that can be used for intra- and inter-country comparisons.

Recently there have been calls for widening the scope of CBR and the need for providing more resources for its implementation so as to include increasing numbers of elderly persons and those affected by chronic conditions. This may provide an opportunity to review the approaches to classification of disabilities in CBR and to develop new approaches based on ICF.

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REFERENCES

Deepak S, Kumar J, Ortali F, Pupulin E (2011). CBR matrix and perceived training needs of CBR workers: A multi-country study. Disability CBR and Inclusive Development Journal; 22 (1): 85-98. https://doi.org/10.5463/dcid.v22i1.16

Deepak S, Pupulin E (2013). CBR, health and rehabilitation. Disability & International Development; 2. Germany

Deepak S, Kumar J, Santhosh B, Gornalli S, Manikappa P, Vyjantha U, Giriyappa R (2014). Violence against persons with disabilities in Bidar district, India. Disability, CBR and Inclusive Development Journal; 25 (2): 35-53. https://doi.org/10.5463/dcid.v25i2.305

Disability Action Plan (2014). WHO global disability action plan 2014-2021: Better health for all people with disability, A67/16, Sixty Seventh World Health Assembly.

Durkin M, Davidson L, Hasan M, Khan N, Thorburn M, Zaman S (1990). Screening for childhood disabilities in community settings"; in "Practical approaches to childhood disability in developing countries - Insights from experiences and research"; edited by Marigold J Thorburn and Kofi Marfo, Project Seredec and 3 D projects, Kent state university, UK

Grandisson M (2015). Developing guidelines for programme evaluation in community-based rehabilitation; P.hD thesis, School of Rehabilitation, University of Ottawa, Canada

Handoyo S (1995). Finding out if your programme works - evaluation and monitoring, Training materials for CBR workers, CBR development and training centre, Solo, Indonesia

Helander E (1999). Prejudice and dignity - An introduction to community-based rehabilitation, UNDP Inter-regional Programme for Disabled People, New York, USA, Second edition: 173-192

Helander E (2010). The origins of community-based rehabilitation. Available from http://www.einarhelander.com/origins-rehabilitation.pdf

Helander E, Mendis P, Nelson G, Goerdt A (1989). Training in the community for people with disabilities. WHO, UNDP, UNICEF & UNESCO, Geneva, Switzerland

Iemmi V (2015). Community-based rehabilitation for people with disabilities in low and middle income countries: A systematic review. The Campbell Collaboration, UK

Kuipers P, Wirz S, Hartley S (2008). Systematic synthesis of community-based rehabilitation (CBR) project evaluation reports for evidence-based policy: A proof-of-concept study, BMC International Health & Human Rights Journal, March. Available from: https://bmcinthealthhumrights.biomedcentral.com/articles/10.1186/1472-698X-8-3 [Accessed on 18 August 2016]

Madden R, Hartley S, Mpofu E, Baguwemu A (2013). “The ICF as a tool to support CBR planning and Management”; in “Linking CBR, Disability and Rehabilitation”; ed. Musoke G. & Geiser P., CBR Africa Network, Bangalore, India

Madden R, Lukersmith S, Hartley S, Millington M, Scarf C, Fortune N, Gargett A, Llewellyn G (2014). Monitoring Manual and Menu (MM&M) for CBR and other community-based disability inclusive development programmes; Centre for Disability Research and Policy, Sydney, Australia, Version 1.0 April 2014. Available from: http://sydney.edu.au/health-sciences/cdrp/cbr-monitoring/

Malawi Council for the Handicapped - MACOHA (2015). National CBR annual report. Malawi Council for the Handicapped, Lilongwe, Malawi

Malawi National Statistical Office - MNSO (2010). Malawi population and housing census 2008. National Statistical Office, Lilongwe, Malawi

McGlade B, Mendoza V E (2009). Philippine CBR manual: An inclusive development strategy. CBM and National Council on Disability Affairs (NCDA), Manila, Philippines. PMCid:PMC2785331

Nind M (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. ESRC National Centre for Research Methods Review Paper, University of Southampton, UK. PMid:18492714

Pahwa A (1990). Manual on community-based rehabilitation - district rehabilitation centre scheme. Ministry of labour and welfare, New Delhi, India

Palestinian Central Bureau of Statistics and Ministry of Social Affairs - PCBS (2011). Disabled Individuals Survey 2011: Main findings report. Ramallah – Palestine.

Qutteina M (2010). Review of the documentation and research component of the Diakonia/NAD Rehabilitation Programme in Palestine. The Norwegian Association of Disabled (NAD)

Schneider M, Loeb M, Mirembe J, Asindua S, Dube S, Hartley S (2002). "Collecting disability statistics: a participatory strategy?" in "CBR - a participatory strategy in Africa"; edited by Sally Hartley, University College London, UK

Shrestha S, Shrestha NK, Deepak S (2009). A community assessment of poverty and disability among specific rural population groups in Nepal; 20(1): 83-97

Thorburn M J (1990). "Childhood disabilities in developing countries: Basic issues"; in "Practical approaches to childhood disability in developing countries - Insights from experiences and research"; edited by Marigold J Thorburn and Kofi Marfo, Project Seredec and 3 D projects, Kent state university, UK

United Nations (1996). Manual for the development of statistical information for disability programmes and policies, Statistics on special population groups, Series 8, No. 8, Department of Economic and Social Information and Policy Analysis/statistics division, ST/ESA/STAT/SER.Y/8, New York, USA

United Nations (2006). UN Convention on the Rights of Persons with Disabilities, New York, USA. Available from: www.un.org/disabilities.

Washington Group (2010). The measurement of disability for the 2010 round of censuses. Washington Group on Disability Statistics. Available from: http://www.cdc.gov/nchs/washington_group/wg_questions.htm

Werner D (1987). Disabled village children - a guide for community health workers, rehabilitation workers and families. The Hesperian Foundation, Palo Alto, USA

World Health Organisation (2001). International classification of functioning, disability and health. World Health Organisation, Geneva, Switzerland

World Health Organisation (2004). Disability and rehabilitation status – Review of disability issues & rehabilitation services in 29 African countries. World Health Organisation, Geneva, Switzerland

World Health Organisation (2015). World report on ageing and health. World Health Organisation, Geneva, Switzerland

World Health Organisation & International Disability Consortium –WHO & IDC (1996). Guidelines for conducting monitoring and self-assessment of community-based rehabilitation programmes. Rehabilitation - World Health Organisation and International Disability Consortium, WHO/RHB/96.3, Geneva, Switzerland

World Health Organisation & International Disability and Development Consortium – WHO & IDDC (2015). Capturing the difference we make: Community-based rehabilitation indicators manual. World Health Organisation, Geneva, Switzerland

World Health Organisation, International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation (2004). Joint position paper on community-based rehabilitation. Geneva, Switzerland

World Health Organisation, International Labour Organisation, United Nations International Children's Emergency Fund, International Disability and Development Consortium (2010). CBR - Community-based rehabilitation guidelines. Geneva, Switzerland

World Health Organisation & World Bank (2011). World report on disability. World Health Organisation and World Bank, Geneva, Switzerland: 45