

**GUIDING PRINCIPLES FOR EVALUATING AND REPORTING ON WORLDWIDE
COMMUNITY-BASED REHABILITATION PROGRAMS**

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GUIDING PRINCIPLES FOR EVALUATING AND REPORTING ON WORLDWIDE COMMUNITY-BASED REHABILITATION PROGRAMS

TERMINOLOGY

CBR: Community-Based Rehabilitation
CBRR: Community-Based Rehabilitation Report
DAR: Disability and Rehabilitation (within the World Health Organization)
DPO: Disabled person's organization
NGO: Non-government organization
PWD: People with disabilities
WHO: World Health Organization

PURPOSE OF THE DOCUMENT: MESSAGE FROM THE CONSULTANT

There is a lot at stake here, since appropriate programs and the development of optimal living spaces can have a profound effect on the quality of many lives. Yet, resources are few and needs are great. As a person who has been blessed with many opportunities, I cannot begin to appreciate the challenges and circumstances of the users of these programs around the world. Thus, the final reports must reflect the wisdom of those who use the programs and those who build and provide them.

This document is intended to: (1) identify guiding principles to be used as a common framework for evaluating all CBR programs (done by analyzing existing CBR evaluation methods and by identify existing strengths and gaps among CBR reports), (2) Suggest a standard format for report writing that will have utility in various countries, and (3) Suggest an approach to guide the development of standard indicators. The document is designed to inspire dialogue among all stakeholders of CBR and, through gathered invited comments, critique, and further research, to lead to final recommendations with regard to CBR evaluation methods. It is hoped that those who read these materials will focus particularly on reviewing and recommending revision of the following: (1) the four guiding principles, and (2) the guidelines for sections of this report (i.e., Introduction, Subjective, Objective, Assessment, Plan). We also would like guidance on who should be involved in selecting standard indicators and how should they be developed.

CBR is multi-sectoral, involving the ministries of health, social welfare, education and labor from its parent countries. Moreover, non-governmental partners, including organizations of persons with disability, community organizations and groups, and national non-government organizations (NGOs) have an essential role in CBR. This report focuses attention primarily on evaluating the health and social components of CBR fundamental to the World Health Organization (WHO) mission. The United Nations Educational, Scientific and Cultural Organization (UNESCO), the United Nations Children's Fund (UNICEF) and International Labor Organization (ILO) could write complementary papers focused on other CBR components.

CBR reports are the source documents that embody the concept of program evaluation for CBR around the world. Review of existing reports revealed a wide variability in sophistication and complexity. One cause of this variation undoubtedly rests in differences among programs and in available resources. It is acknowledged that CBR and its reporting mechanisms need a high level of sensitivity and specificity to the community being served, while at the same time adhering to a standard

language (a taxonomy of discourse). A taxonomy of discourse (Salcido, 2000) is a scientific or social notation for international exchange. The lack of common language in CBR reporting places severe limitations on the dissemination of practical information between CBR programs and among the countries where they operate. A common language will enable communication among diverse groups of people, including people with disabilities (PWD), community leaders, professionals, governments, and sponsoring organizations.

Standardization of CBR reporting is necessary to facilitate cross program comparisons and cross-fertilization. A movement towards common methods of record-keeping, analyses, evaluations, and reporting and registries of persons served in rural health centers and at district levels will be useful in analyzing trends at the community and national levels. Such epidemiological information can help target resources to populations in greatest need and track the outcomes of specific health and social services.

Improved evaluation methodology and standardization of the CBR report format will facilitate the restructuring of health, human, and social services in ways that can enhance the equalization of people with disabilities world-wide. At the same time, it is important to acknowledge that many essential types of information cannot be measured in a standard way, and to embrace the unique qualities of CBR programs and the communities they serve. While a common assessment approach is essential, it is also essential to balance objective with subjective assessment, insuring that both tangible and non-tangible community and person-level benefits are documented by describing those aspects of CBR that are unique and not fully measurable. The comments and suggestions that follow are based on review of existing CBR reports and related materials, with examples from actual reports provided to illustrate the feasibility of the approach recommended.

INTRODUCTION AND CONCEPTUAL BASIS OF EVALUATION METHODS

Disability has a profound affect, not only on PWD but also on their care-givers, families, and society at large. Up to 10% of the population is estimated to have disabilities, which are believed to have a direct effect on over 25% of the population. (DAR, 2000) Only a tiny proportion of people with disabilities in developing countries will ever receive rehabilitation services. For example, no more than about 2% of disabled persons in Africa in 1989 received rehabilitation services, due to the limited number of qualified professionals and restricted resources. CBR was founded with the intent to make rehabilitation services available to a larger proportion of previously unserved persons (Helander, Legris & Opplestrup, 1989), thus making up for a lack of suitably qualified and trained personnel and material resources.

The first step in developing a methodology for CBR evaluation is to articulate a set of fundamental or guiding principles for planning that can serve as a conceptual framework and basis for ongoing evaluations. Four principles are offered with concepts developed from review of the following: (1) the latest DRAFT joint position paper "Community-Based Rehabilitation" (2001), (2) key standard rules on the equalization of opportunities for persons with disabilities, (3) world-wide CBR literature, and (4) existing CBR reports. The recommended guiding principles for CBR are as follows:

1. Seek the equalization of opportunities and support for human rights.
2. Ensure relevance of the program activities to local culture, circumstances, needs, and priorities.
3. Achieve a multi-sectoral approach through collaboration among different international groups, governmental agencies, and non-governmental partners including organizations of people with disability, community organizations and groups, and national NGOs.

4. Move toward achieving sustainability, efficiency, and effectiveness.

FOUR FUNDAMENTAL PRINCIPLES GUIDING COMMUNITY-BASED REHABILITATION

The four guiding principles are intended to provide a unifying conceptual basis for writing about and evaluating the impact of CBR programs. Each principle is followed by a series of example issues or questions report authors are encouraged to address. CBR programs world-wide are invited to add to or develop different questions that relate to these principles and that are more relevant to their particular programs. It is not expected that all CBR programs will address all issues. It is expected, however, that each program will address each of the four principles in some broad way.

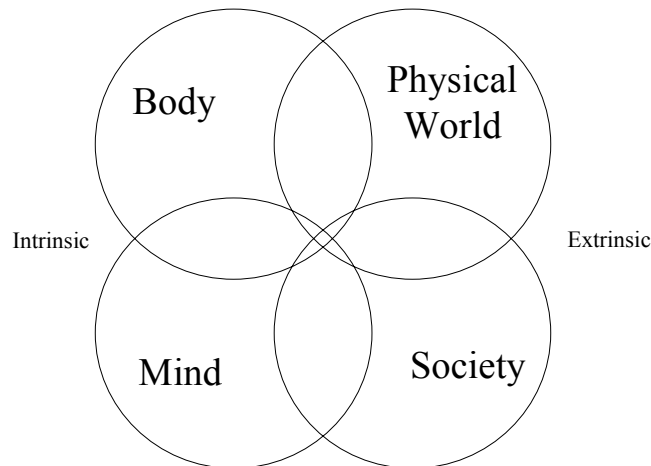
Principle 1: Seek the equalization of opportunities and support for human rights.

Objectives of the CBR program should reflect the philosophical principles articulated in the latest joint position paper, "Community Based Rehabilitation" (2001), thereby supporting implementation of the human rights-focused standard rules developed during the UN Decade of Disabled Persons (1983-1992) (United Nations, 1994).

The fundamental objectives of CBR are to maximize physical and mental abilities and to equalize opportunities for community inclusion (CBR, 2000; DAR, 2001). CBR seeks to guarantee the rights of people with disabilities to live within their communities, to enjoy health and well-being, and to fully participate in educational, social, cultural, religious, economic, and political activities. It is in the interest of governments to support CBR, because, as opportunities are equalized between all people with and without disabilities, PWD will gain the same rights, opportunities, and duties as others. PWD will then be able to take their natural place as productive society members. Through such a strategy, the concept of charity is replaced with the concepts of equalization of opportunities and human rights (DAR, 1998).

In equalizing opportunities it is essential to focus not only on the individuals' health status but also on the environments within which they live. This broadened focus is supported by WHO (CBR, 2001) and by other models that support the alignment of the persons served with the environment (Stineman, 2001; WHO, 2001). Thus, in addition to describing the people served, it is essential that the report detail the social and physical environments in which they live (Brandt & Pope, 1997; Michailakis, 1997a, 1997b; Nosek & Fuhrer, 1992; Stineman, 2000; Stineman, 2001; WHO, 1999). This broad view is particularly important because the physical challenges faced by people around the world differ, as do social infrastructures and culture. The potential for opportunity can be visualized by the intersections among body, mind, physical world, and society (see Figure 1) (Stineman, 1998; 2001). Changes in the physical or mental states of the person (intrinsic) or changes in the surrounding physical or social environments (extrinsic) can enhance or diminish opportunities for equalization. CBR programs operate at both the intrinsic and extrinsic levels.

Logic: CBR is one of a number of programs world-wide intended to support implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The standard rules were developed during the UN Decade of Disabled Persons (1983-1992) when many international human rights mandates formed their political and moral foundations (United Nations, 1994). While implementation of the standard rules is a UN commitment, WHO has been asked to help specifically with the health and social components of the rules. This document focuses on rules 2, 3, 4 and parts of 19 that are most essential to the WHO mission, while recognizing that all the rules are important in considering the impact of CBR.

Figure 1: Human Environmental Interaction

The emphasis here is on establishing an inclusive community, such that the community takes responsibility for overcoming prejudicial attitudes, and physical barriers that limit the participation of people with disabilities. The term "inclusive community" is essential because it focuses on and treats all citizens equally as reflected in the independent living movement. The independent living movement was established primarily by people with disabilities seeking freedom, the rights of self direction, and the opportunity to live in the community rather than in institutions. Both the independent living movement and CBR proclaim that human rights and self-determination principles should permeate all levels of society. The independent living movement is primarily a social model. The model emphasizes that people with disabilities can contribute to their communities and to society at large (DeJong, 1993), and that disability is primarily the result of environmental and societal barriers. It emphasizes self-help and advocacy over professional (rehabilitation) intervention. Self-help is a group phenomenon, not just an individual goal. This movement focuses on achieving a high level of mutual solidarity with regard to community and need for societal change. These principles are consistent with CBR. While, the precise mechanisms of combining rehabilitation (arising from the medical model) with disability services (arising from the social model) remains contentious (Lysack & Kaufert, 1996), the most effective CBR organization will capitalize on merging empowerment strategies from both the medical and social models.

The following are examples of specific issues to be addressed by the CBR program in response to Principle 1:

- What are the human right(s)/need(s) being addressed by the CBR program objectives? Describe any training programs or materials developed that might be of benefit to CBRs in other lands.
- What government initiatives, if any, have resulted during operation of the CBR that could enhance progress toward the equalization of persons with disabilities?
- Describe specific incidents and achievements that relate to implementation of standard rules 2, 3, 4 and 19 or others.

- Is there any evidence of improved community attitudes with respect to people with disabilities (i.e., a local organizational or cultural shift)?
- What specific attempts are being made, or have been made, to move toward becoming an inclusive community?
- What are the needs and priorities as perceived by local PWD, their families, and the larger community?
- Relevant to rule two regarding medical care: Describe how the CBR program influenced the provision of medical care to people with disabilities in the local community.
- Relevant to rule three regarding rehabilitation services: Express how the CBR program influenced the provision of rehabilitation services.
- Relevant to rule four regarding support services: Explain how the CBR program influenced the supply and dissemination of support services including assistive technology.
- Relevant to rule 19, personnel training: Express how the CBR program addressed the training of personnel, including community workers, intermediate supervisors, coordinator managers, and professionals.
- Provide stories about how the lives of PWD have been changed through CBR?
- What is the evidence that the users realize that the information provided on CBR or other programs is meant for them?

While primarily directed towards the four standard rules described above, the effectiveness of any CBR program will depend on the status and compliance to most, if not all, of the other rules. For example, programs directed to awareness raising (rule 1), accessibility of the physical environment (rule 5), and education (rule 6) will have a profound influence on CBR outcome. Thus report writers should not be discouraged from reporting on aspects of CBR that influence implementation of those other rules..

Principle 2: Ensure relevance of the program activities to local culture, circumstances, needs, and priorities- addressed at the community and person levels.

While Principle 1 focuses on the more global concept of human rights, Principle 2 is directed at the local and unique qualities of the community being served. CBR has been described as a "radical approach" that reflects the structure and functions of the indigenous culture (Ager, 1990). It is at the grass roots of the community but branches out to form relationships with existing institutionally-based and specialized centers and other services through development referral systems (Maison Halls & O'Toole, 1993). The health of people and characteristics of the local physical and social environments in which they live will influence the degree to which they are able to function and participate. The more disabled a person becomes, the more isolated he or she is from the physical environment and society. Ironically, in most societies, people with the most serious disabilities are often the least able to access those medical, rehabilitation and social institutions intended to serve them. Access further deteriorates in circumstances of extreme poverty when priorities are often reduced to mere survival. Relevance of local program activities depends on appreciation of the local community environs and the people who live there.

CBR programs are intended to build on resources available in the community, such that knowledge is transferred to and from people with disabilities, their families, and their communities, achieving collaborative problem solving. Although growing out of the needs of local PWD and their communities, through the process of evaluation and dissemination activities, the CBR program becomes part of a larger global network that, through linkages to international organizations, is promoting changes

in local communities that will enhance the inclusion of all people. As part of this network, the local CBR provides opportunities for education, research, and evaluation, thus building cross walks with other CBR organizations. In aggregate, CBR may participate in the larger transformation of health, human, and social services for persons with disability.

Logic: The optimal program develops an appropriate synergistic complementary network capturing the value of multiple formal and informal resources available in the local community. Empowerment of the person with disabilities, the family, the community worker, and community at large are underlying principles of CBR with focus on what the community can do to promote inclusion of PWD (CBR, 2001). Unlike many institutional-based rehabilitation servers, CBR can reach people who lack resources and transportation. Ultimately there must be evidence that the CBR program is owned by the community. Moreover, the CBR program must show how local resources are boosted and harnessed in a manner that is sensitive to the culture and priorities of the local community.

Example of specific issues to be addressed by the CBR program in response to Principle 2:

- Describe the local terrain, community resources, indigenous culture, and attitudes relevant to the social and physical participation of people with disabilities. What are examples of some local cultural attitudes and needs?
- How has the use of simple methods, technologies, and supplies, which are acceptable, affordable, and appropriate to the local setting been encouraged?
- What local supplies and talents have been utilized?
- How has CBR been made relevant to the cultural attitudes and priorities of specific peoples being served?
- Has the project resulted in worthwhile increases in environmental accessibility as described by the local PWD who use the services?

Principle 3: Achieve a multi-sectoral approach through collaboration among different international groups, governmental agencies, and non-governmental partners, including organizations of people with disability, community organizations and groups, and national NGOs.

The dichotomy between the medical and social models incorporates opposing ideologies that have been referred to as the "bottom-up", and the "top down" approaches (Pupulin, 1995). In the bottom up approach it is acknowledged that people with disabilities, their families, and communities are in the best position to know what is needed, and, after gaining appropriate skills, can and should control how rehabilitation is to be implemented (Pupulin, 1995). Strictly bottom-up programs are frequently not sustainable because they tend to alienate governments. These may run for a short period if there is a charismatic leader in the community but, lacking economic support from the government, they are not maintained long-term.

The "top-down" ideology, in sharp contrast, is taken by professionals who believe that they know what the community needs and try to gain approval from the community to meet those needs. Strictly top down programs (of which medical care is typically an example) are in danger of not addressing priorities as perceived by people with disabilities and their community. While perceived as paternalistic by PWD, they tend to be more officially acceptable and easily supported.

Dynamic tension between bottom-up models focused on community inclusion and empowerment and top-down approaches focused on professional control generates a paradox that operates at practical and conceptual levels.(Kendall, Buys, & Larner, 2000) While the philosophy of the CBR program

optimally begins at the grass roots, if effective it must engender sufficient societal and government linkages to achieve attitudinal change, environmental modifications and sustainability. From a government policy stand-point it is compelling to argue that by building a person's potential for independence, CBR avoids the "over-medicalization" of disability. While medical treatments and knowledge can empower patients (Stineman, 2000), over-medicalization of disability tends to encourage dependency on costly government support services. The successful CBR seeks optimal balance by attempting to use the best elements combining the bottom-up and top-down approaches

Recognizing that inclusion, dignity, and participation are difficult to measure, the achievements of such objectives are expressed in part through qualitative narratives in the subjective section. Such narratives describe the aspirations and impressions of the PWD and community workers with regard to perceived changes in coping, reliance, adaptability, and participation in community life. Conversely, recognizing that CBR unrelated to some government priority, policy, or programme has little chance of being sustained, support at the district, provincial, and national levels should be documented. Optimally, the report evidences that the CBR service is giving voice to people with disabilities by raising the profile of disability issues, promoting policy setting activities, catalyzing the global debate, and supporting efforts to restructure health and human services in ways that will improve access and benefits to people served.

The multi-sectoral approach attempts to balance the "bottom-up" and top-down" approaches. The CBR program, by design, (a) gives full voice to people with disabilities through linkages with DPOs and interfaces with other NGOs, while (b) simultaneously networking with existing governmental layers.

Examples of specific questions to be addressed by the CBR program related to Principle 3:

- How is the CBR program responding to mandates established by the parent country's ministries of health, social welfare, education and labor?
- How are CBR program linked with DPOs?
- What barriers (if any) exist to collaborative linkages between the CBR program and district, provincial, and national officials?
- What are PWD's, family members', community members', and officials of the government's perceptions of the CBR program?
- Describe inter-sectoral collaboration, including relationships among CBR, income generating programs, schools, and other programs.
- Address the degree to which rehabilitation professionals work at the community level, i.e., explain the specific working relationships between community workers and available intermediate supervisors or specialists.
- Describe how referrals are made to and from the CBR program to existing local organizations (if available), including preventive services, primary health care services, social services, educational services, and income-generating services.
- Describe flow of information between CBR services and existing local organizations, including preventive services, primary health care services, social services, educational services, and income-generating services. Describe or diagram the infrastructure and referral networks.
- What specific recommendations from PWD have been incorporated into the stated CBR objectives or have been used to modify the program?

- How have manpower resources in the community, including disabled persons, their families, and other community members, been called upon to help plan and actively contribute to the program?
- To what degree do local PWDs and their families have input into how available financial resources are to be spent?

Principle 4: Move toward achieving sustainability, efficiency, and effectiveness: The CBR organization will develop an infrastructure that will have a reasonable chance for long-term sustainability that is effective and efficient.

The CBR organization needs to show potential for sustainability through evidence of collaborative links among donors and implementing agencies. There must be evidence of an ongoing process that includes strategies for eventually achieving financial independence. This includes the setting up of programs locally and the training of indigenous persons to eventually take over and sustain the CBR. The program must prove effectiveness, documenting the extent to which targets and objectives have been met relative to stated aims. Finally, efficiency needs to be addressed by evaluating the impact of the program relative to resources spent. Effectiveness and efficiency are addressed both subjectively and objectively through standard indicators.

Specific issues to be addressed by the CBR program in response to Principle 4:

- Discuss efforts being taken to garner economic resources of the country thus allowing gradual take over of operations and support by the government.
- Document how the CBR program operates financially in coordination and partnership with other government sectors, non-governmental organizations, and community structures.
- Present objective parameters that express effectiveness and efficiency.
- Describe steps taken by the CBR organization to promote awareness, self-reliance, and responsibility for rehabilitation by the community.
- Discuss programs for training local workers.
- Describe how the local community is being groomed to take over CBR responsibilities.

STANDARD FORMAT FOR REPORT WRITING

The CBR report should include five sections:

1. Background.
2. Subjective or descriptive analyses.
3. Objective analysis (report of standard indicators).
4. Assessment.
5. Plan.

The **Background** section will answer the basic interrogatives regarding basis of the program: who it is for, where it is, and over what time period it operated. It will describe aims of the CBR program. The **Subjective** analytic section will reflect the voice of PWD, their goals and needs. To further characterize those needs, it may highlight societal attitudes toward disabilities and describe the physical and cultural environment, social networks, family structure, community resources, and the governmental

infrastructure. By expressing the uniqueness of the community, the subjective section provides backdrop for interpreting the objective analyses. It will be organized around the four basic principles outlined above and detailed below. The objective section will analyze standardized input, process, and outcome indicators for comparing CBR programs from around the world. The subjective and objective sections are written and reviewed in balance such that there is *equal* emphasis on both. The achievement of this balance is essential to CBR, because CBR is aimed at enhancing the opportunities of PWD to live in the ways that *they see fit*. This concept of enhancing opportunities is related to the concept of quality of life (QOL).

QOL has both subjective and objective components that can be organized under the domains of material well-being, health, productivity, intimacy, safety, place in the community, and emotional well-being (Qualitative Impact of Assistance - Cambodia Trust). The subjective and objective components of QOL are reflected in the overall design of the CBR report. The subjective focuses on the experiential or non-measurable aspects of well-being and happiness (reflected by the subjective section of the report), while the objective focuses on the measurable aspects such as functional status, availability of shelter, or help from family (reflected by the objective section of the report). The *Objective analysis* section of the report is a more formalized analysis of service inputs, process, and outcomes. It should consist of standard indicator sets that enable comparisons across programs of CBR. This will require development of a mandatory indicator set (collected for all users) and person-specific indicators that might be designed to reflect individual needs, for example mobility training for those who are blind. The *Assessment* section will summarize and interpret information from both the subjective and objective sections. It will express impact of the program and how findings relate to the four guiding principles. It will conclude with a description of strengths and weaknesses of the CBR program as supported by the previous sections. The *Plan* section will discuss how results of the analyses will be incorporated and used in any future changes to the program. It will outline future goals.

THE BACKGROUND SECTION

This section describes who the CBR program is for, where it is located, and over what time period it operated. It will include a brief history of the geographic location and size of the population being served. It lists the aims, objectives and activities that have been in operation over the reporting period of the CBR project. It discusses (in broad terms) how these aims and activities are intended to relate to the four guiding principles to be detailed in the subjective and the parameters to be addressed by the objective analyses. More detailed descriptions of program objectives and achievements relative to the guiding principles are included in the subjective or descriptive section of the report.

THE DESCRIPTIVE OR SUBJECTIVE SECTION

The descriptive or subjective section is intended to provide a way for CBR programs to present the unique attributes of their organization that cannot be captured by the presentation of standardized indicators. It provides the opportunity to explain how needs, as perceived by the PWD, are being served and used in establishing programs and addressing the achievements of CBR. While funding agencies often have ideas about how they want to design programs, their funds are often best directed in ways that fulfill the needs those communities envision. The subjective section includes qualitative descriptions and anecdotes. Reintegration, dignity, and equalization of opportunity, aspirations of the user (based on what people who are users think), subjective experiences of the staff, qualities of the environment, coping, resiliency, and adaptability are all extremely important but difficult to quantify in standard ways. Subjective outcomes have to do with restoring dignity, overcoming stigma, and gaining autonomy.

Rather than being concerned with standard parameters, such expressions are less tangible and rely on narrative.

For readers to appreciate the CBR reports, it is essential that they be provided some flavour of the physical landscape, locale, social/cultural values, and the peoples and the challenges they face. Without this flavour the human factor is lost, as is the reason for and uniqueness of the program. The subjective celebrates the individual, and the endogenous culture, particularly in programs requiring social skills-training interventions sensitive to the local culture, will be more effective than prescribed modules (Chandler, 2000). Information for this section can include simple descriptions of the landscape, culture, case studies, or focus group sessions with the PWDs served, their families, and their workers. In addition to baseline descriptions, there should be some details about changes in attitudes or the environment that may have resulted from the CBR program. There might also be descriptions of referral mechanisms between CBR, medical and other services, and how these mechanisms have changed. The CBR report writer is encouraged to focus on those guiding principles that are most essential to their program as offered by the general questions above.

The illustrations below were taken from CBR reports and are intended to provide examples of how subjective information might be presented.

1. A report, *Evaluation Report on Community Based Rehabilitation Program Based for People with Disabilities in Botswana* (Mompoti, 2000), provides example text relating to Principle 1, The equalization of opportunities. "Significant progress has been made with respect to attitudinal change toward people with disabilities. This is more so in places where NGOs providing services to people with disabilities are active. Many care givers are now aware of people with disabilities and have been inspired to form committees and associations." To fully address this Principle, the report would go on to describe any specific incidents and achievements that related to implementation of the human-rights-focused standard rules 2, 3, or 4 developed during the Decade of Disabled Persons.

2. A report from Samarth: *A Pilot Study: Community Based Rehabilitation of the Disabled in two Slum Settings of Mumbai* (June 1999) provides example of a vivid picture of community focused on the local physical landscape of relevance to Principle 2, ensuring relevance to local culture. "Roads, drains, living areas, play grounds, garbage dumps all coexist and overlap. While people go about their routine, neither the thought of these conditions being detrimental to their lives nor the fact that their future also gets effected . . . spur them to action. Electrical connections were pilfered, i.e., they were not official, but ad hoc. Most of the amenities, such as toilet facilities and water, are shared with other families. Of course the presence of a large number of hygienic and communal toilets has benefited several neighborhoods, however, children and the very poor still resort to where ever and whenever informally." To more fully address Principle 2, the report would detail how this program was designed to address these local issues.

3. The report from Botswana (Monpati, 2000), above, also provides a barrier to effectiveness. This shows that the program is aware of conflict between different sectors related to Principle 3. The findings reveal that the institutional environment within which the CBR program is being implemented is 'inconducive' owing to the conflicting mandated of ministries of health and local governments. To more fully address Principle 3, the report would go on to describe any progress made between achieving better multi-sectoral collaboration or plans for improving this collaboration in the future.

THE OBJECTIVE SECTION

General Evaluation Model

The objective section of the report will include standardized indicators that allow comparisons across CBR programs. Recommendations for this section were based on review of many CBR reports. Some of the existing reports reviewed were very limited in objective information, others lacked clear aims and did not define their population or their analytic approaches. One of the more methodologically sophisticated studies was included in the evaluation of CBR programs in the Dehub Region in 1998. This was a sub-study of a program in the Dehub zone on a service that had been in operation for two years (Minister of Labour and Human Welfare, 1998). While it is recognized that not all CBR programs will be able to achieve this level of sophistication it provides a nice example of some of the more important issues that might be addressed. In this study, a number of indicators and descriptive variables were organized into domains, including demographic data; economic status; types and causes of disability; perceptions of the PWD, their families, and the community with regard to disabilities; perspectives on CBR program performance, effects, and impact; and the working relationship patterns between local supervisors and clients. Some particularly noteworthy variables within these domains were sources of income for the families, a description of previous measures taken by the PWD or families to solve disability problems that provide insights into beliefs (such as visit to holy water), participation of the PWD in community life, and the strengths and weaknesses of the CBR as perceived by PWD and families. A noteworthy aspect was the inclusion of separate sets of parallel indicators for the various stakeholder groups, allowing for the analysis of and contrast across them. It was noted that PWDs compared to their families viewed the CBR program differently with regard to its strengths and benefits.

Based on review of a number of reports, the following sub-sections for the objective analytic section is recommended:

1. Analytic aims: What are the objectives of analyses?
2. Selection and training of evaluators: Who is collecting the data and when?
3. Evaluation and sampling of the CBR population receiving services: How are subjects being selected?
4. Data collection techniques: How is the data being collected, stored, and checked for accuracy?
5. Tools used: Which standard indicators (see below) are being measured?
6. Data handling: What assurances are there of subject confidentiality?
7. Analysis: How is the data being described?
8. Results of analysis: What are the findings?

The Development of Standard Indicators for Planning and CBR Evaluations

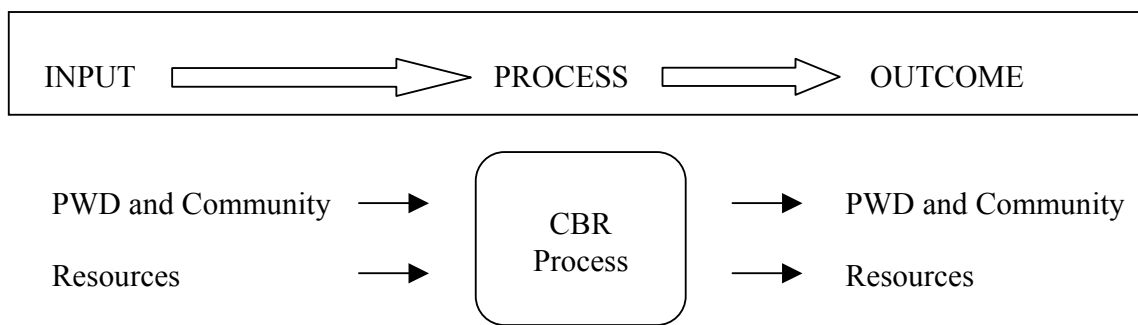
While it is realized that the principles of CBR prevent absolute replication of models from one program to another (Bangalore: Seva-in-Action, 1992), it is essential to incorporate some standard measures so that cross-program comparisons can be made. The objectives of standard measurement are to: (1) provide a scientific basis for understanding the needs of PWD and their communities; (2) improve communication among PWD, families, community workers, health professionals, and others; (3) permit the comparisons of CBR program impact across communities and countries; and (4) develop a systematic scheme for health information systems that can eventually be used in epidemiological monitoring. These standard indicators should measure input, process, and outcomes of CBR.

Input Indicators include initial traits of the people served and their communities at baseline, and those financial, material, and human resources that are available and applied to the CBR.

Process Indicators describe how the CBR operates. They include such measures as linkages between the CBR and other programs, number of clients/patients served, and measures of organizational structure. Examples include indicators such as how long community workers remain in the program.

Outcome Indicators represent change in the status of people served and the community that are believed in part attributable to CBR. The outcome indicators need to parallel the input indicators making it possible to identify changes. User outcomes are ultimately related to resources spent in determining outcomes of the process, effectiveness, and efficiency.

Figure 2: Diagram of Measurable Indicator Dimensions



General analytic methods: The analytic focus is on showing, based on objective data, how objectives related to the four guiding principles have been achieved. Analytic methods would include procedures such as frequencies, means, cross-tabulations, and plots showing the various parameters pre- and post-CBR implementation. There may be tables or plots illustrating relationships among the parameters, i.e., between resources used and number of persons served or some outcome. Optimally there is some description of the population or individuals before and after implementation of the CBR program to address its impact.

When promoting and developing standard measures for CBR, it is important to recognize variations in the skill and educational level of the community workers or others entrusted with the primary collection of data. Many of the local community workers (those who provide the hands-on care) will have less than a high school education. While questionnaires may be prepared by health professionals, data is typically collected by non-professionals. Thus, the standard language used in formulating the parameters will need to make sense to PWD, those who care for them, and local community workers. Moreover, each of these stakeholders will tend to respond to some of the same question differently. Differences in response are illustrated by the following typical responses to the question, "What is the cause of disability?", comparing PWD or their families (Schneider et al., 1999) and health professionals.

Table 1: Different Conceptions of Disability Causality

PWD and family	Health professionals
Illness	Injured spinal cord
Before and during birth	Traumatic brain injury

Accident	Arthritis
Violence	Cancer
Witchcraft	Lung disease
Aging process	Hip fracture
Other	Other

ASSESSMENT

The assessment section of the report summarizes the subjective and objective findings relative to the four functional principles of CBR. Principle 1, The equalization of opportunities and support for human rights, can be addressed both by the subjective and objective sections of the report. Principle 2, Ensuring relevance of the program activities to local culture..., is primarily addressed by the subjective section. Principle 3, Achieving a multi-sectoral approach, is supported through qualitative description of the program. Principle 4, Sustainability, efficiency and effectiveness, comes into play both in qualitative description and in the objective analyses.

After summarizing findings, the assessment discusses strengths and weaknesses of the program. This includes discussions of effectiveness, progress, impact, and efficiency (Mompoti, 2000). Effectiveness is the extent to which targets and aims have been met. Progress is the advancement of implementation compared to the planned schedule. Impact is the overall effect on health and social development of the community, including education and income sustaining activity. Efficiency is the effect of the program compared to the resources spent. Ideally, comparisons will eventually be made with respect to normative standards obtained from aggregate data from many CBR programs. Such comparisons would require many years and resource commitments that are not currently available. In addition to the standard parameters, differences and unique qualities of the CBR program and the people served are highlighted.

PLAN

The plan, as articulated in the report, is supported by the previous assessment section. This is the program's opportunity to capitalize on its strengths and state how it plans to address specific weaknesses as perceived by PWD, by the community workers and others. The plan, as all sections, needs to focus on each of the guiding principles particularly on Principle 4, "Sustainability".

AN APPROACH TO GUIDE THE DEVELOPMENT OF STANDARD INDICATORS

The development of standard indicators for use in the objective section of CBR reports is beyond the scope of this paper. The development and/or selection of a standardized set should be a multi-cultural, multi-national project recognizing that there is some small core set of elements that makes sense across all peoples. The following should guide indicator development: (1) Indicators must be relevant to the peoples being served, standard, and reliably measured; (2) The burden of data collection must be reasonable, so that the resources required for collection and analysis do not siphon away resources that would otherwise be used for care of CBR users and communities, (3) The process of collecting information should reflect the process of CBR in such a way that it becomes an integral and useful part of user assessment. By meeting these objectives, the standard assessment serves two purposes, allowing: (1) assessment of the user for establishing an individual program and (2) evaluation of the CBR program. To achieve these purposes, a small set of key indicators needs to be developed and applied by all the

programs. The final selection of such indicators would be through the consensus of stakeholders, with the approach possibly modeled after that used in forming the WHO Quality of Life Assessment Instrument (WHOQOL, 1993). The following guidelines for indicator development are recommended and should occur through a consensus process combining input from many CBR stakeholders from around the world:

1. Begin by surveying the materials already being collected by CBR programs. One logical set of indicators might be derived from the CBR Training manual.
2. Attempt to modify those materials, and enhance their relevance to PWD through review and consensus among the stakeholders, including PWD, NGOs, community workers, academicians, etc.
3. Add certain input, process, or outcome indicators, if needed, to fulfill measurement of the four fundamental principles.
4. Pretest all indicators in a variety of CBR programs.
5. Undertake psychometric to reduce the number of items to the most parsimonious and meaningful set. This would eliminate items that are not relevant or reliable and that are inconsistent or redundant. That approach would be cost effective, since it would reduce data collection burden.
6. Implement indicators and continuously monitor.

At a minimum, the CBR report must address each of the four guiding principles, and have distinct background, subjective, objective, assessment, and plan sections. It must include analysis of standard indicators, once such indicators have been identified. These indicators, which will need to evolve through a guided process of international consensus building, will provide the methodology through which CBR programs can compare themselves to others throughout the world.

REFERENCES

- Agar A. The importance of sustainability in the design of culturally appropriate programmes of early intervention. *International Disability Studies* 1990;12(2):89-92.
- Bangalore: *Seva-in-Action*. 1992, 6 pp. Seva-in Action, 2487, 17th Main 25th Cross, Banashankari II Stage, Bangalore -560 070 India.
- Brandt EN, Pope AM (eds.). *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. Washington, DC: National Academy Press, 1997.
- Community-Based Rehabilitation with and for People with Disabilities*. 2000 Joint Position Paper. Geneva: ILO, UNESCO, UNICEF, WHO, draft.
- Chandler D, Quinlivan R. Social skills training modules in an intensive community support program. *Adm Policy Ment Health* 2000 Mar;27(4):211-20. Kaiser/Telecare Program for Intensive Community Support, CA, USA. dwchandl@humboldt1.com
- DeJong G. Health care reform and disability: affirming our commitment to community. *Arch Phys Med Rehabil* 1993;74(10):1017-1024.
- Disability & Rehabilitation Team. *Proposed Strategy Paper 1999-2000*. Geneva: Disability/Injury Prevention and Rehabilitation Department, Social Change and Mental Health Cluster, World Health Organization, December 1998.
- Disability & Rehabilitation Team. *Draft Strategy Paper 2000-2001*. Geneva: Management of Noncommunicable Diseases Department, Noncommunicable Diseases and Mental Health Cluster, World Health Organization, November 2000.
- Helander E, Legris M, Ooppelstrup H. *Community-based rehabilitation in Benin: report on a visit 4-12 February 1989*. Geneva: WHO, 1989 (29 pp.).
- Kendall E, Buys N, Larner J. Community-based service delivery in rehabilitation: the promise and the paradox. *Disabil Rehabil* 2000 Jul 10;22(10):435-45. Centre for Human Services, Griffith University, Australia. E.Kendall@mailbox.gu.edu.au
- Lysack C, Kaufert J. Some perspectives on the disabled consumers' movement and community based rehabilitation in developing countries. *Actionaid Disability News* 1996;7(1):5-9.
- Maison Halls G, O'Toole B. Community based participation: rehabilitation rooted in community action. In: Finkenflugel H (ed.), *Primary Health Care Publications 7*. Amsterdam: VU University Press, 1993, p. 89-94.
- Michailakis D. Why opportunity is the thing to be equalised. *Disability & Society* 1997;12(1):17-30.
- Michailakis D. *Government Action on Disability Policy: A Global Survey*. Stockholm: Office of the United Nations Special Rapporteur on Disability, 1997, 249 pp.

- Minister of Labour and Human Welfare, Debub, Eritrea. *Tasting the Fruits of the CBR Programme: Evaluation of CBR Programme in Debub Region*. Final report prepared for printing, MLHW, Asmara, November 1998.
- Mompati T. *Evaluation Report on Community Based Rehabilitation Program for People with disabilities in Botswana*. For the World Health Organization and Ministry of Health. Department of Social Work, University of Botswana, Gaborone, June 2000.
- Nosek MA, Fuhrer MJ. Independence among people with disabilities: I. A Heuristic Model. *Rehabilitation Counseling Bulletin* 1992;36(1):1-20.
- Pupulin E. The Concept of Community Based Rehabilitation: reflections on current status and future perspectives. *NU News on Health Care in Developing Countries* 2/95, vol. 9.
- Qualitative Impact of Assistance to Disabled People*. Report on the Cambodia Trust - Quality of Life Study.
- A Report from Samarth: A Pilot Study: Community Based Rehabilitation of the Disabled in two Slum Settings of Mumbia* June 1999.
- Salcido R. The Language of Wound Care: Taxonomy of Discourse-Editorial. *Advances in Skin and Wound Care* 2000;13(6):252 & 254.
- Schneider M, Claassens M, Kimmie Z, Morgan R, Naicker S, Roberts A, McLaren P. *We also count! The extent of moderate and severe reported disability and the nature of the disability experienced in South Africa*. Summary Report. Pretoria, South Africa: Department of Health, October 1999.
- Stineman MG. The spheres of self-fulfillment: A multidimensional approach to the assessment of assistive technology outcomes. In: Gray DB, Quatrano LA, Lieberman ML (eds.), *Designing and Using Assistive Technology: The Human Perspective*. Baltimore: Paul H. Brookes Publishing Co., 1998, pp. 51-74.
- Stineman MG. Medical Humanism and Empowerment Medicine. *Disability Studies Quarterly*, Winter 2000;20(1):11-16.
- Stineman MG. Defining the population, treatments, and outcomes of interest: Reconciling the rules of biology with meaningfulness. *Amer J Phys Med Rehabil* 2002;89(2):147-159..
- United Nations. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. New York, NY, USA: United Nations, 1994.
- World Health Organization, Assessment, Classification and Epidemiology Group. *International Classification of Functioning and Disability*. Beta-2 Draft, Short Version. Geneva: WHO July 1999.
- World Health Organization. *International Classification of Functioning, Disability and Health: ICF*. Geneva: WHO. 2001.

World Health Organization. WHOQOL Focus Group Work. [MNH/PSF/93.4] Geneva: Division of Mental Health, WHO, 1993.

World Health Organization. WHOQOL-100: Facet Definitions and Questions. [MHN/PSF/95.1.B.Rev.1] Geneva: Division of Mental Health, WHO, 1995.

This report contains the collective views of an international group of experts, and does not necessarily represent the decisions or the stated policy of the World Health Organization. This document references a number of DAR staff, DAR documents that are still in draft form, and draft documents from other WHO clusters. Thus it will need to be updated to reflect final versions of the documents listed. This document is intended as a vehicle to inspire comments from a variety of CBR stakeholders reviewers. It is not intended to be definitive. It will be revised based on those reviews. The consultant gratefully acknowledges the contributions and input of Dr. Richard Salcido and the anonymous reviewers.

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