

**A REVIEW OF COMMUNITY BASED REHABILITATION
EVALUATIONS: QUALITY OF LIFE AS AN OUTCOME MEASURE
FOR FUTURE EVALUATIONS**

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ABSTRACT

This review examines key articles in evaluation of community-based rehabilitation carried out in developing countries and proposes family quality of life as an outcome measure of community-based rehabilitation. The concept of community-based rehabilitation is reviewed, quality of life and family quality of life measurement scale is presented. It presents a practical approach to future evaluations of community-based rehabilitation programmes. This review presents the features of community-based rehabilitation evaluation (i.e., service delivery system, technology transfer, community involvement, and organisation and management), methodology, and findings. Implications are defined for the enhancement of community-based rehabilitation through practical suggestions for programme coordinators involved in community development for rehabilitation, equalisation of opportunities, and social inclusion of people with disabilities.

INTRODUCTION

The World Health Organisation (WHO) introduced the Community-Based Rehabilitation (CBR) strategy as part of its goal to accomplish health for all by the year 2000. The Alma-Ata Conference and Declaration of 1978 on Primary Health Care (PHC) creates a new vision for providing promotive, preventive, curative and rehabilitative services for the main health problems in the community (1). The Declaration of Alma-Ata states that people have the right and duty to participate individually and collectively in planning and implementation of their health care. This concept led to development of the first CBR models.

This paper examines relevant literature and research concerning evaluation of CBR and is divided into five sections: (a) CBR foundation, (b) past and current evaluation, (c) review of CBR evaluation, (d) summary of evaluation results, and (e) quality of life as an outcome evaluation for CBR. This paper proposes family quality of life (FQOL) as a CBR outcome measure and presents a practical approach to future evaluations using the only existing FQOL measure. The practical approach is based on the premise that CBR aims at enhancing opportunities of people with disabilities and their families to live their lives as they choose (2) and is rooted in quality of life (QOL).

Community-Based Rehabilitation: Foundation

In 1950, the World Health Assembly (WHA) called for development of rehabilitation programmes for people with disabilities. It was not until 1966 that the WHA adopted a resolution stressing the importance of rehabilitation, whereby it urged member states to develop their rehabilitation services as an integral part of the national health system. This review of CBR focuses on (a) conceptualisation, (b) components, and (c) principles.

Conceptualisation

CBR is a strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of all children and adults with disabilities (3). The CBR concept is both simple and complex in nature (4). The simplicity has to do with its origins, i.e., delivery of rehabilitative services to people with disabilities in their communities. CBR's complexity is the result of the current concept of CBR programmes as multi-disciplinary, i.e., visiting people with disabilities and their families in their homes; providing appropriate information, therapy and/or training; and facilitating rights and duties of people with disabilities, family, and community members (5).

Components

The primary component of CBR as a concept and ideology is that community members are willing and able to mobilise local resources and provide appropriate services to people with disabilities. Other components of a multi-disciplinary CBR programme include: (a) creating positive attitudes towards people with disabilities, (b) providing functional rehabilitation services (e.g., physical therapy, occupational therapy, orientation and mobility training, speech therapy,

counselling, orthotics and prosthetics), (c) providing education and training opportunities (e.g., early childhood intervention and referral especially to medical rehabilitation services, special education in mainstream or special schools, sign language, Braille training, training in activities of daily living skills), (d) creating micro and macro income generation, (e) providing care facilities (e.g., respite care), (f) preventing causes of disabilities, and (g) managing, monitoring, and evaluation of CBR programmes (4).

Principles

The five basic CBR principles include: (a) utilisation of available resources in the community, (b) transfer of knowledge about disabilities and skills in rehabilitation to people with disabilities, families, and communities, (c) community involvement in planning, decision making, and evaluation, (d) utilisation and strengthening of referral services at the district, provincial, and national levels that are able to perform skilled assessments with increasing sophistication, make rehabilitation plans, and participate in training and supervision, and (e) utilisation of a coordinated approach among education, health, and social systems (6). Despite the identification of fundamental CBR principles, there are significant variations in implementation across countries. It should be acknowledged that since CBR's inception two decades ago, complexities arising from these initiatives in diverse communities with their unique cultural, social, and economic conditions, make it difficult for CBR to meet all needs of people with disabilities.

EVALUATION OF CBR: PAST AND CURRENT

CBR has been the focus of some form of evaluation since the first field-testing of the manual *Training in the Community for People with Disabilities* (7). Early reports state that only two of the 43 countries represented by the six regional zones in which the WHO operates mentioned any evaluation and research on CBR (8). Earlier country reports are limited to issues such as initial consultant visits, training workshops held, and number of stakeholders involved in training (8). Subsequent evaluation studies presented extensive sets of data on the number of people identified with disabilities, the number of people with disabilities who received assistance, and the type of assistance (9). This review highlights (a) four features of evaluation, (b) individual and programme evaluation, and (c) process and impact evaluation.

Four Features of Evaluation

CBR evaluation refers to a standard to make objective judgements of activities and outcomes of a CBR programme. There are significant variations in implementation of CBR, and it is widely acknowledged that the CBR concept is highly adaptable to meet specific needs in the developing world. The challenge here is the need to provide a method of CBR evaluation that allows each significant variation of the CBR programme to encapsulate components, principles, features, and core evaluation criteria. Four features of CBR on which evaluation might focus are service delivery system, technology transfer, community involvement, and organisation and management (7).

First, service delivery system relates to how services and training are provided to people with disabilities and their family members at the community level. Specific issues include, among others, utilisation of the primary CBR worker; training family members to teach people with disabilities; and partnerships among the CBR worker, people with disabilities, and family members of people with disabilities.

Second, technology transfer relates to technical skills that the primary health-care worker/local supervisor of the CBR programme should possess. Specific issues include, among others, teaching technical skills to CBR workers at low cost and in the shortest possible time; the nature and extent of skill the CBR worker should have; early identification of disabilities; and use of appropriate technology.

Third, community involvement relates to training people with disabilities to ensure that training is not the sole concern of the family members and the CBR worker, but also of the community where the person lives. Examples include assessing change in community attitudes towards people with disabilities and mobilising community resources to support and assist people with disabilities.

Fourth, organisation and management is a feature of CBR that ensures effectiveness of a programme. Specific issues related to this CBR feature include linkages within the referral network to the primary health-care worker, person with disability, family member, and the community; identification of appropriately trained personnel; and importance of people with disabilities as key personnel in the management of CBR programmes. In this paper, the summary of evaluations are classified according to the four features of CBR, and some of the evaluations cover more than one feature of CBR.

Individual and Programme Evaluation

Jonsson (10) provides a framework for CBR evaluation consisting of individual and programme evaluation. The individual evaluation involved (a) functional aspects with components such as daily living skills, communication skills, mobility, and behaviour; (b) educational aspects with components such as school attendance, school involvement, and educational achievement; (c) vocational aspects with components such as vocational training, placement, and income generation; and (d) social aspects with components such as participation in family life and participation in community life. Programme evaluation consists of the overall aspects, with components such as effectiveness, efficiency, relevance, impact, and sustainability.

Process and Impact Evaluation

Campfens (11) identifies process and impact as two principal types of CBR evaluation. Process evaluation is an ongoing, systematic collection of information to keep pace with what is happening, ensuring that a programme is in accordance with objectives, and assessing how activities are carried out and how inputs are used (11). Impact evaluation involves assessment of the programme or a component of it at a point in time (11). Its purpose is to determine the extent to which the goals and objectives of the programme have been achieved as a result of planned outcomes and to identify what changes (i.e., environmental and contextual) have occurred because of the programme.

Campfens (11) states that it is important to view both process and impact evaluation as part of a continuous programming process. Viewing evaluation as a continuous process provides a framework, whereby problem identification, planning, implementation, and process/impact evaluation are integral to evaluation. Furthermore, it enables information from each component to merge and provides an opportunity for each component to be revisited continuously.

SUMMARY OF CBR EVALUATION

A complete review of CBR evaluations remains difficult, because most of them remain unpublished and furthermore, little quality research on CBR has been published. In unpublished reports aimed at an internal audience, effectiveness and impact have often been approached through subjective views of parents of children with disabilities and, more rarely, people with disabilities themselves, in terms of the programme's usefulness (12). This review is based on

journal articles published during the period 1987 to 2002. The criteria for inclusion was that they featured one of the four features of evaluation. These 30 evaluations were published in the following journals: (a) Disability and Rehabilitation, (b) Child: Care, Health and Development, (c) International Disability Studies, (d) Actionaid Disability News, (e) International Journal of Rehabilitation Research, and (f) publications of United Nations Development Programme. The review's focus is four features of evaluation: (a) service delivery system, (b) transfer technology, (c) community involvement, and (d) organisation and management. CBR programmes evaluated in these articles are from the 15 following countries: Afghanistan, Bangladesh, China, India, Indonesia, Jamaica, Lao, Nepal, Palestine, Pakistan, Philippines, South Korea, Ukraine, Vietnam, and Zimbabwe.

Service Delivery System

Service delivery system evaluation has focused on three broad areas: (a) utilisation of primary health-care worker/community based rehabilitation worker (13, 14, 15, 16); (b) benefits of community-based rehabilitation workers versus outside personnel coming in to provide training (13, 17, 18, 19); and (c) training family members to teach people with disabilities with a broader goal of integration and peace-building (20, 21).

Methodologies used in the evaluations varied in nature, ranging from practical methods to examine the quality of medical rehabilitation (12) to using reliable scales such as a 10-item questionnaire adapted from the international pilot study on childhood disabilities (14). Other evaluations used individually-tailored assessments to record changes in status for different types of disabilities (21), as well as using interview schedules and focus group discussions (16). Researchers indicate that CBR enhances successful integration, service delivery to persons with disabilities in their home environment, efficient utilisation of resources, and cost savings in tertiary care (22).

Technology Transfer

Most of the technology transfer evaluations reviewed focus on the nature and extent of skills CBR workers should have (11, 23, 24), as well as on identifying disabilities through application of simple detection techniques (25, 26, 27). Another evaluation area within technology transfer relates to a model for training personnel at various levels in the CBR programme (28, 20, 29). Methodologies used in these evaluations varied in nature ranging from Strengths, Weaknesses,

Opportunities and Threats (SWOT) analysis (27) to the use of International Classification of Impairment, Disability and Handicap (25), as well as questionnaires adapted from the draft United Nations Development Programme (UNDP) Guide on Evaluation of Rehabilitation Programmes for Disabled People.

Community Involvement

Most community involvement evaluations assessed attitudes of the community towards people with disabilities (30, 31, 32, 24, 19) and particularly attitudes of CBR workers towards people with disabilities (33). Other areas of focus include identifying and utilising community resources in the CBR programme (34, 27) and community participation through mobilising support for the social rights of people with disabilities (20, 35, 16). Methodologies used in these evaluations varied in nature ranging from asking caregivers to tell life stories of children with disabilities in their own words, followed by guideline interviews on subjective determinants of neighbourhood support (30), to an attitude measurement developed specifically for the Indian context (33).

Organisation and Management

Organisation and management evaluations reviewed focus on organisational models in implementing CBR programmes (36, 20, 14, 37, 22, 24, 38, 39) and personnel in CBR programmes (40, 27). Furthermore, applied research has proved CBR to be effective and acceptable as an approach to delivering basic rehabilitation services (41). Case study was the methodology frequently used in these evaluations (36, 40, 37, 22, 38, 39). Other methodologies include use of a questionnaire to assess knowledge, attitude, and practice levels (24) and interviews with standardised, open-ended questions (20).

SUMMARY OF EVALUATION RESULTS

By and large, findings of the evaluations reviewed provide encouragement and hope to pursue CBR as a strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of people with disabilities. Most notable among the findings are:

1. CBR is highly effective and valuable for people with disabilities in the community (20, 40, 21).

2. CBR makes it easier to integrate people with disabilities through education programmes (38).
3. CBR makes it possible to train generic community workers in delivery of rehabilitation and prevention services to people with disabilities and their families (25, 28, 27, 29).

Findings also revealed areas that needed to be strengthened for CBR to be an effective strategy for achieving objectives of WHO's health for all initiative. Most notable among them are:

1. CBR programmes failed to teach activities of daily living skills to persons with disabilities in a successful manner (e.g., aids and appliances were provided without an impact on functional ability) (12).
2. CBR personnel acknowledge benefits of the programme but point to several problems including lack of rehabilitation education for them (23).
3. Voluntary care entailed in CBR conception and practice further contributes to exclusion of women not only from the labour force but from most other aspects of life (35).
4. An effective training curriculum for CBR workers should contain a multi-disability training approach (24).

Both quantitative and qualitative methods were used in the evaluations reviewed. It is evident that very few evaluation studies involve assessment of the programme or a component of it at a point in time (a) to determine the extent to which the goals and objectives of the programme have been achieved as a result of planned outcomes, (b) to identify what changes have occurred in functional ability as a result of the programme, and/or (c) to identify what environmental and contextual changes have occurred. Only two evaluations (42, 43) reviewed are impact evaluations; and the rest are process evaluations.

Based on close review of evaluations, policy makers in international developmental agencies and bi-lateral donor agencies are likely to ask "So what"? Policy makers are interested in evidence from both process and impact evaluations in order to recommend CBR as a strategy for rehabilitation, equalisation of opportunities, and social inclusion of persons with disabilities throughout the world. The next section of this paper proposes an outcome measure that could provide impetus towards research benefiting advancement of CBR.

QUALITY OF LIFE: OUTCOME EVALUATION FOR COMMUNITY BASED REHABILITATION EVALUATION

This section focuses on (a) individual quality of life as an outcome for CBR evaluation and (b) family quality of life as an outcome for CBR evaluation. Quality of life (QOL) is defined as individuals' perception of their position in life in context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (44). QOL has emerged as a potentially unifying concept in setting goals for services and for assessing their impact on people's everyday lives (45). The unifying concept of quality of life enables service providers to reorganise resources around individuals rather than rearrange people in programme slots (46, 47).

Individual Quality of Life: Outcome for CBR Evaluation

Measurement tools that have been developed to measure QOL for individuals with disabilities have multiple domains with multiple items in each domain. Various measurement methods have been used to assess QOL for people with disabilities, including surveys and questionnaires (48, 49), interviews (50), and open interviews and surveys (51, 52). Few tools have considered separate versions for people with disabilities in different life stages (48, 53, 54).

Individual QOL measures may be used for various purposes, including programme evaluation, research analysis, policy development, and meeting individualised needs (55). First, these measures could guide programme development as well as evaluate effectiveness of services in enhancing quality of life. Second, they enable evaluators to aggregate, compare, and contrast findings related to quality of life across evaluations. Third, they can also be instrumental in guiding policy by identifying unmet needs that may be used to influence resource allocation decisions. Finally, they could be tailored to meet individual needs, environments, and preferences, which would then allow prioritizing and focusing on domains of QOL that are most relevant to a particular individual within a particular context.

Among the evaluations featuring QOL, one (42) used Comprehensive-QOL Scale. Another (48) suggests that QOL was substantially lower among people with physical disabilities who received no rehabilitation services compared to those who did receive physical rehabilitation, community-based rehabilitation, and labour market assistance. QOL scores tended to be highest, however, among those who received a combination of all three services. This study

suggests that an integrated approach may be the best way for maximising impact of individual rehabilitation services.

With regard to individual quality of life, an outcome measure that can be used in CBR evaluation is the World Health Organisation Quality of Life Assessment (44). The WHOQOL was developed simultaneously across fifteen international field centers and includes hundred items and twenty four facets relating to quality of life, which are grouped into four larger domains: physical, psychological, social relationships and environment. It also includes one facet examining overall quality of life and general health perceptions. Psychometric analyses of the WHOQOL showed that facets' Cronbach's alphas ranged from .65 (for the physical environment facet) to .93 (for the work capacity facet) (56).

Family Quality of Life: Outcome for Community-Based Rehabilitation Evaluation

An equivalent outcome for families with respect to support for families is enhancement of family quality of life (47, 57). Researchers have proposed FQOL as an outcome measure for early intervention services (58), and it has been suggested that FQOL for individuals and their families may be the only acceptable outcome of services and policies (47). Researchers in Canada and the United States have each provided a framework for ascertaining perceived quality of life in families. Canadian researchers developed a theoretical framework and an accompanying survey for gathering information about family quality of life (59).

Brown et al. (59) developed the Family Quality of Life Survey that measures four concepts quantitatively: attainment, satisfaction, opportunities for improvement, and initiative by family members to take advantage of opportunities. Brown et al. (59) defined opportunity operationally as "options available to families that are relevant to their needs" (p 210). Also, the concept "initiative" was referred to as, "families taking advantage of available opportunities" (p. 210). These four concepts were measured in nine key areas of family quality of life: health, leisure, financial well-being, family relationships, support from other people, support from services, careers and career preparation, spiritual and cultural life, and community and civic involvement. The Family Quality of Life Survey also encouraged participants to provide a considerable amount of qualitative information. The psychometric properties of the Family Quality of Life Survey is not yet established.

A group of researchers from the United States (60) created the foundation for a family quality of life research programme through qualitative inquiry in order to develop grounded theory for conceptualising family quality of life domains and indicators. FQOL has been defined as conditions where the family's needs are met, family members enjoy their life together as a family, and family members have the chance to do things that are important to them (60). This concept focuses on the individual with disability and other family members from their positions within the family and community (61). The investigators of family quality of life, based on extensive qualitative (60) and quantitative (59) analyses, have identified five domains of FQOL. These findings were the basis for a pilot version of a Beach Center Family Quality of Life Scale. Park et al. (62) conducted initial development and psychometric evaluation of the pilot scale. After further evaluation of the factor structure of the scale, Park et al., (62) reported that family quality of life consists of five unidimensional factors: Family Interaction, Parenting, Emotional Well-being, Physical and Material Well-Being, and Disability-Related Supports.

The Beach Center Family Quality of Life Scale measures levels of family perceptions of the importance of different domains of family quality of life, and their satisfaction with those domains. The scale contains twenty five items and five subscales: Family Interaction (six items), Parenting (six items), Emotional Well-being (four items), Physical/Material Well-being (five items), and Disability-Related Support (four items). The psychometric properties are very good. The Cronbach's alpha for the total instrument is .94 (63). Each of the five subscales display unidimensionality and internal consistency: Family Interaction (alpha=.92), Parenting (alpha=.88), Emotional Well-being (alpha=.80), Physical/Material Well-being (alpha=.88), and Disability-Related Support (alpha=.92).

IMPLICATIONS FOR PRACTICE

The ILO, UNESCO, UNICEF and WHO Joint Position Paper on CBR with and for People with Disabilities (2004) states that through CBR, families of individuals with disabilities and members of the community can work towards equalisation of opportunities for all community members with disabilities. The position paper promotes increased participation of people with disabilities including family members of individuals with disabilities. Furthermore, Rule 13 (3) of the Standard Rules specifies that "states should initiate and support programmes of research on social, economic, and participation issues that affect the lives of persons with

disabilities and their families”(p. 31). Hence, CBR evaluation must encompass all family members in QOL measures, and this can be achieved by using a family quality of life measure.

The Beach Center FQOL Scale can be a starting point in addressing impact evaluation, as it is the only available quantitative tool on FQOL. It applies to families with children from birth to early adulthood. It can be used with multiple family members in gaining their perspective (using a 5-point Likert-type format) on the extent to which they believe each indicator is important and the extent to which they are satisfied the indicator is realised in their family. The Beach Center FQOL scale can be administered through a paper and pencil format or through an interview with family members individually, or in a group. The salient feature of the scale is that results are mapped so that the dimensions of importance and satisfaction are compared. This enables users to “assign” particular indicators to one of the following quadrants:

1. High importance/Low satisfaction (priority indicators for more support).
2. High importance/High satisfaction (indicators representing family strengths).
3. Low importance/Low satisfaction (indicators that are not priority areas for more support).
4. Low importance/High satisfaction (indicators that are not priority areas for more support).

Upon completion of the FQOL Scale, the CBR programme coordinators can identify perspectives of the entire group of families served, as well as those of individuals within the total group and within family units. Through the information gathered, CBR programmes will focus on indicators that families report are of high importance and low satisfaction. These indicators will be the place to begin when planning provision of family support. Group activities can also be planned for those indicators that all, or most families believe are of high importance and low satisfaction. Additionally, individual activities can be planned to support those indicators where individual families or individual members within families need support.

Once domains of family quality of life are understood and their correlates assessed, it is possible for service and support providers to implement a number of programme-based quality enhancement, thus enabling CBR programmes to focus on the correlates and predictors of a life of quality for people with disabilities and their families. Upon identifying significant predictors, CBR programmes can make programmatic changes to enhance quality of life (64, 65).

CBR plays a significant role in the lives of individuals with disabilities and their families. Hence, it is imperative that future CBR evaluations provide empirical evidence on whether

or not it enhances quality of life. The tools such as the WHOQOL and the Beach Center FQOL scale can be used to gather evidence, that CBR programmes indeed do enhance individual quality of life and family quality of life. This evidence will enable policy makers to continue to advocate inclusion of CBR in public policies, as an effective strategy within general community development for rehabilitation, equalisation of opportunities, and social inclusion of all children and adults with disabilities.

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