

# ECONOMIC ISSUES FOR SC'S CBR PROGRAMMES FOR DISABLED CHILDREN

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## Introduction by Sue Stubbs, Disability Advisor

When Save the Children decided that a global Review of its CBR related work was needed, an initial planning meeting over 3 days was held with representatives from all 6 geographical regions where SC works. It was felt at this meeting, that an aspect of CBR work that is frequently ignored or addressed inadequately is the whole area of 'economic issues'. This was formulated in a specific objective within the Review TORs:

### ***Objective 6: To assess SCF's CBR work in relation to economic issues, both in terms of process and impact***

Then in the field staff contributions to the Terms of Reference, economic issues were prioritised. Some of the questions we were interested in exploring over time were;

- ◆ To what extent is the effectiveness of the CBR strategy influenced by external economic situations, eg economically poor environments, countries in transition, industrialised contexts
- ◆ How effective is CBR in overcoming poverty, and how sustainable is this?
- ◆ How can evidence be collected to demonstrate the cost-effectiveness of CBR or otherwise?
- ◆ How can the wider and long-term economic benefits of CBR to the disabled person, their family and the community as a whole be demonstrated?
- ◆ What are the specific issues relating to disabled children and economic issues within CBR? Eg can focus on encouraging parents to work directly with their disabled child be detrimental in the overall family income generating capacity?
- ◆ How can the economic benefits of early childhood intervention and rehabilitation be demonstrated?
- ◆ What is the role of micro-credit within the CBR strategy?

There was a strong agreement that CBR practitioners tend to bury their heads in the sand (like ostriches) around economic issues, but that increasingly this was going to make it more difficult for CBR to gain support. It was agreed that part of the Review would include the recruitment of an Economist with a development/disability perspective who could work with participants to begin to address some of the above questions. It proved very difficult to find an economist who had both a disability and development perspective who was available at the time of the Review. Eventually, Ann Elwan was approached shortly after she had finished her paper on Poverty and Disability for the World Bank. It was felt that Ann's long experience with the World Bank would help participants become familiar with a major donor economic perspective on disability. This was not intended to imply that SC should agree with and support the World Bank perspective, but would hopefully clarify the similarities and differences between the two perspectives, and enable staff and partners be in a better position to examine economic issues in planning, monitoring and evaluation.

The following report written by Ann Elwan is the result of her discussions with people within SC, reading of the literature including some SC CBR evaluations and her attendance at the Review Seminar where she was able to meet with the 70 participants. It represents her personal perspectives based on these experiences. It does not reflect a formal World Bank view, neither does it reflect a formal Save the Children perspective. It does not answer all of the questions listed above – we soon realised that these were ambitious and needed longer term research. It is a basis for further work and discussion that will hopefully be helpful to CBR planners, policy makers and evaluators.

Annex 1 is a description of the controversial World Bank research tool called DALY. This is used particularly in the health sector for planning and resource allocation. Practitioners such as David Werner (author of *Disabled Village Children* and other manuals) have been heavily critical of this tool, claiming that it can result in a disabled person's life being less valued than non-disabled person's life. This is refuted by Bank personnel, who state that when used sensitively by Senior Health Personnel, who acknowledge its limitations, together with other measures, it can actually help planning take into account by better capturing other factors that influence health and well-being other than morbidity and mortality. The tool was developed at the time that the medical model and definition of disability was generally accepted. Bank personnel acknowledge that revision may be needed as the social model has come to be more widely accepted.

It is included here in this paper not to recommend its use, but solely to inform SC staff and partners so that CBR policy makers and evaluators are aware of planning and evaluation tools that are being used by major donors. Again, it is included to provide an informed basis for further discussion.

Annex 2 is an analysis of some recent SC CBR evaluations focusing on quantitative information. What is clearly demonstrated by this analysis is that the project that is the most traditionally 'therapy' based – the x-SC supported Fiji programme that has a strong physiotherapy focus and traditional health approach, reveals far more information than others which were primarily qualitative in their methodology, such as the Amawoti and Mozambique evaluations. In the main body of the report, there are some suggestions for areas that SC might wish to investigate further, and the development of ways of measuring qualitative indicators is one of them.

One of the main lessons learnt from this consultancy, was that there are no big 'secrets' about economic evaluation of CBR – the questions, methodologies and analysis have to be based firmly within a clear framework of values. For Save the Children, this means that any cost-effective analysis has to be located within a Child Rights framework. This means that of course, an underlying principle that children's lives should not given a monetary value. The harsh reality however is that in practice they are, particularly the lives of disabled girl children. By getting better at describing and measuring 'benefits' of CBR to disabled people, their families and communities, it is hoped that donors and policy makers will be more convinced of the importance of supporting strategies such as CBR. This paper is a small step along this route.

Sue Stubbs, August 2000.

## Executive Summary

*Traditional cost-benefit analysis is often not applicable in the social areas.* This is particularly true of SC's CBR projects focusing on children with disabilities, where the rights-based objectives are multiple, the programmes use a variety of approaches and have several different kinds of outcomes which are (largely) non-measurable in financial terms. This is not to say, however, that programme benefits should not be measured at all. Evaluation involves reviewing how effective programmes have been in achieving a range of rights-based objectives. For some of the objectives it is difficult to define indicators that measure achievement, and this is an area where much more work is needed.

*The overall framework for economic evaluation of SCF's CBR programmes is largely limited to cost-effectiveness analysis,* given the aims/objectives of participation, inclusion, and self-reliance for disabled children, and the acknowledged appropriateness and efficacy of the CBR approach. In other words, economic evaluation entails looking at whether the program's objectives are being achieved with an efficient use of resources.

*There is a wealth of information about "effectiveness" or achieving certain objectives within the various country presentations, reports, and staff experience.* The overlapping and interconnected objectives complicate the analysis. Some of the more abstract objectives can be translated into a series of more easily observable ones. Staff at policy level, with their knowledge of a wide range of programmes in different country circumstances, are well placed to define a comprehensive series of questions addressing the full range of CBR objectives, and a set of indicators designed to measure progress towards achieving it. Programme planners at field level can adapt the questions and indicators based on local knowledge.

*Understanding the initial situation in the project area is required to gauge progress.* Because of the nature of disability – a complex relationship between a person with an impairment and the particular culture and context -- a standardized approach to collecting baseline information may not be possible. The method should be participatory, including consultation with key stakeholders, and should be integrally linked to a programme plan – i.e., it should result in action and improved access to services.

*Impacts should be quantified to the extent necessary to determine effectiveness.* This is not to say that *only* quantified results are important, and impacts should be identified and described through examples and case studies, even if quantification is difficult. Often, however, quantification *is* possible through careful monitoring and record keeping, low-cost surveys, interviews, etc; and without it, it is difficult to determine the need for, and ways to achieve, improvements.

*The programme context needs to be defined so that coverage can be determined.* For example, together with information about how many people were reached by a program, it is useful to know how many the programme was trying to reach. The distinction between *process* and *outcome* indicators is important -- reaching a large number of people through a short-term media event may not have the sustained impact as changing the behaviours of a smaller number of people who can make a real difference.

*Efficiency relates outputs (impacts/effects/results) to inputs (resources).* In terms of *financial* resources, relevant questions are, for example, "Can more (or better) results be achieved with

the same inputs?” Cost comparisons with alternative programmes, such as national schemes or other community based approaches with similar objectives; as well as questions about cost differentials between countries or areas within countries, are part of the internal exercises of policy makers in implementing agencies. Funding agencies are interested in knowing that cost effectiveness is being addressed by implementing agencies.

*Full evaluation includes reviewing all aspects of a project or programme.* In an atmosphere of heightened debate about the efficacy of aid programs, programme proposals are increasingly expected to address, among other things:

- the current field situation vis a vis coverage and quality of existing programmes, and the capacity of the proposed programme to address any shortfalls
- geographical or numerical coverage, etc.;
- description of objective(s);
- rationale for project design;
- sustainability and replicability (with financial, technical and institutional aspects, including political will, host country commitment, community ownership, availability of funding, and potential for mobilizing community resources);
- the value added by the sponsor/implementer and proposed program;
- monitoring and evaluation mechanisms, including measures of project/programme progress,
- responsibilities and schedules for various assessments/studies, etc., as part of time-bound action plans or preparation/design milestones
- the establishment of effective cooperation with partner organizations and the completion of assessments.

*Indicators are needed to measure progress towards objectives.* Objectives and indicators are agreed early on (but maintaining flexibility). Program-specific indicators are needed to measure how well the interventions achieved their objectives (beyond numerical targets). For example, if the objective is inclusion of disabled children in schools, beyond simple numerical targets, interviews or other follow up may be needed to determine success from the point of view of the child, his/her classmates, teachers, etc. Where it is not feasible to set initial targets, project design can describe at what point the question should be re-visited.

*Monitoring and Reporting help to measure progress* and to be aware of any problems or issues arising from the information. They are most useful when they stimulate a critical look at progress and possible programme adjustments; and they can provide valuable learning experience, helping to build capacity and contributing to sustainability. Reporting needs to strike the right balance in terms of frequency, flexibility, content, etc. For CBR programmes in particular, flexibility is very important, and the frequency should not be too high, given the slow nature of changing behaviours and removing barriers, and the risk of diverting excessive resources away from important programme activities. The information contained in reports should be useful to those preparing the report as well as those reading it.

*A comprehensive review during implementation may be crucial,* to re-examine objectives, progress, indicators, etc. while there is still time to incorporate any indicated changes into the program. The review, facilitated by the availability of reports, asks where the project stands, where should it be by the end of the project period, and what changes are needed. Workshop format is useful for reviews.

*Poverty affects programme implementation and sustainability.* It is difficult to know where best to spend scarce resources where most communities are poor; and priority-setting is an interesting area for SC to look into. Widespread poverty and scarcity of resources for CBR programmes also increases the importance of financial management and priority setting within programs, based on observed programme results. Mobilizing community participation helps to decrease reliance on external resources, but sustainable CBR programmes ultimately need to be linked to long term financing sources. CBR programmes help to tackle poverty through improving access to education; and where relevant, have a role in increasing access income support schemes. There is a view that opportunities for income generating schemes in very poor areas may be limited; but if IG schemes are part of CBR programs, adequate management and technical support needs to be provided. If SC does not see itself as having a comparative advantage in IG schemes, there may be scope for coordination with other agencies, so that CBR and IG schemes are mutually beneficial.

## ECONOMIC ISSUES FOR SC'S CBR PROGRAMMES FOR DISABLED CHILDREN

### I. Economic Analysis and SC's CBR Projects.

1.1 *Traditional cost-benefit analysis is often not applicable in the social areas.* Cost-benefit analysis is based on measuring the benefits of a project in financial terms (for example, the amount that beneficiaries are willing to pay for additional services, such as electricity or water, provided by an infrastructure project) so that benefits can be compared to costs. In the social areas, it is not usually feasible to measure benefits in this way, and this is true of CBR projects focusing on children with disabilities. It has, however, been used in the context of rehabilitation of people with disabilities, but has been limited primarily to projects or programmes with an objective of *increasing paid employment through rehabilitation*<sup>1</sup>. In this context, project benefits are quantified in terms of the increase in wages and salaries over those that would have been earned in the absence of the rehabilitation project; and the analysis tends to be limited to working age populations, and to be specific to particular labor markets.

1.2 In Save the Children's work to benefit disabled children through CBR programs, the objectives relate to enabling disabled children to enjoy full lives, be self reliant and independent and to participate actively in their respective communities. The objectives are consistent with SC's rights-based approach and are inherently different from those of the projects using 'traditional' cost-benefit methodologies – and the benefits are not easily measurable in financial terms. This is not to say, however, that programme benefits should not be measured at all. Without some measure of benefits, it is difficult to evaluate programs. This section looks at CBR objectives (or aims/goals)<sup>2</sup>, broadly defined to include several kinds of desirable outcomes or qualities of a project, and how these objectives are related to programme and project evaluation.

1.3 SC's CBR programs tend to *have a range of objectives*. Some are basic to all programs, and others may be specific to particular locations or programmes. The objectives have been discussed in several documents, and will not be reviewed in detail here. It is useful to note, however, that not only are many, if not most, not measurable in financial terms, but, for many of them, it is difficult to define indicators that measure to what extent they are being achieved, and this is an area where much more work is needed. Evaluation of Save the Children's programmes has to involve, among other things, a review of how effective the programmes have been in achieving this range of rights-based objectives.

1.4 The fundamental objectives relating to improving children's lives through a rights-based approach translate into various constituent objectives. It is beyond the scope of this paper to attempt a comprehensive and exhaustive classification, but it is important to note that these are wide-ranging and diverse, some relating to individual aspects (such as increased mobility, independence, self-confidence, etc.), others relating to family or social objectives (such as inclusion/participation in family and community activities, etc.). By their very

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<sup>1</sup> See for example, Rehabilitation International, "The Economics of Disability: International Perspectives", Hammerman, S. and S. Maikowski, eds., March 1981, New York.

<sup>2</sup> This paper does not distinguish between goals, aims, and objectives, as the purpose is simply to find ways to measure progress towards achieving them.

nature, CBR programmes use a variety of approaches, and have several different kinds of outcomes. Some intermediate results relate to practical areas such as improved access to existing or new services (CBR worker visits, day care arrangements, transport, schools, health services, Government grants, etc.) which are expected to contribute to achieving the larger objectives. Improved access to information (e.g., by sharing of experience) is also an important input to realizing other benefits.

1.5 SCF's objectives, based on child rights, are *multiple* and (largely) *non-quantifiable* – making the analysis fundamentally different from the more traditional type of analysis in the first paragraph. In reviewing SCF's programmes, 'economic analysis' would largely be limited to *cost-effectiveness analysis* – i.e., looking at whether the program's objectives are being achieved and whether this has been done with an efficient use of resources. The relevant questions are of the nature "can this (or these) objectives be achieved more cost effectively through different program or project interventions?" This poses a question as to how to define the alternatives. It now appears to be widely accepted that a community-based approach to rehabilitation is preferred to an 'institutional' approach which does not have the same objectives, so that a comparison between CBR and an institutional approach is not the most relevant comparison for SCF's purposes. The overall framework for economic evaluation of SCF's CBR programs, then -- given the aims/objectives of participation, inclusion, and self-reliance for disabled children, and the acknowledged appropriateness and efficacy of the CBR approach – is built around the question "Are the programmes designed and implemented *effectively* and *efficiently*?"

## II. Cost-effectiveness.

### Are SCF's CBR programmes effective?

2.1 *Effectiveness* has to do with effects or results. Are CBR programmes achieving results? Or "Do CBR programmes achieve their objectives<sup>3</sup>,"? As outlined above, one of the complications is that there are several objectives (or aims or goals) just a few examples.....

- Promoting and protecting the rights of disabled children
- Including disabled children in community activities
- Including disabled children in schools
- Promoting awareness about the needs of disabled children, etc.

2.2 These are not *competing* objectives, but they are overlapping and interconnected to some extent. Some encompass a series of objectives (e.g. protecting child rights encompasses several different kinds of rights). For the purpose of determining effectiveness, some of the more abstract objectives can be translated into a series of more easily observable ones.

2.3 Most programmes (of any kind) achieve *some* of their objectives *some* of the time. For example, a CBR programme that has not yet been able to increase the number of disabled children attending school, may have made substantial gains towards achieving another objective, such as increasing community awareness. Much depends on local circumstances.

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<sup>3</sup> Again, for these purposes, objectives are not distinguished from goals or aims, as the idea is to find ways to measure progress towards them.

2.4 *Staff at policy level* would be well placed, because of their knowledge of a wide range of programmes in different country circumstances, to define a comprehensive series of questions addressing the full range of CBR objectives, in order to answer the question “are SCF’s CBR programmes effective?” That is, a series of questions relating to each objective, and a set of indicators designed to measure progress towards achieving it. For example, on the objective of including disabled children in community activities, relevant questions could include, for example:

- Are disabled children in the programme area being included in community activities? (related questions arise: e.g., were they not being included before?)
- Is the change related to the programme?
- How many children are now being included?
- What kinds of activities?
- How positive/successful is the experience?
- How do we know this? – or – what kind of indicators will help us assess this progress?

2.5 *Programme planners at field level* are likely to be better placed to know which objectives are achievable within a given time frame; and could adjust the set of questions and indicators based on local knowledge.

2.6 There is a wealth of information about “effectiveness” or achieving certain objectives, within the examples of impacts from the various country presentations and reports.

- Haiti: 2000 people (in addition to families already involved) had been reached through awareness-raising.
- China: changed attitudes; positive impact in decision making; improvement for all children. Not quantified. Can it be quantified?
- Vietnam: identified specific aims for each phase: (e.g, first phase -- influence policy, replication; second phase –access for disabled children and their families). Reduces the danger of attempting too many things at once, dissipating efforts, and losing track of specific goals. Mentioned a specific achievement – 150 children in mainstream schools. (Would be useful to know out of how many approached, etc.)
- Kyrgystan: Achievements included (i) progress made by disabled children (mentioned children overcoming depression; independent walking—some can be quantified); and (ii) awareness raising (a measure of success being government donation of a building); (iii) influencing curricula (iv) access to education; (v) 23 graduates became employed; (vi) private sector employment; and (vi) creating national and regional network.
- Zanzibar: mentioned how many children with disabilities were integrated into the education system.

2.7 **It is important to understand the initial situation in the project area.** Several presentations mentioned how many children with disabilities were identified as being within the area of the CBR scheme. Some then mentioned how many were being supported by CBR. The importance of the initial information was clear from the Nepal and Sri Lanka presentations, and particularly noted by the parents’ group at the seminar. This kind of baseline information is needed to monitor progress and define benchmarks, etc. Because of the nature of disability – a complex relationship between a person with an impairment and the

particular culture and context -- a standardized approach to collecting baseline information may not be possible. The method should be participatory, including consultation with key stakeholders, and should be integrally lined to a programme plan – i.e., it should result in action and improved access to services.

**2.8 Impacts should be quantified to the extent necessary to determine effectiveness.** Based on the presentations only, many of the achievements cited were not quantified. This is not to say that *only* quantified results are important. It is clearly important to identify and describe impacts (results) through examples and case studies, even if quantification is difficult. Often, however, quantification *is* possible through careful monitoring and record keeping, low-cost surveys, interviews, etc; and without it, it is very difficult to determine how programme improvements can be achieved (paras. 2.10 – 2.13)

**2.9 But even quantified impacts need to have the context defined.** This is one example of where the notion of *coverage* comes in. Together with the figure of how many people were reached by, say an awareness raising program, it is useful to know how many people was the awareness-raising programme *trying* to reach? Or, if not in specific numbers of people, in what areas, or through which channels, etc., to give an idea of degree of success, what works, what doesn't, etc. For example, in Kyrgystan, how many graduates were in the program, and how many did not find employment? What factors contributed most to finding employment? Was the training relevant to the identified job market, etc.? It is important to distinguish between *process* indicators and *outcome* indicators. For example, reaching a large number of people through a short-term media event may not have the sustained impact as changing the behaviours of a smaller number of people who can make a real difference.

#### **Are CBR programmes cost effective? (“efficient”)?**

2.10 *Efficiency* relates **outputs** (in this case, impacts/effects/results) to **inputs** (resources) In terms of *financial* resources, the question gives rise to a series of related questions:-

- “Can more (or better results) be achieved with the same inputs?”
- “Can the same results be achieved with fewer inputs?” or even
- “Are there relevant alternatives i.e, with the same objective(s)?”

However, in the context of CBR programmes, where one of the aims is to empower communities, the unlocking of existing community resources through the involvement of disabled people and parents in programme activities is, in itself, a success. Local involvement is, in this sense, not an *input* to be minimized. But again, it is important that locally mobilized resources, including human resources, are used to their best advantage – i.e., in ways that, in turn, contribute to further community development.

2.11 The broader aspects of the question on alternatives (e.g., institutional versus CBR approaches) tend to get debated in the literature and at conferences, etc., but a question like:-

“Are there other alternatives? e.g., national programmes with outreach schemes, or even other community-based approaches, that have the same objectives, where costs (inputs) and results/impacts (outputs) can be compared?”

is within the scope of policy-makers within implementing agencies like SCF, as are questions of the first type above, such as:

“Why did it cost more to achieve the same objectives in country x than in country y, or in area a than in area b?”

2.12 Clearly to be a useful exercise, the objectives need to be narrowly defined, and costs carefully calculated, etc. Where there are multiple objectives, there are likely to be ‘objections’ to this kind of question -- e.g., “why only look at the costs of integrating children into schools, when the programme also raised awareness?” There are no easy answers. Such an exercise in efficiency analysis may involve combining several impact or results indicators, categorizing where and how money and time are spent, etc.

2.13 As mentioned earlier, these tend to be internal exercises. Funding agencies are interested in knowing that cost effectiveness is being addressed by agencies implementing programmes; and implementing organizations tend to ask these kinds of questions of their own programmes.

### III. Comprehensive Programme Evaluation

3.1 To evaluate a programme fully, all aspects -- not just cost-effectiveness -- need to be reviewed. For example, it is not sufficient to ask if the program’s overall objectives are being met cost-effectively, without reviewing whether the some of the intermediate impacts or objectives are appropriate, or whether the programme is sustainable in the longer run<sup>4</sup>. This section looks at some of these factors, and others, that are being given increasing importance in an atmosphere of heightened debate about the efficacy of aid programs.

#### Considerations for Programme Design.

3.2 Aspects of the project/programme that the initial proposal is increasingly expected to address include:

- Demonstrated knowledge of the field situation (e.g., quoting relevant data sources or other types of information; observations on coverage and quality of Government or other services for disabled children in the proposed programme area)
- Capacity of the proposed programme to address particular aspects of the current situation, describing geographical or numerical *coverage*, e.g. target proportion of communities/households, which particular problems is it designed to address -- children, adults, access, participation, awareness, etc.
- Description of objective(s)
- Rationale for the proposed project design. (e.g., decisions regarding components such as training, technical assistance, awareness-raising, etc.; choice of location; replication in several areas; etc.)
- Sustainability and replicability. This has financial, technical and institutional aspects. Political will needs to be assessed, and indications of host country commitment, etc. at various levels of government determined; likelihood of eventual community ownership; capacity building (training, technical assistance). The country presentations have highlighted how important financial sustainability is to programme

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<sup>4</sup> One of the reasons for a community-based approach is the realization that, unless programmes are based in participation and on a reliance on community resources, they may not be sustainable; and this affects costs in the longer term. SCF promotes the participation of disabled children, parents and disabled people’s organizations, consistent with both the participation objectives themselves, and with the desire for sustainability and long-term cost-effectiveness.

success. The availability of donor or other funding, and the potential to raise additional funding if necessary, over the life of the project need to be assessed. The potential for mobilizing community resources needs to be assessed, and has importance in terms of programme ownership as well as financial viability

- Value added by the sponsoring organization and proposed program. The proposed role of the implementing agency in this kind of project builds on its strengths, for example, in terms of capacity (a) to target disabled children, particularly in difficult environments, such as poor, overcrowded urban neighborhoods or scattered rural areas; and (b) to incorporate community preferences.
- Incorporation of monitoring and evaluation mechanisms into project design. Measures of project/programme progress, responsibilities, and assessment schedules are defined *a priori*.

(The above 'list' is not necessarily exhaustive or exclusive.)

3.3 The last aspect of project design noted above is one of the most important: approval by funding agencies such as international development organizations, increasingly depends on appropriate *a priori* definitions of performance indicators and arrangements for monitoring and supervision. An example is the increasing practice of specifying the procedures for beneficiary consultation up front, and requiring that they be implemented by a certain time; or, less stringently, identified within a timeframe specified prior to project approval.

3.4 Some other examples of time-bound actions or preparation/design milestones increasingly being used are the establishment of effective cooperation with partner organizations (other funding agencies and/or other specialist agencies cooperating on certain aspects of the program, etc.), and the completion of assessments and/or other kinds of studies, etc.

3.5 Some elements for consideration in project design:

- ◆ need for baseline information early on.
- ◆ building on the experience of, and coordinating with, projects funded by other donors, NGOs, etc.
- ◆ the *developmental nature* of the project; flexibility is important, incorporating the ability to quickly recognize the need for any changes in design. (This emphasizes the need for indicators and monitoring, and maximizing the likelihood of successful implementation).
- ◆ Components or measures designed to achieve the program's objectives – outlining the contribution that the various components (or actions or interventions to be supported under the program) are expected to make towards meeting the objectives. Put another way, a description of project design describes where each component, such as awareness raising in schools, child-to-child approaches, etc. fits into the program; and answers questions as to how decisions reached as to, for example, whether to build community centers, how many? where?, etc.
  - if *institutional capacity-building* is an objective, project design may incorporate training, cooperation, workshops, etc. to achieve the objective;
  - if *participation* is particularly important, need to identify the stakeholders to participate, and in which aspects of project design, implementation, evaluation, etc.). Project design includes ways of determining if the project is meeting its

objectives, if implementation is on schedule, and ways of measuring project outputs.

### **Indicators.**

3.6 *Indicators* to measure progress towards these objectives are defined at the beginning of the project. For example, if a project objective is to include disabled children in schools, then indicators may address, for example, progress on raising awareness among school officials, and improving physical access, as well as the numbers of disabled children attending school.

3.7 Indicators are program-specific. If they are based on proportions of target population (e.g., numbers of disabled children, or numbers of households with disabled children), *an initial (baseline) survey and a follow-up survey* are necessary. It is also useful to have figures from other areas for comparison. Surveys are relatively expensive, particularly where household access is difficult (e.g. scattered rural populations), but without such surveys, it is very difficult to assess coverage or evaluate effectiveness. Where this is too time-consuming or expensive, there may be some potential for alternative ways of assessment (sampling, focus groups, etc.).

### **Quality of programme interventions.**

3.8 Indicator(s) are needed to measure how good the interventions have been (beyond numerical targets). Following the example of school inclusion, surveys and interviews may be needed to capture whether the school inclusion has been successful from the point of view of the child, his/her classmates, teachers, etc.)

3.9 Other surveys of, for example, parents of disabled children to determine their knowledge about the program, their opinion about quality, etc. Initial surveys are useful, as a way of getting a handle on the community, the numbers, needs, etc. of disabled children, or other children with needs. Without such a survey, it is difficult to know how successful the programme interventions are at reaching children and their families.

3.10 If it is not possible to set any kind of target initially, then project design should describe at what point the question should be re-visited (e.g., if indicator is proportion of children contacted after local teachers have been contacted – set a date for these contacts, etc.).

### **Monitoring and Reporting.**

3.11 Monitoring and reporting help to measure progress and to be aware of any problems or issues arising from the information. In general, monitoring and reporting are most useful (beyond their immediate information value) when they stimulate those involved in the programme to take a critical look at progress and think about what needs to be changed. Reporting can be a very good learning experience, helping to build capacity and contributing to sustainability; field staff and HQ staff may need to work together in designing the content and format for reporting -- informative to field offices and headquarters, and not too burdensome. Those responsible for preparing reporting information should understand how the information is to be used, both at the local and other levels.

3.12 *Frequency and Flexibility.* Reporting requirements need to strike the right balance in terms of frequency, flexibility, content, etc. For CBR programmes in particular, flexibility is very important, and the frequency should not be too high, given the slow nature of changing behaviours and removing barriers. Also, if field offices are expected to report at short intervals, the risk is that preparing reports becomes an end rather than a means, and diverts too much energy and other resources away from important programme activities (monthly or quarterly reports would probably too frequent? Semi-annual?) One possibility is to set the first report date during the proposal/appraisal stage, with the understanding that the subsequent reporting dates will emerge at the time of this first report, when there has been time for some feedback.

3.13 *Content.* Reports should summarize current status in programme implementation, explain deviations from agreed implementation plans, outline constraints and corrective measures to be taken, and help to define or re-define the work plan over the next agreed time period. The information contained in reports should be useful to those preparing the report as well as those reading it. Agreed indicators should be included. But indicators, charts, tables, graphs, etc., are often more useful when accompanied by some (not necessarily long) text about what they mean, and what actions or changes of direction, etc., if any, are indicated by the information. If the content of reports is too detailed, they can lose track of the underlying progress. Guidance/training may be needed initially by those responsible for the reporting. For example, headquarters, from its perspective of effectiveness and efficiency, may initiate the design of the reports it would like to receive; and field staff, with their immediate knowledge of the local conditions, can provide valuable insights.

#### **Reviews.**

3.14 In addition to routine reporting, projects or programmes often benefit from more substantial reviews. From the donors' point of view, a relatively comprehensive review during implementation (whether at mid-term or some other point) may be crucial in order to re-examine objectives, progress, indicators, etc. while there is still time to incorporate any indicated changes into the program). The review asks where the project stands, where should it be by the end of the project period, and what changes are needed. Reviews are facilitated by the availability of reports as discussed above.

3.15 The trend towards organizing project reviews in the form of a workshop, attended by all those responsible at the various levels of project implementation recognizes that the workshop format can help in improving work relationships as well as in other project-specific areas. The recent seminar in Swaziland is a very good example of inter-programme dissemination of information about lessons learned, good practice, etc. But for individual programs, SC may want to look at additional aspects of the programme as part of a review – for example, how is the Government (or other institutions) involved in the programme; how does it (they) view the results; what will be its (their) future role? etc.

## IV. Poverty and CBR Programmes.

4.1 **Poverty affects programme implementation.** CBR programmes tend to be based in poor communities. Where most communities in a country are poor, it is difficult to know where best to spend scarce resources. It would be useful to have a way to determine priorities in terms of defining programmes for children with disabilities.<sup>5</sup> This is complicated by the usual lack of data. This may be a promising area for SC to look into. Widespread poverty and scarcity of resources for CBR programmes also increases the importance of financial management and priority setting within programs, based on observed programme results. The seminar and related documents and reports showed a growing realization that programmes have to find ways to organize themselves, and improve their own management. Mobilizing community involvement in the programme helps to decrease reliance on external resources, but sustainable community-based programmes ultimately need to be linked to long term sources of financing for health, social and education sector financing.

4.2 **Income generating schemes are looked at as a way to tackle poverty at a local level.** There was a general feeling among the review participants that opportunities for income generation schemes in poor communities are limited. Another area of general agreement was that *if* IG schemes are to be part of SC-supported programs, there is a need to provide, or ensure in other ways, the required management and technical skills.

[SC position paper concludes that SC does not have a comparative advantage in IG schemes. Possible areas for further investigation....(i) further review of the IG schemes mentioned as successful in the review (Vietnam) and other positive experiences mentioned by Peter Coleridge; and (ii) scope for coordination with others so that IG and CBR programmes are mutually beneficial]

4.3 **Other poverty-related aspects.** The experience with increasing access to income support schemes, where relevant, seems positive, and CBR programmes seem to have a role to play in this area. Participants recognized one of the ways to tackle poverty is through education. SC does not necessarily have a comparative advantage in improving the educational system, but SC is tackling the education of disabled children, so they are not left behind.

4.4 **Comparative Advantage.** There are benefits to each agency or organization carrying out the activities in which they have a comparative advantage, and cooperating with others through various partnerships when this is beneficial. One example was the use of the literature produced by specialists (Enabling Education Network – EENET; Healthlink, for some of the consciousness-raising. And, as mentioned above, since SCF's comparative advantage is not in income-generation, possibly work in cooperation with those that do have experience and a comparative advantage to create synergy between the CBR and IG schemes.

4.5 **Self-sustainability.** There is a growing realization that programmes have to improve their own management, and become self-sustaining, and that this is difficult in poor communities. The use of volunteer workers could perhaps be reviewed further. The opinion was expressed that there is a responsibility on the local programmes to educate (almost 'advertise') to inform about CBR, in order to be able to carry out fundraising.

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<sup>5</sup> A discussion on DALYs in Annex 1 looks at their role national priority setting.

### Global Burden of Disease and Disability Adjusted Life Years (DALYs)

*This section is based on two sources, the World Development Report 1993: Investing in Health (WDR), and Background Paper No. 12 prepared for the WDR. The information in the WDR is from Chapter 1 “Health in developing countries: successes and challenges”, particularly the section “Measuring the burden of disease”. Appendix B of the WDR gives details on the concept of the global burden of disease, and detailed figures by age and region. The terminology here is taken from these two sources.*<sup>6</sup>

The Global Burden of Disease (GBD) is a relatively new measure, developed in the early 1990s to estimate the burden of disease due to more than 100 causes.<sup>7</sup> It aims to combine (a) losses from premature death with loss of healthy life resulting from disability. It is measured in terms of disability adjusted life years (DALYs). With the mortality-based measures often used to assess the importance of different diseases, no weight would be given to a disease which typically results in blindness, for example, and not death. As the World Development Report of 1993 (WDR93) points out, “most assessments of the relative importance of different diseases are based on how many deaths they cause ... There are however many diseases or conditions that are not fatal but are responsible for great loss of healthy life: examples are chronic depression and paralysis caused by polio.”<sup>8</sup>

In order to quantify the full loss of healthy life, by death or by onset of disability, diseases were classified into 109 categories (according to ICD, ninth version), covering all causes of death and about 95 percent of the causes of disability. For each death, the number of years of life lost was defined as the difference between the actual age of death and the expectation of life at that age in a low-mortality population. For disability, the estimates were based on extensive age- and sex-specific information on incidence of disease, the proportion of disease incidence leading to a disabling outcome, the average age of disability onset, the duration of disability, and the distribution of disability across the six classes of disability severity. DALYs are then computed by combining death and disability losses, and including adjustments for age weights and a discount rate. The sum across all ages, conditions, and regions is referred to as the global burden of disease (GBD). The GBD measures the present value of the future stream of disability-free life lost as a result of death, disease, or injury in 1990; it is based on events that occurred in 1990, but includes the loss of disability-free life in future years.

The concept and resulting estimates were designed to be of use to those concerned with planning health services. DALYs calculated in this manner indicate, for example, that nearly 46% of healthy life years lost in the world are due to communicable diseases; in Sub-Saharan Africa, the percentage is about 71%, in established market economies, the percentage is less than 10%. For non-communicable diseases, the situation is reversed, with over 78% of healthy life years lost in established market economies, and only 19.4% in Sub-Saharan

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<sup>6</sup> Note that terminology within the area of disability is evolving. In section 1 of this Annex, the substitution of the word “impairment” for “disability” may be more in tune with current usage.

<sup>7</sup> Murray, C. and A. Lopez, “Quantifying the Burden of Disability: Data, Methods, and Results” in **The Global Burden of Disease in 1990**, February 1994. Background Paper Number 12 for the World Development Report 1993: Investing in Health, (Abstract)

<sup>8</sup> World Development Report, 1993. **Investing in Health**, World Bank, Oxford University Press, 1993.

Africa.<sup>9</sup> More than 80% of the DALY loss from diarrhea is a result of infections in children under age 5. More than half the burden of tuberculosis is borne by the 15-44 age group.

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<sup>9</sup> Details by cause of disease and region are given in Box table 1.3 on page 27 of WDR93.

### Examples from Programme Evaluations.

1. The emphasis here is on quantification, although this is not the only important aspect of evaluation. However, it is difficult for a time-bound evaluation effort to deal with all these aspects at once. The programme evaluations are tackling several strategic questions – perhaps as a result of the context of the first major reviews of the CBR approach, etc., and quantification/efficiency type questions tend to be viewed from a somewhat different perspective. Also, getting a handle on the quantitative aspects requires prior agreement/understanding about what needs to be quantified. Much of the very basic information is quantified –e.g. expenditures -- and most evaluations contain information about the *numbers of people* in the various programmes. The Viet Nam evaluation, measuring expenditures *per disabled child* (while recognizing that there are other beneficiaries) is a good example.

2. However, finding measures/indicators for the programmes' benefits to disabled children (among other things) is not straightforward. The evaluations (and again the anthology) have some information about numbers of children in school, etc. But some things which are much harder to quantify are noted as anecdotal evidence. The question is how much of what is being noticed as a benefit can be *measured* in some way? Some of it is conceptually simple (number of children being visited, receiving therapy, accomplishing new tasks, socializing with others, attending school, etc.), although there may be practical difficulties with data collection. However, when these measures are discussed, practitioners tend to quickly note their inherent problems (what about quality of school attendance, etc?), but these are *challenges* to define ways of describing quality, not reasons to avoid quantification altogether.

3. When indicators can be collected, there is a new range of information available...and questions such as “why does \$A per child in country B seem to “produce” a better record in terms of school attendance (for example), while \$C per child in country D seems to be associated with poor results in school attendance but better socialization?”

4. Answers to (or at least insight into) such questions and the range of indicators and other responses could open up new issues, and guide a focussed review (Are the indicators capturing the desired information? Are the programmes' activities or emphases different? Is there a difference in staff training? Do country or local circumstances contribute to the differences? Are there differences in attitude in ministries, schools, etc. that account for variations in results? etc.). And then, with confidence about validity of indicators, and the factors behind “good” levels of indicators, comparability (or reasons for non-comparability), experience can be shared from one programme to another.

5. This is not advocacy for blind attention to “productivity or efficiency indicators.” Rather, it is advocacy for a special focussed look at indicators / measures / quantification: what information have they given so far? If not much information is being gained from the quantified information already collected, why not? What more quantification can be done, based on existing information, reports, etc.? What changes are needed in future reporting?

(Text in italics is from the evaluations cited)

## 1. The Fiji Evaluation.

The evaluation provides substantial basic information, useful for looking at 'effectiveness' questions. It gives information about the types of records being kept and the sources of information, and also looks at these the quality of the information itself, and the uses it is being put to, as well as potential improvements.

Example of information:

- On caseloads: The total number of cases, the average caseload, highest and lowest caseloads;
- On child-adult ratios: Ranges, numbers in remote islands, settled areas, average; and
- On new referrals, according to type of disability.

Also on case example for areas, as well as giving numbers of cases, also gives the population base, which helps to give an idea of coverage.

For various areas, the info. given included:

- Registered current CRA cases
- Total sub-division population
- % of pop being seen
- Approx % of adult cases in CRA caseload (ie over 19yrs)

And information about the subdivision (number of zones, settlements, villages, schools and types of school, etc.)

Sources for the information are cited, and include programme annual reports, evaluation interviews, CRA records and monthly reports.

Also, the report outlines the **activities** undertaken by CRAs (which helps to compare programs, and to understand how resources are being used, etc.) – 17 activities listed, from screening, assessment and education at MCH clinics to fundraising.

**Impacts** are listed, in qualitative terms. (e.g., *“Some Ways in Which Health, Well-Being and Independence of CRA Clients has Changed*) – quotes from PH nurse, parent, and others.

Also the evaluation recognizes the **importance of information (and research)**

“Information and research are fundamental in supporting the Programme’s capacity to enhance its profile, to engage senior level commitment, to secure ongoing and additional funding, and to positively influence policy and practice in relation to disability.”

And recognizing that data from different regions provides allows comparisons, and further investigation of reasons for differences, etc. that can be valuable in improving interventions or record-keeping, etc.

*“Although this data may be basic, it is nevertheless a valuable resource, and greater use could be made of them. It was beyond the scope of this evaluation to assess the accuracy of CRA records and reporting, but a triangulated random sample indicated*

*some variability across CRAs, that could be overcome, at least in part, with greater support and supervision.”*

The evaluation notes the importance of information both for programme uses and **beyond** -- i.e., the contribution made by the information brings the programme into the international exchange of knowledge and experience

*“the CRAs are the only people currently keeping disability-related records and statistics across much of Fiji, particularly in the rural and remote areas.”; “Others have recognised the value of the CRA statistics, which are now being shared with the FDPA and .... are providing much of the foundation for internationally funded development of a national database on disability in Fiji” and “There is a recognised urgent need for research in the field of disability and community-based assistance, and the CBR Programme is well-placed to facilitate this”*

The evaluation identified needs in some areas of research, one of which is the need to strengthen basic data about the prevalence and nature of disability in Fiji. (This lack of basic information about disability in developing countries is one of the things that struck me most when I was reviewing the literature. Data collected by CBR programmes can help.)

The evaluation included in its recommendations....

*“The CRAs maintain a basic system of registers and monthly reports that provide a sound informational basis from which to develop and/or link further data gathering strategies. However, the existing CRA records could be strengthened by: expanding and/or clarifying some statistical categories (eg. linking CRA records with wider PHC and disability database needs and systems, undertaking random triangulated reviews of records and work to monitor and enhance the accuracy of reporting, within the context of regular support, supervision and performance appraisal mechanisms”*

The Fiji evaluation also includes a section on **programme funding, cost effectiveness and cost benefit**. The section explains funding sources, and the effects of the sources on the programme. It also describes major Programme expenditure, and points out some of the shortcomings of the original budget and their effects, presents the training budget, and makes recommendations based on the review.

The evaluation concludes that *“assessing the cost effectiveness and cost efficiency of the CBR Programme is difficult when many of the criteria for success are qualitative in nature (eg quality of life, impact of education and preventative work) and the costs of not doing anything can be hard to calculate (eg the socio-economic cost of an untreated disability on an individual, whole family)”*, but nevertheless drew some useful conclusions, particularly regarding factors which tended to constrain the cost effectiveness and efficiency of the Programme, and how the constraints had been addressed in some areas. It described the limitations in undertaking quantitative analysis (one being unavailability of specific budget detail), and notes that a useful comparison would be that of *the cost per client* in providing alternative and complimentary rehabilitation services provided by others. *“A comparison of such costs against the total number and coverage of people seen over a year would also be valuable, although it is important to stress that these figures would need to be considered in conjunction with qualitative criteria related to rehabilitation outcomes and most importantly,*

*with client outcomes in terms of return to maximum 'occupational performance' ...such analyses require the consideration of costs including salaries, materials and equipment, recurrent costs (including running and maintenance of buildings and equipment), and costs incurred by clients and carers during rehabilitation."*

The information collected as a result of the Programme enables evaluators to make observations about trends in disability, and consider how these trends will affect programmes in the future. (Appendix in the Fiji evaluation)

## **2. Evaluation of the Amaoti Disabled People's Association**

The February, 2000 DART report states that the evaluation 's outcome "...is to give direction to ADPA, by providing feedback on which to base further planning and development of the organization." Although it contains detailed qualitative evaluation, there is very little, if any, quantification. It describes, as it is intended to, a valuable **internal** review process, but, from the point of view of an potential funding agency, would likely be only part of a comprehensive review. (there is probably another report which deals with the programme's statistics --resources, expenditures, numbers of disabled people, quantified impacts, etc.?)

## **3. Evaluation Report, Vietnam Programme.**

The section on Programme Costs (p.9) presents information on various types of expenditures per disabled child. This seems to be a very informative way to look at expenditures – but also makes note of *"the many benefits perceived by parents, other family members, volunteers, teachers and officials as a result of their involvement with the CiC programme."*

In Part 4, among the seven focus areas for the evaluation were effectiveness, efficiency, impacts, sustainability and replicability. In the evaluation, the anecdotal evidence is informative, but quantification would help in understanding progress.

The information in Annex 2 about the numbers of disabled children is useful. (But hard to tell what the benefits have been. Have all these children benefited in some way from programme interventions? In what ways?)

## **4. Mozambique.**

The evaluation is qualitative in purpose, and the reasons for lack of quantification is fairly well explained (so on the whole, not as relevant to this note as the other evaluations)

## **Other Projects.**

This section describes some of the indicators used in evaluating a health project. They would not be the same as indicators for a CBR project, but some areas are analogous, and therefore illustrative. Some other things of possible interest are: the emphasis on indicators in a multi-lateral supported Government project -- perhaps an SCF CBR programme would not require as many; the use of classifications for achievements, etc.; and no calculation of an economic rate of return.

#### Project Objectives:

- Improve quality and coverage of health services: impacts mentioned in the evaluation are access to PHC services and utilization rates. Beneficiary survey showed the main reason for not going to health centers was lack of financial resources, then distance and lack of transportation. The beneficiary survey also asked about perceptions of the structure of the health system (essence, organization).
- Provide iodine, provide safe water, etc. Impact is measured in terms of numbers of wells drilled and rehabilitated, no. rural people served. (Success attributed to active and generalized involvement of the communities and private sector in well building and maintenance, to community understanding of water and health linkages, and substantial reduction in the water fetching burden of women and young girls).
- Other objectives (population, etc.): indicators; knowledge of contraceptive methods, user rates, etc.
- Policy Objectives (unstated): intensifying policy dialogue between Government, among bilaterals and multilaterals, civil society organizations, and the private sector. Project supported shift from centrally funded and managed PHC to a system fully run and managed by communities. Project strengthened NGO capacity and participation, paving the way for a co-financed sector wide development program. Beneficiary surveys and focus groups indicate a high level of awareness in the population about the structural changes in the health system.

#### Also noted in the evaluation:

- need to measure project outcome in terms of contribution to reform as well as immediate health indicators, and to monitor this kind of progress. Importance of financial sustainability and sustainability of community involvement – community involvement also dependent on training and management.
- Many community health centers became development poles within the villages they serve.
- Beneficiary awareness of services greatest for vaccination, then in order, child delivery, pre-natal care, pharmacies.
- Evaluation classification has three levels for achievement of objectives: substantial, partial, negligible (and not applicable); and three for performance – highly satisfactory, satisfactory, and deficient.
- The project evaluation showed a table of key indicators for project implementation, and another table of indicators for project operation.
- No economic rate of return or net present value was estimated.