Evaluation of Community Based Rehabilitation for Disabled

Children in Urban Slums in Egypt

ALAA G. SEBEH

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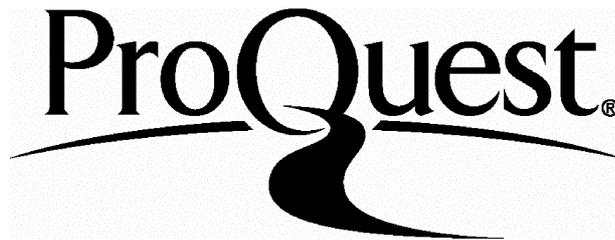
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ABSTRACT

This research compares three programmes serving young intellectually disabled children in the slums of Cairo and Alexandria. These are a Community Based Rehabilitation (CBR) project dependent on local resources and parental involvement, an Outreach project dependent on well trained specialists and a Mother and Child Health (MCH) centre based project offering parents weekly training sessions.

Outcome measures are child progress, assessed by the Griffiths Mental Developmental Scales and the Receptive-Expressive Emergent Language Scale, parental attitudes measured by the Short Form of the Questionnaire on Resources and Stress, and the social support network using the Family Support Scale. The research also tests the hypothesis that parents are more involved in teaching their young intellectually disabled children when the developmental programme objectives accord with their priorities rather than being imposed by professionals. Short term sustainability of the CBR programme outcomes after withdrawal of external support is examined.

Children from the CBR project (27), Outreach programme (24), MCH programme (26) and a waiting list control group (28) were assessed before the intervention, and twelve and eighteen months later (the control group after twelve months only). Family involvement in two programmes was assessed by counting the teaching-related activities in the previous day from the mother's description, with construct validity checked through two additional measures taken on the MCH group alone.

Children in the CBR and Outreach groups made significantly accelerated progress compared with the MCH and Control groups. Parents in the CBR group reported significantly greater change in level of support from their family and community, family involvement in teaching and positive parental attitudes.

The research demonstrates the successful impact of home based intervention for disabled children in urban slums in Egypt. The CBR approach had additional advantages in terms of mobilising local support and increasing parental positive involvement. It was more cost effective, and thus has greater prospects for sustainability.

DEDICATION

To my parents and Simone, my wife, for their patience, support and encouragement during the course of this study.

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institution of learning.

ABBREVIATIONS

CBR	- Community Based Rehabilitation
CES	- Child Expectation Scale
DPI	- Disabled Persons International
DQ	- Developmental Quotient
EE	- External Examiner
FGD	- Focus Group Discussion
FRS	- Family Resource Scale
GO	- Governmental Organisation
HSQ	- Home Screening Questionnaire
IDEA	- Individuals with Disabilities Education Act
ILO	- International Labour Organisation
IQ	- Intelligence Quotient
MA	- Mental Age
MCH	- Mother and Child Health
NGO	- Non-Governmental Organisation
OMAR	- Operation Monitoring and Analysis of Results
OR	- Outreach
PEQ	- Parent Evaluation Questionnaire
PHC	- Primary Health Care
PQ	- Progress Quotient
QRS-F	- Friedrich short form of the Questionnaire on Resources and Stress
REEL	- Receptive- Expressive Emergent Language Scale
SETI	- Support, Education and Training for Education (formal use - Special Education Training Institute)
TCPD	- Training in the Community for People with Disabilities
UN	- United Nations

UNDP   - United Nations Development Project

UNESCO   - United Nations Educational Scientific and Cultural Organisation

WHO   - World Health Organisation

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1. CHAPTER ONE: INTRODUCTION

1.1 Disability as a global issue

Many estimates of the prevalence of disability have been made in the past. The World Health Organisation (WHO) calculations published in 1976 estimated that 10% of the world's population was disabled, of whom more than 80% lived in developing countries (WHO. 1976). The reliability of these figures is unsure, as a large number of surveys and studies have been made in 55 countries since that time and results vary dramatically from 0.2 to 21 per cent (Helander. 1993). These variations reflect the lack of standardisation of disability definitions and survey techniques.

After a thorough study of many disability statistics, Einar Helander of the United Nations Development Project (UNDP) published his most recent calculations based on the prevalence of 'moderate and severe' disability. He estimated a global average of 5.2 per cent: 7.7 per cent for developed countries and 4.5 for developing countries (Helander. 1993). From these figures it can be estimated that the total number of disabled people in the world, in 1993 was around 300 million, of whom 200 million lived in developing countries.

Helander forecasts that due to rapid population growth, the number of disabled persons in the developing world will have increased from 200 million to 435 million, by the year 2025, and will have increased from 100 to 138 million in the more developed countries, by the same time. These figures highlight the urgent need for solutions about how best to provide the services necessary for disabled persons and their families.

An enormous gap currently exists between what services are required and what is actually provided. Furthermore, this gap is widening because services are not expanding at the same pace as the population growth. There is also an acute shortage of professionals trained to work in this field. Very few disabled persons have access to services, which are usually centre-based and situated in big cities. Moreover, the vast majority of them are isolated and not integrated into their communities.

1.1.1   Development of rehabilitation services - An historical perspective

Since the late 1960s, the institution-based system of rehabilitation has been criticised for not responding to the needs of disabled people. Experts concluded in 1969: "..it is obvious that the pace at which personnel were being trained and other necessities for rehabilitation services were being developed, was not adequate to meet the current problem and certainly incapable of coping with the predictable growth in the number of persons requiring professional help..." (The International Society for Rehabilitation of the Disabled. 1969). At that time and until the mid 1970s, it was thought that the problem could be solved by putting in more money to expand the institutional system, train more qualified personnel, and eventually reach all those in need (Helander. 1995).

In 1974, the WHO started to review its policies concerning disability and rehabilitation. Its findings were reflected in this statement "... rehabilitation services are practically non-existent or grossly inadequate in developing countries, ... there is an apparent lack of coordination ... when advanced rehabilitation services and technology have been introduced..... the result has often been discouraging or a complete failure"(WHO. 1976).

The problem was not primarily due to a lack of financial resources. Essentially, it lay in the inadequacy of the conventional 'medical model', which segregated vocational, educational, social and medical 'rehabilitation'. The early 1980s witnessed the evolution of a set of new definitions which led to a clearer and more realistic understanding of the

nature of disability as a 'social' rather than an 'individual' issue. In 1980, the WHO promoted a new definition which distinguished between impairment and disability:

> **"Impairment:** is any loss or abnormality of psychological, physiological or anatomical structure or function.

> **Disability:** is any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal from a human being.

> **Handicap:** is a disadvantage for an individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual."

This distinction between impairment and disability contributed a great deal in making medical rehabilitation more functional. However, this definition still focused on disabled people as 'the problem' and still represented the medical model of disability.

In 1985, Disabled Peoples' International (DPI), which represents the disabled persons' movement all over the world, advocated the following definition which states clearly that society causes disability:

> **"Impairment:** Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body.

> **Disability:** The disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities."

This definition led to a new perception of the problems confronted by disabled people and represents the social model of disability (Coleridge. 1993). In this model, society, rather than the impairment is seen as the disabling factor. It was realised that whatever the impairment, people are disabled by different sources of deprivation, as well as the physical, attitudinal and social barriers which prevent their full participation in society. The 'problem' of disability was perceived for the first time as being located in society as a whole, not in the individual. According to this model of disability, it is society that must adapt to accommodate the disabled person, not the disabled person who has to be 'normalised' into society.

This shift in the definition of disability led to a parallel development in the use of the term *'rehabilitation'*. Thus the term was widened considerably to include not only action directed towards the disabled person, but also action designed to meet the disabled person's needs in term of changes in their environment and in society in general.

One recent operational definition which expresses this change is promoted by Helander (1993):

> *"Rehabilitation includes all measures aimed at reducing the impact of disability for the individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation includes not only the training of disabled people but also interventions in the general systems of society, adaptations of the environment and protection of human rights..."* P17.

1.1.2 The international response to disability

The past two decades have witnessed the growth of an international movement in recognition of disabled persons. Many disability issues were recognised and reflected in the **United Nations (UN) International Year of Disabled Persons** in 1981. The **UN World Programme of Action Concerning Disabled Persons** was adopted by the General Assembly in 1982. It was considered the basic reference document containing international guiding principles concerning the rights of disabled persons, and the main description of possible components of national programmes. It is still considered one of the basic documents and guides for promoting *'full participation and equality'* of persons with disabilities.

During the 1980s, self-help groups in many developed countries strengthened the position of disabled people at a national and international level. They succeeded in putting the necessary pressure on their governments to legislate to protect their rights. At the international level, DPI, which consists of disabled persons representing their national organisations, obtained consultative status with the United Nations Educational, Scientific and Cultural Organisation, (UNESCO) and WHO in 1983. The DPI worked closely with the UN to develop the World Programme of Action Concerning Disabled Persons. The concept of 'advocacy' was also developed at this time to promote the interests of those who need support in expressing their needs and fighting for their rights.

A number of other UN instruments have been issued in support of people with disabilities. The **UN Convention on the rights of the child**, a very powerful instrument issued in 1989, has a special article, no 23, which states the right of disabled children to *'special care, education, training, rehabilitation etc. designed in a manner conductive to the child achieving the fullest possible social integration and individual development.. "*

In education, the **World Declaration on Education for All** states that *"steps need to be taken to provide equal access to education to every category of disabled persons as an integral part of the educational system."* (1990)

This was followed up in 1994 by the World Conference on Special Education in Salamanca with the **Salamanca Statement** urging all governments to *"adopt as a matter of law or policy the principle of inclusive education"*, and proclaiming that *"those with special educational needs must have access to regular schools who should accommodate them within a child-centred pedagogy capable of meeting these needs"*. (UNESCO. 1994)

The most recent and detailed UN document is the '**Standard Rules for the Equalisation of Opportunities for People with Disabilities**'. The rules were adopted by the General Assembly in December 1993 (United Nations. 1994). They describe what governments are expected to provide for disabled people, as the minimum standard in various areas of life. The implementation of the rules will be monitored under the direction of the former Swedish Minister of Social Affairs, Mr. Bengt Lindqvist.

In March 1995, the Social Summit in Copenhagen came out with a strong commitment to *"promote the Standard Rules and develop strategies for implementing the Rules.... so that people with disabilities can contribute to and benefit from full participation in society...."*

1.1.3 The emergence of CBR

During the **UN Decade of Disabled People (1983 - 1992)**, and along with the four guiding principles of the World Programme of Action Concerning Disabled Persons, the **Community Based Rehabilitation (CBR)** approach was launched by the WHO as a means of putting those principles into practice. These four guiding principles are:

A) Disabled persons should remain within their own communities and share an ordinary lifestyle, with necessary support.

B) Disabled persons should take part in decision-making at all levels, both in general community affairs and in matters that particularly concern them as people with disabilities.

C) Disabled persons should receive the assistance they need within the ordinary structures of education, health, social services etc.

D) Disabled persons should take part in the general social and economic development of society, and their needs should be included in national planning. Disabled persons should have adequate opportunity to contribute to national development.

1.2 Community Based Rehabilitation

1.2.1 Description

The essential elements of CBR and its objectives have been well formulated in a joint Position Paper titled *'Community-Based Rehabilitation - CBR - For and With People With Disabilities'* published by the International Labour Organisation (ILO), UNESCO and WHO, in 1994:

> **"Community-based rehabilitation is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services".**

> **"The major objective of CBR is to ensure that people with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities and achieve full social integration within their communities and their societies. This objective uses the broader concept of rehabilitation, that is, one which includes equalization of opportunities and community integration".**

In this context services are provided for the disabled person in the environment where they live, the main aim being his/her *independence and integration* in the society. This is mainly achieved by the mobilisation of local resources; the family of the disabled person and disabled people themselves being the most important resource of all. Community Based Rehabilitation is primarily based on community participation where local people and family members, who are the primary caregivers, are provided with adequate training and supervision using a technology closely related to local experience.

Community Based Rehabilitation is seen as the most cost-effective and best way to meet the needs of disabled people in developing countries and to enable their social integration. The goal of CBR is to demystify the rehabilitation process and give responsibility back to the individual, family and community. A local worker or volunteer is recruited from the community and trained to show a member of the family how to carry out the training programme. A simplified method of rehabilitation is therefore promoted which, in the WHO scheme, is described in the WHO manual: *Training in the Community for People with Disabilities* (TCPD)(Helander, Mendis, Nelson, & Goerdt. 1989).

CBR attempts to use existing organisations and infrastructure for the provision of services. Simple tasks are delegated to auxiliaries or volunteers whose performance is monitored by a 'local coordinator' (or 'intermediate-level supervisor' according to the WHO). CBR attempts to involve the community in the planning, implementation and evaluation of the programmes. Links are established with higher referral services to cope with more specialised needs.

In the early 1980s, the WHO launched CBR as an integral component of Primary Health Care (PHC). The WHO programme is based on the TCPD manual which consists of 30 training packages dealing with all aspects of impairment, and a set of four guides for use at community level by disabled people, teachers and community rehabilitation committee. Through the manual, rehabilitation technology and professional knowledge and skills are demystified and made accessible to disabled people, their families and CBR workers.

As a result of this, many CBR programmes have developed as a component of PHC (Lundgren Lindquist & Nordholm. 1993) and the work of CBR has been integrated into the PHC workload. However, this approach has been criticised for being medically oriented and a more multi-sectoral approach has been called for. In addition, later development in CBR has shown that the programmes and the communities served need to aim at wider social change and development rather than focusing just on disability (Coleridge. 1993). Yet, it was realised that this aim could never be achieved unless a sense of ownership develops among local people towards their project, and disabled people are

part of an ongoing community development programme and have a leading role over their projects.

1.2.2   Strengths of the CBR approach

Despite certain constraints, as discussed later, many years of experience prove that the CBR approach is more effective than any other approach to rehabilitation. Some successful features of CBR programmes are as follows:

1. Many CBR programmes create new and successful strategies for awareness-raising. CBR has increased public awareness of disability issues, thus generating greater support for disabled persons. CBR seeks first to change the disabling negative attitudes of society towards disability and people who have a disability

2. Although community and consumer participation are often nominal, examples do exist of CBR programmes managed by disabled people, and of programmes leading to the formation of parents' and disabled peoples' groups. CBR has become an excellent tool for promoting the participation of disabled persons in decision-making, and for their integration into society (Werner.1995).

3. CBR fosters a holistic approach to the disabled persons, focusing on their physical, health, educational, social, and all other needs.

4. It facilitates the delivery of basic rehabilitation services to disabled people, particularly those in the rural areas, and thus minimising disabling conditions.

5. CBR has promoted the mobilisation of community resources, including available manpower, materials and funds.

6. It is evolving a core of rehabilitation manpower who can provide rehabilitation services at the community level where most disabled persons are unnerved by professional rehabilitation workers.

7. There are many examples of the successful use of appropriate technology and transfer of professional skills to the community. In fact CBR recognises that local people may even do things better than the professionals themselves (Werner. 1995).

8. CBR has mobilised, to a certain extent, secondary and tertiary levels of service-providers through the referral networks, and these in turn have utilised local communities to monitor and follow up beneficiaries released from these institutions.

9. CBR has promoted multisectoral collaboration and coordination especially between GOs and NGOs, international, national and local organisations, as well as between different ministries involved in a CBR programme.

1.2.3 Problems of the CBR approach: challenging Issues

Various problems face the development and expansion of the CBR approach in developing countries. One of the most commonly reported in project reports or evaluations, is the reliance for funding on external donors, and the lack of governmental commitment to full support of CBR programmes (Tjandrakusuma, Krefting, & Krefting. 1995). Rehabilitation services have traditionally been given low priority in the resource allocation of government budget and manpower. Further well-documented problems are the lack of collaboration and of a multi-sectoral approach in the implementation of the programmes, the lack of coordination between GOs and NGOs, and the lack of coordinated information exchange at national and international levels (Helander. 1993).

However, while these are the most frequently reported problems facing CBR, they do not reflect the whole situation. Other issues are more challenging but less reported in the

literature. The following issues were perceived at the commencement of this study as the major problems hampering the implementation and the expansion of this approach:

1.2.3.1 Professionals and specialised centres

One of the biggest obstacles to successful Community Based Rehabilitation is the lack of adequate professional support and referral (Werner. 1995). This is mainly caused by the shortage of professionals, the lack of their involvement, and the confusion and lack of understanding of the concepts of CBR. Professionals are seen in this study a major factor in the development, success and sustainability of any CBR programme.

Normally, all CBR programmes are initiated by professionals, supported and backed up by them. The referral services, one of the corner stones of CBR, depends entirely on them. Professionals in this context include all paid workers who are in close contact or involved with disabled people. They exist in all sectors of rehabilitation: health, education, vocational and social as well as in voluntary organisations. Specialised centres include health centres, special education schools, day care centres, training institutions....ect.

Shortage of professionals

In the majority of developing countries there is a severe shortage of professional personnel. Moreover, many of them work in the private sector or emigrate to countries which offer better salaries or career prospects. In general, professionals tend to remain in the big cities and prefer to work in institutions.

This shortage of trained personnel in all sectors relevant to CBR affect, in particular, the feasibility and efficiency of the referral services (Pupulin. 1992).

Lack of involvement

Most of the challenges facing the implementation of the CBR approach are those related to the resources required for its implementation. The domination of the conventional approach to rehabilitation is still the trend in the majority of developing countries. Almost all resources are directed towards the specialised services which serve only a small fraction of the population, while scant resources are allocated to CBR which could serve the majority of the population, especially in rural areas.

One major product of the old conventional approach is the relatively large number of rehabilitation professionals and specialised centres, who could turn out to be *the most important resource for the success* of the new CBR approach. Mobilising these professionals and specialised centres to adopt new roles in the context of CBR is considered a key issue for its expansion and success.

However, to date little effort has been made in that domain. Attempts to redefine roles and to allocate needed resources for the training and reorientation of professionals have been very limited. The disproportionate allocation of funds into the conventional system is not such an easy thing to change and reallocation of resources would require a great effort.

Lack of understanding:

At present, almost all professionals are still working in centre based programmes. The vast majority are not convinced of the potential of the CBR approach, and not even open to understanding and grasping its concepts and ideology

However, it should be noted that *the involvement of the professionals in CBR programmes without adequate understanding of its concept, philosophy and strategy can be more devastating than beneficial.* For example, the misunderstanding of their roles as CBR project initiators could be the major threat to the project sustainability.

Project initiators are normally professional service providers brought in by external institutes, organisations, donor agencies or specialised centres to launch a CBR project in a local area. They provide the financial and/or the technical support needed to set up the programmes. Although the majority of programme initiators have succeeded to a great extent in establishing and promoting effective CBR projects, some of them are unaware of their negative contributions to the prospects of future sustainability of such projects.

After launching the project and working for a few years, many of these initiators find it difficult to hand over the project to local management. Some of them are unable to withdraw, while others are unwilling.

Some of the possible reasons for remaining in projects are:

- External initiators may become so emotionally attached to what they perceive as their own project that they grossly underestimate the potential and ability of local people to run the project independently. They cannot even perceive their capacity nor do they believe in them.

- In cases where the programme has proved successful, some external agencies attempt to maintain links with the programme to prove their involvement and contribution to its success.

- Some donor agencies are deliberately willing to extend support to their local partners for as long as possible in order to facilitate their own fund raising, or to secure the supply of funds from other major donors.

- Some specialised institutions extend their control over the CBR projects to maintain their 'laboratories' for their research or their 'fields' for the practical element of their training courses.

- External initiators may wish to remain in the local programmes to gain practical experiences in working in a CBR project or in a developing country: expatriates working in developing countries is a growing profession.

- If a project depends heavily on external resources (staff, funds...etc.) provided constantly for them, outsiders may feel obliged to remain in the project to ensure its continuity.

Therefore, one of the main challenges facing the future of the CBR approach, and which greatly affects the sustainability of the programmes, is the 'redefinition' of the roles of professionals and specialised centres in the context of CBR. The level and form of their involvement and intervention should be addressed and researched in particular.

1.2.3.2 Sustainability and independence

What is meant by project sustainability?

Sustainability of a CBR project refers in this context to whether a project can be sustained and run from local resources after the full or partial withdrawal of the agent that initiated and implemented the project. As this agent is usually located outside the served area, they may be termed *'project initiators'* or *'external initiators'*.

One of the most frequent limitations of CBR programmes is *dependence on external resources.* Many of these programmes are initiated and maintained by outsiders, who

introduce this concept into the local communities, train the community workers but gradually become fully involved in the project and are unable to withdraw as discussed above.

Does the approach to rehabilitation adopted affect programmes' sustainability?

The conventional approach to rehabilitation is a 'top-down' approach dominated by professionals and decision-makers who believe that they know what the community needs. When these professionals, influenced by the ideologies of the conventional system, attempt to initiate CBR projects, they try to involve local people, disabled persons and their families in meeting those needs. However, professionals usually maintain their control over the project as they are not confident that local people have the potential and capacity to run their own project.

Such an approach results in outreach programmes. The external initiators succeed in providing some services, but normally according to professionals' priorities rather than those of the people with disabilities and their communities (Pupulin. 1995). Such programmes continue to depend on external resources and are never owned and controlled by local people. Therefore, their prospects for future sustainability are poor.

One of the major strengths of the CBR approach lies in its 'bottom-up' approach, which emphasises the ownership and full involvement of the beneficiaries in such programmes. However, those who strongly believe in the 'bottom-up' approach and do not fully understand the CBR concept, may reject the government and the assistance required from professionals and rehabilitation centres to sustain the projects and to provide specialised services. They sometimes perceive the government and professionals as alienated from the local community and unable to meet their real needs. Again, such an approach is not sustainable because the local community *cannot* maintain their projects on their own without *any* external support.

The CBR approach aims to mobilise and later to *rely on local resources* in running their projects. Thus, external support can become problematic for CBR concepts and strategy, if it is perceived by local people as the *backbone* of their project.

Moreover, dependence on external support makes programmes vulnerable to collapse and raises concerns about *sustainability,* as it is unlikely that project initiators will provide long lasting financial and technical support.

Is project sustainability a realistic goal?

It is unrealistic and impractical to ask a project to be 'self-sufficient' or 'independent' when it is based in a very poor area with an extreme lack of financial and technical resources. We cannot expect local people, disabled persons and their families to become specialised professionals or to raise all the money a project requires from their own resources. There will always be a need for some external technical and financial input.

However, despite this constant need, which is sometimes met by national resources, any CBR project should aim to achieve self-sufficiency and independence with the **minimum extent of external support** needed to ensure its sustainability. This is only achievable using community resources.

Accordingly, programme sustainability can only be considered as a realistic goal if the project can be *owned by the community,* using and depending on local resources.

Sustainability of projects has become a central issue in CBR development. Finding out the minimum extent of external support and the appropriate strategies to ensure this sustainability should be among the first priorities of researchers and policy-makers.

1.2.3.3 Evaluation and research

Momm and Konig (1989 a) observed that rarely in the history of services for disabled persons has an approach attracted as much unqualified support as CBR. During the last decade, nearly all UN agencies, international organisations and donor agencies have adopted and promoted this approach.

Remarkably, and despite the fact that there is widespread support for the CBR approach, little progress has been made in developing the means to *understand better both the functioning and effect of these projects*. The widespread expansion of CBR and the wide range of associated criticisms are not based on scientific evidence, but mainly on subjective opinions or presented as lessons from experience.

CBR evaluation has been made more difficult by the lack of adequate documentation. The aims and objectives of many programmes are largely unclear, unspecified, not timescaled, and not measurable. They are neither clearly stated in the project documents, nor perceived and understood in the same way by project management, community workers and beneficiaries. Many key terms such as 'integration', 'empowerment' and 'community participation' are not well defined or given indicators. The situation is made worse by the absence of baseline data and the lack of agreement on process and impact indicators.

Many project holders and managers see research studies, especially those related to evaluation, as a luxury in a situation of scarcity of resources and severe lack of services. They think that all energy and resources should be focused on fulfilling the urgent needs for services and on basic survival.

Different community oriented approaches are claimed to be more feasible and effective than CBR. Each approach has potential benefits and shortcomings as well. To date there is an extreme lack of comparative evaluation of different approaches and no objective evidence to prove that any one approach produces better outcomes than any other (O'Toole & McConkey. 1995). Overall, there is a lack of adequate and rigorous evaluation of CBR, and of appropriate evaluation methodology.

1.2.3.4 Definitions

The term CBR was pioneered by WHO in 1981, but since that time, there have been wide ranging criticisms of the model, a variety of interpretations and misinterpretations, and promotion of alternatives.

As a concept, CBR is not understood in the same way by all those who use this label to describe their projects. This confusion is reinforced by the fact that each CBR project is different. This difference is to be expected because each project should reflect the local community which owns the project, and all communities are different (Pupulin. 1995). However, hundreds of projects use the CBR label to facilitate their fund raising.

Major confusions arise in the use of the word 'community' (Mendis. 1992). The term 'community' has different definitions and interpretations in developed and developing countries, and in urban as opposed to rural settings. The 'sense of community' and its implications appears to be different in each case.

However, the more serious confusion occurs between notions of 'community-level' and 'community-based'. Padmani Mendis, one of the originators of the CBR approach, stressed the difference between these two terms. The former refer mainly to services made available within the home/community usually by community-workers under the supervision of professionals/ trained workers from institutions or organisations. It is considered as an extended form of the 'Outreach' approach, in which responsibility lies with external organisations i.e. knowledge, and therefore control, is held by service providers from outside. On the other hand, 'community-based' describes a project where responsibility for the CBR programme lies with the local community; and knowledge, and therefore control, is made available to people with a disability, their families and community.

Another problem of CBR involves misinterpretations relating to the manner of its implementation. In the early stage of CBR development , the WHO, the original promoter of the approach, was very rigid in its view on how programmes should be implemented

(Werner. 1995). This rigidity was based on the assumption that it would avoid or limit confusion.

A decade after the emergence of CBR, Einar Helander, one of the original authors revised and updated the original definition in an attempt to avoid any misinterpretation or wrong use of the term (see Appendix I). His recent description can be considered the most clear and comprehensive description of CBR to date (Helander. 1993). However, he noted that relatively few existing programmes follow his description.

He also noted that the label CBR facilitates fund raising and attracts international attention. Hundreds of projects use the CBR label, and yet many lack genuine community involvement, and are not managed by local management. Most so-called CBR projects are in fact 'Outreach' programmes, entirely dependent on external resources to provide services. The same author suggests that confusion could be avoided if different ideas and designs use different terms to describe them. For examples, Miles (1989) has proposed a system called 'Information Based Rehabilitation', while earlier Momm and Konig (1989 b) presented the 'Community-Integration Programmes' approach.

While the CBR strategy ought to be highly flexible, there are certain limits which should not be passed. The basic principles mentioned previously, should be incorporated into any programme wishing to be described as CBR.

As discussed earlier, the lack of real understanding of the CBR concept is not only a serious limitation in the use of this strategy (Pupulin. 1992), but can be more destructive than beneficial.

1.2.3.5 Families

The CBR approach is based mainly on the assumption that family members will be fully involved in the rehabilitation process of their disabled child. However, one factor has often counteracted the potential benefits of the home-based component of CBR programmes. It concerns the necessity for all able-bodied members to go out to work during the day in order to feed and ensure basic survival of the family (Balasundaram & Woods. 1990). In these circumstances the appropriateness of a parent-training home-based programme has obvious limitations, as has been reported by Miles (1985) for many low income countries like India, Pakistan, St. Lucia, Botswana and Zimbabwe.

Despite this, very little has been done to explore the level and extent of parental involvement in CBR programmes, as well as the possibility and validity of involving other local persons in the rehabilitation of disabled children other than their parents. Moreover, mobilisation of local resources to provide the necessary help and support to parents has not yet been documented, investigated or researched properly.

1.3 Rehabilitation and CBR in Egypt

Egypt has been considered among the leading Arab countries in providing special education opportunities and services for people with special needs. However, in the early 1980s both the quality and quantity of these services whether provided in schools, centres or institutions were proving insufficient. It is estimated that out of approximately two million persons with an intellectual disability, only a few thousands were receiving services.

Development of rehabilitation services had been ad hoc, without strategy or vision, and there had been a lack of cooperation and integration between service providers.

Since this time, along with the positive international response to the United Nations Decade of Disabled Persons, Egypt has witnessed a gradual improvement in all type of services provided to people with disabilities. This movement has been supported by the wife of the President, Mrs. Susan Mubarak. Although there have been some initiatives to establish community oriented programmes supported by international donors, the institutional based approach still dominates all rehabilitation services. Recently however, there has been a move away from the medical and charitable model.

CBR in Egypt is still very young. In 1987 WHO ran training courses on its Manual for a large number of government health workers, but nothing resulted from this training and the project failed. One cannot speak of national policy or even a national debate on this subject; the only work started to date is by a few isolated enthusiasts. The majority of these are more community oriented, some of them refer to themselves as CBR.

1.4 CARITAS- Egypt, SETI Centre: Background

In 1985, the Ministry of Social Affairs approached CARITAS - EGYPT to establish a centre for training special educators. In 1986, Caritas launched its pioneering project of the SETI Centre which stood for Special Education Training Institute. The Centre's short intensive training courses run on a modular basis were mainly offered to non-qualified special educators working in this field. A few courses were also provided for psychologists, social workers, physicians, centre directors, parents...etc. In addition, most of the teachers working with the newly established training programmes in the various governmental and non-governmental organisations, had in fact no previous knowledge and/or experience in intellectual disability and depended mainly on the SETI Centre for their training.

Many years of experience showed that the provision of skilled manpower would not have a considerable impact on the problem of intellectual disability in Egypt as a whole, because professionals would be still working in institutions. Indeed, it was discovered that an institutionally oriented approach - with the available resources of staff and finance - will only be concentrating on a few places and a restricted number of disabled persons. Even a tenfold expansion would not be sufficient to reach all individuals in need.

A community-oriented approach had to be adopted as the only strategy by which the increasing number of persons with intellectual disabilities could be served.

In order for this strategy to reach its maximum efficacy, centres and professionals in turn had to adopt new roles, different from their previous roles in institutional-based rehabilitation (IBR).

Such new roles involved providing a network of professional support services, training and technically supervising the community personnel, offering specialised services that can rarely be provided at the community level, as well as managerial support and finally liaisoning with referral services.

The implementation of this new approach, which is adopted by SETI Centre, called for the creation of demonstration pilot projects and the training (or re-training) of professionals to cope with the requirements of the new roles handed to them. .

This strategic change had quite an impact on the quality of services and training programmes provided by the Centre. Indeed, a number of pilot projects illustrating this new approach were successfully implemented and later used to offer practical training in the Centre's training programmes. These training programmes in turn met the needs of a number of governmental and non-governmental organisations in both their CBR and IBR projects. A considerable number of training courses were conducted by the Ministries of Education, Social Affairs and Health.

The SETI Centre thus modified its original aim and became a 'multipurpose community oriented centre' with a new strategy of work designed to be a model for Egypt and other developing countries. A model that shows how best to utilise centres and professionals so as to serve the largest possible number of people with intellectual disability, either through these centres or in the community.

The Centre's activities became mainly focused on providing training opportunities to professionals and non-professionals, as well as on adopting new models of service delivery both for people with an intellectual disability and children at-risk and their families.

As the Centre's orientation was diverted from its initial purpose, its name similarly underwent changes, and now stands for Support, Education, and Training for Integration. The training component is still maintained but covering both the institutionally based and the community oriented approaches in service delivery.

1.4.1   SETI CBR programmes - Origin of the study

The next section will describe how some of the problems confronting the CBR approach in general, influenced and affected the development of CBR services in SETI. As a result, different approaches to community rehabilitation programmes were adopted within the same centre, even within the same department, i.e. the CBR department. The commitment, dedication and belief of each staff member in their own project's ideology and underlying concepts, made them resistant and unwelcoming of any kind of change.

From this position sprang the idea for this study. The researcher, being the head of this department, viewed the variation and difference between the programme approaches as advantageous and a source of varied experiences. He strongly believed that no one, universal approach can satisfy and cater for all the needs of disabled persons and their families. Moreover, there was a need to examine whether these approaches which were perceived as 'contradictory' approaches, could actually be seen as 'complementary' to each other, being more or less appropriate according to the setting.

Therefore, the researcher attempted to address this situation from a scientific point of view. The study design attempts to investigate "which approach works better in which situation?" through a comparative evaluation of the different approaches adopted in SETI.

It is important for the reader to understand how the perception and comprehension of the CBR concept developed among SETI staff, and how this is reflected in the programmes' development and implementation before describing the difference between the projects in this study.

1.4.2 SETI CBR programmes - Development

1.4.2.1 The Cairo Community-Based Programme

In 1991, as part of the centre's policy to decentralise some of its services, a pilot 'community-based programme' was initiated. At this time the whole concept of CBR was very new in Egypt. The programme was launched by an ex-patriate from Handicap International with a very capable and dedicated team, who had no experience in community work but good experience in working with children with intellectual disabilities. The programme idea was based on utilising the Caritas Community Development Centres located in the poorest slums of Cairo as centres for community based programmes.

The team demonstrated an exceedingly high level of motivation and commitment to disabled children and the work. They related very well to families, but not to the same extent to the local community. Nearly all the team were females as it was believed that this would facilitate their introduction and working with families in such slum areas, but this also lead to less contact with the local 'male' community.

Members of the team acted in accordance with their understanding of CBR, but did not place a very strong emphasis on the need to train community workers. They believed their role was mainly to deliver services through involving family members in a home-based rehabilitation programme for their disabled child.

According to the main programme 'Participatory Review'(Coleridge, Shukrallah, Isakov, Sebeh, & Kabesh. 1995), drawn up by three external consultants, the programme's initial philosophy was to incorporate work with intellectually disabled children into existing educational and health services. Instead what was created was a programme offering home visits, clubs, classes and small workshops (as described below). The programme was originally intended to operate with volunteers as the main source of support to parents and children in home visits. However, this policy failed as there was difficulty finding committed volunteers, and they did not have enough skill or time to do the home visits, and left the programme shortly after they began.

One of the major positive findings of the review was the significant impact the programme had on disabled children and their families due to the high level of therapy. The services were mainly provided by skilled professionals from SETI who did most of the home visits. However, the review raised strong doubts about the prospects for project sustainability if SETI withdrew from the projects, as the financial and technical support, and management of the programme depended on the centre.

Description of the Cairo programme

The project **aims** to deliver rehabilitation services to children with intellectual disabilities in the community where they live. This includes training the disabled person to be independent and to promote integration, changing the attitudes of people in these communities towards disabled people, helping as many families as possible at a minimum cost, and finally improving the conditions of the disabled child's family.

Currently, three projects are running in three different slums. One of them has a Caritas centre as its base and the second is using premises belonging to the Italian Embassy within a few minutes'walk of SETI's own base. Only the third project, which is the subject of this research, has a base belonging to a local society and which can be regarded as part of the local community.

About 130 children were involved in the whole programme, during the time of the research. The project used a network of 15 volunteers supported by 13 full-time salaried staff: four local coordinators recruited from the communities served, and a team of ten professional staff from SETI. However the project involved in this study, uses one local coordinator and around four volunteers, though staff numbers vary.

The *local coordinators*, who are all parents of disabled children included in the programmes, started as volunteers and developed sufficient knowledge and skills to play a local leadership role in the projects. The local coordinators are full-time salaried staff, who were recruited from the areas served to facilitate the implementation of the projects locally. They were originally going to be employed permanently by the centre, but management is currently reviewing the philosophy and strategies of the Cairo project, and it is felt that recruiting them into SETI would be opposing the gradual withdrawal of SETI from the services.

The role of the *volunteers* is more focused on running the weekly clubs and classes. The volunteers are either community members or students from the Institute of Social Science who spend five months practical training in the project.

> **Home visits** are seen as the main form of service delivery. The programme is dependent on *professionals* (SETI staff) to assess the children and then design a teaching programme for parents to carry out at home. During the initial phase of the project, there was a dependence on volunteers, whether outsiders or from the local community. They carried out weekly home visits to assist and guide the parents in implementing the educational and developmental programme decided on by the professional team. Due to an increase in the drop out and consequent turnover of the volunteers during the first few years of this, *SETI staff and local coordinators* decided to do the weekly home visits themselves.
>
> Each project runs its own **weekly club**, which provides a good opportunity for the disabled children to go out of their home, to play with non-disabled children and

their family members as well. Moreover, it provides a forum for parents to learn from each other and to share their experiences, feelings and concerns.

Classes are run once a week by the mothers and volunteers with the aim of teaching children in a class-setting. The classes are taught by volunteers, and prepared by SETI staff.

Summer Camps, outings and some leisure activities are run to provide recreation for families and to promote integration of the disabled children in their families.

A **low-cost workshop** is also run by a SETI staff and provides aid, equipment and toys.

Vocational Training is available in two of the three project areas where a small carpentry workshop and a kitchen are available.

At the time of the study, there was also an attempt to provide employment for three adults with intellectual disabilities through small income generating projects, but this failed to continue for various reasons.

Referrals are made to a variety of medical and rehabilitation centres in Cairo.

How best to describe the Cairo programme approach?

Until the time of the Review in January 1995, four years after its start, the Cairo programme was still entirely managed and controlled by SETI. It was clearly stated in the review that "At the time of the Review the programme is entirely run (and hence 'owned' by SETI); none of the three community programmes is autonomous" P.18. Therefore, based on the findings of this Review, the term which will be used to refer to the Cairo programme in this study will be 'Outreach' programme.

Since the beginning of the Cairo programme various labels have been used to describe the projects. Although the programme aims to reach a final stage when the label 'CBR' can be correctly used, this did not happen during the first three years. Among the labels used were: 'Grassroots rehabilitation programme', 'Rehabilitation programme with a community based approach', 'Outreach programme', 'Home-based outreach rehabilitation programme'... etc.

The indecisive attempts to label the programme are significant because they reflect the debate, within SETI at that time, about what the essential elements of a CBR programme are. Some of the CBR advocates within SETI wanted to introduce major changes into the Cairo programme to facilitate its conversion to a CBR model, although they recognised the difficulties the programme would encounter due to its original status as 'Outreach'.

This debate was seen by the centre management as a major constructive process in the search for the most appropriate approaches to rehabilitation to be adopted by SETI. The centre management stressed that CBR was not necessarily the 'best' approach and that other alternatives and models should have equal opportunities to be tested.

Therefore, in 1993 the decision was made within SETI centre management to set up a new programme under the supervision of the same CBR department but adopting a different approach in the slum areas of Alexandria. The programme staff were requested to implement all the basic principles of the CBR approach in this pilot demonstration project. The intention was to provide the opportunity for both the CBR and outreach approaches

to be fully experimented in two different cities, Cairo and Alexandria, with similar populations, in order to learn from both experiences and determine the most appropriate for use in different settings.

1.4.2.2 The Alexandria Community-Based Programme

The Alexandria programme, adopting the CBR approach, was set up in spring 1993 as a result of agreement between the Ministry of Health and Caritas-Egypt to introduce services for children with developmental disabilities, among the other activities of the MCH centres in Alexandria. This was an initial attempt by SETI to utilise the existing health infrastructure in the provision of rehabilitation services to disabled persons.

The programme aims, within a cost effective approach, to improve and promote the quality of life of the largest possible number of people with disabilities through both the family and the community. More specifically, the intervention aims to maximise the potential of children with intellectual disabilities in terms of developmental progress, integration within their families and societies, as well as the development of positive parental attitudes.

The programme focuses on three main aspects: prevention, early detection and intervention, and providing rehabilitation services to people with disabilities.

It aims to mobilise and later on to **rely on community resources** to take on the responsibility of providing services and the necessary support to the parents. It aims specifically to achieve the maximum possible extent of *independence of parents and/or local community* by the end of the intervention.

The CBR project is particularly concerned with involving parents in *assessing* their child with intellectual disabilities, and *designing* and *teaching* the programme to be achieved.

The Alexandria CBR programme plan of action is based on the gradual expansion of the number, age range, level and type of disabilities of beneficiaries, as well as the range of services and activities included in each project. This gradual expansion occurs through the transition of each project from one stage to the next. Although the programme design assumes that all projects go through four consecutive stages, any project can be confined to one of the stages and limit its services to what is included in that stage. This depends mainly on the extent of success achieved in the previous stage and the level of enthusiasm and commitment showed by the personnel involved, as well as the availability of local resources.

> **The first stage** is focused on providing training opportunities to the appointed MCH staff on prevention, early detection and early intervention. The training is given in the form of workshops, practical training and in-service training.

> The beneficiaries of this stage are children from birth to twelve years old with intellectual disabilities, as well as children with cerebral palsy but not those who have severe multiple disabilities.

> During this stage a centre-based early intervention and rehabilitation service is provided to the disabled children and their families once every week, in addition to medical care and referral services.

> The last part of this stage is oriented to community based activities and services, as preparation for the transition to the following stage, which witnesses the actual implementation of the CBR project. Thus SETI staff assist the MCH personnel in conducting the situation analysis of the target area, identifying the beneficiaries, detecting new cases, organising public awareness meetings and contacting local authorities and relevant resource persons. In addition there is the introduction of new services on a trial basis for children and their families, such as fortnightly clubs and occasional outings.

The second stage sees the provision of weekly home visits instead of the centre based ones, as well as a variety of community based services, as described below in the Outreach programme, but offered through local resources.

The third stage witnesses the expansion of the CBR services to include beneficiaries of all ages, and with all levels and types of intellectual disabilities, while people with any type and level of disabilities are served in the **fourth stage**.

The Alexandria CBR Programme was initially launched in 1993 by only two full-time Caritas staff members and one part-timer. The programme was confined for the first four months to the first stage, which took place in Karmouz, one of the poorest slum areas of Alexandria. *The projects looked at in this study are the Smouha MCH project which was at stage one at the time of the study, and the Karmouz project which was at stage two.*

1.4.3 Description of the three studied projects

The research conducted involves three early intervention initiatives. Two of the projects are part of the Alexandria 'CBR' programme but run in different stages, as explained above, while the third project belongs to the Cairo 'Outreach' programme. All three projects provide services in slum areas of the cities, characterised by low-cost housing with a high density of population. All the projects have young intellectually disabled children as their target population. The three projects were initiated and supervised by the Caritas-SETI Centre, adopting different strategies in an attempt to determine the most appropriate for use in Egypt.

1.4.3.1 The Cairo 'Outreach' Project

The project is part of the Cairo Outreach programme, and involves four professional staff from   SETI, one local coordinator and a varied number of volunteers (around five). The project provides its services to an average of fifty disabled children and their families in one of the three slums area served by the Cairo Outreach programme.

Children and parents of the Outreach project receive services in the form of weekly home visits, the majority of them are carried out by the professional team of SETI. The SETI staff assess the children and specify the educational and developmental programme which should be followed by family members during the week. Children attend weekly classes run by mothers and volunteers (local and external) but prepared by SETI Staff, in addition vocational training, outings and summer camps are organised. Many children in the project benefit from the aids and equipment provided by the low cost workshop, and the referral system.

1.4.3.2 The Smouha Mother And Child Health Centre Project

The MCH project, which constitutes the first stage of one project of the Alexandria CBR Programme, is a centre based project with no home visits. It provides one or more training sessions per week to every child according to his or her needs. The child must be accompanied by parents during the sessions. The centre's aim is to offer some professional services to the children as well as to demonstrate how the programme could be implemented at home.

The project personnel consist of eight MCH staff: five physicians, two nurses and a social worker. It serves fifty children with intellectual disabilities and their families.

This project is of particular importance because if it is successful, it could be generalised to cover all parts of Egypt. These numerous well distributed centres are the best available governmental infrastructures for providing at least a modest service to the vast majority of

children in Egypt with intellectual disabilities, and from which many CBR programmes could be launched.

1.4.3.3 The Karmouz CBR Project

The project is at the second stage, and is also part of the Alexandria CBR programme. The personnel are seven physicians, nurses and social workers appointed from the MCH staff as well as three recruited community workers and twenty volunteers. This project serves nearly 80 children with intellectual disabilities and their families.

It provides the same sort of services as outlined in the Outreach programme description above, but is different in that it depends mainly on local resources to provide services, and it promotes parental involvement to a greater extent. The weekly home visits are conducted by local staff who are either community workers or MCH staff. The educational and developmental programmes are decided upon jointly by both the parents and the home visitor. Weekly clubs, classes and outings are organised by local staff, volunteers and parents with a minimal support from SETI staff. Children who need more specialised services are referred through the local MCH centre who manages the whole project with a local steering committee. Occasionally, summer camps are organised mainly by SETI staff and funded through them as well.

The community workers, who started as volunteers and proved to be very efficient and dedicated, were recruited by the local management of the project. Being recruited from and paid by the local community, the community workers felt obliged to report regularly to the project local management rather than SETI staff. This was seen as a crucial step towards future independence of the local community to run their own project.

1.5 Summary

Despite the wide expansion of CBR programmes during the last decade, many challenging issues have still not been addressed on a scientific basis. Some of these challenging particularly affected the development of CBR services provided by Caritas-Egypt, SETI Centre. These problems resulted in the creation of two different community-based approaches to rehabilitation: the Cairo 'Outreach' programme and the Alexandria 'CBR' programme.

The study to be described in this thesis is a comparative evaluation of three early intervention projects, a **centre-based** project and a **CBR** project belonging to two different stages of the Alexandria CBR programme, and an **'Outreach'** project belonging to the Cairo 'Outreach' programme.

The following chapter reviews available literature and suggests the appropriate methodology for evaluation of CBR programmes. In particular, it suggests the questions to be asked and the approach to be adopted in this study considering the current stage of development of CBR.

2. CHAPTER TWO: APPROACHES TO CBR EVALUATION

2.1 Evaluation of CBR: literature review

Community Based Rehabilitation (CBR) programmes have expanded rapidly over the last fifteen years. Despite some attempts to investigate whether CBR works or not, results to date have been very equivocal.

The first part of this chapter will present and discuss the main findings in the literature. It will look both at the paucity of evaluations and their lack of quality, given the great expansion of CBR since its early development 15 years ago. It will then question why, despite the urgent need, there have been so few attempts to develop appropriate scientific approaches to CBR evaluation.

The second part of this chapter will attempt to determine the most appropriate methodological approach to CBR evaluation by reviewing, comparing and discussing the different types of evaluations. Participatory versus objective; qualitative versus quantitative; outcome versus process; and long-term versus short-term evaluations will be considered.

The discussion will be followed by a review of evaluation studies of early intervention programmes in western countries, in an attempt to learn from a well-developed and researched field which has some similarities to CBR. This will aim, in particular, to examine the possibility of adapting some of the most suitable research designs, methods and tools for use in developing countries.

2.1.1 Critical Review of the literature

A review of the literature on CBR evaluation reveals that the majority of what has been published is very elementary. While much of the literature highlights the importance and urgency for evaluation, very few publications describe actual evaluations or discuss methodological issues.

The literature on CBR evaluation can be classified under the following headings:

- Introductory notes and general guidelines

- Simplified evaluation tools for use by programme implementors and beneficiaries

- Unpublished evaluation reports of field trips by independent evaluators

- Published evaluation reports

2.1.1.1 Introductory notes and general guidelines

These constitute a limited number of simplified explanatory notes, mainly presented in book chapters, describing the evaluation process in general and its implementation in the context of CBR , e.g. (Helander. 1993; Helander, Mendis, Nelson, & Goerdt. 1989; Jaffer. 1993; Jamieson. 1992; Martlew & Connolly. 1995; McConkey. 1990)

These publications tend to highlight the importance of and the urgent need for CBR evaluation, but restrict their contribution to theory by only suggesting priority areas or programme aspects to be evaluated.

In addition to the theoretical frame of the CBR evaluation, two of the publications in this category present their own practical experiences in relation to problems facing CBR evaluation in general. The first publication (Jaffer. 1993) illustrates the inconsistency between the local evaluation results of a CBR programme in Punjab, Pakistan, and the results obtained by an external Western evaluation team. The author, who was personally involved in the evaluation, calls for a more participatory approach in CBR evaluation. A detailed description of this issue will be presented later in this chapter.

The second publication based on the experience of Action Aid India, emphasises the importance of the process of changing attitudes, and of convincing the local partners about the value and benefits of carrying out evaluation, before they embark upon it.(Thomas & Thomas. 1995).

2.1.1.2   Evaluation tools

Most of the evaluations of CBR programmes, especially those related to the WHO,

depend upon the WHO assessment tool described in the TCPD manual (Helander, Mendis,

Nelson, & Goerdt. 1989). Although the tool has been widely criticised (Jaffer. 1993;

Miles. 1985; Werner. 1987), its simplified and illustrated form make it apparently suitable

for use at a local level, after performing the necessary field testing and adaptation.

However, it should not be considered an appropriate tool for scientific evaluation due to

the lack of any psychometric or validation studies. It depends heavily on criterion-

referenced outcome measures. Moreover, there is no description of any criteria for the

scoring system so it is open to subjectivity bias. Further problems associated with this

form of measurement are described in Eayrs and Jones (1991).

It should be noted here that despite the frequent criticisms of the WHO evaluation tool,

very few attempts have been made to develop a better alternative. One of the few attempts

was the development of the Guide on "Operation Monitoring and Analysis of Results"

(OMAR) (Jonsson. 1994), which was released in draft form for field testing. The strength

of this tool lies in its design as an integral, systematic and valid component of programme

construction. Its presentation in the form of computer software might encourage the users

to analyse their data and to learn more about their programme. However, the evaluation

tool is highly focused on individual impairments and only covers a few aspects of the

programmes. Moreover, it has never been researched, validated or standardised in any

setting, which also makes it inappropriate for use in scientific evaluations.

2.1.1.3   Unpublished Evaluation Reports

Although these are few in number, when considered in relation to the ever expanding
number of CBR programmes, unpublished evaluation reports still constitute the largest
portion of the literature on CBR evaluation. They are mainly the reports of evaluations
done at the request of donor agencies. Usually, they are carried out in a very short period
by external Western evaluators.

This body of literature consists mainly of descriptive reports of field-trips and programme
visits; many of them cannot realistically be termed as evaluation. Most of these
unpublished reports are circulated through different disability resource centres or are only
for the private use of the international GOs or NGOs supporting disability programmes in
developing countries.

This review of unpublished evaluation reports is based on a very recent research study
(Rutten-Woerdeman. 1995). This study attempted to investigate the possibility of
developing indicators to assess community participation in community development
programmes, and for it the author reviewed as many evaluation reports as possible. The
researcher was only able to identify and review nineteen reports which fitted her definition
of "evaluation report", as follows:

> "A paper which reviews a Community Disability Programme in a systematic way,
> using specified tools and criteria for data collection and data analysis and/or
> indicated in the title to be an evaluation of such programme".(P. 48).

From these the author highlighted the following features:

- Many of the evaluation reports are simply descriptions of activities done during the evaluation period. Many reported the results of their investigations but did not outline how the investigations were carried out. Nor do they review the objectives and /or evaluation questions in any systematic way.

- Results of evaluation reports are mainly based on people's subjective opinions, either the participants or the evaluators themselves.

- Many of the indicators used in evaluations may not actually gauge the variables intended for measurement, e.g. finance, beneficiaries and local participation were used as indicators for sustainability in some of these reports, but may not be used in the same way in other studies. Inferences taken from these indicators and their relationships to the programme component in question are usually decided upon by the external evaluators or programme participants, depending on how they define or perceive these components. The reliability of these indicators is therefore questionable.

- Many of the terms used in evaluation, like 'participation - integration' or 'sustainability', are not clearly described or defined. Different interpretations of what 'CBR' means will have a significant impact on the design of methodology to measure its effectiveness. For example, variation will occur according to whether one thinks of social development in terms of 'raising levels of awareness', 'popular education', or 'empowerment'. Different definitions lead to different methodologies being adopted (Garaycochea. 1990).

- The sources of information are often not specified thus making it difficult to draw conclusions or to interpret the results.

After reviewing the 19 evaluation reports, the author concluded that: "It is not possible, in most evaluations, to understand how the evaluation team arrives at certain conclusions and recommendations" P.77.

On the other hand, the positive aspect of the majority of the 'unpublished evaluations' is their attempts to adopt a participatory approach. Almost all the reports point out the importance of the learning process experienced by all the participants during the period of the evaluation. This approach in evaluation will be discussed further.

2.1.1.4   Published Evaluation Reports

Extensive searches of many database services reveal only a small number of published articles on CBR evaluation, reflecting the shortage of attempts to approach this subject scientifically. Most of the evaluation results were either published in the proceedings of international conferences, in international newsletters or through the international agencies involved in the evaluated projects. The fact that very few evaluations have been accepted for publication in internationally recognised scientific journals demonstrates the lack of quality attempts to evaluate CBR until now.

In the course of this review only ten papers have been identified which are published in scientific journals, and present the evaluation of at least one aspect of a CBR programme (Finnstam, Grimby, Nelson, & Rashid. 1988; Gershon & Srinivasan. 1992; Lagerkvist. 1992; Lysack & Krefting. 1993; Mariga & McConkey. 1987; O'Toole. 1988; O'Toole. 1989; O'Toole. 1991; Shown. 1991; Thorburn. 1992;)

Out of these publications, three present the evaluation of the Guyana project (O'Toole.
1988; O'Toole. 1989; O'Toole. 1991). This evaluation research is almost the only study
which can be considered satisfactory. The reasons for this and the study itself will be
described later.

The fourth publication presents the evaluation of the Punjab, Pakistan project (Finnstam,
Grimby, Nelson, & Rashid. 1988).The WHO community-based rehabilitation approach
was used in a village and a slum area in Pakistan, and the effect of training was evaluated
after 1-2 years by an occupational therapist, using the questions and assessment tool from
the TCPD manual.

The fifth publication evaluates the achievements of two CBR programmes in the
Philippines and Zimbabwe (Lagerkvist. 1992). The WHO assessment tool was used with
added scoring. Changes were assessed for six types of disability in subjects who had been
in the programme for at least six months. Results showed a gain in scores in 78% and
93% of the samples respectively. The author concluded that the WHO CBR programme is
highly effective.

The two evaluations outlined above focus on the individual's impairment and depend upon
the WHO assessment tool, which due to its lack of psychometric validity casts some doubt
on their results.

These three evaluations are the only ones which attempt to evaluate whole projects. Of the
other five publications, three are more descriptions than evaluations(Gershon &
Srinivasan. 1992; Mariga & McConkey. 1987; Shown. 1991), while the last two evaluate
only one aspect of the project, as described below:

Evaluators of a CBR project in Indonesia asked the question "What are the characteristics and motivations of CBR volunteers?"(Lysack & Krefting. 1993). Using a sound methodological qualitative approach they found that volunteers perform considerable duties and face numerous difficulties in the course of their CBR activities. They also found that incentives play an important role in determining the motivation and ultimate performance of volunteers.

The second piece of research (Thorburn. 1992) evaluated some aspects related to the parent perceptions of a CBR programme in Jamaica. The main two research questions were: "what are the parents views about the project in general, and specifically about the community workers' home visits?". The second question was: "what are the effects of the programme on the parents in term of changes in their knowledge, attitudes and practice?". Despite the subjectivity and the presence of other methodological problems described by the author in the report, results have shown a great satisfaction and improvements among the parents. The author demonstrated a significant improvement in the knowledge of parents regarding their children's disability, from 49% adequate understanding before to 92% after the initiation of the programme. There was a 67% increase in positive attitudes towards the disabled child, 72% of parents were spending more time giving their child attention or playing with them and 76% of the parents said that their child had become more independent as a result of the programme.

While only the evaluation of the CBR programme in Guyana can be considered satisfactory, the other studies are useful examples with which to illustrate various methodological problems, as discussed later. The existence of the Guyana project evaluation shows that satisfactory evaluation is possible, but it also leads us to ask why there are not more studies of its kind.

2.1.2   Historical perspective of the development of CBR and its evaluation

It is necessary to review the existing literature in this area within the historical context of CBR development, to give some insights into why CBR evaluation is still at such an embryonic stage.

The initial development of CBR in the early eighties was accompanied by a considerable number of evaluations (Finnstam, Grimby, Nelson, & Rashid. 1988; Mendis & Nelson. 1982; WHO. 1982) conducted by the WHO who aimed to prove the success, appropriateness and feasibility of this new approach. All the projects concerned were WHO pilot projects, none of which was evaluated independently at any stage (Miles. 1985). The evaluations were largely subjective and dependent on the WHO evaluation models, based on non- standardised checklists of functional abilities. These WHO related evaluations have been criticised by O'Toole (1987). He illustrates in his critique the contradiction between the apparent evidence of programme failure from the contents of some of the reports, and the final published conclusions which report great success.

A more detailed critique, based on personal experience, is provided by Jaffer (1993). The author illustrates the contradictions and inconsistencies in the results of evaluations done on projects in eight villages and four slums of Punjab, Pakistan, which were all part of the same CBR programme. The projects had been criticised in various reports by local project coordinators and consultants, as being unsuitable for local conditions and fraught with problems. However, a team of external Western evaluators selected only the successful project at Hair for evaluation, and reported improvements in 80% of disabled people (Finnstam, Grimby, Nelson, & Rashid. 1988). This was in contrast to all the other projects in the programme, which according to the local evaluation, reported improvements in only 16 to 23% of disabled people. The final conclusion according to an external official

publication was: 'the evaluation carried out has proved that the programme was a successful one'(UNICEF. 1985).

In this example the author is highlighting the possibility of generating misleading results by manipulating the 'technique' of the evaluation. He describes it as follows:

> "This technique of evaluation is like that adopted by many normally private schools, who allow only those students to sit in external examination who have passed rigorous internal tests - this ensures an almost 100% success in the external exams, and good publicity for the school". (P. 55)

The same conclusion was recently reached by one of the few methodological evaluation studies to report programme failure (Tjandrakusuma, Krefting, & Krefting. 1995). The author focuses on the contradictions between their own results and those of previous evaluations, citing 'the process of data collection' as the explanation. For example, there was reliance on the reporting of casual comments or stories told to visitors, or the staff themselves making comments about what was happening in the field. The author also indicates the discrepancy between what is said and what is actually done within a project.

2.1.3 Conclusion

The vast majority of the CBR evaluations carried out to date are simple, subjective, informal and inadequate. Almost all of them are led by external evaluators who carry them out in an extremely short space of time.

Methodological weaknesses include the absence of a control group, which is essential if changes are to be ascribed to the project itself. Also there has been an overriding concentration on the measurements of the impairments of disabled persons. Unpublished evaluation reports often attempt to cover the different aspects of a project through a qualitative approach but they fail to follow a consistent methodology for many reasons.

This lack of a methodological approach and the unknown validity of instruments used, prevent these evaluations being taken as a base from which to develop more appropriate methods. However before addressing the question of development of scientifically valid evaluations, it is necessary to consider some fundamental issues surrounding evaluation itself, especially in relation to the rapidly evolving nature of CBR.

2.2 The evaluation dilemma: discussion of some controversial issues in methodology

Almost all the CBR evaluations to date have been conducted for use by project workers and funding agencies. Hardly any of the literature considers CBR evaluation from a scientific point of view, or compares different models and approaches that could be used, or even gives suggestions for future research.

The following section will present a discussion of controversial issues relating to possible approaches and methods, in an attempt to decide upon the most appropriate for use in the evaluation of CBR. It will be followed by a consideration of these recommendations in the context of the current phase of CBR development.

If CBR is considered as a social development programme (ILO, Unesco and WHO. 1994)), then the broader issues associated with the appropriate evaluation of social development projects must be addressed. This review will discuss methodological issues with particular reference to their implications in developing countries.

During the course of this review, the term *project community* will be used to refer to all those involved in the project , i.e. the people concerned and others who have responsibility for implementation (Rahman. 1990).

2.2.1   Participatory versus Objective evaluation

2.2.1.1   The participatory approach

Over recent years participatory evaluation of social development projects has gathered wide popularity and support. Many CBR specialists advocate its use, as it is considered a good method by which the participants can evaluate a programme with outside assistance only to facilitate the process.

Participatory evaluation is an evaluation decided, designed and carried out by those involved in the work being evaluated. Their active participation in the exercise runs right through its planning, implementation, and the interpretation of the results of evaluation. It is mainly a self-evaluation carried out by the project participants primarily for their own use. Project staff also participate in the process for management information purpose and to assist the participants (Feuerstein. 1986).

This approach resulted from the search for a 'utilisation-oriented' model (Feuerstein. 1986), following the widespread non-use of evaluation findings and recommendations (Stecher & Davis. 1987). It was seen as a 'radical' move away from the belief that an evaluator must be 'independent' and 'impartial', for the evaluation to be scientifically valid. However, this move encountered great resistance and resulted in splitting of the professional evaluators into two camps. These two schools of thought are best described by Mulwa. (1993):

> "There were those evaluation researchers who maintained the conviction that the experimental approach to evaluation could not possibly be abandoned, being the most 'authentic' and 'effective' methodology to establish 'causal' inferences of change and isolate the 'causal' effects not associated to the programmes' effects. The other school of thought was more pragmatic in its approach.... and would argue that evaluation results, no matter how valid, will never be taken seriously,

for the improvement of programme or change of policy unless all stake-holders or constituents interested in the evaluation (or those affected by the evaluation findings) were somehow involved right from the planning stage of evaluation through to the final recommendations".(P. 58)

Participatory evaluation provides the basis for comprehensive evaluation of multi-element types of programmes, such as social development projects - including CBR. Longer and closer contact with beneficiary groups can be established leading to much more comprehensive information gathering. It also provides the opportunity for the project community to learn and develop: a far more positive experience than having judgement passed on them by outside agents (Feuerstein. 1988; Garaycochea. 1990; Helander. 1993; Rahman. 1990). As social development implies, participatory evaluation enhances the sense of confidence and capacity among local people, and thus echoes the empowering principles central to most social development interventions (Tandon. 1990). Even more, it can be seen as an intervention in itself, an empowering intervention, and this in turn is central to CBR programmes.

Problems of the participatory approach

This approach to evaluation does have some shortcomings. Many of the evaluation methods and tools used in participatory evaluations depend on interviews, questionnaires or reports from local people rather than using well developed, standardised tools. Validity problems associated with self-reports have been highlighted by many authors.

For example Palta *et al* (1982) found that individuals tend to self-report heights and weights which differed from their actual values. Sacks *et al* (1980) reported that two administrations of the same questionnaire to the same group of individuals at two different points in time revealed many discrepancies in personal health data reporting. Accuracy of recall, in many cases can also be questioned (Patrick & Beery. 1991). Harlow and Linet

(1989) reviewed self-reports with medical records and found only a fairly limited range of information was accurately recalled.

Additionally, subjective bias due to a variety of personal motives can be a problem for validity. Robson (1993) noted that pupils could be motivated to make a particular strong effort in a test, knowing the importance of 'good results', or to please or help their teacher.

Additional problems specific to developing countries

This subjective approach to evaluation may encounter many additional problems when it is applied to developing countries. The high level of education in developed countries, tends to make people more aware of their problems and their needs. Questionnaires and interviews are considered in Western research to be useful means for participants to voice their opinions and express their needs.

In less developed countries, however, the attitudes and traditions of the non-educated majority, in addition to the lack of democracy and awareness of basic human rights, contribute to a situation where participants are likely to conceal the negative aspects of what is being evaluated.

There is also a tendency to magnify any minor positive impacts resulting from a project as a sign of gratitude to those who provide this sort of service. This attitude is further exaggerated when these services are seen as a luxury in a very disadvantaged area, or if disabled people and their families are unaware of their basic rights. Moreover, many local people are apt to highlight the positive aspects of a project to impress the outsiders, particularly international visitors, and to respond positively to inquiries especially if they

realise that their project is being evaluated. Respondents may be influenced by what they imagine the questioner requires, and will reply in such a way as to impress their needs on a potential supporter.

In addition to the above, many of the participatory evaluations in developing countries involve an external evaluator. One of the major disadvantages relating to foreign external evaluators is their unfamiliarity with the local language. The translation process can interrupt the normal flow and interaction of a discussion. Local people may feel uncomfortable with what they perceive as an outsider coming to make judgements about their project (Lysack & Krefting. 1994), despite assurances that the evaluation is a learning experience for all of them and should not be seen as judgmental.

Another challenge to participatory evaluation is the influence of the group on individual behaviour in one of the most frequently used methods, the 'Focus Group Discussion' (FGD), particularly when a topic has the potential to make informants uncomfortable. For example, Lysack & Krefting. (1994) noted that in Indonesian society it is not culturally acceptable to disagree with a group consensus, nor to provide a response that has negative connotations for someone. The authors felt that despite using skilled indirect questions there were some topics about which respondents were clearly withholding their views. Thus based on this evidence, FGDs may produce biased data.

McConachie and Zinkin (1995) state that for the results of an evaluation to be interpreted, it is necessary to outline the steps that were taken to overcome social conformity in interviewees' answers. However, the suggestion by some authors (Brewer & Hunter, 1989; Morgan, 1989; Catherine, 1994), of incorporating both group and individual interview techniques to solve this problem, could be considered inappropriate in the context of developing countries as discussed later.

In conclusion, it is necessary to focus on the fundamental tenet upon which participatory evaluation in developing countries is built. As the name suggests, the participatory approach implies a partnership between the project community, especially the donor agency or outsiders, and local people (Feuerstein. 1986). Working in partnership with local people is fundamental if development is to be sustained..... But how far is it feasible or successful?

Partnership in social development: is it a realistic goal?

Experience suggests that partnership between two unequal partners is very hard to build and maintain. Many authors have stressed the difficulty of creating partnerships when the local partner feels powerless and incapable in relation to the outsiders, or does not feel a sense of mutuality and shared vision (Kelly & Van Vlaenderen. 1995; Schrijvers. 1991; Tandon. 1990; Verhagen. 1990). Tandon. (1990) claims that in such situations all attempts at partnership building in social development projects between a grassroots organisation and its international donors have failed.

Several authors highlight the relationship between the concept of participation and dialogue (Boeren. 1992; Genganje & Setty. 1991; Kelly & Van Vlaenderen. 1995; Rajakutty. 1991; Schrijvers. 1991). They regard dialogue as the kind of communication which enables participatory development to take place. "Through dialogue a commonality of individual perception is facilitated and this is used as a basis for any social action" P.372 (Kelly & Van Vlaenderen. 1995). However, they are pessimistic about the possibility of dialogue in a development context. They outline the difficulties involved in bringing about dialogue when the two participants wield different degrees of power in a given situation. They draw the same conclusion as Brazilian pedagogue Paulo Freire (Freire. 1972). He highlighted how in the relationship between oppressed people and their oppressors there is a break-down of the dialogical process leading to inter-subjectivity. However it is precisely

in those situations where dialogue is not easily attained that participatory methodology is usually proposed by funders as the most appropriate approach.

Consequently, Tandon (1990) realised that partnership in evaluation cannot function if the project community, outsiders and local people, do not incorporate and believe in, or cannot achieve partnership. His experience suggests that "where such partnership has not been encouraged, promoted, and sustained within the development initiatives, it is impossible to promote or implement ideas of partnership in evaluation of those development efforts" P.98. He also concludes that it is better to recognise the difficulties in this explicitly than to overlook or ignore fundamental differences between the two partners.

Concluding from the above, many social development project evaluations in developing countries, including CBR projects, are subjected to major bias as they are carried out in response to a request by a donor agency and most probably in its presence. It is unrealistic under the threat of discontinuation of funding of a project, to expect beneficiaries and local partners to declare their project a failure. It is highly probable that participants will confine their contribution to what they think can be disclosed.

2.2.1.2   The objective approach

As noted before, almost all the unpublished evaluation reports, which constitute the vast majority of the evaluation effort in CBR to date, adopt the participatory approach to evaluation in preference to the objective approach. Although the former has many advantages and there is no doubt about its relevance in CBR, the scientific methodological approach to evaluation is also of crucial importance.

Conventional evaluation aims to be more 'scientific', i.e. objective, impartial, and unbiased (White. 1993). Scientific research is judged in terms of its reliability and validity. It requires the "collection of systematic, methodologically sound data"(White. 1993) P.356, and its findings should be generalisable (Robson. 1993).

The scientific evaluation approach is different from participatory evaluation. The latter, as mentioned before, is considered mainly a learning process for the project community at the local level, and the results are mostly confined to improving the project itself and are not generalised further. Scientific evaluation on the other hand, produces results which can in principle be replicated and generalised (Robson. 1993), and is considered as a necessity for the advancement of knowledge in the field concerned.

Objective scientific evaluations are more convincing and influential. The more the findings of an evaluative exercise are seen to be independent of the judgements and prejudices of the evaluators, service providers and those who commissioned the evaluation, the greater their power to influence other people (St.Leger, Schnieden, & Walsworht-Bell. 1992).

Problems of the objective approach

There are however some challenges to this traditional approach to evaluation. Normally, scientific evaluation adopts set tools, questions, indicators and analysis procedures prior to any 'field work'. Some authors (Rahman. 1990) argue that indicators should be developed in the context of the individual project's or programme's actual objectives, and central attention should be given to the local people's culture in the formulation of indicators. Moreover, the same authors add that imposing parameters on the local people will certainly affect the 'empowering' and ' enabling' process central to any social development programme.

A further problem is that scientific evaluation reports may be reflections of an academic style of inquiry and may not be designed to be read or understood by local beneficiaries of projects, or used as a tool for the local management (Marsden, Oakley, & Pratt. 1994)

A mixed approach

Some authorities assert that evaluation should be objective and neutral and thus argue that the participative approach, by its very nature, cannot facilitate this. Conversely there are those who argue that objective and external types of evaluation are in conflict with the principles of partnership, equality and reciprocity.

It should be stressed that the participatory form of evaluation is not a formal substitute for external evaluations (Verhagen. 1990). Feuerstein (1986), one of the early pioneers in this approach, maintains that participatory evaluations are not intended to replace the more traditional evaluation methods. However, she added that they can often make those methods that are useful more appropriate and effective.

Ideally a balance between external and internal elements is required (Verhagen. 1990). A joint approach could be considered, with many different forms of evaluations that enhance partnership between the groups within a project community.

2.2.2   Qualitative versus Quantitative evaluation

2.2.2.1   *The qualitative approach*

In social development programmes, the measurement of levels of service provision may not necessarily be as important as the measurement of human dignity, mutual respect, and solidarity (Rahman. 1990). Education and the experience of organisation at a grass-roots level, rather than material benefits, might be the most important gain in the people's own assessment of what they have achieved from a project. Therefore, much of the literature related to project evaluation in developing countries supports the qualitative method of evaluation e.g. Marsden and Oakley (1990).

One of the most comprehensive summaries of the advantages of qualitative methods in the evaluation of social development projects is provided by (Oakley. 1990) P.33;

Advantages of Qualitative Methods

- Qualitative evaluation is *naturalistic*, in the sense that the evaluator does not attempt to manipulate the programme or its participants for the purposes of the evaluation. Naturalistic inquiry studies processes as they occur, and not on the basis of a pre-planned experiment. As a social development process unfolds, a naturalistic approach would be sensitive to changes in direction, unexpected outcomes and differential impact. Since naturalistic inquiry is not locked into searching only for predetermined and expected outcomes, it is able to identify and describe what actually happens as a result of a project.

- Qualitative evaluation is *holistic,* in that evaluation exercise sees the programme as a working whole which needs to be both understood and analysed from many different perspectives. This holistic approach ensures that detailed attention is given to the different dimensions of a social development project: context, participants interrelationships with other projects, activities, and so on.

- Qualitative evaluation employs *inductive analysis,* in the sense that evaluator seeks to understand the outcome of a social development project without imposing pre-determined expectations. This inductive approach begins with specific observations and builds towards general patterns of project outcome; the evaluator gathers qualitative data on programme outcome through direct observation of programme activities and in-depth interviews with participants, without being limited to stated pre-determined evaluation goals. The approach is also essentially *interpretative,* build up through description of the significant facts, figures, and characteristics of the project which are an accurate reflection of its overall complexity. This continuous interpretation provides the raw material which forms the basis of the project's evaluation.

- Qualitative evaluation, by its very nature, implies a *continuous and close contact with the participants of a programme* in their own environment. The qualitative approach emphasises the importance of getting close to project participants in order to understand more authentically their realities and the details of their everyday lives. The evaluator intensifies this close contact through physical proximity for an extended period of time as well as developing a closeness resulting from the shared evaluation experience. Qualitative evaluation demands participation and commitment of the evaluator and discourages detachment and distance, which are characteristics of other approaches to evaluation.

In summary, qualitative approach is essential to explain what *happens* in a social development project which seeks to *promote* the kinds of objectives we have seen. These abstract objectives, like participation, are phenomena which occur over time, and can not be measured by a single 'snap-shot' form of exercises. Qualitative evaluations is more concerned with *describing* the characteristics and properties of a process like participation, for example, over a period of time, and then with *interpreting* the data and information available in order to make statements concerning the nature and extend of the participation which has occurred.

Other authors stress the importance of qualitative methods for generating insights into the causal processes which underlay project outcomes. They can also determine which of the components of a multifaceted programme contribute to its outcome. However, the search continues to find culturally relevant ways of measuring programme quality.

Problems of the qualitative approach

The lack of objectivity is highlighted by Oakley (1990) as the major disadvantage of qualitative evaluation.

A second concern is the problem of wider applicability, i.e. to what extent is the information obtained from a relatively small sample relevant to a larger population?

Thirdly, sampling problems in qualitative research can arise in the selection of locations, the timing of observations and the choice of interviewees. As probability sampling from a larger known population is seldom feasible, problems of external validity are difficult to avoid (Broughton. 1991). The same author notes that when problems of reliability and observer bias arise in qualitative research, they are 'often more difficult to assess than are these problems in quantitative methods" P.464.

Finally, it must be acknowledged that qualitative methods may not succeed in obtaining information which reflects reality. Lee (1990) notes that embarrassment or perceived differences in status between investigator and respondent, can lead to a reluctance to reveal the real facts to a relative stranger. The author emphasises that qualitative methods rely heavily on the ability of the investigators to establish rapport, and the validity of the results obtained, especially when sensitive information is sought, may hang on the quality

and manner of the interaction with the respondents. In developing countries, this approach

needs skilled, highly-trained investigators (Lysack & Krefting. 1994), who may not easily

be available at the local level. This is in addition to the difficulty of building partnerships

between unequal partners, as discussed earlier.

2.2.2.2   The quantitative approach

Traditionally, this has been the dominant evaluation approach, and is concerned with

measuring and giving a numerical value to project outcomes. It is concerned with "the

effort expended, the _effect_ of the project in terms of its original objectives, and the

efficiency of the use of project resources" (Oakley. 1988) P. 3. Essentially this approach

measures a project's tangible or material performance, and overwhelmingly this

performance tends to be the sole criterion for judgement of the project's outcome. This

approach has been viewed as an acceptable reflection of project success or failure (Oakley.

1990).

Measuring implies an attempt to quantify observed changes in numerical terms while

judging suggests an attempt to assign value to those changes, that is, to grade each change

as 'bad' or 'good' in accordance with a previously established expectation (Hatch. 1983).

One of the strengths of quantitative approaches is their potential for utilising simple

evaluation techniques, which may be made easy to administer, analyse and interpret. This

is a central issue for local social development programmes, such as CBR. Numbers should

provide objective, reliable statements which can be combined to give an overall picture.

Moreover, it is possible to quantify non-tangible objectives, such as attitudes and feelings,

as well as observable events and objects.

Problems of the quantitative approach

Despite its widespread use and acceptance, the quantitative approach is not without its critics. One area of criticism revolves around the issues of attribution and causality. When evaluating in strictly quantitative terms, it is necessary to question what the cause-effect links are between a project and its outcome, i.e. how far can perceived outcomes be attributed to project activities? (Oakley. 1990).

Moreover, the same author views the quantitative approach as a limited, static form of evaluation which is unable to reflect in adequate detail the important outcomes of projects which are not exclusively quantitative in nature. It can be time-consuming: its techniques can lead to major evaluation exercises which absorb the time and energies of project staff, at the expense of other activities.

Furthermore, it is suggested that this approach has a built-in bias towards predicted favourable outcomes, and rarely reflects the unforeseen consequences of project interventions. Essentially it is argued that this evaluation paradigm is externally conceived and implemented, and it takes little note of the people who directly experience the realities of a project's outcome. Its scope is limited to what can be quantified and measured, and is unlikely to include non-material, non-tangible development objectives.

Concepts such as 'participation' are difficult to define in specific, quantifiable terms. It is also difficult to predict how such objectives might manifest themselves, (Oakley. 1988; Weiss & Rein. 1970). In other words, although a quantitative approach is an acceptable way of understanding one dimension of project outcome, it is inadequate as the sole technique for evaluating social development projects (Oakley. 1990).

A mixed approach

Many authors have called for a combined qualitative and quantitative approach to evaluation. Caldwell, Reddy, and Caldwell (1983) point out the limitations of a survey method in rural South India, and call for a mixed approach, discussing the strengths and weakness of different qualitative and quantitative approaches. Broughton (1991) suggests ways in which both may be used together in a given evaluation effort. He emphasises the potential for discovery of the qualitative methods, whereas the quantitative methods provide confirmation of predicted outcomes.

Garaycochea (1990) emphasises that "the debate should not be between quantitative and qualitative measurements. You can put a number on anything if you wish to; it is the interpretation of that number which is important" P.5. Both approaches could be easily used together.

It is suggested that quantitative indicators are easier to understand and administer at the local level. But as we are dealing with social development projects, we are concerned not only with results which are quantitative, but more importantly with processes which are qualitative. Qualitative evaluation allows social development projects to be seen as *dynamic and evolving* and not necessarily following a pre-determined direction. This approach therefore, can be responsive to innovative projects, and more importantly to objectives which are not easily measurable.

In summary, as Oakley (1990) stressed, the evaluation of social development projects should be qualitative as well as quantitative. Both types of social development dimensions must be included if a full understanding of the outcomes is to be achieved.

2.2.3   Outcome versus Process evaluation

2.2.3.1   The outcome approach

For the purpose of this review, outcomes and impacts will be discussed under the same heading; Cohen and Kibel (1993) define 'outcomes' as "observable or measurable changes in the behaviour of target populations" and 'impacts' as "changes in social indicators reflecting reductions in problems" P.334.

Traditionally, evaluation has been restricted to questions concerning outcomes. The effects of a programme have been used to measure how far a programme has met its stated objectives or goals.

The outcome/impact approach has long been favoured by donor agencies. Its advantages are outlined as follows, by two major European bilateral aid agencies who have funded evaluations of primary health care projects in developing countries (Pirsig. 1992)

Table 1. Advantages of impact evaluation as elicited from 7 senior health planners of 2 European bilateral aid agencies. [Quoted from Schrettenbrunner & Harphan (1992) P.133]

Demonstrable results

> They are strong arguments for the relevance of a project
>
> They give information for effectiveness and efficiency calculations
>
> They are a higher goal to reach
>
> Impact measures are politically more impressive
>
> They legitimise intentions to improve health
>
> They enable comparisons
>
> They are easily communicated and easily understood by lay people, opinion-makers and influential people
>
> They convince economists who think that 'health projects are not economically productive'

Conceptual advantages

> They make planning more rational and goal-oriented
>
> They are invaluable for national and district health planning
>
> They teach us to understand the complexity of the situation

Aid agencies are reluctant to move away from the outcome-impact approach:

" ...as these types of evaluations are perceived to have political clout, despite the conceptual and methodological problems associated with them...this situation is an example of policy leading science, as opposed to science leading policy" P.134 (Schrettenbrunner & Harphan. 1992).

Problems of the outcome approach

By measuring project outcomes, evaluators are only looking at a part of the overall picture. Without asking 'how' an intervention works, or looking at what is actually going on within a project, the nature of what is being evaluated may be obscured or misunderstood (Robson. 1993).

Evaluation reports tend to focus on the situation only at the time of the evaluation, and do not assess the process of change which may be taking place, or may have taken place already.

2.2.3.2   The process approach

This type of evaluation deals more with the questions 'Why' and 'How', rather than 'What'. It is the systematic observation of the processes which occur within an intervention, the processes involved. Feuerstein (1986) states: "Knowing why a programme succeeds or fails is even more important than knowing it does.." P.7.

The changes associated with social development are not easily quantifiable. They have socio-economic, cultural and political dimensions, and can best be assessed when looking at the process of transformation (Schrettenbrunner & Harphan. 1992).

Scholars of social development emphasise the necessity of seeing evaluations as developmental and process-oriented rather than judgmental and product-oriented (Marsden & Oakley. 1990). They see the social development project as a process in itself, and they advocate for the evaluation to be seen as an organic part of that process. Moreover, Garaycochea (1990) argues that with process-orientated projects, it is often not possible or desirable to contrast 'before' and 'after' situations, because of the usual

absence of base-line data, and also because of its minimal relevance to projects of this

kind. The same author concludes that evaluation is about selecting the elements of a

project which best reflect its nature.

Process data are necessary for a more complete interpretation of intervention effects

(Marfo & Cook. 1992). In situations where statistical analysis indicates that treatment has

failed, process data become especially crucial because they can indicate the extent to

which the treatment failure may be related to conceptual, implementation, or

methodological problems (Weiss. 1972). The absence of process data is a constraint on the

generalisability and replicability of findings (Marfo & Kysela. 1985).

Problems of Process evaluation

Process evaluation in developing countries faces various problems. These are mostly

related to the definition of what is intended to be measured (McConachie. 1995). For

example, a review by O'Reilly (1988) of 33 measurement instruments used to assess the

relationship between social support and/or social network and health status, found only

modest agreement in conceptual definitions and frequently concepts were not defined at

all. The range of variables used to operationalise these concepts confirms the lack of

specificity and ambiguity in their definition. No data were reported on the validity and

reliability of these instruments, and the authors also highlighted the cultural

inappropriateness of the tools used (McConachie. 1995).

It is worth noting that developing measurements as 'process indicators' is not easy. Some

of the concepts which constitute the process of change are difficult to define and interpret;

community participation, empowerement, equity....etc. (Rutten-Woerdeman. 1995). For

example, Rifkin *et al* (1988) highlight the problems of finding measurements of the

process rather than the impact of community participation on health programmes,

especially the notion of participation which refers to a whole range of processes (Rifkin. 1986).

In situations where resources are limited and human suffering is involved, the most important evaluation question may pertain not to the establishment of cause-effect relationships, but to whether a particular problem has been ameliorated or not (Julian, Jones, & Deyo. 1995). Cohen and Kibel (1993) support this view and suggest that in complex, dynamic environments where both programme personnel and programme aims may be changing, evaluation questions relating to cause and effect are less important than those relating to impact.

However, although this approach to evaluation is well recognised and approved of by scholars, it has not been accepted by many of the donor agencies. Thus it seems likely that outcome-impact evaluation will continue to dominate in developing countries as long as the aid agencies who fund most health projects, continue to influence evaluation design (Schrettenbrunner & Harphan. 1992).

A mixed approach

A combination of process and outcome evaluations is advocated by many authors. Hughes, Cordray, and Spiker (1981) stress that whenever an outcome evaluation is conducted there is the need to also provide data regarding the implementation of the programme that led to the outcome. Biervliet (1979) further notes that for policy and decision makers, the issue of accountability requires the inclusion within the evaluation of some measure of a programme's effectiveness in relation to expenditure and manpower, and its success in comparison to alternative programmes with the same goals. The efficacy of a programme should be determined not merely on the basis of outcome measures but also on the relationship between process and outcome variables (Marfo & Kysela. 1985).

2.2.4 Long-term versus Short-term Evaluation

2.2.4.1 Short-term Evaluation

Short-term evaluations tend to be carried out in a period of between three to six weeks. This short duration limits the examination to the existing situation without any possibility of manipulation of the situation by the evaluators. It includes investigation of possible causal relationships by observing and analysing the current situation and then looking retrospectively at what might have caused any changes to occur. They are also called retrospective studies.

Short-term evaluation is a very useful exploratory tool, as it can give an indication of relationships between variables. It also enables a more rigorous style of research to be carried out in situations where it is impossible or impractical to directly manipulate independent variables. For example, it might be intended to investigate the possible reasons for disabled children being abused in a village where a CBR programme is implemented. Variables such as home environment, intelligence, type and severity of the disabling condition are attributes of the child that cannot be directly manipulated by the evaluator, but do not exclude the potential for searching out patterns of association.

Short-term evaluations tend to be less costly, require fewer resources, be more practical and provide the possibility of involving all the people concerned in a participatory way.

Problems of short-term evaluation

The central drawback of short-term evaluation is that it cannot prove the existence of causal relationships between variables (Cooke. 1989). Therefore, perceived outcomes cannot be ascribed in any reliable way to the programme being evaluated.

In addition, many other practical problems exist such as the pressure of time and deadlines. Participants may be difficult to contact or not available, either because they are busy or they are keeping themselves out of the way of the evaluators. People in power may be obstructive or may decide to alter the system or the context in important ways during the study (Robson. 1993). External problems can range from political incidents to weather conditions.

Another major problem of short-term evaluation, especially participatory evaluation, is the quality of the partnership relationship that is built. A real partnership which constitutes mutual trust and confidence takes a long time to build and requires careful nurturing in order to be sustained. Tandon (1990) believes:

> "To attempt a sudden, short-duration, quick-fix partnership during a limited-purpose social development evaluation exercise will be both unrealistic and difficult" P.99.

In short-term evaluation, building such trust could be part of the purpose or a result of the evaluation, but assuming its existence prior to the evaluation is unrealistic.

2.2.4.2 Long-term evaluation

Long-term evaluation allows for the careful design and implementation of a systematic monitoring and evaluation process throughout the course of a project. It allows the monitoring and evaluation process to be built into the project's organisational and implementation structure, and is undertaken as an ongoing activity during the lifetime of a project. "The process of continuous monitoring and evaluation negates the need for a rushed job at the end" P.111 (Verhagen. 1990). It also allows the impact of different phases of a project to be looked at separately from the overall effects.

Problems of long-term evaluation

Building relationships and alliances between the different groups in a project community is not easy. The process of shared evaluation is time-consuming and personal. "Trust and solidarity are not easy things to legislate for, and are usually built through individuals.... A common feature which might disrupt this development is the rapid turnover of staff, especially in Northern NGOs." P.12 (Marsden & Oakley. 1990)

To evaluate fully social development programmes, the process over the whole period of time must be considered "... and this requires more than a limited 'snap-shot'. Conventional retrospective evaluation, therefore, is not adequate" P.32 (Oakley. 1990).

2.2.5 Discussion and Conclusion

The type and style of evaluation which is most appropriate for use with a given project will vary across time, and will depend on the different interests within the project community. By using an assortment of different techniques a more complete picture of process and progress can be built. Through the successful combination and coordination of these different techniques, it should be possible to provide the information required by members of the project community, in response to changing circumstances at all levels (Marsden & Oakley. 1990).

With the emphasis on building trust, partnership and participation, the results of different evaluations should be made available to all parties and consolidated into a single text which forms the basis for action in the future(Marsden & Oakley. 1990).

All methods have their strengths and weakness, and recognising this leads to a preference for a multi-method approach (Robson. 1993). A combination of different evaluation models and methods could be the approach to CBR evaluation which best satisfies all the requirements. Several methods of inquiry are likely to be better than any single one in shedding light on an issue (Robson. 1993).

The participatory approach to evaluation on its own is very questionable, though it does have several merits which must not be overlooked. On the other hand, it seems that we cannot do without objective independent evaluation either. Results of a participatory approach can be used to complement the information obtained from an independent evaluation. Comparing the results could be very valuable in assessing the validity of

results, as well as the validity of the tools and methods used. This is in turn, could be a crucial indicator of the efficiency of the participatory evaluation for future use.

Furthermore, carrying out participatory evaluation after getting the results of an objective evaluation, provides a good opportunity for sharing and discussing both sets of results before taking decisions accordingly. Such a step could be highly useful for two reasons. Firstly, to involve the beneficiaries and make them feel that the evaluation research is part of their project, allowing them to learn and make use of the results for the benefit of the project. Secondly, to make them aware that their personal contributions are important. The existence of another evaluation that may support or contradict their opinions, may make them more cautious and more accurate in future participatory evaluations.

The quantitative approach to evaluation is considered to be the easiest in its application and assimilation at the local level, and is seen to provide the most convincing conclusions. However, we can not eliminate the qualitative approach, since there are many aspects of CBR programmes that cannot be explored or analysed except through qualitative methods. The apparent solution then would be the application of an evaluation approach that amalgamates both quantitative and qualitative methods accordingly.

Using the positive aspects of each method may solve the problem. For example, the controversial issue of comprehensive or selective evaluation could be solved in this way. Participatory evaluation has the advantage of being general enough to comprehensively cover all the aspects of a project, while the objective approach, can be used to investigate the prevalent problematic aspects, identified as a result of the participatory evaluation, in addition to the core, fundamental aspects of the projects.

With long-term and short-term evaluations, combining the two methods does not pose a problem, as they can be applied in parallel to the same project. Moreover, the results of a

series of short-term participatory evaluations can form a kind of long-term evaluation. In this way we can compare the results, and consequently the efficiency of both the objective long-term evaluation and the combined participatory short-term ones.

In summary, all methods have strengths and shortcomings, and in order to obtain information which is accurate and complete, a broad approach is needed. A complementary approach, where different methods serve to check and balance each other, would yield the most comprehensive results. This view of method combination is supported and well summarised by Broughton (1991); " This combination is especially powerful because each can then be used to assess and counteract the biases and shortcomings of the others" P. 463.

2.2.6 Model of 'satisfactory' evaluation research

In view of the conclusion drawn above, as stated earlier, only one study has attempted to evaluate a CBR programme in what can be considered a satisfactory way (O'Toole. 1988). The research study in question examines the relevance and effectiveness of a CBR project implemented in two rural areas of Guyana. The research attempts to answer the following questions:

- Does CBR produce meaningful change in children and their families?

- Do parents welcome the role of greater involvement in the child's rehabilitation?

- Is the recruitment of volunteers from the community a realistic way of introducing the programme?

- Is community involvement a realistic expectation?

- Is CBR cost-effective?

Two groups of home visitors were recruited; one comprised 26 volunteers from the community, and the other constituted 26 nursery teachers, to provide the services for 53 disabled children. A Multiple- Baseline Design was adopted to assess the child's progress. Children were assessed fortnightly using the Portage checklist during the intervention, as well as being assessed at a pre-, post- and 6 month follow-up stage, using the Griffiths Scales of Mental Development. The quantitative gains were balanced with a qualitative analysis of questionnaire and interview data. The intervention process was explored both quantitatively and qualitatively via the development of a battery of questionnaires and interviews to provide measures of the parent's perspectives. Measures used consisted of a standardised open-ended interview, in addition to an adapted form of the Malaise Inventory (Rutter, Tizard, & Whitmore. 1970), Self-Rating Scale (Judson & Burden. 1980), Child Rating Scale (Worchell & Worchell. 1961) and Sentence Completion Questionnaire (Thurston. 1960).

The Griffiths Test revealed significant changes for both groups of children at post-test and 6 month follow-up test. The analysis of Portage scores revealed similar progress. Under baseline conditions the overall gain was 0.67 items per month, per subtest, while under treatment conditions the figure rose to 1.95. However, the figure dropped to 1.02 items per month, per subtest, six month later at the follow-up.

The mothers observed changes in themselves, feeling more relaxed and confident, and less depressed. The changes were however more characteristics of the 'volunteer' mothers than the 'nursery' mothers.

Analysis of the results showed that the degree of child progress did not seem to be dependent on the educational level nor the financial resources of the parents, nor was it related to the degree of impairment. However, more progress was seen in physically and intellectually disabled children rather than in those with severe speech and hearing

problems. A more significant factor affecting child progress appeared to be parent involvement in the programme.

The work of the volunteers suggested that it is feasible to train persons from the community to work with disabled children. Furthermore, the volunteers were significantly more involved than the teachers. Finally, the cost of the programme, excluding the cost of the referral services, was £27.00 (or approximately US $48.00) per child, per year.

As mentioned in the previous review of CBR evaluation, and in view of the discussion earlier, this evaluation research can be considered a satisfactory model for a variety of reasons. The evaluation attempted to use an 'objective' multidimensional, multi-methods, longitudinal approach. A battery of measures was used to counter-balance the strengths and limitations of individual methods. More precisely, the research succeeded in combining quantitative and qualitative methods and measures, to give an overall view of the different dimensions of the programme.

The 'objectivity' of the research was ensured by using a set of well-developed and researched tools, some of them standardised, in addition to performing several independent and inter-observer reliability checks to avoid any sources of bias.

'Process' evaluation was achieved by investigating which of the intervention strategies facilitated the different areas of competence in the children and their families. Also examined were how families interact with the programme, and how the programme affects the parent-child interaction, and parent and child competence.

However, although considered satisfactory, no control groups were included in the research, thus the effects of the intervention were not controlled for. The emphasis was on evaluating the project in-depth, and so the chance to compare the adopted approach with alternative approaches was lost. Moreover, the attempt to address a number of ambitious questions in one study affected the degree to which some of them were answered. Not all questions were addressed equally well, although the selection of priority questions was useful. For example, questions concerning the programme effect in relation to child and family characteristics require a controlled comparative experimental design to be answered more precisely (Telzrow. 1993). Another example is the question of cost-effectiveness of the programme, which is a major issue in itself and requires a more sophisticated research design if it is to be answered properly.

2.3   Early Intervention for Disabled Children: A Review of Evaluation Trends.

During the last decade, some radical developments have occurred in the field of early intervention for disabled children. Instead of working only with the child, the new approach is family-centred and constitutes those practices defined by Murphy *et al* (1995), they "a) include families in decision-making, planning, assessment, and service delivery; b) develop services for the whole family and not just the child; c) are guided by families' priorities for goals and services; d) offer and respect families' choices regarding the level of their participation" P.25.

These developments have been reflected in the methods used in evaluation, and they contribute further to already existing similarities between CBR and early intervention programmes. Although not all the practices used in early intervention are relevant to CBR,

reviewing this well-researched and studied field could be a valuable starting point in the attempt to develop CBR evaluation strategies.

Early intervention programmes were first developed in the 1960s in the USA with projects such as Head Start (Zigler & Valentine. 1979). These early programmes worked with 'at risk' or socially deprived children. The reported success of the Head Start programme provided the impetus which led to a proliferation of early intervention programmes for disabled children in other western countries (Marfo & Kysela. 1985). Among these programmes was the well-known Portage scheme for developmentally delayed children, which was developed in Wisconsin in 1969 (Shearer & Shearer. 1972).

The 1970s and early 1980s witnessed a considerable number of studies attempting to evaluate the effectiveness of early intervention with disabled children, for example (Barna, Bidder, Gray, Clements, & Carner. 1982; Clements, Evans, Jones, Osborne, & Upton. 1982; Ludlow & Allen. 1979; Woods, Corney, & Pryee. 1984). The vast majority of these studies attempted to answer one question "Does early intervention work?". At this stage in the development of early intervention and its evaluation, the focus was on the children (Eayrs & Jones. 1991) rather than their surroundings. The various methodological problems associated with this approach are outlined and discussed in a number of review papers (Eayrs & Jones. 1991; Ferry. 1981; Harris. 1988; Shonkoff, Hauser Cram, Krauss, & Upshur. 1988; Sturmey & Crisp. 1986). They are summarised in the following discussion:

1) Narrow range of outcome measures

Most evaluations looked at changes in the child rather than a broader-based evaluation. Parent support and involvement in early intervention was not defined and measured in

terms of impact targets, and was difficult to evaluate due of lack of assessment tools (Bricker, Bailey, & Bruder. 1984).

Most measurements were carried out using standardised assessment tools, such as the Bayley Scales of Infant Development, the Griffiths Scales of Mental Development ....etc. Thus, the main outcome measures were changes in developmental quotient (DQ), intelligence quotient (IQ) or mental age (MA). Review papers highlight the common problems associated with using these standardised measures, especially relating to the inadequacy of focusing on a single outcome measure, and therefore possibly missing more subtle programme effects, as well as the poor correlation between some of these measures and social adjustment.

The alternative measure used to assess intelligence was 'Goals Set and Achieved', which is advocated by some authors (Harris. 1988). These are criterion-referenced outcome measures which depend mainly upon developmental goals. However, Eayrs (1991) and Sturmey & Crisp. (1986) stress the problems of reliability, as well as problems in determining equivalence of goal difficulty and the criteria for success in this form of measurement.

2) Lack of follow-up data

A frequent design problem identified in several publications is the absence of sufficient longitudinal follow-up data (Casto & Mastropieri. 1986; Eayrs & Jones. 1991; Ferry. 1981; Sturmey. 1991; Sturmey & Crisp. 1986). Follow-up data are essential to evaluate the maintenance of any developmental gains and the possibility of washout effects. Very few studies include follow-up information, and of those papers that do, the results have been disappointing (Aronson & Fallstrom. 1977; Ludlow & Allen. 1979; Sloper, Glenn, & Cunningham. 1986). Much of the existing evidence supports short-term gains (Aronson &

Fallstrom. 1977; Barna, Bidder, Gray, Clements, & Carner. 1982; Clements, Evans, Jones, Osborne, & Upton. 1982; Ludlow & Allen. 1979; Woods, Corney, & Pryee. 1984), but there is a lack of agreement about whether longer-term effects exist or not. There is also considerable variation in the periods of follow up, and a lack of consensus about what constitutes a valid length of time (Eayrs & Jones. 1991).

There is a lack of studies which report the relationship between predictor variables and long-term outcomes. One of the studies which does do this is a comparison of two groups of children receiving two- or eight-weekly home-visits over 3 years (Sandow & Clark. 1978). Results showed that children receiving two-weekly visits made greater gains than eight-weekly visited children in the first year; while during the second year, the eight-weekly visited children made greater gains than the two-weekly visited children. At three years, there was no significant difference between either of these two groups and a third control group.

The only long-term intervention studies which followed children for more than ten years, are those relating to the Head Start project, in which the initial follow-up showed the fade-out of initial IQ gains by the time disadvantaged children entered grade school (Bronfenbrenner. 1975; Ciccirreli. 1969). However, a later follow-up showed a number of long-term positive effects in the intervention group in terms of social outcomes, delinquency, etc. when compared with a control group (Berrueta-Clement, Schweinhart, Barnet, Epstein, & Weikart. 1984).

Marfo and Kysela (1985) state that the immediate programme impacts which can be demonstrated and evaluated by short-term evaluation are those seen by the interveners as secondary or mediator variables, such as: parental attitudes and coping skills; parent-child and overall family interactions; utilisation of relevant community support services; and parental instructional competence. He argues that it is upon these mediator variables that

ultimate child developmental progress rests and that immediate positive changes in the

child's environment will produce long-term developmental gains (Bronfenbrenner. 1975).

However, (Stoneman. 1989) points out some difficulties facing longitudinal studies. The

author highlights the need to use two assessment instruments at different ages to assess the

development of a child, while across instruments MA data are often not comparable. The

author also notes other problems arising from the inappropriate selection of MA

assessment tools.

3) Lack of Process measures

A further characteristic, which represents the most serious weakness of programme

evaluation in that period, is the almost complete lack of process measures in outcome

evaluations (Marfo & Cook. 1992; Mitchell. 1991). In Marfo's review of 20 evaluation

studies in five western countries, only two studies involved the collection of some form of

process data (Bricker & Dow. 1980; Hayden & Haring. 1977; Marfo & Kysela. 1985).

Bricker and Dow (1980) measured the degree of parental participation in the intervention,

while Hayden and Haring (1977) recorded classroom observations to monitor the

implementation procedures of a centre-based programme.

Examples of process measures that can be included in an evaluation were suggested by

Marfo and Cook (1992). They are duration of treatment, number of home visits, and the

extent to which visits focused on the child, parent , home, or all three. Also, measures of

the extent of parental commitment to programme routines, proportion of programme

components actually covered, as well as indices of the match between planned and

implemented activities.

Essentially, it should be noted that process-type evaluation involves the evaluation of a service relative to criteria of 'best practice'. Central to the successful working of this type of evaluation is the assumption that a general consensus exists about what constitutes good practice (Eayrs & Jones. 1991). Although obtaining a general consensus may appear difficult, a tool for the evaluation of early development projects has been developed by Mitchell (1991). It consists of 51 criteria which embrace both process and outcome variables, and in it programmes are rated on the extent to which these are met. This objective scale is considered a good criterion-referenced assessment, as it has clearly specified items, and instructions on the appropriate activities required to score each item (McConachie. 1995).

4) Lack of control group

The majority of evaluations of early intervention projects do not include a control group. Sturmey and Crisp (1986) noted in their review of outcome studies of Portage in the late 1970s and early 1980s, that only one of these studies included a control group (Clements *et al.* 1982). This means that the effects of normal development and the various non-specific effects of intervention are not controlled for. The lack of a control group weakens the study design and prevents it from being truly objective.

5) Lack of use of qualitative methods

Almost none of the studies used qualitative methods in their evaluation. One of the few that did is the evaluation of the parental involvement component in a centre-based project (Dale. 1992). Qualitative methods are crucial for gaining an understanding of variables such as parents' views of the intervention, or the views of non-participants.

Research questions

As mentioned earlier, the majority of the early intervention efficacy research studies in this period, attempted to answer the same question i.e. "does the programme work?". However, a limited number of other questions were also addressed, such as which children and families are most likely to benefit from this service in particular, and who should be assigned to other services that may better meet their needs and resources? Many studies reported significant differences in progress rates for certain types and levels of conditions (Barna, Bidder, Gray, Clements, & Carner. 1982; Bidder, Hewitt, & Gray. 1982), while one study looked at the intensity of the intervention (Sandow & Clark. 1978; Sandow, Clarke, Cox, & Steward. 1981). Some studies also showed the possibility of predicting child outcomes from a wide range of family variables, for example maternal education (Cullen & et al. 1981), education in behavioural principles (Clark, Baker, & Heifetz. 1982; Dumas & Whaler. 1983), and socio-economic class (Dumas & Whaler. 1983) as predictors of child skill gains.

Recent development of early intervention services for disabled children

The gradual move during the early 1980s from a child-centered approach to a more family oriented approach, was a natural result of the desire to work in partnership with parents (Mittler, Mittler, & McConachie. 1986) and increase the involvement and participation of the families in programmes. However, "outcome measures employed to assess the efficacy of early intervention have not reflected the wide range of goals suggested in the theoretical and conceptual literature" P.321 (Marfo & Kysela. 1985).

The second half of the 1980s witnessed a critical analysis of the early intervention efficacy research (Dunst. 1986; Eayrs & Jones. 1991; Gibson & Harris. 1988; Marfo & Kysela. 1985) . This resulted in the labelling of the studies at this point in time as *'first generation*

efficacy research' (Guralnick. 1989; Marfo & Cook. 1992). With the end of this decade came a conscious recognition of the inadequacy of using developmental gains as the predominant dependent variable. Other variables relating to child social integration, personality development, parental satisfaction and well-being, uptake of other services etc., were advocated as being equally, if not more important (Eayrs & Jones. 1991; Ferry. 1981). Moreover, (Cunningham. 1986) suggests that the focus of early intervention has to move away from 'behavioural products' towards 'family support'. In other words, it was acknowledged that research must go beyond the traditional question of 'does it work?' to examine the manner in which specific dimensions of the intervention process contribute to the observed intervention outcomes (Dunst. 1986; Fewell & Vadasy. 1987).

The objectives of the *'first generation efficacy* research' were driven by financial and political influences. The impressive number of studies and reviews which concentrated particularly on efficacy research conducted up until the mid-1980s, tended to "demonstrate to funders and policy makers that continued fiscal support and possible expansion of services are justified" P.20 (Marfo & Cook. 1992). The survival or expansion of early intervention services was perceived to hinge on the outcomes of efficacy research.

This stage ended with the advent of the Public Law 94-142, and 99-457. Early intervention services became an established integral part of publicly supported human services (Marfo & Cook. 1992). Thus research was less affected by political power and more directed to generating data that would lead to the development of more effective models and to improving the quality of intervention.

In the 1990s, new state and federal initiatives have put pressure on local programmes to change established practices and become more family-centered (Murphy, Lee, Turnbull, & Turbiville. 1995; Simeonsson & Bailey. 1992). For example, part H of the Individuals with Disabilities Education Act (IDEA) states that families should direct assessment, be

included in planning and implementation of all the requirements of part H, and even be

compensated when performing official business as members of state coordinating councils

(Public Law 102-119, 1991). One of the implications of this new emphasis is that

programmes must be able to monitor and document the ways in which they include

families (Murphy, Lee, Turnbull, & Turbiville. 1995). Therefore, in order to measure a

programme's use of family-centred practice accurately, there was a need to develop

evaluation instruments which reflect a clear definition of such practices, and can measure

how, and how well, families are included in programmes (White, Taylor, & Moss. 1992).

Impact of the new trend in early intervention on its evaluation

As a result of this new trend in service provision in early intervention programmes and the

move to maximise the benefits for both the child and the family, evaluation has moved

away from assessing only child outcomes towards the evaluation of complex services.

Thus research no longer relies exclusively on empirical data but combines both

quantitative and qualitative methodologies. In addition to this is the recognition of the

importance of full involvement of parents or caregivers in each stage of the evaluation

(Eayrs & Jones. 1991).

Evaluation now includes among its outcome variables the extent to which the service meet

the family needs, i.e. parent and family outcomes, such as parental satisfaction with the

programme, parental interaction style, parental coping strategies and family well-being

(Marfo & Dinero. 1991).

Moreover, many instruments have been developed over the past decade to assess the

various aspects of this new family-centred approach. Among the widely used instruments

are: the Short-Form of the Questionnaire on Resources and Stress (Friedrich, Greenberg,

& Crnic. 1983), the HOME Inventory (Caldwell & Bradley. 1984), the Family Support

Scale (Dunst, Jenkins, & Trivette. 1984) etc. However, only a few have published reports

describing the instruments' psychometric properties, for example (Mahoney, Sullivan, &

Dennebaum. 1990; Murphy & Lee. 1991).

Several variables have emerged as important determinants of programme efficacy. They

include the following: extent of parental involvement; locale of intervention (home-based

versus centre-based); programme duration and/or intensity; intervener training; the timing

of implementation (early versus late), and variety and frequency of accessing other

services (Marfo & Cook. 1992).

Therefore, the types of questions mostly asked in *'second generation early intervention

efficacy research'* is summarised by Shonkoff *et al.* (1988) as follows:

> 'What kinds of services have what kinds of impacts on which kinds of children in
> which kinds of families?'.

In other words, programme evaluation is not concerned exclusively with demonstrating

whether a programme works or not, but also with *how* a programme makes its impact.

Studies reflecting the new trends in evaluation of early intervention

There are two outstanding research studies published in the 1990s, which represent the

few recent attempts at what is described as *'second generation early intervention efficacy

research'*. One of these studies evaluates an intervention that occurred during the time of

the research, while the second uses the results of a project plus some additional data

gathered after the intervention. They were selected because they illustrate the new

approach to early intervention evaluation, because they involve children with intellectual

disabilities, the duration of the intervention is more than a year and the intervention is

home-based.

The first study (Marfo & Dinero. 1992) attempts to examine the question: What

mechanisms determine or influence the outcomes of early intervention? More specifically,

it looks at the combined influence of three classes of variables relating to the child, the

programme, and the family, on (1) child developmental outcomes (defined in terms of

post-intervention developmental age and rate of developmental outcomes), and (2)

parental satisfaction with the intervention process and its perceived impact on the child.

Examples of child independent variables were: chronological age, developmental level,

nature and severity of disability. Family variables included demographic characteristics

such as family income, parents' education, and parents' age, expectations of the child,

family resources, and quality of home environments. Programme variables were: time

spent in the intervention, parent satisfaction with the programme, parent knowledge gain,

and parent perception of work competence.

Various assessment tools were used, such as the Alpern-Boll Developmental Profile

(Alpern & Boll. 1972), the Parent Evaluation Questionnaire {PEQ} (Marfo, Browne,

Gallant, Smyth, Corbett, & McLennon. 1988), the Child Expectations Scale {CES}, the

Family Resource Scale {FRS} (Leet & Dunst. 1985), and the Home Screening

Questionnaire {HSQ} (Coons, Gay, Fandal, ker, & Frankenburg. 1981). Two hundred

families were involved in the study with no control group.

Multiple regression analysis showed that the variables relating to the child and the family

exerted a much stronger influence on the outcomes than those relating to the programme.

Of these, the child variables exerted the strongest influence. The child entry-level

characteristics exerted a stronger influence than all the other variables in the prediction of eventual child developmental level.

Family variables were the next most important after child attributes, in the prediction of child outcomes. Parental expectations and the quality of the child's home environment contributed significantly to the prediction of positive outcomes. Hence, it is suggested that within the constraints placed on developmental outcome by the child's level of competence at programme entry, these two variables should be given serious consideration in the design, delivery, and evaluation of programmes.

Marfo and Dinero (1991) suggest the addition of another class of variables pertaining to the utilisation of other medical, psychological, and social services outside the intervention programme, such as the variety of other services accessed, and the frequency of accessing

These findings suggest that evaluation of early intervention should incorporate all these sets of variables in order to understand the complexity of the processes and the outcomes of intervention more completely.

The second study (Davis & Rushton. 1991) described the evaluation of a home-based, family-focused counselling intervention, providing support for 31 English-speaking and 16 Bangladeshi families of children with intellectual or multiple disabilities in a deprived area of London. The study investigated the hypothesis that counselling support facilitates general parent adaptation and that this is reflected in improved adaptation of the child with disabilities.

The model adopted in this intervention used personal construct psychology as the framework for understanding how families can come to adapt to the circumstances -

emotional, material and financial - in which they find themselves. It is proposed that if the parents feel more supported, they will construe themselves more positively, and this will be reflected in their ability to cope with the situation confronting them, and will lead them to perceive their child and their partner more positively. As a result of such changes, the child's social environment for development will be enhanced. The parent advisors were mostly professionals already involved with the families of children with impairments and a local Bangladeshi mother. The team received special training so that they could offer psycho-social support.

In this well-controlled study, the mothers and children in the intervention groups showed significant positive changes compared to those receiving the usual services from the local child development team. Mothers changed positively in their rating of perceived support and family functioning, and in their constructions about their child, themselves, their husbands and family relationships. Although systematic teaching was not included, their children also showed improvements in developmental progress and behaviour problems. The programme was especially successful for the more deprived and initially less well-supported Bangladeshi-origin mothers.

Study analysis in view of controversial methodological issues

It is instructive at this point to analyse the two studies described above in view of the four controversial issues discussed earlier in the review of CBR evaluation.

With regard to the first issue i.e. the participatory versus the objective approach to evaluation, we can see that the latter dominates the efficacy research in early intervention. This trend is illustrated in the two studies described above, where independent researchers gathered all the data using some well-developed assessment tools and a considerable number of standardised tests. Sound statistical methods were used to analyse the data and

draw conclusions from the results. The second study in particular, gained additional

validity by adopting a controlled comparative experimental design, where the effects of

alternative types of programmes were compared by using a pre/post-test approach (White.

1993).

On the other hand, there is very little of the participatory approach to be seen in these

early intervention studies. Parents or caregivers were neither included in the design of

evaluation research, nor in the analysis of the results. They were not involved in collecting

data from other parents except when considered as an interveners and after formal

training, as was the case in the second study with a local Bangladeshi mother who was

recruited to join the team. In general, parents only participated by answering the

questionnaires and filling out forms.

With respect to the qualitative versus quantitative issue, both studies looked beyond the

traditional question of whether the programme works, to what makes the programme

work better and even how the intervention works. Although qualitative methods were not

used in both researches, the two studies represent a satisfactory attempt to seek out

qualitative information using quantitative methods.

Both process and outcome measures were elaborated in the studies, as the first one

examined the effect of the three classes of variables related to child, programme and family

upon prediction of outcomes; while the second research was mainly investigating the effect

of counselling and supporting parents on the parents themselves as well as on their

disabled children.

As for the duration of the evaluations, neither of them can be considered as long-term. The

first evaluation study, despite the availability of pre- and post- intervention developmental

data from programme records, cannot be considered as satisfactory longitudinal research

due to two constraints: first, the instrument used to obtain the data, the Alpern-Boll

Developmental Profile (Alpern & Boll. 1972), does not have strong psychometric

properties. Second, the family variables were gathered concurrently with post-intervention

developmental measures; thus the authors have to assume that these variables are

relatively stable when using them to predict intervention outcomes (Marfo & Dinero.

1992). The second piece of research must be considered to be a short-term study as the

average duration between the pre- and post- intervention assessments was around 15

months.

Summary and conclusion

The review of the current research designs for evaluation of early intervention has revealed the domination of the 'non-participatory' objective approach. Quantitative methods are used to assess a wide range of programme outcomes not solely child progress. In recent years evaluation has focused on the extent to which services meet family needs in terms of parental satisfaction with the programme, their coping strategies, the extent of support available, etc. A large number of new assessment tools have been developed during the last decade. In addition there have also been a few attempts to include qualitative and process evaluation.

The predominant approach thus differs from the picture revealed on reviewing the literature concerning the evaluation of social development projects. The conclusion drawn from the latter recommended adoption of a mixed evaluation approach to balance the strengths and shortcomings of each method, and to produce a comprehensive overview.

However, before deciding on the approach to be adopted for the current study, it is of crucial importance to discuss options in the light of the current stage of development of CBR.

2.4 The implication of the current development stage of CBR for evaluation methods.

The general conclusions concerning the evaluation of CBR must at this point be examined and refined in the light of the current stage of development of CBR. What is needed in evaluation at the present time may not reflect exactly the recommendations as outlined above.

Research and evaluation should always be flexible, appropriate, practical and responsive to changing needs rather than static and theoretical. The following discussion will cover the problems and constraints which make certain approaches more appropriate than others for evaluation of CBR in this particular stage of its development:

1- One of the key issues relating to the efficiency of CBR is the **involvement of professionals**. During the development of CBR in the early eighties, the involvement of professionals and specialised centres at all levels of a CBR programme was stressed as being important. Later development showed that programme success and sustainability are difficult to achieve without the back up and support of professionals (Helander. 1993; Werner. 1995).

However, nowadays it appears that the extent of professionals' involvement is more marginal. Although CBR advocates for the mobilisation of existing resources at all levels, hardly any success has been achieved in mobilising one major resource, i.e. the professional and specialised institutions. The majority are still 'locked into' the centre-based approach.

If we accept that one of the best ways to expand and to improve the quality of CBR is to fully mobilise and involve the professionals and their institutions at all programme levels, then we must adopt a different approach to convince them. Specialists will have to be convinced by the same means and methods that they use to advance their knowledge and skills. Professionals will only be convinced when presented with the results of research which is carefully and systematically designed, or high quality articles in scientific journals.

Most CBR literature is in the form of newsletters and booklets for the people involved. The fact that most CBR evaluation literature is unpublished or simplified, may increase the belief among professionals that the CBR approach is not built on a scientific basis and can never replace the centre-based approach.

Despite the general acceptance of qualitative research methods and their benefits in evaluation among professionals working in the wider development field, they are not yet recognised by more traditional professionals in developing countries. The majority still advocate objective quantitative methods. As many difficulties may be encountered when trying to demonstrate to professionals and decision makers the effectiveness of CBR programmes, quantitative approaches are currently seen to be crucial for providing 'hard' (and therefore presumably more convincing) evidence.

Quantitative results are easily communicated and understood, and can be more persuasive at all levels. This is especially true among health professionals on whom the success of the referral system depends, and who place more weight on impact measures (Schrettenbrunner & Harphan. 1992).

The same principle can also be applied to other concerned bodies within a project community: governmental officers, decision-makers, disabled people and the parents of disabled children may all be better mobilised if shown convincing scientific evidence of CBR's success.

2- The majority of CBR programmes are still in their 'conception' phase and although their project communities are taking steps towards independence and sustainability, this is not yet completed. Due to factors discussed earlier, participatory evaluation at this stage in the development of CBR should be seen as an intervention in itself (Tandon. 1990): a learning exercise for the project community, an empowering intervention and a management tool for the local people. It should be considered an integral component of the intervention, necessary to understand and improve the process rather than a method to evaluate the intervention in itself.

However, **depending on only *full participatory* methods of evaluation should be rejected** until democratisation and the necessary knowledge and experience of participants are available (AGKED and MISEREOR. 1991), and most importantly until self-finance has been achieved. Partnership in evaluation can be attained only when beneficiaries start to perceive the importance of evaluation and begin the process themselves (Verhagen. 1990). Suggestions about how partnership and mutual dialogue can be fostered in contexts where partners are unequal are made in Kelly and Van Vlaenderen (1996).

Therefore, at the current stage of CBR development, participation, as suggested by some of the rapid appraisal studies (Chambers, Pacey, & Thrupp. 1989) should be seen functional to the evaluation, assisting the evaluation team to determine whether the project succeeded or not and to come to a final decision. Its inclusion is essential if evaluation is to account fully for the qualitative changes that may or may not have taken place.

Recognising the limitations of an evaluation is perhaps more acceptable than pretending a full participatory approach is being used. The review of 19 CBR evaluation reports (Rutten-Woerdeman. 1995) revealed the inappropriateness of describing the evaluation as participatory when the project participants were only answering the questions of the evaluator, or being a guide to the evaluator. Very often programme beneficiaries are marginalised and the evaluation findings and recommendations are not used, thus making no significant impact on the programme's developmental cycle.

3- There is no universal approach to CBR implementation, and its strength lies in its flexibility and ability to respond to specific settings. The question faced by every project implementor and decision-maker is: what is the best approach for setting up a CBR programme in our particular situation? Very little objective evidence is available to suggest that any one approach produces better outcomes than another (O'Toole & McConkey. 1995). Hence, decisions have to be based on opinions and beliefs which are necessarily subjective.

Each different approach to CBR should be evaluated on the basis of *comparison* rather than looking in depth at one project in isolation of its surroundings; thus innovations need to be compared to traditional approaches in order to prove their relative effectiveness.

The external evaluator, in order to assess the position of a project in its sociological context should seek out a diverse range of information sources, contact other organisations and seek opinions and comparisons, rather than being restricted to the local organisation as the only source of information (Verhagen. 1990).

The evaluation process itself should provide some degree of comparison, so that people can gain a more distanced view. By considering their own project in a wider context they can achieve greater understanding of the processes in which they are engaged (Garaycochea. 1990).

Comparisons can also act as a powerful means to convince professionals and decision makers about CBR. They are easy to understand and to communicate to others.

4- In view of the lack of attempts to evaluate CBR at all levels, especially the local level, the current stage in the development of CBR urgently requires *simplified but rigorous evaluation methods and tools, for use at the local level.*

In this situation, models of quantitative methods are strongly recommended because of their potential simplicity and straightforward application by CBR workers. This is in contrast to formal qualitative methods which at this stage are confined to a limited number of experts and skilled academics, and are difficult to adapt especially when comparison is needed.

At the moment, professionals are required to select and adapt appropriate tools for evaluation, or to develop new ones. They have to face the challenge of finding more simplified but reliable and valid tools. Moreover, they must recognise the further challenge of quantifying the qualitative aspect of the evaluation so that local people can assess some of those aspects which are presently confined to skilled external evaluators.

In the future, as CBR programmes mature, the local workers will have the expertise to use qualitative methods, but this process is expected to take a long time.

5- Quantitative, objective evaluation approaches evolved before the qualitative, participatory ones. This is the normal development of scientific oriented evaluation research, with the former method answering the basic, essential questions and the latter emerging in response to it.

This development of evaluation methods, upgrading and refining over time, has enriched our knowledge of evaluation in general, as well as of the projects that have been

evaluated. But this progression must be constructed and based on what has gone before, i.e. results from traditional preliminary research findings.

In a new research field like CBR, there is a need to go through the same developmental, evaluation stages as any other research field. Independent, objective and quantitative research methods will answer some of the most urgent questions and will be considered the basis for further development of evaluation methods. This approach is appropriate for the high-priority questions that exist in this current stage in the development of CBR.

CBR is still in its evolving stage, and it has to be scientifically evaluated in its different contexts and settings, in order to study its processes and impacts. Research and evaluation are crucial in order to increase the efficacy and efficiency of CBR programmes.

2.5 Conclusion

It is interesting to note the degree to which current research designs for early intervention evaluation concur with the theoretically desirable characteristics outlined above. After considering the present phase of development of CBR, and reviewing the literature on CBR, social development and early intervention projects, it is possible to conclude what is required of a CBR evaluation study.

The evaluation should compare the intended CBR programme with others similar programmes or with those adopting different approaches. For that purpose it must utilise a quantitative approach, with a longitudinal research design to allow for objectivity, and a wider range of outcome measures than just those relating to child development. These should include in particular outcomes that reflect the impact of a programme on families, and the way that they cope with their disabled child.

To strengthen the design further would require the inclusion of process evaluation,

focusing on the programme characteristics which make one programme work better than

another, especially those factors which lead to better outcomes for the families.

Finally, it is worth mentioning the conclusions of some recent publications on the

evaluation of early intervention for disabled children which strongly support the approach

to be adopted for the evaluation of CBR in this study. The authors of these publications

(Innocenti, Hollinger, Escobar, & White. 1993; Taylor, White, & Kusmierek. 1993;

Telzrow. 1993; White. 1993) have advocated the use of scientific methods, in well-

controlled, longitudinal (Casto & White. 1993), systematically designed research that

compares the effects and costs of alternative types of programmes [examples include

(Innocenti, Hollinger, Escobar, & White. 1993; Taylor, White, & Kusmierek. 1993)].

They consider this *comparative approach to evaluation* one of the most important tools

for improving the quality of early intervention programmes for children with disabilities

and their families.

3. Chapter Three: Research Methodology

This study is a comparative evaluation of three different approaches to the provision of rehabilitation services for disabled children in Egypt. It concerns three Early Intervention projects in the slum areas of Alexandria and Cairo. The study attempts to fulfil the evaluation requirements outlined in the previous literature review. It has a quantitative, objective, longitudinal design, and considers a wide range of outcomes.

3.1   Setting

The areas served are characterised by low-cost housing with a very high density of population. All projects have young developmentally disabled children as their target population. The three projects were initiated and supervised by the Caritas-SETI Centre, adopting different strategies in an attempt to determine the most appropriate for use in Egypt.

The first project uses Mother and Child Health (**MCH**) professionals to advise parents. The second one is an **Outreach** project and the third one is a Community Based Rehabilitation (**CBR**) project. The families were involved in one of the three projects for one year.

The MCH project is a centre based one which provides one training session per week to every child, who is normally accompanied by his/her care giver. The aim of the project is to offer some professional services to the children as well as to demonstrate how teaching activities could be implemented at home.

In contrast, children and parents on the **Outreach project** receive services in the form of weekly home visits, the majority of which are carried out by the professional team of SETI. The SETI staff assess the children and specify the educational and developmental programme which should be followed by family members during the week. In addition disabled children benefit from vocational training, provision of aids and equipment, as well as a weekly club and classes run by mothers and volunteers, but directed by SETI staff.

The CBR project is particularly concerned with involving parents in the assessment of their child, and with the design and teaching of the programme used. Moreover, the project aims to mobilise and later to rely on community resources to take on the responsibility of providing services and the necessary support to parents after the partial withdrawal of the professionals from the project. The programme aims specifically to achieve the maximum extent of *parental and local community independence* by the end of the intervention (twelve months in this study). The support of the professionals during the follow up period is confined to the backup, training and referral services.

The CBR project provides the same type of services as mentioned in the Outreach programme, with the difference that it depends mainly on local resources to provide services and it promotes more parental involvement. Therefore, the weekly home visits are conducted by local staff who are either community workers or MCH staff. The educational and developmental activities are jointly decided by parents and the home visitor. Weekly clubs, classes and outings are organised by local staff, volunteers and parents with a minimal support from SETI staff. Children who need more specialised services are referred through the local MCH centre which is managing the whole project with a local steering committee. Additional summer camps are organised mainly by SETI staff and funded through them as well.

3.2 Aims and Objectives

The aim of this research is to compare the efficacy of three early intervention programmes adopting though a controlled pre-test / post-test design.

1) The outcomes of the CBR project will be better than the MCH and the Outreach

    programmes in terms of children's progress and the development of positive parental

    attitudes, and satisfaction with social support received by parents.

2) Parents will be more involved in teaching their young intellectually disabled children

    when the educational and developmental programme is designed according to their

    priorities rather than imposed by professionals.

3) The outcomes of the CBR project can be maintained independently (through parents

    and the support of their local community), for a period of six months after the

    withdrawal of home visitors if the intervention is structured and designed to reach that

    aim within one year. The outcomes examined will be in term of child progress, positive

    parental attitudes, and the amount of perceived support from the local community.

3.3 Subjects

The target group for this research is disabled children and their families. The children included were intellectually disabled, aged between two and twelve years old. The study also included some children with additional physical disabilities but excluded those who could not at least hold objects in their hands, as the Griffiths test is inappropriate for them.

As research similar to this study has not previously been conducted in the CBR field, there was no basis from which to calculate the sample size needed to demonstrate statistically valid group differences. Thus the sample size was eventually decided upon in the light of the only other similar research in early intervention with disabled children. In accordance with the Tower Hamlets study (Davis & Rushton. 1991), the present study had groups of around 26 subjects, and this was expected to be sufficient to indicate the effects hypothesised.

Selection

Random selection was not feasible, as the Outreach group was part of an on-going project which had been serving the area for more than two years. To compare the effect of the intervention across all the groups equally, it was crucial to identify and recruit newcomers in the Outreach programme as the CBR and MCH groups had not previously received any sort of service or intervention. Therefore, the Outreach experimental population was very restricted, and nearly all newcomers who fitted into the inclusion criteria were included. In order to make the other groups comparable to the Outreach group, it was necessary to use the characteristics of this group as the basis for the matching process.

Group Matching

Groups were matched on the variables that were thought to be the most relevant to the outcome of the study, i.e. to contain a spectrum of disability, a balance of the sexes and a spread of ages. Matching the exact number of children with cerebral palsy among the groups was impossible due to its relatively low incidence in the population.

As both the CBR and the MCH were in their initial phase during the implementation of the field work, it was decided by the programme management team to restrict the number of children served in the initial phase to the first 40 children in the two projects. Of these only 29 children in the CBR project and 31 children in the MCH project met the inclusion criteria and were included in the research.

A partial selection of the CBR, MCH and Control groups occurred near the end of the recruitment phase so that they could be matched with the characteristics of the Outreach sample. Three children were recruited at a later stage in the CBR project for matching purposes, two with cerebral palsy, as one of the three children with cerebral palsy in the initial group had dropped out during the first month of the intervention. Also two children aged 10 and 11 years old were recruited later because the average age of the original group was slightly below that of the Outreach group.

Recruitment

Recruitment was carried out using the following strategies:

1. Newcomers to the Outreach programme were recruited from their waiting list, as well as through the expansion of the project, to serve a wider geographical area than before.

2. Identified families were asked to nominate other families who have a child with an intellectual disability.

3. A large proportion of the CBR and MCH families were already beneficiaries of the MCH health services. These services included health education, monitoring and follow-up for pregnant woman, immunisation, medical treatment as well as some social services.

4. All projects were advertised through local pharmacies, mosques, churches and by word of mouth among parents of disabled children.

Table 2. Breakdown of methods of subject recruitment.

	CBR	Outreach	MCH	Control
Referral by professionals	2	7	10	12 (including 6 MCH project dropouts)
Referral by parents	7	9	3	2
Media	2	-	-	-
Mosques and churches	4	8	-	-
Schools waiting list	2	-	4	3
Identified within MCH	10	-	8	11
Total	**27**	**24**	**25**	**28**

Control group

The control group was selected from children living in similar slums and with the same level of disability. They were also comparable to the subjects included in the programmes in their type of disability, age and sex. The control group was selected mainly from two sources:

1) Children who were on waiting lists at the time of initiating the project and who would not be receiving any service for a year. The majority of this group came from the waiting list of the MCH project as there was no prospect of expanding the number of beneficiaries in the following year. A few children who were on the CBR waiting list and living out of the geographical area served by the project were also included. In fact, including these children in the research placed them on the priority list and will have speeded up their opportunities of receiving services when the programme expanded to their area.

2) The dropouts from the MCH group. As quite a number of the MCH group were expected to drop out during the intervention period, it was designed to over recruit at the beginning and to record the MCH dropouts results with the non-intervention control group.
Thus the analysis is not one of 'intention to treat', which would keep the dropouts in the MCH group for eventual analysis, but it is a 'treatment received' analysis.

Dropout

Two children from the outreach programme dropped out, due to parental dissatisfaction with the programme. Two other children dropped out of the CBR programme, one child with cerebral palsy, due to parental dissatisfaction with the programme, and the other due to mother's death and moving to live with an older sister in another district. Six children dropped out from the MCH project within the first six weeks of its implementation, three due to parental dissatisfaction that the programme did not meet their expectation, and three due to long distance and transportation problems as they had to carry their children.

3.4 Sociological context

The study uses a stratified group matching strategy to equate the groups of families involved in the research. The research design is further strengthened by restricting the sampling frame to a limited population, only recruiting families from areas characterised by low socio-economic status. It should be noted that the two slum areas of the Outreach and CBR programme are small in surface area and have a very high population density, which is not the case for the two other groups.

The Outreach area is one of the most tense areas of Cairo due to a previous religious confrontation between the Muslim majority and the Christian minority. This means that there is greater influence from the mosques and churches on the participants, in comparison to other projects areas. The religious beliefs of some of the families greatly affected their attitudes and behaviours towards their disabled children. For example, a Muslim child was considered a 'blessing'. He was very welcomed and loved by his family members as well as the neighbours. Another Christian family considered their disabled child to be their 'cross', which they had to carry all their life. As a result this child was also well-accepted within the family, and benefited from the caring attitude shown by all the family members.

The CBR slum area, Karmouz, is believed to be the most hostile and aggressive area in Alexandria, with the highest crime rate and level of drug abuse. The area has the highest population density in the city, with very narrow disorganised streets which attract underworld elements, causing the area to be unsafe. This situation created a reluctance among some parents to mix with others or to open their houses to an unknown person. It might also have caused an overprotective attitude among some parents, who at the beginning of the project did not even like their child going to the nearby shops alone.

However the areas from which the research subjects are drawn are judged to be more alike than different, and no cause of bias in parental attitudes is expected.

Evaluating parent commitment

Recruitment for all the groups was done using the same procedures. This was mainly advertising the services through different media and recruiting all comers who fitted the inclusion criteria. Even families nominated by other parents were not visited with an offer of service, but were expected to hear about the programme from other parents and to ask to participate in the programmes. It was thought that parents' asking for the service would guarantee the selection of motivated parents, who in turn would contribute more towards the success of the innovations, especially during the initial pilot phase of the CBR and the MCH projects.

The outreach project did include a small number of families who had been on the waiting list for one to three months, but the majority of families were recruited from the newly served area and had never heard about the programme before. Therefore a difference in level of enthusiasm for the project was not expected.

It was very difficult to assess the degree of *initial* commitment of parents to the different programmes, as nearly all parents who were approached by other parents or had heard about the services showed great willingness to take part in the programme. With the outreach programme this was because services were offered at home and no extra demands were put on from parents. On the other hand, parents of the MCH and the majority of the control groups had been asked to come on a weekly basis to the centre, which was a very demanding task for many of them, as this meant going out regularly with their children in public, maybe even carrying them, and struggle with the local transport.

Therefore, parents of the MCH and control groups could be seen as having been more motivated and committed to take part in the programme, although a few weeks after their enrolment, the parents of the two other groups were also requested to attend a weekly club with their children. The same request was made of the MCH groups four months after the

beginning of the intervention but on a fortnightly basis, and then from the eighth month on a weekly basis. Therefore, it was assumed that parents in all groups were equally enthuthiastic and committed to the programmes, and no major differences existed between the groups that might affect the results.

The six dropouts of the MCH group who were added to the control group, could have caused a decline in the level of parent enthusiasm and motivation in that group in comparison to the other groups. Consequently, child progress and other outcome measures could have been affected, therefore a conservative approach will be adopted in interpreting significance levels of obtained differences between the control group and the three intervention groups.

3.5 Measures and Procedures

3.5.1 Independent Variables

1. Age

All the children included in the study were aged between two and twelve years at the beginning of the intervention. The exact age of the majority of children was known from their birth certificate. However a small minority did not have their certificates for various reasons, and the age of these children was reported by parents or records from the MCH or other health centres.

Each group of children was split into three subgroups according to age. The first group constituted the children aged between two and five years, the second included children from five to nine years, and the third from nine to twelve years old.

2. Gender

3. Parental age

Mother and father ages were recorded through parent reporting. If not known by parents, the birth certificate was used. It was thought that parental ages could have some influence on parental attitude and behaviour towards their children, especially if the child had been born when the parents were getting old and was more likely to have been unexpected or unwanted.

4. Mother education

Mothers were classified into three categories according to their educational level. The first category was made up of illiterate mothers, the second included mothers who knew at least how to read and write, and the third constituted mothers who had finished their high school education. This information was collected by interviewing the mothers.

5. Birth order and number of disabled siblings

Birth order was seen as one of the important items of demographic data to be collected. It might affect the level of involvement of family members in sharing the responsibility for the disabled child. It might also affect the marital relationship, and parental attitudes towards the disabled child . For example, one father in the MCH group had re-married a year after his first wife had given birth to their disabled child, and was not attempting to have another child with her as he thought she was the cause. Having more than one disabled child in a family may produce a similar effect, therefore the number of disabled siblings was collected for a subanalysis of this group of families.

6. Aetiology and additional disabilities

All children included in the study were intellectually disabled. Not all of them were professionally assessed or diagnosed, as it was against the project policy to refer any child for an intelligence test. Getting the label of intellectually disability through a non-standardised test usually conducted by non-experienced psychologists would have more damaging effects than benefits. The fact that mildly intellectually disabled children in deprived areas are not usually noticed, and integrate well into their society, made the management team reluctant to refer any child to an assessment centre. Only moderately or severely intellectually disabled children are easily recognised by their family members, neighbours, relatives and MCH staff, and only these

children were therefore referred to the project. This approach to identifying the target group proved to be very efficient. All the children referred to the project and assessed by both the researcher and the independent evaluator, were later found to have a development quotient of less than 50.

All children included in the study were referred for medical assessment and diagnosis. 14% of the overall number of the intellectually disabled children in the study have additional cerebral palsy, 31% epilepsy, 27% Down's syndrome, 13% speech problems, 5% physical, and 10% were undiagnosed. There were no difference between the groups in extent of additional disabilities.

3.5.2   Dependent Variables

3.5.2.1   Child developmental level

Procedures

Children's progress was assessed using the Griffiths Mental Developmental Scales (Griffiths. 1954)and the Receptive-Expressive Emergent Language Scale (REEL) (Bzoch & League. 1971). The speech scale of the Griffiths test is not suitable for non-English speakers, so the REEL was used instead to measure communication and language development. The Practical Reasoning Scale was also excluded from the Griffiths test as it depends heavily on spoken language.

The Griffiths scales were initially designed to enable a detailed differential diagnosis of mental status in disabled children in addition to measuring general ability in non-disabled infants. The test provides a detailed profile of six skill areas and offers a sensitive evaluation of the

developmental progress of the child. The test was standardised on a sample of 2,260 children (Griffiths. 1970), constituting a representative crosss-section of the British population.

As emphasised by many authors (Powell. 1989), most tests require the scorer to make judgements both during administration and scoring, which are subject to personal bias. The Griffiths test was specifically selected for its extensive and explicit scoring criteria which greatly minimises the involvement of judgement. It also covers the age range of the subjects in the present study.

The Receptive-Expressive Emergent Language Scale (REEL) covers the first three years of communication and language in child development. The scale is designed to assess communication skills that an infant typically acquires in the first thirty six months of life. The nature of this scale, being very detailed and covering both the Receptive and expressive domains of language acquisition, makes it very suitable to assess children with intellectual disability. The scale is very well studied and standardised on a large group of British children (Bzoch & League. 1971). As it is only covering the first three years of life, it is less culturally dependent and very appropriate for use in Egypt

The way the data will be presented in the results is according to a 'Progress Quotient' (PQ), calculated using a combination of the scores of the Griffiths test and the REEL, to indicate the extent of progress achieved by each child. The Griffiths test has never been standardised in Egypt, so this study does not use the term 'Developmental Quotient' (as originally used in the Griffiths Test), in an attempt to remind the reader that the scores derived here are only for the purpose of this study. The PQ is used to indicate the baseline level of disability and the extent of progress achieved by each child.

Reliability

Since the Griffiths test has never been used in Egypt in a scientific study before, the researcher had to train an 'external examiner' (EE), in the use of the test, to assist him in the assessment of the children in the study. The EE was an experienced special educator, and had been a researcher in many previous studies and was not an employee of Caritas.

When the training was completed, inter-assessor reliability was established between the EE and the researcher. They jointly assessed several children, who were not in the project, to gain agreement on how to carry out the assessment and scoring levels. This task was relatively easy, as the Griffiths test has a straightforward established procedure that is well described in the manual and had been practically demonstrated to the researcher during his Griffiths' training in the UK

The EE was not completely 'blind' to the programmes that the children were enrolled in. The fact that the Outreach programme is located in Cairo while the CBR and MCH are in Alexandria made him aware of which children belonged to which project. On the other hand, the EE was unaware that the Alexandria children were derived from three different groups: the CBR, the MCH and the control group, as all assessments were made in the MCH centres. The EE was not informed of the hypothesised differences between the programmes, nor of the aims and nature of the study.

In order to check the reliability of the results and scoring system of the two examiners, eight children at the beginning and ten children at the end of the intervention were assessed twice with an interval of three weeks by the both examiners. Checking inter-examiner reliability at the end of the intervention was important, to detect any drift in their scoring due to their experience in practice. The results of the first testing were not available to each examiner when he carried out the second testing.

Children assessed by the two examiners were randomly selected from the MCH and CBR programmes. The children were those who simply turned up in the health centres on the scheduled days of the assessment. To counteract any practice effect, half of the children were assessed by the EE and then by the researcher, whereas the other half were assessed by the researcher first and then by the EE. The inter-observer reliability was calculated using Kappa. Results revealed a high level of agreement among the two raters as the range of Kappa was (0.75 to 0.95) with an average of 0.86.

All four groups of children with intellectual disabilities were assessed: the CBR group, the MCH group, the Outreach group and the control group. They were tested by either the external examiner or the researcher before beginning the intervention and twelve months later. Follow-up assessment was conducted 18 months after the beginning of the intervention for the CBR and MCH groups, and after 20 months for the Outreach one. At the follow-up testing neither of the examiners knew the initial results.

The progress of every child was measured according to the change in progress quotient between two time points. It was then divided by the duration of that time interval in months to give the progress per month.

3.5.2.2 Parental attitudes

Procedures

Parental attitudes were explored using the Short Form of the Questionnaire on Resources and Stress (QRS-F) (Friedrich, Greenberg, & Crnic. 1983). This 52 item instrument was adapted from the 'Questionnaire on Resources and Stress (Holroyd. 1974)' which was originally a 285 true/false-item tool. It was developed to measure the impact of a developmentally delayed or disabled child on other family members. It is considered to be a general measure of adaptation and coping, as it measures both the positive and negative impact of the child on the family.

This questionnaire examines four distinct factors: (See Appendix II)

Factor 1, **Child Competence**, consists of 20 items reflecting the respondent's perception of the specific behavioural/ attitudinal/cognitive difficulties presented by the child. Sample items include; 'X' can't pay attention very long, 'X' can walk without help, 'X' is able to go to the bathroom alone.

Factor 2, **Family Stress**, consists of 14 items assessing the respondent's perception of problems faced by themselves, other family members, or the family as a whole. Sample items include; Sometimes I avoid taking 'X' out in public, Sometimes I feel very embarrassed because of 'X', There is a lot of anger and resentment in our family.

Factor 3, **Future Anxiety**, consists of 9 items, all containing a future pessimism about the child's prospects of achieving self-sufficiency. Sample items include; I worry about what will happen to 'X' when I can no longer take care of him/her, 'X' will always be a problem to us, 'X' is limited in the kind of work he/she can do to make a living.

Factor 4, **Parental Adjustment**, consists of 9 items that are related to the respondent's emotions and perceived stress. Sample items include; It is easy for me to relax, I get upset with the way my life is going, Caring for 'X' puts a strain on me.

This widely used instrument was selected for this research because out of all the tools considered, it was the most acceptable for use in Egyptian settings. The majority of the items are relevant to the Egyptian culture and contain very few inappropriate items which needed to be modified, as outlined later.

The QRS-F was translated by the researcher into the Egyptian dialect. Minor changes were made in the wording of some questions, while maintaining their central concepts. A back

translation into English was also carried out by an independent translator and a few alterations were again made to keep the meaning intact.A pilot study was done to explore the need for any modifications, i.e. irrelevant and unclear questions were modified.

Mothers of all four groups were interviewed by the two examiners at both the beginning and the end of the interventions, and all but the control group were assessed again at the follow-up stage.

Problems of translation

1. In item # 1, "---- doesn't communicate with others of his/her age group", the exact translation of 'communicate' could not be used, since it only occurs in Classical Arabic and would not be understood by an uneducated mother. Therefore, another synonym in colloquial Arabic had to be used which gives the combined meaning of 'understand' and 'express'.

2. In item # 5, "The constant demands for care for ---- limit growth and development of some one else in our family", the word 'growth' had to be omitted, as its counterpart in Arabic means the biological/spontaneous growth that is induced by age and not by any sort of intervention. The word 'development' on the other hand bears the meaning of both progress and learning.

3. In item # 7, "I have accepted the fact that ---- might have to live out his/her life in some special setting (e.g., institution or group home).", the word 'fact' was replaced with 'idea', since its exact synonym in the Arabic translation connotes 'an inevitable incident' whereas in the original item 'fact' refers to the event of spending the rest of his/her life in an institution. However, this item does not pose a problem in its translation as much as in its context. In this project's setting, an institution housing the mentally handicapped is not an option. In fact, it is almost non-existent, and most people do not possess the slightest idea of what an institution is. As a result, most parents, on answering this item, believed it was best for their child to be

served by an institution, especially when they grow old. Of course, this is a reverse indicator of what was intended to be assessed.

4. In item # 10, "---- is able to fit into the family social group", the exact translation of 'fit' gives the meaning of 'adapt' and 'suitable'. Since this was not the intended meaning in the questionnaire, it was replaced by Arabic words meaning 'integrated' and 'participate'. 'Group'was also replaced with 'life' since it is never used in Arabic in connection with the family.

5. In item # 16, "Taking ---- on a vacation spoils pleasure for the whole family", the meaning of the word 'vacation' had to be replaced with an Arabic word meaning 'outing', since in the project setting and especially in the slum areas, it is extremely unlikely for people to leave home or go on holidays.

6. In item # 25, " ---- is over-protected", 'over protected' does not have a synonym in the colloquial language, therefore in the Arabic translation we used words expressing the implied meanings of this word i.e. 'fear for him' and ' protect him more than any other member in the family'.

7. Item 38: " ---- can ride a bus", is completely outside of the likely experience of intellectually disabled children in the urban slums, since buses in these areas are very crowded and this makes it extremely difficult for a disabled person to get on or off a bus on his/her own. The same applies for other existing means of transportation. Furthermore, the target group in this research are less then twelve years old and it is most unlikely for them to leave their districts, and if they did, they would be accompanied by their parents. This item is therefore unlikely to be informative.

8. Item # 41: "People can't understand what ---- tries to say", proved to be vague and unsuitable. On hearing this question, parents usually asked explanatory questions.

3.5.2.3 Parental involvement

How parental involvement is approached can have a strong impact on the nature and outcome of the intervention that is provided. In this study, two different approaches to parental involvement are examined. The first one, mainly adopted by the CBR programme, promotes more the family-centred approach that includes families in decision-making: planning, assessment and deciding on the plans and, even, the educational and rehabilitation programme of their disabled children on a weekly basis. This approach emphasises parental empowerment and the acquisition of the knowledge and skills needed for the future sustainability of the project. The second approach, on the other hand, as adopted by the MCH project, involved parents in a much more passive way. It viewed parents as the observer and receiver of services, with the intervenor primarily providing services direct to the child, and demonstrating for the parents how to implement a weekly programme, suggested by the project staff, at home.

In this study it is hypothesised that parents will be more involved in teaching their young intellectually disabled children if the educational and developmental programme is designed according to their priorities rather than imposed upon them by professionals.

Procedures

As no culturally appropriate tools were available to test this hypothesis, a new method was developed to do so. It consists of three stages:

(i) to identify the parent's priorities for the education and rehabilitation plan of their disabled child.

(ii) to rate whether the most recent programme for their children matches the parent's priorities or not.

(iii) to assess the extent of parental involvement mainly by counting 'teaching-related activities', explained later.

Therefore, the above mentioned hypothesis were examined through the analysis of the results by comparing the extent of parental involvement to the degree of matching of programme priorities.

(i) Identifying parent's priorities

MCH parents were interviewed four months after the beginning of the intervention by the researcher during one visit to the MCH centres. The interviewer explained to mothers that he was interested to know more about their child, and their daily life activities to better plan the services for their child. The interviewer spent some time in general conversation until it was felt that the mother was reasonably relaxed.

Discussions with mothers about their child: their strengths, weaknesses and their needs, gave the researcher the opportunity to find what educational and developmental priorities the parents identify for their children, plus their hopes for future progress.

To help parents in identifying realistic, short-term objectives for their child, the researcher reviewed with each mother the various domains and sequences of normal child development. From there, he enquired about the actual developmental level of her child, from her own point of view and requested her to identify the next three most realistic improvements she would like her child to achieve within the following weeks. The researcher did not know what type of programme had been received by the child in recent sessions.

(ii) Rating of parent priority/ programme match

A panel of five early intervention specialists, not involved in the programmes covered by the research, compared the improvements requested by the parents against the written programmes drawn up by MCH Personnel. They rated whether the last programme suggested by the MCH

professionals had been relevant to the parents' priorities, or whether there was a discrepancy between the two.

They further compared the parent priorities with every programme they have been given during the whole year of intervention. They examined how often the professionals' programmes met the parents' priorities in these twelve months. They took into account all the different programmes that were given to parents to see if they coincided with the parents' priorities or not.

From these data, three groups were identified in the research. The first group was the MCH parents who had been given a programme which met their priorities. These parents were combined with all the CBR parents whose priorities had been incorporated into the programmes that they had been working on. The second group was the MCH parents who were given a programme that partially matched their priorities. The third group was the MCH parents who were given a programme totally mismatching their priorities.

(iii) Assessing parent involvement

The degree of family involvement was assessed using three measures:

(a) Number of Teaching-Related Activities (TRAs)

A set of defined criteria were developed to count the number of TRAs that family members engaged in. These criteria (see appendix III) were not intended to map the general pattern of parental involvement with the disabled children, but more specifically the extent of their involvement in relation to the child's educational and rehabilitation plan.

A pilot study was carried out with mothers who receive services at the SETI centre, to examine the feasibility of assessing parental involvement by counting TRAs. Two main problems arose during the interviews. The first was that mothers were unsure about what was happening when

they were not with their disabled child, i.e.. what activities other family members were engaging in. The second was the failure of mothers to describe their child's activities in enough detail. Possible reasons for this are problems of recall, or unawareness of the type of information valuable to the interviewer.

This meant that the researcher had to use many prompt questions to extract the needed information. Examples of questions asked were: "what did the child do when he got up in the morning?... what did he do next?.. what happened after that?.... did anybody help him in the toilet or did he manage on his own?...what sort of play did he indulge himself in?...what sort of toys did he play with?," etc. The researcher also sought to find out what the other family members were doing at a given time. Finally, mothers were asked directly about any TRAs carried out as part of the child's most recent programme.

These interviews were carried out by the researcher with all the mothers on the MCH and CBR programmes, five months after the beginning of the intervention. MCH mothers were interviewed at the same time as identifying their priorities. Mothers of the CBR programme were interviewed during the weekly club. They were asked to describe the child's activities during the preceding day, and to state whether there was any physical involvement from family members to help the child in these activities. If the preceding day did not reflect the child's normal pattern of daily activities, then the previous day was considered instead.

From these interviews the researcher was able to count those events classed as TRAs, according to the criteria.

To check the reliability of the results and the scoring system, ten mothers not involved in the study but included in the Alexandria CBR programme were interviewed by the researcher in the presence of the EE. Both examiners counted the number of TRAs for each child independently and their scores were then compared. Results revealed a high level of agreement among the two raters (0.82 to 0.96) with an average of 0.88.

(b) Number of appointments attended

Family involvement was further examined by comparing the number of appointments made with the number of appointments attended. The MCH personnel were asked to record all the appointments made, whether attended or missed.

(c) Level of family enthusiasm

MCH personnel and CBR workers were asked to rate family enthusiasm towards their teaching and involvement with their child on a three points scale.

3.5.2.4 Independence and community support

The Family Support Scale (FSS) adapted from (Dunst, Jenkins, & Trivette. 1984) was used to measure parent satisfaction with various sources of local support. The scale was administered by the researcher by interviewing parents of all groups pre- and post- intervention, and then 18 months after the start of the intervention. It requires parents to rate how helpful eighteen different sources of informal and formal support have been in the past three months. Parents were asked to rate each of the sources listed on a 0- to 4-point scale (0, *not at all helpful*; 1, *somewhat helpful*; 2, *moderately helpful*; 3, *quite helpful*; and 4, *extremely helpful*). Parents could also indicate that the source of support was 'not available'.

Whether the outcomes of the CBR programme can be maintained, was assessed by looking at child progress, parental attitudes and amount of local support. These variables were measured before the withdrawal of external supports and six months after. The comparison of these results reflects the degree of independence achieved by parents and local community during the follow up time. Moreover, results of the CBR group will be compared with those obtained in the Outreach and MCH groups, in which professional inputs were maintained, at the end of the follow up period.

Further procedural issues

1. Duration of the intervention

The length of the intervention was determined by a number of factors. One year was thought to be the minimum period of time in which to produce reasonable outcomes in the target groups, and thus permit meaningful comparisons between the three different approaches to rehabilitation. In was also thought to be a realistic period of time in which to establish the needed infrastructure, and ensure transfer of the knowledge and skills required by the local community to run their project with minimal external support. It was expected that in the second year of the intervention parents would be able to carry on working with their child by themselves, and would use and depend more on the local resources that were created or mobilised during the first year of intervention. It should be noted that this period is also the duration of the second stage of the Alexandria CBR programme.

2. Contamination effect and assessor bias

Many of the investigations, tests and interviews in this research were carried out by the researcher himself. As the co-ordinator of the CBR Department of the SETI Centre, Caritas, Egypt, he was not involved directly in any of the programmes involved in the comparison. The three programmes were run and supervised on an equal basis by his Department.

A contamination effect was considered unlikely as the outreach programme is located in Cairo, while the CBR and MCH programmes are in two separate locations in Alexandria, far apart from each other. Although the MCH and CBR staff mixed with each other in a bi-monthly meeting, there was an atmosphere of competition between the two teams

rather than a desire to learn or to adopt the approach of the other. The main incentive for both the teams was to prove the success of their project and get the praise of the others.

On the other hand, the Cairo Outreach programme and the Alexandria CBR programme were both initiated by the same organisation (Caritas-Egypt), therefore the risk of overlapping and imitation between the two programmes was expected. This was overcome by assessing the new-comers in the existing Outreach programme during the preparation phase and before the implementation of the newly initiated Alexandria CBR programme. Any modifications made during the implementation of both programmes were carefully described. In addition, the commitment, dedication and belief of each staff member, in their own project's ideology and underlying concepts, made them resistant and unwelcoming of any kind of change. Thus, although there was some co-ordination between the two projects, the teams stuck largely to their original strategy and plan of work, and the changes recorded were therefore limited.

3. Parent consent

The programmes were explained to the parents and they were told that different programmes existed and some investigations had to be carried out to know whether the programme had been successful for their child or not. In practice, there was no choice of programme as there was only one in each area. It is not appropriate to get formal written consent from parents in such CBR programmes.

3.6 Statistical methods

The study design consisted of measurements taken at three different time periods in four groups of children, a control group and three intervention groups. The intervention groups were measured pre intervention, twelve months post intervention and at a follow up of 18-20 months. Repeated measures ANOVA with time as the within group factor and treatment group as the between group factor were performed, giving a between group comparison, a between time comparison and a group-time interaction.

In comparison of measures taken pre and post all four groups were included. In comparisons involving pre, post and follow-up times only the three intervention groups were included because there was no follow up of the control group.

Before inclusion in analysis variables were tested for normality using the K-S Lilliefors test. Where the analysis of variance showed differences between groups post hoc comparison were made using either Scheffes method or paired or unpaired t-test as appropriate. Where multiple t-tests were performed the level of significance used was reduced to 0.001 rather than 0.05.

Variables with a non-normal distribution were analysed using the Mann-Whitney U test and Kruskal Wallis one way analysis of variance for independent groups and the Wilcoxon test for repeated measures.

The X^2 test was used to assess the relationship between two categorical variables unless expected values were less than five in which case Fisher's Exact test was applied.

The association between two continuous variables was investigated using the Pearson correlation coefficient for normally distributed variables and the Spearman rank correlation coefficient otherwise.

4. Chapter Four: Results

4.1 Comparability of Groups

The partial group matching sampling approach adopted in the recruitment of subjects for this research was adopted in order to aim for comparability of groups mainly in characteristics thought to be influential to the outcomes of the interventions. These characteristics consist of age, gender, mother education, mother age, father age, number of siblings with handicapping conditions and birth order. The dependent characteristics are the child and family baseline data that include a 'progress quotient' for each child as well parental attitudes and the extent of social support available to each family before the intervention.

Table 3. Comparison of Groups on Demographic Variables.

Variables	CBR (n = 27)		Outreach (n = 24)		MCH (n = 26)		Control (n = 28)		Test of Sig.	Prob.
	M	SD	M	SD	M	SD	M	SD		
Child age (months)	90.0	35.2	93.7	33.6	87.9	39.5	89.8	38.1	$X^2_3 = .18$	P = .98
Mother age (years)	36.7	5.2	38.3	9.0	39.4	8.7	37.9	6.7	$F_{3,95} = .51$	P = .68
Father age (years)	44.7	5.3	46.5	9.5	46.5	10.3	44.9	8.0	$F_{3,92} = .32$	P = .81
Number of children	3.7	1.5	3.0	1.2	3.7	1.6	3.4	1.1	$X^2_3 = 3.67$	P = .3
	Percentage		Percentage		Percentage		Percentage			
Sex of child									$X^2_3 = 1.03$	P = .79
- Male	55.6%		66.7%		57.7%		53.6%			
- Female	44.4%		33.3%		42.3%		46.4%			
Maternal education									$X^2_3 = 1.04$	P = .75
- Illiterate	74.1%		70.8%		61.5%		67.9%			
- Educated	25.9%		29.2%		38.5%		32.1%			
Disabled siblings									$X^2_3 = 5.89$	P = .12
- No Disabled Siblings	66.7%		87.5%		84.6%		89.3%			
- Disabled Siblings	33.3%		12.5%		15.4%		10.7%			
Birth order:									$X^2_6 = 4.57$	P = .6
- Single:	.0%		.0%		3.8%		.0%		(rows 1+2	
- Ist	29.6%		33.3%		19.2%		28.6%		combined	
- Last born	40.7%		54.2%		42.3%		35.7%		for $X^{2)}$	
- Other	29.6%		12.5%		34.6%		35.7%			

Equivalence of the groups

All groups involved in the study were found to be comparable initially (see Table 3). There were no significant differences among the characteristics of families and children in the four groups. Moreover, as can be seen in Table 4, the intervention and control groups were very similar on dependent measures taken before the implementation of the programmes. There was only one significant difference between groups in term of parent attitudes. MCH parents had higher negative attitude scores at baseline in comparison to all other groups.

Table 4. Comparison of Groups on Dependent Variables

Variables	CBR		OR		MCH		Ctrl		Test of sig.	Prob.
	M	*SD*	*M*	*SD*	*M*	*SD*	*M*	*SD*		
Progress quotient	34.6	10.5	35.0	11.0	35.8	10.7	36.7	8.9	$F_{3,101} = .22$	P = .88
Parent Attitude	38.0	5.0	36.9	3.3	42.4	3.0	38.7	5.0	$F_{3,101} = 8.11$	P = .0001
Mental age	28.6	10.7	31.1	11.7	29.3	13.7	31.8	14.0	$X^2_3 = 1.26$	P = .74
Social Support	4.6	1.8	4.8	1.2	4.3	1.4	4.3	1.5	$X^2_3 = 2.39$	P = .50

4.2 Child progress

Child progress is calculated on the basis of the difference between 'progress quotient' scores before intervention, twelve months after intervention and at the end of the follow-up period for all intervention groups. The change in progress between two time points was then divided by the duration of that time interval in months to give the progress per month.. Scores of the control group were only calculated on the basis of the first twelve months of the intervention as the follow-up assessment was not carried out with this group.

Table 5. Means and 95% confidence interval of change in 'Progress Quotient' scores per month between pre intervention, post intervention and follow up for all four groups.

		Mean change	95% Confidence Interval
CBR	Pre to Post	.59	.47 to .70
	Post to FU	.29	.20 to .37
Outreach	Pre to Post	.45	.38 to .51
	Post to FU	.27	.23 to .32
MCH	Pre to Post	.11	.05 to .17
	Post to FU	.00	-.05 to .05
Control	Pre to Post	-.06	-.10 to -.01

*** $p < 0.001$ ** $p < 0.01$ * $P < 0.05$

Table 6. Analysis of variance of change in Progress Quotient in intervention and follow-up period.

	ANOVA	Repeated measure ANOVA
	During intervention period (all four groups)	During intervention and FU (three intervention groups)
Group	$F_{3,101} = 66.82$ ***	$F_{2,74} = 38.33$ ***
Time	.	$F_{1,74} = 115.18$ ***
Group x Time	.	$F_{2,74} = 9.18$ ***

One-way analysis of variance showed that the difference between the groups in the change detected in progress quotient per month during the first twelve months of intervention was highly significant ($F_{3,101} = 66.82$, P = .000: Table 6) Post hoc comparison between the groups were performed using Scheffe test and revealed that all intervention groups had a significantly accelerated rate of progress in comparison with the control group (Table 5 and 6). The Sheffe test also showed that the progress in both CBR and Outreach programmes was significantly greater than the MCH. The CBR group improved slightly more than the Outreach one (see figure 1), but this difference was not significant according to Scheffe test. Therefore the hypothesis that the children's progress in the CBR project would be better than in the MCH and the Outreach programmes is partially supported by these findings.

In the repeated measures analysis of variances comparing the three intervention groups over two time periods there were significant group and time effects and a group by time interaction which implied that the changes in progress quotient were behaving in a different way over time in different groups. These differences are illustrated in Table 5 and Figure 1.

The CBR and Outreach groups continued to make significant improvement in the follow-up period. However, the rate of the progress in the follow-up period was only about half that in the initial period. Although no significant differences were found between the rate of progress of the CBR and Outreach groups, they were both significantly higher than the MCH group. The latter showed no change in 'progress quotient' at all and only succeeded in maintaining the previous gain.

Figure 1. Progress Quotients at 12, 18 and 20 Months

Fig. 1 Progress Quotients
at 12, 18 and 20 Months
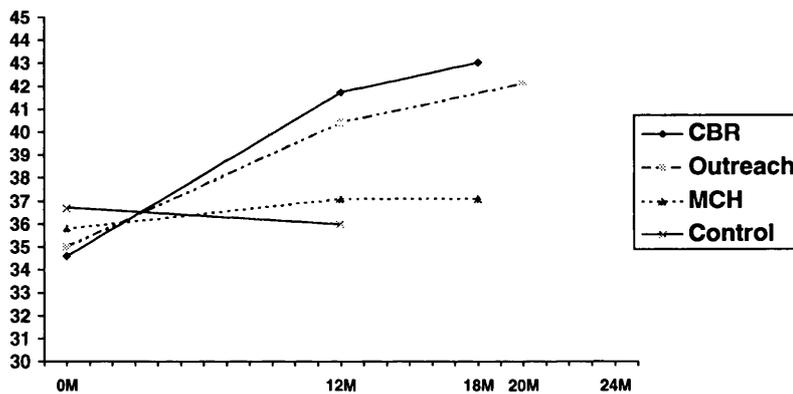
Once again, these findings partially support the first hypothesis of this study that child progress in the CBR programme can be maintained independently, through parents and the support of their local community, for a period of six months after the professionals have withdrawn active involvement. The fact that the Outreach groups demonstrated a similar drop in the rate of child progress while services continued to be provided by the professionals during the follow-up period, suggests the slowing in rate of progress arises from reasons other than the withdrawal of professionals.

4.3 Parent Attitudes

The Short Form of the Questionnaire on Resources and Stress (Friedrich, Greenberg, & Crnic, 1983) measures the impact of a developmentally delayed or disabled child on other family members through four different factors, labelled as 'Child Competence' as perceived by mothers, 'Family Stress', 'Future Anxiety' and 'Parental Adjustment'. Drop in total scores or in any of these factors in comparison to the initial ones indicates a positive change in parental attitudes.

Table 7. Means, Standard Deviation of total scores and factors of 'QRS- Short form' at three different points for all four groups.

		CBR group		OR group		MCH group		Ctrl group		
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Total	Pre	37.96	4.99	36.92	3.33	42.38	2.96	38.75	5.01	
	Post	26.18	3.89	29.00	3.81	35.08	4.81	37.89	4.82	
	FU	26.55	3.76	28.83	2.53	34.23	5.22	.	.	
Child	Pre	14.22	2.22	11.71	2.27	16.38	1.42	14.21	2.63	
Competence	Post	8.70	2.15	9.25	1.92	12.81	2.35	13.61	2.92	
	FU	8.52	1.97	9.13	1.62	12.38	2.43	.	.	
Family	Pre	9.11	2.98	8.17	1.63	10.58	1.86	9.93	2.48	
Stress	Post	5.00	2.00	6.54	1.84	7.54	2.27	9.71	1.96	
	FU	5.33	2.06	6.29	1.40	7.19	2.37	.	.	
Future	Pre	7.85	.36	7.85	.34	7.92	.27	7.79	.42	
Anxiety	Post	7.22	1.31	7.50	.59	7.88	.33	7.75	.44	
	FU	7.19	1.30	7.71	.46	7.88	.33	.	.	
Parent	Pre	6.78	.85	6.17	1.09	7.50	.65	6.82	.98	
Adjustment	Post	5.26	1.29	5.71	1.33	6.85	1.22	6.82	.90	
	FU	5.52	1.16	5.71	1.12	6.77	1.18	.	.	

Comparability of groups at pretest

At pretest, one way analysis of variance showed that there were significant differences between the groups in total scores as well as in three out of four factors of the 'QRS-Short form': child competence, family stress and parent adjustment ($F = 8.11$, $p = .0001$; $F = 18.98$, $p = .0000$; $F = 5.07$, $p = .0026$; $F = 9.09$, $p = .0000$). However, no statistically significant difference was found between groups in relation to the 'future anxiety' factor ($F = 0.71$, $p = 0.55$). Also, MCH parents had higher negative attitude in total scores at pretest in comparison to all other groups (see Table 7)

Table 8. Repeated measures ANOVA with time as the within subject factor and group as the between subject factor in total scores, child competence, family stress, future anxiety and parental adjustment of the 'QRS-Short form'.

	A) Comparison of all four groups			B) Comparison of CBR , Outreach and MCH					
	Pre x Post ($F_{3,101}$ Value)			**Pre x Post x FU** ($F_{2,148}$ Value)			**Post x FU** ($F_{2,74}$ Value)		
	Group	Time	Gp x Time	Group	Time	Gp x Time	Group	Time	Gp x Time
Total Scores	20.10 ***	527.82 ***	58.70 ***	26.71 ***	506.46 ***	10.33 ***	29.10 ***	1.51 -	4.20 *
Child Competence	23.23 ***	238.46 ***	28.53 ***	37.24 ***	214.40 ***	10.98 ***	29.13 ***	4.53 *	0.62 -
Family Stress	11.36 ***	236.23 ***	35.02 ***	7.15 ***	225.25 ***	11.32 ***	8.24 ***	0.83 -	5.05 **
Future Anxiety	2.98 *	12.43 **	3.64 ***	4.56 **‡	9.71 ***	3.44 ***	4.44 *	2.68 -	4.66 *
Parent Adjustment	10.79 **	47.34 ***	11.53 ***	12.66 ***	41.75 ***	5.06 **	10.45 ***	0.72 -	2.10 -

*** $p < 0.001$ ** $p < 0.01$ * $P < 0.05$

Repeated measures two-way analyses of variance were conducted to compare scores of all

groups before the intervention, twelve months later and at the end of the follow up period.

Three separate ANOVA were performed since the control group was not included at

follow up. As seen in Table 8, these analyses revealed highly significant differences

between the groups in the total scores as well as in each component. The analyses which

included the pre and post time periods showed clear differences in the time factor, but the

analysis of post and follow-up time periods only indicated some change over time in child

competence and group by time interactions in total scores, family stress and future anxiety.

Table 9. Means and 95% confidence interval of differences in total scores, child competence, family stress, future anxiety and parental adjustment of the 'QRS-Short form' between pre intervention, post intervention and follow up for all four groups.

		Total Scores			Child Competence			Family Stress			Future Anxiety			Parent Adjustment		
		Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig.T est	Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig. Test
CBR	Pre to Post	-11.78	-10.12 to -13.44	***	-5.52	-4.42 to -6.62	***	-4.11	-3.27 to -4.95	***	-0.63	-0.10 to -1.16	-	-1.52	-1.01to -2.03	***
	Post to FU	0.37	0.90 to -0.16	-	-0.19	0.21 to -0.58	-	0.33	0.68 to -0.01	-	-0.04	0.04 to -0.11	-	0.26	0.50 to 0.02	-
OR	Pre to Post	-7.91	-6.71 to -9.12	***	-2.46	-1.68 to -3.24	***	-1.62	-1.10 to -2.15	***	-0.38	-0.10 to -0.65	**	-0.46	-0.05 to -0.87	-
	Post to FU	-0.17	0.68 to -1.01	-	-0.13	0.31 to -0.56	-	0.25	0.09 to -0.59	-	0.21	0.42 to -0.01	-	-0.00	0.37 to -0.37	-
MCH	Pre to Post	-7.31	-5.99 to -8.63	***	-3.58	-2.78 to -4.39	***	-3.04	-2.50 to -3.58	***	-0.04	0.10 to -0.18	-	-0.65	-0.23 to -1.01	***
	Post to FU	-0.85	-0.37 to -1.33	***	-0.42	-0.02 to -0.82	-	-0.35	-0.01 to -0.69	-	-0.17	0.07 to -0.41	-	-0.08	0.37 to -0.19	-
Ctrl	Pre to Post	-0.86	-0.28 to -1.43	**	-0.61	-0.19 to -1.02	**	-0.21	0.19 to -0.61	-	-0.03	0.10 to -0.16	-	-0.00	0.26 to -0.26	-

** $p < -0.01$.

*** $p < -0.001$.

As outcomes of the first twelve months of the intervention (pre versus post), further analysis, using paired t-test across time within each group, revealed that all intervention groups showed an overall positive change in parental attitudes, while no significant differences were detected in the control group (see Table 9) . The CBR group had an improvement of 11.78 in total score compared with a change of 7.91 in the outreach group and 7.31 in the MCH group, the improvement in the CBR group was significantly greater than that in the outreach and MCH groups (Scheffe test p <0.05). The main areas of change were child competence and family stress.

Parents' perceptions of their children's competence and their family stress were improved in all groups after the intervention. However, their level of anxiety about the future of their disabled children was not affected in any of the comparison groups. Only Outreach parents, as can be seen in Table 9, showed a significantly lower level of 'future anxiety' after the first year of the intervention ($t = 2.84$, $p = 0.009$).Yet, this gain was not maintained during the follow up period and, as an outcome of the whole intervention period, the Outreach group was similar to all other groups in showing no significant difference in this factor ($t = -2.01$, $p = 0.16$). Also, the Outreach group did not show any significant changes as a result of the intervention in the 'parent adjustment' factor while the CBR and MCH groups had a high significant positive changes ($t = 5.47$, $p = 0.000$; $t = 4.26$, $p = 0.000$).

No statistically significant differences were found within the groups during the follow-up period except for a small change in total score in the Outreach group (see Table 8 and 9). Scores of the Outreach and MCH groups remained nearly unchanged, except a drop in score in the 'future anxiety' factor in the Outreach group (see Table 9). This indicate that the continuity of their intervention during the follow-up period preserves the previously gained scores but did not lead to a further positive change in parent attitudes. All the gains in scores in the CBR group were also maintained despite the withdrawal of the direct professional input from the project. (Post hoc comparisons between the groups taken in pairs at pre, post and follow up time are presented in Appendix IV).

The differences between the size of the effect of each programme on its target group is illustrated in figure 2. This shows that the CBR programme had the greater positive impact on parental attitudes, followed by comparable positive changes in both the Outreach and the MCH groups, while the control group retained their level of attitude score during the intervention period. All gains were maintained during the follow up period.

Figure 2. Changes in Total Scores of Parental Attitudes

Fig. 2. Changes in Total Scores of Parental Attitudes
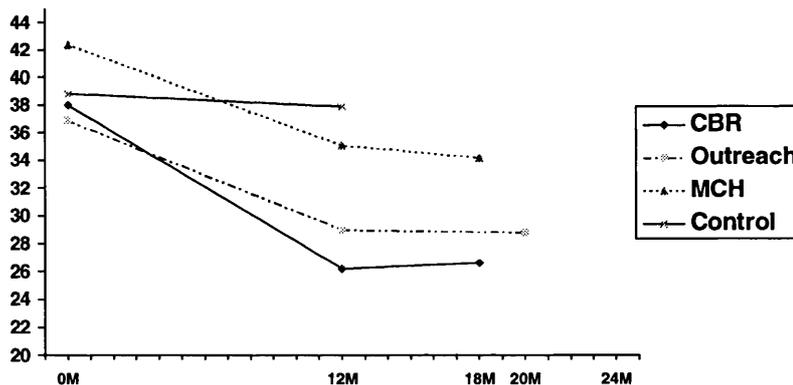
These findings support two of the hypotheses of this study. The first one is that the outcomes of the CBR project are better than the MCH and the Outreach programmes in terms of the development of positive parental attitudes. The second one is the maintenance of the outcomes of the CBR programme independently for a period of six months after the partial withdrawal of the professional input.

4.4 Family Support

Measures of amount of support from the local community, using the Family Support Scale (adapted from Dunst, Jenkins and Trivette 1984) was collected before, after and at 18 months after the start of the intervention. Parents of all groups were compared with respect to the total number of sources reported, total scores of helpfulness, scores of helpfulness derived from informal sources (e.g. parent and families) and scores of helpfulness from formal sources (e.g. professional services).

Table 10. Means, Standard Deviation of total number of resources, total scores of helpfulness, informal sources of helpfulness and formal sources of helpfulness of the 'Social Support Scale' at three different points for all four groups.

		CBR group		Outreach group		MCH group		Ctrl group	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
Total No	Pre	2.3	.8	2.5	.6	2.4	.6	2.4	.6
of	Post	10.4	1.3	7.0	.7	5.4	1.4	2.4	.6
Sources	FU	10.4	1.5	7.1	.7	5.5	1.6	.	.
Total scores	Pre	4.6	1.8	4.8	1.2	4.3	1.4	4.3	1.6
of	Post	19.7	3.6	11.7	2.1	10.5	3.2	4.4	1.3
Helpfulness	FU	19.7	3.7	12.5	1.4	10.8	3.5	.	.
Informal	Pre	2.5	.9	2.7	.7	3.0	1.0	3.1	1.0
Sources of	Post	12.3	2.1	7.6	1.4	6.8	1.7	3.1	.8
Helpfulness	FU	12.5	2.3	8.0	1.2	7.1	1.8	.	.
Formal	Pre	2.1	1.1	2.0	.8	1.3	.7	1.3	.8
Sources of	Post	7.4	1.8	4.1	1.2	3.7	1.8	1.3	.9
Helpfulness	FU	7.1	2.0	4.5	1.1	3.7	2.0	.	.

Comparability of Groups at Pretest

No statistically significant pretest differences were found on any of the measures of family support except for the formal support (see Table 10). Parents of the CBR and Outreach groups reported slightly higher degrees of helpfulness from formal sources of support than the parents in the MCH and control groups ($F = 7.31$, $p = 0.0002$).

Table 11. Repeated measures ANOVA with time as the within subject factor and group as the between subject factor in total number of resources, total scores of helpfulness, informal sources of helpfulness and formal sources of helpfulness of the Social Support Scale.

	A) Comparison of all four groups			B) Comparison of CBR , Outreach and MCH					
	Pre x Post ($F_{3,101}$ Value)			Pre x Post x FU ($F_{2,148}$ Value)			Post x FU ($F_{2,74}$ Value)		
	Group	Time	Gp x Time	Group	Time	Gp x Time	Group	Time	Gp x Time
Total No of Sources	140.61***	1413.88 ***	282.87 ***	80.20 ***	1350.61 ***	119.05 ***	104.79 ***	2.11	0.54
Total Scores of Helpfulness	80.90 ***	1014.24 ***	203.50 ***	52.16 ***	932.76 ***	80.47 ***	68.77 ***	5.71 *	2.82
Informal Sources Helpfulness	69.58 ***	1295.89 ***	255.51 ***	48.17 ***	1278.72 ***	109.38 ***	70.63 ***	24.0 ***	1.21
Formal Sources Helpfulness	62.69 ***	313.48 ***	65.90 ***	36.11 ***	247.46 ***	22.44 ***	37.48 ***	0.06	2.73

*** $p < 0.001$ ** $p < 0.01$ * P< 0.05

Repeated measures two-way analyses of variance were conducted to compare parents of

all groups with respect to the total number of sources available to them, total scores of

helpfulness, scores of helpfulness derived from informal sources (e.g. parent and families)

and finally scores of helpfulness from formal sources (e.g. professional services). As seen

in Table 8, when comparing pre and post intervention scores, the analyses revealed highly

significant differences across groups and times in all the four measures. However, in the

comparison of the post and follow-up scores there were less marked drops over time with

only the informal sources of helpfulness and total scores of helpfulness were significant.

Table 12. Means and 95% confidence interval of differences in total number of source of helpfulness, total scores of helpfulness, scores of informal sources of helpfulness, scores of formal sources of helpfulness of the Social Support Scale between pre intervention, post intervention and follow up for all four groups.

		Total No of Sources			**Total Scores of Helpfulness**			**Informal Sources of helpfulness**			**Formal Sources of Helpfulness**		
		Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig. Test	Change Means	Confidence Interval	Sig. Test
CBR	Pre to Post	8.15	8.61 to 7.69	***	15.07	16.35 to 13.80	***	9.78	10.51 to 9.05	***	5.30	6.04 to 4.56	***
	Post to FU	-0.00	0.15 to -0.15	-	-0.04	0.55 to -0.62	-	0.22	0.45 to -0.006	-	-0.26	0.19 to 0.71	-
OR	Pre to Post	4.50	4.81 to 4.20	***	6.92	7.50 to 6.33	***	4.83	5.26 to 4.41	***	2.08	2.55 to 1.62	***
	Post to FU	0.08	0.20 to -0.04	-	0.80	1.32 to 0.27	**	0.46	0.73 to -0.18	**	0.33	0.65 to 0.01	-
MCH	Pre to Post	2.96	3.55 to 2.37	***	6.19	7.24 to 5.15	***	3.85	4.40 to 3.30	***	2.34	3.01 to 1.68	***
	Post to FU	0.07	0.19 to -0.03	-	0.27	0.66 to -0.12	-	0.27	0.45 to 0.09	**	-0.00	0.30 to -0.30	-
Ctrl	Pre to Post	-0.04	0.23 to -0.30	-	0.04	0.49 to -0.42	-	0.04	0.32 to -0.25	-	-0.00	0.26 to -0.26	-

** $p < 0.01$.

*** $p < 0.001$.

Further analysis, using the paired t-test across time within each group, revealed that the three intervention groups reported improved levels of all measures of support during the first twelve months of the intervention while the control group did not change (See Table 9). The CBR groups had a much higher improvement in total scores of helpfulness (change of 15.07) than both the Outreach and MCH groups (change of 6.92 and 6.19 respectively). The improvement in the CBR group was significantly greater than in the Outreach and MCH groups (Sheffe test $P > 0.05$). No significant differences were detected between the latter two groups.

During the follow-up period, paired t-tests revealed no significant differences in the total number of available sources as well as in the perceived helpfulness of formal sources in the three intervention groups, indicating that all new sources of support were only mobilised during the first year of the intervention. The significant change shown in the repeated measure ANOVA in that period in relation to the perceived helpfulness of informal sources was due to the significant gain of informal sources of support in the MCH and Outreach groups ($t = -3.03, p = 0.006$; $t = -3.41, p = 0.002$). The other significant change detected in the repeated measure ANOVA during the follow-up period was due to a significant gain in total scores of helpfulness in the Outreach group ($t = -3.10, p = 0.005$). However, as can be seen in Table 9, all significant differences detected during the follow up period are caused by a very minimal gain in scores of less than one.

The comparison of the size of difference in the total scores of helpfulness caused by the interventions across the groups is well demonstrated in fig. 3. As illustrated, during the first year of the programmes, parents in the CBR group reported significantly greater support from their family and community following the intervention than the Outreach and MCH programmes. The two latter groups showed an equal increase in the total scores of helpfulness. The score gains in the three groups were maintained with no further increase during the follow up period.

Figure 3. Changes in Total Scores of Helpfulness

Fig. 3. Changes in Total Scores of Helpfulness
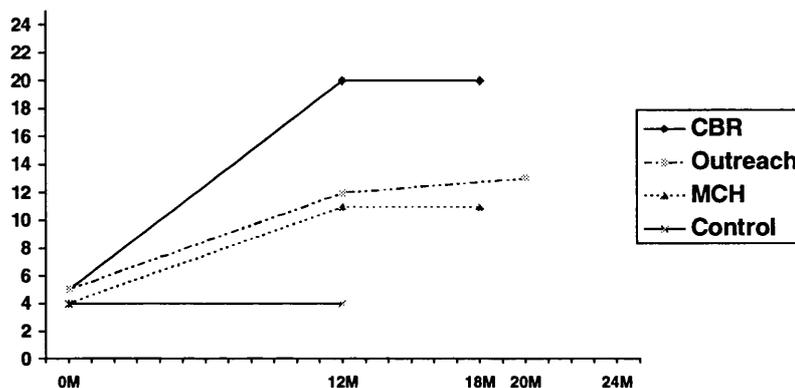
These findings support the hypothesis that the outcomes of the CBR intervention could be maintained independently and through the support of local resources after the withdrawal of professional staff.

4.5 Parent Involvement

Family involvement in the CBR and the MCH programs was assessed by counting the number of teaching-related activities from the mother's description of their child's activities in the preceding day, with construct validity checked through two additional measures taken on the MCH group alone, i.e. attendance rate and enthusiasm rate.

Three groups of children were identified in the study according to whether their parents are working on programmes which match their priorities or not. Deciding on which group each child belonged to was made by a panel of five independent early intervention specialists. Their decisions were based on comparing the improvements requested by the parents of each

child against the written programmes directly received from the MCH Personnel. Table 1.3

gives examples of how the categorisation was made by the panel of experts.

Table 13. Examples illustrating the programme matching and classification procedures

	Parent priorities	Concurrent programmes		No of matched programs	Match Categ.
Child no.1	• Dress and undress himself • Wash his hands and face • Pronounce his name correctly.	• Thread beads • Cut papers using scissors • Give name and family name on request.	*	1	b
Child no.2	• Pronounce words more clearly • Stop dribbling • Put on her clothes	• Draw horizontal and vertical lines • Put on her blouse • Name and imitate animal sounds.	* *	2	c
Child no.3	• Write his name • Stop making sound and noises • Stop beating his sister.	• Match red colour • Put on clothes himself • Understand 'on' and 'under'.		0	a
Child no.4	• Walk alone • Feed himself • Pronounce words to express himself.	• Walk holding adult hand. • Hold cup half full • Comprehend simple questions.	* * *	3	c
Child no. 5	• Know full address • Fasten her clothes • Help in domestic tasks.	• Jump off two steps • Draw triangle and square • Name colours.		0	b /

Matching Categories:

a = Totally mismatched (all programmes suggested by MCH professionals are not according to parent priorities)
b = Partially matching (only one suggested programme is according to parent priorities)
c = Matching priorities (at least two suggested programmes are according to parent priorities).

b / Although all current suggested programmes were not according to parent priorities, decision were made to categorise the type of programmes as 'partially matching' because one of the parent priorities programme was among the MCH suggested programmes in the last two months.

For the purpose of the analysis, parents who were categorised as the 'totally mismatched' group were merged with the 'partially matching' group into one group which consists of 15 MCH parents. The third category 'matching priorities' was composed of two groups, the first one consists of 11 MCH parents who were given a programme which met all or most their priorities, and the second one consists of the 27 CBR parents who have been working on a programme that is within their priorities (see Table 13).

Figure 4. Number of 'teaching related activities' according to the extent programmes matched parent priorities.

Fig. 4. Number of 'teaching related activities' according to the extent programmes matched parent priorities.
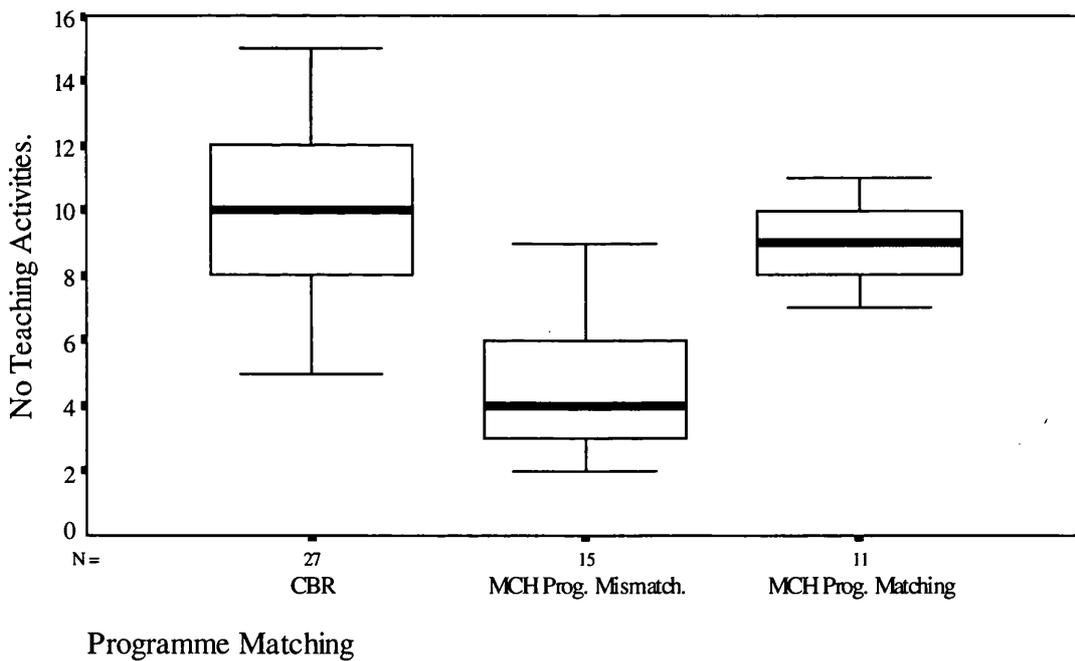
Analysis of the results consisted mainly of a comparison of the extent of parental involvement with degree of programme matching to priorities. As indicated in Fig. 4, a Mann-Whitney U test revealed that children of the MCH group whose programmes matched their parents priorities reported a significantly higher number of teaching related activities than the mismatch group did ($z = -3.7855$, $p < 0.005$).

Table 14. Results of measures taken as indicators of parental involvement

	MCH mismatching group ($n = 15$)	MCH matching group ($n = 11$)	CBR group ($n = 27$)
No of Teaching-Related Activities (m)	4	9	10
Attendance Rate (n)			
Low (a)	10	1	
High (b)	5	10	
Enthusiasm Rate (n)			
Cooperative	2	8	
Not Cooperative	13	3	

m = *median*

n = *Number*

a = *Number of mothers who attended less than 60% of scheduled sessions in the MCH centre.*

b = *Number of mothers who attended 60% or more of scheduled sessions in the MCH centre.*

Additional measures

Analysis of results revealed a significantly higher rate of attendance at the weekly sessions among mothers of the MCH whose children's programme matched their priorities than those whose children's programmes were not matching their priorities (Fishers Exact test p = 0.005). Similar results were obtained in regards to rating of parent enthusiasm. Professionals of the MCH centre rated the former group of mothers significantly more cooperative than the latter group (Fishers Exact test p = 0.003).

Table 15. Relation between level of mother education and programme matching.

		Mothers Education		
		Illiterate	*Educated*	**Total**
Programme Matching	● *Programme Mismatch*	9 (56.3%)	6 (60%)	15
	● *Programme Match*	7 (43.8%)	4 (40%)	11
Total		16	10	26

Mann-Whitney U test revealed that the level of mother education has no effect on the number of teaching related activities (p = .314). Also, results of the X^2 test showed no significant relationship between mothers education and programme matching (Fishers Exact test p = 0.58). As seen in Table 15, 60% of educated mothers have mismatched programmes, while 56.3% of the illiterate mother have mismatched programmes.

All these results strongly support the hypothesis of this study and suggest that parents are more involved in teaching their young intellectually disabled children when the educational and developmental programmes are designed according to their priorities rather than suggested by professionals.

4.6 Post Hoc analysis

Post hoc analyses were performed to investigate the association between change in progress quotient and variables which could have future practical implications for the programmes, especially to see whether a particular programme is more effective in a particular age or sex group. Associations among five main variables (child age, gender, mother education, presence of other disabled siblings, birth order and entry level of disability 'progress quotient baseline') and the change in progress quotient were examined and are presented in Table16, 17 and 18.

Table 16. Correlation of level of disability before the intervention with the change in progress quotient for all groups.

		Progress Quotient Baseline	
		r
Change in	• **CBR**	-.07
Progress Quotient	• **Outreach**	+.12
(pre x post)	• **MCH**	-.27
	• **Control**	-.11

*** $p < 0.001$ ** $p < 0.01$ * P< 0.05

The analysis revealed no statistically significant correlation between the progress quotient baseline and child progress. Thus, children of all levels of disabilities were equally likely to make progress.

Table 17. Mean 'Progress Quotient' change during the first year of intervention for each group by age group. (Number of children in brackets)

	Age Group per months		
	24 - 71	**72 - 119**	**120 +**
CBR	.67 (8)	.62 (12)	.43 (7)
Outreach	.62 (6)	.39 (10)	.38 (6)
MCH	.03 (10)	.20 (9)	.12 (7)
Control	-.15 (10)	-.01 (9)	.00 (9)

Table 18. Two-way analysis of variance of change in progress quotient by intervention group and age.

Two-Way ANOVA	**Group Effect**	$F_{3, 93} = 77.36$	$P = .000$
	Age Effect	$F_{2, 93} = .976$	$P = .381$
	Group x Age Interaction	$F_{6, 93} = 3.66$	$P = .003$

Two-way analysis of variance of change in progress quotient by intervention group and age (see Table 18) showed a significant group effect and a group by age interaction. CBR and Outreach showed improvement in all age groups. This is in marked contrast to the MCH and control groups. In the age group 24-71 months, MCH had no effect on progress while control children if any thing deteriorated. In children over 72 months MCH had a small effect and control children showed no change. Both CBR and Outreach were highly effective in children in the youngest age group. CBR maintained this in children aged 72-119 months, but Outreach seemed slightly less effective. For children older than 120

months both groups had a similar effect, but less progress was made than in the younger age groups.

This post hoc analysis raises interesting questions about the comparative efficacy of the programmes on children of different ages, but the results should be interpreted with caution since the numbers are small.

Finally, two way analysis of variance on child progress were also performed with intervention group as one factor and gender, mother education, birth order, disabled siblings as the second factor. All these analyses found, as expected, a group effect but no effect of the second variable or interaction. This indicates that change in group was not related to gender, mother education, birth order or the presence of disabled siblings.

Therefore, after investigating several possibilities which could have future practical implications for the programmes, we find that only the child's age could be considered important in deciding which programme work better.

5. Discussion

The focus of this study has been to compare the outcomes of three early intervention projects in the slum areas of Cairo and Alexandria. The main difference between the three projects lies in the role of professionals and parents in the intervention. In the CBR project, professionals are behind the scenes, training, supporting and backing up the work of the local community workers. They work in partnership with the local community and are aiming especially at empowering parents of disabled children. The CBR intervention is designed and planned in a way that will ensure future sustainability and achieve maximum independence from outside support, relying on local resources to run the project. In both the Outreach and MCH projects, services are provided mainly by professionals, but the Outreach project is community-based, whereas the MCH project is centre-based.

5.1 Child Progress

5.1.1 Initial Impact

During the first twelve months of the interventions, pre- and post-test comparisons using progress quotient were suggestive of positive programme impact. Children of all intervention groups showed accelerated rates of progress while the progress quotient of the control group declined. The progress of the CBR and Outreach groups was much higher than the MCH. The progress in the CBR group was slightly better than the Outreach group but the difference was minimal.

Although the rate of progress of the CBR and Outreach groups continued to accelerate (i.e. increased above baseline rate), it did so less rapidly during the follow-up period. The rate of improvement dropped to half that achieved during the first twelve months of the

intervention. On the other hand, the MCH group did not further improve in mean progress quotient during the follow-up period, simply maintaining the gains already achieved.

These findings suggest the superior success of the home-based projects, CBR and Outreach, in comparison with the centre-based one, the MCH, in terms of direct effect on child progress. This finding is of great importance as it is the area which is the particular focus of centre-based interventions, ie. the learning of new skills by children.

When the two home-based projects were compared, the CBR group showed a slightly higher rate of acceleration of progress than the Outreach group. This can be taken as support for the CBR approach of services provided mainly by community workers, and only backed up by professionals, as opposed to the Outreach approach of services provided by professionals.

Age effect

While no association was found between gender, mother education and the presence of other disabled siblings and the degree of child progress, post hoc analysis did raise interesting questions about the comparative efficacy of the interventions with children of different ages.

The CBR and Outreach projects showed improvements in all age groups. However the MCH project appeared to have no effect on progress for the youngest children, aged 2-5 years. This result while further confirming the efficacy of the CBR and Outreach approaches, in comparison to the MCH one, has added weight because in theory the MCH approach is more specialised and the staff should have more expertise with the youngest children.

The 6-9 years age group improved in both the CBR and Outreach projects, though the rate was very much higher in the CBR group. This could be interpreted in terms of the positive impact of CBR on the social life of the disabled children who start at that age to have more interaction with family members and the outside society, and thus have better

access to learning opportunities. The MCH group showed a minimal improvement while the control group did not change.

For children aged 10 years and older, the CBR and Outreach approaches both had a similar effect but the progress was slower than in the younger age groups. This might suggest that, in general, home-based interventions are more effective in younger age groups than older ones. However, these interpretations should be considered with caution since the numbers involved are small.

5.1.2 Follow-up

The follow-up period witnessed the withdrawal of direct professional input in the CBR project. This major change was accompanied by a drop in rate of child progress in comparison with the initial period. Despite this drop, the rate of progress of the CBR group continued to be accelerated above baseline suggesting that child progress in this group can be maintained for at least six months without the professional input through parents and local resources.

Moreover, a similar drop occurred in the Outreach group, while the professionals continued to provide their services as before, suggesting that the slowing down in rate of progress in the CBR group may be due to reasons other than the withdrawal of professionals. Most probably, the progress rate shown during the follow-up period is the more realistic one, while the high rate of progress seen during the initial period is an unsustainable one.

Two main factors could contribute to this unexpected initial gain. The first one is the effect of *previous deprivation* which is very common in developing countries, where negative attitudes and lack of awareness contribute in the isolation and neglect of disabled children, and undermine any learning or training opportunities. The second factor is the *initial enthusiasm* which is usually aroused in parents, community workers and local people at the beginning of such projects but fades out in time.

Therefore, the drop in the rate of acceleration of child progress in the CBR group during the follow-up period is likely to be due to factors other than the withdrawal of direct professional input. This finding reinforces the claim that child progress in CBR programmes can be maintained independently, through parents with the support of their local community.

5.1.3 Measurement Implications

As no other appropriate Egyptian developmental tests are available, the Griffiths and the Receptive- Expressive Emergent Language Scale (REEL) tests were used to assess child progress. All western assessment tools have items which are not culturally appropriate in Egypt. Despite the attempts to modify or to exclude such items in the Griffiths test, it remains inadequate and cannot be recommended for further use without standardisation. The same applies to the REEL but to a lesser extent, as it covers only the first three years of communication and language in child development, which are less culturally dependent and more or less universal.

The Griffiths is a sophisticated test that needs standardised materials, and therefore cannot be simplified for use at a local level. Also, the use of the Griffiths tests is restricted to those who have had formal training through recognised bodies available mostly in Britain. Very few professionals are qualified and trained to use this test in developing countries.

The lack of assessment tools necessary for objective evaluation and suitable for local use, is one of the challenges that must be taken up by professionals in developing countries. Devising appropriate tools for use in CBR programmes, or standardising the most relevant available ones, should be seen as a priority task for those working in academic institutions in developing countries. It would be a major contribution to the advancement of CBR, essential if reliable and accurate results are to be obtained.

5.2 Parent Attitudes

5.2.1 Initial impact

After the first twelve months of the study, overall positive changes in parental attitudes were seen in all intervention groups. Unlike the findings in child progress, the CBR project had a significantly greater positive impact on parental attitudes than did the Outreach project. The latter showed a similar level of positive change to the MCH group, while no change was detected in the control group.

These findings suggest that the CBR approach produces better results in terms of changing parental attitudes than the other approaches. The reasons for this might lie in the aim of the CBR approach to mobilise and involve all family members, neighbours and the local community in the rehabilitation programme for the disabled child. It also aims to empower parents of disabled children to take over the responsibility of the project in conjunction with their local management group. In particular, parents in the CBR project were encouraged to be more involved in the rehabilitation of their disabled child by working on tasks which matched their own priorities. It is probable that a combination of all these aspects of the intervention resulted in a more positive attitude among CBR parents than amongst parents of the other projects.

Despite the changes in parental attitudes, the level of anxiety of parents about the future of their disabled children was not changed in any of the groups. This finding can be interpreted in many ways. It could be that the parents did not feel fully supported by the limited services provided only once per week, and that a formal structure could not alleviate the load and share in their responsibility for their disabled child in the future.

In all the projects, the question most frequently asked by parents which reflected their anxiety about the future of their child was: "What will happen to my child after my death?" None of the projects offered a satisfactory answer to this question or even had a plan to address this need in the future. Parents of all three groups felt that all the responsibility for the training and teaching fell on them and their family members, with neither their local nor

wider community sharing in this. Even the local support available in the CBR programme is based around the assumption that the responsibility for the disabled child is and will remain with the family.

The study also revealed that the CBR and MCH interventions had a positive effect on 'parental adjustment' but the Outreach intervention did not. This might be because the Outreach programme focused more on the child and less on the parents. Also, the intimate relations which were easily developed between the community workers and the CBR parents could have contributed to their improvement in adjustment. The finding that the MCH project produced positive effects and the Outreach project did not, even though both provided services through professionals, should be interpreted with caution. However, it should be noted that the actual change although statistically significant, was small.

5.2.2 Follow-up

The follow-up period witnessed no change in any of the groups. This could indicate that the positive changes in parental attitudes occur mainly during the first year of the intervention and the continuity of the interventions during the following six to eight months only preserve the previous gains. This finding has particular relevance to the CBR programme as it demonstrates the potential of the CBR programme to be self-sustained after the withdrawal of the professionals.

5.2.3 Measurement Implications

The Short -form of the Questionnaire on Resources and Stress was chosen for use in this study because it seemed to cover the aspects of parental attitudes that needed to be examined, and it proved its efficacy. Despite the lack of local standardisation, the fact that the instrument detected no change in anxiety levels of parents about the future of their disabled child in all the groups, reflected the sensitivity and suggested the 'validity' of the instrument.

The researcher and the external evaluator found the instrument easy and fast to administer, and especially easy for parents to understand. One of its major strengths lies in its "one answer" form: 'yes' or 'no'. This avoided hesitation and confusion, plus the prompting normally involved with this type of questionnaire, especially when administered to illiterate mothers. These factors make this instrument widely applicable for use by local community workers in CBR programmes.

It is highly recommended that this tool be standardised in developing countries and be used more extensively in the evaluation of CBR .

5.3 Family Support

5.3.1 Initial Period

Investigating the sources of local support available to families in the study, and the extent of helpfulness of those mobilised, revealed a similar pattern of results to those of parental attitudes. CBR parents reported the highest level of perceived support from their local communities after the first year of the intervention. The positive change in total scores of helpfulness of the CBR parents was more than twice that reported by the Outreach and MCH parents. The latter two groups showed similar levels of positive change, while no change was detected in the control group.

5.3.2 Follow-up

Furthermore, by the end of the follow-up period parents of all intervention groups reported nearly no changes in comparison to the initial period. There was no difference in the total number of available resources and in the perceived helpfulness of formal sources. The only significant gains were in scores of total helpfulness for the Outreach group and in the perceived helpfulness of informal sources for the MCH group, and these were caused by a minimal gain in scores of less than 'one'. Thus a change which is statistically significant in the results, may not reflect a clinically important change in resources.

No change in scores was detected in the CBR group during the follow up period. Thus the CBR programme succeeded in maintaining the previous gains despite the partial withdrawal of professionals, which might have been considered a major source of formal support during the initial period.

5.3.3 Implications

The difference between the 'CBR' and 'Outreach' approaches

The findings on family support reflect one of the major strengths of the CBR approach. The CBR approach attempts to remove the physical, attitudinal and social barriers which prevent the full participation of disabled persons in their societies, as outlined by the social model of disability (Coleridge. 1993). Therefore, the CBR programme focused its intervention equally on three elements of a triad: the disabled child, their family and their society. Positive change of attitudes, and the mobilisation and involvement of local resources were seen as crucial in achieving that aim.

In addition, the CBR programme was working towards *empowering* parents of disabled children to work more confidently with their children and to take over the responsibility of running the project as part of its local management group. Again mobilising all sorts of sources of family support, whether formal or informal, was considered indispensable for the empowerment process.

Hence, these expected findings reflect a major difference between the CBR and Outreach approaches. The former is mainly working towards the establishment of self-sustainable projects depending on mobilised local resources with minimal support and back up from external resources. On the other hand, the only prospect for future sustainability of the Outreach programmes (and MCH as well) rests on the continuation of services provided by external resources. This is further discussed below.

Family Support: a 'Process' or 'Outcome'?

Mobilising local sources of support for families of disabled children can be considered in two different ways in community rehabilitation programmes. It can either be seen as a goal in and of itself and hence be evaluated as an 'outcome' measure, or as a 'process' which eventually leads to the achievement of the more concrete objectives in the project. From the experience of this research, it is suggested that mobilisation of local resources should be considered as an 'outcome' in itself. It is easier understood by local people as an objective of the project, and by considering it as an 'outcome', it will be emphasised more by community workers during the implementation of the project.

Measurement Implications

In using the Family Support Scale to measure the level of family support in this study, its value as an assessment tool was realised. From the practical experience of using the tool,

the researcher realised its relevance and appropriateness for use, as a management tool in CBR programmes.

The tool is straight forward and easy to understand and can be carried out by local staff. It is flexible in its administration as it allows modifications, that is addition or deletion of items to fit the nature and type of support available locally. It lists and clarifies the most frequent formal and informal sources of helpfulness normally available to parents, in addition to the possibility of adding some items which reflect the sources of support specific to the project setting where the tool is to be used.

Results are easy to analyse and interpret. They reflect, to an extent, the strengths and weakness of a projects. As a management tool, it can be very useful for project planning as it lists all the possible sources of support. This assessment scale is highly recommended for use as a monitoring and recording tool in CBR projects.

5.4 Parent Involvement

5.4.1 Parent Involvement discussion

This aspect of the study is of particular interest, as it was an attempt to investigate one of the major processes which lead to better outcomes in early intervention programmes in general, and CBR in particular.

The question investigated was whether working on a programme that is based on parent priorities will lead to greater involvement of parents in the training of their child, or whether it is merely a strategy of the CBR project management aimed at future sustainability.

As all the CBR parents worked on programmes based on their own priorities, the investigation centred on the MCH group. Here the professionals of the governmental

health centre suggested, or even imposed, the child's programme for implementation at home. Therefore, parents in the MCH project were classified into groups according to whether their child's programme matched their own priorities.

Results were strongly supportive of the CBR approach to working with parents. The MCH parents who had programmes matching their priorities showed a much higher level of involvement than those working on programmes that did not match their priorities. There was evidence of a high number of teaching-related activities, taken to reflect a high level of involvement, by two groups of parents: firstly the CBR parents, and secondly the MCH parents who were given a programme that matched their priorities. The latter group of MCH parents also showed a higher rate of attendance at weekly sessions, and were rated by the MCH professionals as having a higher rate of enthusiasm towards their teaching and involvement with their child than the other MCH group.

These results reflect one of the major features of the CBR approach, i.e. the emphasis on parental empowerment and regarding parent involvement as crucial in the training and teaching of the disabled child. It stresses the importance of transferring the required knowledge, skills and simplified technology to the parents. The CBR project in particular involves parents in assessing their children and deciding on the appropriate rehabilitation programme for them. This is seen by the project management as an essential process to ensure future local independence and sustainability.

Also, this finding suggests that allowing decisions about the child's training programme to be made in partnership with parents, and working according to their priorities, could result in greater levels of parental involvement in any programme, providing that the tasks set are realistic.

5.4.2 Measurement Implications

Measuring the extent of parental involvement in the rehabilitation of their disabled child is extremely important but at the same time very difficult. As stated earlier, none of the tools developed in the West were found to be culturally appropriate in developing countries. Hence there was a need to develop a method suitable for this study in Egypt, and for potential use in other CBR projects, in similar settings, with the necessary modifications.

During the administration of the three stage method that was developed for the study, the researcher realised further advantages which made it useful as a management tool outside of the research frame. It has in fact been widely used in the CBR programme, since the end of the study period and has proved to be very helpful and effective.

It was felt that the *first stage* of the procedure, where parents identify their own priorities, was useful for training and helping parent to identify realistic goals to be achieved in the following weeks.

Parents were found to be more interested in hearing and learning about the normal pattern of child development and the various related training methods, when it was within a discussion about their own child. This was also true when discussions were on an individual basis, rather than group discussion or in parent training which took place during the weekly club.

The *second stage* of the procedure, where a rating was made of the extent to which programmes match parent priorities, was very helpful in documenting parent priorities, and allowed the project coordinators at a higher level to discuss the appropriateness of the programme design with the community workers and parents as well. It was also found very useful for discussion during the staff and parent training programmes.

The researcher realised that the *third stage* procedure, which involved counting the number of teaching related activities through a detailed and thorough description of the

daily life activities of the disabled child and the relevant activities of family member, had many advantages:

- It allowed the researcher to discover many details about the daily life activities of the disabled children and their families which could be used in the programme design and as a sources of suggestions for teaching activities for the disabled child.

- It provided a documentation of the daily life activities of the disabled child and family members which was useful in supervision, as well as in discussions in staff meetings and training. It could also be used in later analysis of content, and in comparing family involvement and child progress at different time intervals.

- It provided a wide range of information which was helpful in the formulation of better approaches to family involvement.

- It revealed many misunderstandings and malpractice in the training of the disabled child which greatly affected the efficacy and outcome of the training programme, especially relating to behaviour management.

- It provided a good medium for a practical training of family members based on their involvement and practices during the previous day.

Although this assessment method proved to be very informative and easy to administer by a community worker, it did have some shortcomings. The main problem was one of recall. Some of the mothers were not precise enough in their descriptions, or did not remember all the details needed to count an activity as a teaching one. The other problem was the absence of the mothers for any reason, as some were not present for the majority of the time with their child. Other recognised weaknesses were the lack of established validity and reliability of this method. However, it is felt that the many advantages outweigh the disadvantages and this tool is highly recommended to be used as an integral part of CBR programme planning and implementation and evaluation.

5.5 The approach adopted to evaluate CBR in this study

As a reminder to the reader, it should be noted here that a great deal of the discussion on CBR evaluation in general, and in this study in particular, is presented in the literature review chapter. This was done to allow the reader to fully understand the reasons behind the approach that was adopted in this comparative study.

The literature review, suggested the adoption of a mixed approach to evaluation of CBR in general. An approach which combines; participatory with objective methods, quantitative with qualitative methods, outcome with process methods, and finally long-term with short-term methods. It was recognised that all methods have strengths and weakness and it was suggested that a successful combination and coordination of the different techniques could provide accurate and complete information. Suggestions about the nature of this combinations were also made, where different methods serve to check and balance each other.

These general recommendations were followed by a discussion about the current stage of development of CBR, and its implication for the evaluation methods that have to be used. This discussion concluded that what is needed in evaluation at the present time does not reflect exactly the recommendations made.

It is important to highlight that the methods used in this evaluation research were not developed with the primary intention of representing a model for satisfactory evaluation of CBR. Manstead and Semin (1988) made the obvious (but often neglected) point that the strategies and tactics selected when carrying out a piece of research depend very much on the type of research question you are trying to answer (Manstead & Semin. 1988). The purpose of this research was the comparative evaluation of different intervention approaches, rather than evaluation of the CBR programme itself. Furthermore, the selection of the programme aspects to be evaluated, and the outcome variables to be measured also depend on the comparison nature of the study. This comparison was confined to the outcomes variables common and appropriate to all three programmes.

Moreover, the methods selected in this research were subjected to practical constraints as implementation was carried out mainly by a single-handed researcher, restricted in time and resources.

Therefore, the approach adopted to evaluate and compare the three projects in this study was a quantitative one to allow for objectivity, with a longitudinal research design to detect sustained effects. It included a broad range of outcome measures impact on child progress, impact on parental attitudes, and extent and degree of helpfulness obtained from mobilisation of local support, resulting from the programmes. Process evaluation was also included by examining which programme characteristics made one programme work better than the others.

5.6 Implications for Future Evaluation

The results of this study strongly suggest the efficacy of the evaluation approach used, particularly with regard to certain aspects of the CBR programme. Overall the comparison with other programmes emphasised the superiority and highlighted the strengths of the CBR approach.

The quantitative methods adopted in all aspects of the evaluation successfully answered the research questions posed, and proved to be informative, clear and reliable. Moreover, with the exception of the Griffiths test, all the measurement methods and tools selected were found to be easy to use at the local level and suitable for incorporation into any CBR evaluation.

In particular, the quantitative assessment of parental involvement showed the potential of this approach for measuring the 'process' and not just the 'outcome' of intervention.

The need for qualitative data

The 'hard data' gathered by adopting quantitative methods provided only limited interpretations. It failed to describe the properties and characteristics of the programme concerned. It examined only what was intended for investigation and did not explore the strengths and weakness of the innovations. Moreover, we can only use the hard data to speculate about what actually happens as a result of the programmes.

Therefore, it is strongly recommended that future comparative evaluation studies provide some qualitative data on at least one aspect of the programmes involved. However, if studies only intend to concentrate on the evaluation of one CBR programme, then a mixed, balanced approach combining both quantitative and qualitative methods should be used.

The need for a longer 'longitudinal study'

Although this study followed a longitudinal design, it was only for a limited time. The long term impact of CBR on a disabled person is a major indicator of its success. However, in such a short time only certain aspects of this impact can be assessed. Therefore, it is strongly recommended that the period of the follow-up be extended as much as possible. It should be noted that the researcher is intending to continue the follow-up of the groups included in this study for a longer period.

The need to investigate the administration of assessment tools at a local level

The claim that all the assessment tools and methods, except the Griffiths test, were found to be easy to use, both in evaluation research and by local workers. However this claim is based on the subjective opinion of the independent evaluator and the researcher.Further investigation is required into their feasibility and efficacy. This could be done by comparing results from community workers and professionals to examine the reliability of their scores.

The need to compare CBR with centre-based daily services

Although this study showed the superiority of the CBR approach in comparison to a centre-based programme (the MCH), critics of CBR could argue that services provided only once per week in a centre do not represent the centre-based approach. Some critics are still convinced that special education schools, day care centres, and traditional services are the best solution. Therefore, there is an urgent need to develop some comparative evaluation research to compare CBR with traditional services, especially as there is still no comparative evidence to favour one or the other, especially in terms of cost and coverage.

The need to include a measure of behaviour

Despite recognition of the extent of problems created in families by an intellectually disabled child with behaviour problems, and the importance of measuring the impact of rehabilitation programmes on the management of such behaviour, this aspect was excluded from this study because all the western tools considered were inappropriate for use in Egypt. Assessment tools for behaviour problems are particularly culturally dependent and locally adapted tools can yield misleading results. While the researcher recognises this limitation, locally developed tools are still strongly recommended for inclusion in the assessment of CBR programmes, especially for use with people with intellectual disabilities.

The need to compare parental involvement in CBR and Outreach projects

The MCH group was used to investigate the effect of working on a programme which matches parent priorities on the level of parental involvement. The reason for selecting the MCH group is that a range of programmes had been drawn up which matched and mismatched parent priorities, in addition to being in a centre-based project where the contact with parents is minimal.

However, results showed that the real competition was between the CBR and Outreach projects, and it would be interesting to know the extent to which the rehabilitation programmes in the Outreach group matched parent priorities and the consequence of this on their degree of involvement. The results of this would be relevant to the debate on CBR versus Outreach, especially with regard to the issue of sustainability as discussed below.

5.7 Implications for future practice

The results of this study have revealed the superiority of the home-based CBR and Outreach programmes in comparison to the centre-based MCH one. This result was expected as the MCH project is only the first stage of the CBR programme in Alexandria, and is more concerned with the training and orientation of professionals in preparation for the implementation of the CBR project in the second stage. This was explained earlier in the introduction chapter.

It could be said that the true investigation was actually a comparison between the CBR and Outreach programmes. These represent two entirely different approaches and many people still confuse the two terms. The following section attempts to clarify the major differences between the two approaches in the context of a discussion about one of the most important, but problematic issues in regard to rehabilitation programmes: *the role of professionals* and *sustainability*.

5.7.1 The role of professionals

As emphasised in the Introduction chapter, the role of professionals is crucial to the success of CBR. It could be said that the major differences between the CBR and Outreach projects is how the professionals actually intervene in such programmes. The role of professionals and specialised centres in modern CBR is entirely different from their role in traditional approaches to rehabilitation.

Until now the complex role of professionals in CBR has not been explained clearly in terms of operational objectives. The author has thus drawn up a set of detailed recommendations to address this, with a view to their incorporation into overall project aims and strategies, at the service planning stage. The SETI centres in Cairo and

Alexandria are currently attempting to follow these guidlines as part of their role as a model for other CBR programmes, and are including them on their training courses. The recommendations for special roles of professionals compared with those of the CBR workers are as follows:

5.7.1.1 Recommendations

1. Promoting implementation and expansion of CBR programmes at the local level:

- Spreading the concept, philosophy and strategy of work of CBR among other professional and specialised centres through meetings, seminars, conferences, training courses and media.

- Initiating, supporting and backing up local CBR projects by working in partnership with local people, disabled persons and their families.

- Providing guidance and technical assistance to local organisations wanting to set up a rehabilitation programme in their area.

2. Supporting the management of local CBR projects:

- Mobilising existing national, provincial and district resources to support local CBR projects.

- Involving and gaining the support of government and local authorities in CBR programmes.

- Promoting multisectoral collaboration and coordination especially between GOs and NGOs, international, national and local organisations, as well as between different ministries involved in the CBR programme.

- Creating links between local projects and district and national resources, as well as with referral services.

- Assisting the local management in the planning and evaluation of their CBR programme.

3. Training and teaching:

- Training of CBR workers and local people involved in CBR programmes.

- Planning and re-designing the curriculum for the training of all disciplines involved with disabled people and their families.

- Providing existing professionals with the knowledge and skills needed to fulfill their new roles in the context of the CBR approach through refresher courses and in-service training.

- Providing practical training opportunities in the specialised centres to trainees from various training institutions.

4. Simplification of technology:

- Simplification of the advanced technology, making it available to people at the local level.

- Manufacturing and providing low-cost appropriate equipment, aids and toys needed in the rehabilitation programmes.

- Supporting local CBR projects to establish Low Cost Workshops (LCW) to cater for the needs of local disabled people.

5. Providing high-tech rehabilitation services:

- Providing specialised services not available at the community level, to referred disabled people.

- Working with people with severe disability, e.g. people with severe cerebral palsy, autism, severe communication problems, or multiple disability.

- Assessing and confirming diagnosis in difficult situations.

6. Producing printed and audio-visual materials:

- Producing simplified materials for use at the local level. This could include teaching or awareness rising materials eg. slides, video-films, posters, booklets, brochures, etc.

- Developing printed and audio-visual materials to address training needs and raise awareness amongst professionals and trainees.

- Documenting models of good practices in rehabilitation programmes.

- Working towards dissemination, and sharing of information and experiences.

7. Supporting and empowering disabled people and parents of disabled children:

- Providing support and guidance to disabled people and their families.

- Informing disabled persons and their families of the services available, and facilitating their access to these services e.g. counseling, therapy, medical care, allowances, loans, pensions, grants, ect.

- Setting up and supporting disabled people or parent organisations, associations or groups at local, national and international level.

- Providing various forms of training to disabled persons or parents of disabled children.

8. Protecting the rights of disabled people:

- Informing disabled people and their families about current laws and legislation, and of their rights.

- Lobbying and pressurising government to issue new laws and legislation to protecting the rights of disabled people.

- Advising legislators on technical aspects of new laws.

9. Changing the attitudes of the public and other professionals:

- Organising public awareness programmes and campaigns through media; International Day of Disabled People, special Olympics, marathons, festivals, school activities, special events, etc.

- Enabling their colleagues to value and support disabled people and parent organisations and groups.

- Recognising and 'valuing' opinions, knowledge and skills of disabled persons and parents of disabled children.

- Encouraging and supporting other specialised centres and professionals to adopt similar roles and approaches to rehabilitation in their services.

10. Advancing knowledge about CBR :

- Encouraging and facilitating scientific research and publications.

- Organising national and international scientific events aimed at exchanging information and advancing knowledge on CBR e.g. conferences, seminars, workshops, or meetings.

If professionals involved in CBR correctly understand what their role should be, and confie their intervention to the supporting activities outlined above, then projects would have a better chance of sustainability. In addition, the professionals would be able to expand services, both by reaching a greater number of children and by setting up more projects.

5.7.2 Programme Sustainability

The following discussion considers the implications of the study findings in the context of a general discussion on programme sustainability. It will be followed by the suggestion of some strategies which can be adopted in the initial phase of any CBR programme to facilitate its future sustainability

One of the major differences between the CBR and Outreach approaches is the extent of dependence on outsiders. The CBR approach aims to mobilise and later on to rely on local resources to run the project. Although this is a problem area for CBR with many CBR projects still dependent on external resources, the approach provides a much better prospect for future independence than does the Outreach one, which will always need outside support.

This dependence on external support makes programmes vulnerable to collapse and raises concerns about their sustainability, as project initiators are unlikely to provide financial and technical support indefinitely.

While acknowledging that support from outside the community is a constant need, any CBR project should be aiming to achieve self-sufficiency and independence with a *minimum of external support* to ensure its sustainability. This is only achieved by using community resources.

Programme sustainability can only be considered a realistic goal if the project can be *owned by the community* and by using and depending on its local resources.

Therefore, CBR project initiators should carefully design and implement their interventions, especially during the initial phase as discussed below, to maximise the mobilisation of local resources in an attempt to minimise the extent of external support needed by local people to sustain their project.

5.7.2.1 How important is the initial phase?

To answer this question, it is necessary to analyse the different sort of activities which normally take place during the initial phase of a CBR programme. In theory, these activities can be classified into two categories: one group of activities which directly affect the disabled child, their families and their local community, and a second group of activities which affect these target groups only indirectly.

The first group of activities are best described as relating to *direct service provision.* These activities include :

- weekly home-based training sessions,

- parent training,

- provision of aids and equipment,

- transferring the simplified rehabilitation technology to local people,

- establishment of an effective referral system and other relevant services.

This group of activities represents the type of services which in an Outreach programme are normally offered by professionals, whereas in a CBR programme, the aim is to offer the same services through local resources.

The second group are activities which do not directly affect the target groups, but constitute *support activities* and form the backbone of the project. They comprise those activities which distinguish a CBR programme from an Outreach one. Such activities include:

- working in partnership with a locally identified body which should take over the responsibility of running the project after the withdrawal of the outside initiators.

- involving disabled people or their families in decision-making and setting up a local association or group.

- establishing a local steering committee with representatives of the different sectors involved, as well as the beneficiaries.

- getting the approval and support of local authorities and resource persons.

- establishing a sound management scheme and providing training to local people in managerial skills.

- community awareness and education programmes.

- mobilising existing resources.

This category includes the kinds of support activities which build a sense of ownership over the project among local people, and thus lead to its sustainability and self-sufficiency.

Many community oriented projects have deliberately focused in their initial phase on *service provision* and had less emphasis on *support activities*. These projects were based on the belief that good service provision would lead to satisfaction of the beneficiaries, and this would in turn bring about greater potential for sustainability of the project.

It has been argued that any project should have a strong start, with a big push at the beginning so that positive results can be perceived and realised as soon as possible. This initial success could facilitate and encourage the involvement and contribution of local and governmental authorities, as well as other local resources. Moreover, it could facilitate fund raising and financial contribution from beneficiaries and the local community.

Furthermore, it could be argued that parents will never become involved in the rehabilitation of their disabled child if they have a negative attitudes towards their child. Therefore, by focusing the intervention in the initial period on changing parent attitudes, mainly by seeing their child progressing as a result of professional intervention, positive parent attitudes can be nurtured. Of course this argument could be counteracted by the findings of this research that suggest that community workers could achieve similar, if not greater, results if given the training and self-confidence to do so.

However, the reality is that many beneficiaries and local people see themselves as *the targets* of the project and not part of it. They are grateful and appreciate any sort of help offered but gradually they become *passive receivers* of these services, and this can particularly affect the self esteem of disabled people and the parents of disabled children.

This leads to the development of a negative perception among local people towards the project as a whole. They perceive it as a project *owned, controlled* and *run* by a *foreign organisation*. This development is totally against the philosophy of CBR. A project at this stage should confine itself to being an 'Outreach' project.

The same could happen to the community workers and volunteers who are guided and controlled by this external organisation. They may feel obliged to refer to and report to them rather than to the local management.

Some professionals advocate the importance of starting to provide services themselves, in order to understand what is meant by working in the community and what the reality of such work is. This allows them to gain the experiences necessary to guide and support the community workers in the future. This argument is supported by the fact that the majority of professionals are from educated social groups and are therefore alienated from poor local communities. The communication skills needed to establish a rapport between themselves and local people are essential if working partnerships are to be established. However, the result of this may be that, after experiencing the high level of professional services offered by external project personnel in the initial phase, many disabled persons and their families will no longer accept the services if provided by local workers.

Thus it can be seen that the initial phase of a programme is crucial to its future success, and it seems as though the path chosen at the initial phase is irreversible once embarked upon, and therefore must be planned with the utmost care.

5.7.2.2 Is it possible to convert an 'Outreach' programme to a 'CBR' one ?

Many of the issues discussed above are reflected in the experience of SETI centre programmes. The Cairo community oriented programme started at a time when the whole concept of CBR was very new in Egypt. As mentioned earlier in the introductory chapter,

the staff members acted in accordance with their understanding of CBR, which at the time put little emphasis on the need to train community workers. They believed that their role was mainly to deliver the services through involving family members in a home-based rehabilitation programme for their disabled child, and to create some community activities.

The programme ended up with a form of 'Outreach' rather than 'CBR'. SETI staff provided a high level of therapy to the disabled children which in turn created high levels of interest and commitment from parents.

The philosophy behind the launching of the community oriented programme, which is outlined here, was to create a pool of dedicated experienced professionals, from which a core could be formed to launch different community oriented programmes across Egypt. Therefore, the focus was more on gaining experience and the building up of this group, as well as serving the local communities.

Moreover, in the 1995 programme review (Coleridge, Shukrallah, Isakov, Sebeh, & Kabesh. 1995), it was emphasised that the significant impact on disabled children which created high levels of commitment from parents, could be considered a threat to project sustainability if not maintained at the same level. The review P.53 warned that... "if the emphasis on individual attention through home visits diminishes, there will be a drop in the improvement of children with the probability that interest and commitment from parents will fall off".

In other words, it was recommended to continue to provide the high levels of education and therapy for children to keep the interest and commitment of parents, if projects are to be sustained. However, this recommendation was made at a time when SETI management was trying to gradually withdraw from projects, and the major problem being faced was how to maintain the same level of technical therapy, as provided before by SETI professionals, through the new community workers.

While being the pivotal issue, the problem of withdrawal without a loss in the level of services, was not the only area of concern. The review highlighted many other problems which affect the prospects for future sustainability and thus the chances of conversion to a CBR approach:

1. The projects depend mainly on SETI. The prospects for technical, financial, and administrative sustainability in each area without SETI are not good.

2. The local ownership of only one of the three outreach projects is a problem. One project operates entirely out of a Caritas facility which is not owned by the community, and the other operates from the premises of a local society but these are owned by the Italian Embassy and therefore do not offer a good long-term prospect.

3. No parents' association has been formed in any of the three areas. The likelihood of setting up such associations is not good, due to legal and bureaucratic obstacles.

4. There are no local bodies to hand over the projects to. The review stated "..it seems that the problem of devolution to a local body has not been considered strategically by SETI" P.56. The financial dependency on SETI seems likely to remain as long as there is no ownership by the community.

5. There has been no systematic situation analysis in any of the areas, and it seems that little use has been made of existing facilities and resources in the three areas. The review added :"The programme is now faced with the difficulty of building links with other services from a situation where it has been operating in comparative isolation" P.57.

This experience shows how difficult it is for a programme that was initiated as 'Outreach', to be converted to CBR. However this is assuming that it is always desirable to convert Outreach projects to CBR. Although the CBR programme showed superiority over the Outreach one, one should not neglect the importance of the latter type of programmes in

settings where parents or families are not available, or in cases of severely impaired

children, or in areas where the CBR approach has been tried without success.

5.7.2.3 Implications of the study for the initial phase of a CBR project

One finding of the study relevant to this issue is the notable drop in the acceleration rate of

child progress after the first year of the intervention. As discussed earlier, this would

suggest that the rate of child progress seen in all three projects during the follow up

period, is in fact the true reflection of the interventions, while the initial 'jump' in the rate

of progress is probably due to previous deprivation and the initial enthusiasm for the

project.

These findings could have a significant impact on the planning and organisation of

activities during the initial phase of a CBR programme. If these findings are replicated in

future studies, then project planners can be assured that disabled children will progress just

by being part of a programmes, even if they are not the sole focus of the programme.

Furthermore, these findings should help to convince professionals that the sustainability of

a project is more important than any short term goal.

The findings emphasise and reinforce the need to keep a balance between service provision

and support activities during the initial period of any CBR programme. A greater emphasis

on support activities than on direct service provision, on the basis that disabled children

will probably make marked progress even in response to less intensive intervention, would

ensure that while parents' enthusiasm was maintained during the first year while, the focus

could be on developing the measures needed for future sustainability.

Another useful finding of this study is the fact that all positive changes in parental attitudes

and perceived sources of support and helpfulness, by parents in all the groups, occurred

during the first year of the intervention, while the follow-up period witnessed nearly no

change at all. This suggests that parents and local communities are more responsive to projects during their initial phase rather than at any other time, and any changes liable to happen will occur during the first year of the intervention. Therefore, on the basis of this it can be seen that the initial phase of any CBR programme is the best time to mobilise local resources and to activate the empowering process of parents of disabled children. Again all these activities are 'support activities' needed to build a self-sustainable project. Therefore, these findings reinforce the emphasis on the 'support activities' during the initial period of any CBR programme.

5.7.2.4 Strategies to be adopted during the initial phase of a CBR programme to facilitate its future sustainability

Before presenting some practical suggestions, there are two fundamental issues which exert particular influence over the ultimate prospect for programme sustainability. The first is the *involvement of the government* (Helander. 1993) and national resources in the programme, and the second is the integration of the CBR programme into a more comprehensive *community development* (Helander. 1995 b) programme serving the whole community. Obviously these matters will largely be out of the hands of project planners, and so will not be further discussed here. However of the strategies which can be implemented, the provision of a balanced emphasis, addressing both *service provision* related activities and *support* activities are crucial. The initial phase of a project should embrace the following:

- **Empowering local people and building their managerial skills,** enabling them to manage the programme in partnership with the project initiators. These steps are of vital importance in helping local people *to analyse and express their needs* in relation to the projects' future sustainability. It is suggested that external initiators should ask at the end of each period of support:

"What is the minimal external support needed from 'us' to ensure the sustainability of 'your' project ?".

- **Planning the withdrawal** from the project after a limited period of support, and fixing an expected date for the withdrawal in conjunction with the local management. The announcement of the date of withdrawal should be accompanied by a reassurance that some support will always be available if needed. Such an announcement will help to develop a sense of ownership among the local people over the project as well as to encourage them to plan, implement and evaluate their project together.

- **Mobilising and involving the maximum of local resources** at the local level. The prospect of any project sustainability depends heavily on the extent of mobilised local resources and the possibility of relying on these local resources to run the project independently after the withdrawal of the initiators. Awareness-raising activities is of great importance in this issue and would have tremendous impact on sustainability.

- **Transferring knowledge and skills** to the local level. This is crucial if community workers and families are to be given a realistic chance of maintaining and continuing the work of the project themselves.

- Providing **financial training and practical technical assistance** to the local management on issues related to fund raising, budgeting, managerial skills, income generating projects ..etc.

- **Strengthening the role of disabled persons.**

- Providing a continuing **high level of therapy and rehabilitation** to people with disabilities through local resources will ensure the involvement and motivation of disabled persons and their families.

- **Networking and liaison** between local, district, national and international resources as well as building a network of referral services.

- By implementing the **Child-to Child** programme, local children may become more motivated and have a greater sense of commitment to the project which will reap benefits in future generations. Weekly clubs to gather all beneficiaries, workers, local children and volunteers have an invaluable impact on sustainability.

- **Recruiting and training full time community workers** on whom the sustainability of the project depends. Creating and maintaining a high level of motivation, commitment and dedication of CBR workers facilitates the sustainability of a project. Although volunteers are an extremely valuable resource within a project, relying on them to sustain the project is very risky and unrealistic.

- **Estimating and calculating the exact cost** of the project in each area served and having a *separate budget* for each local project. Such budgets might include incentives for volunteers, community workers salaries, aids and equipment, transportation, etc. The local budget *should not include* 'temporary' external technical and administrative costs, but the latter should be calculated from the local level and detailed separately. From these figures, the *proportion of local contribution* to the project budget could be calculated and targets to increase this proportion in each following year can be set. In fact, this method could be very helpful to local people to realise *how much their project costs* and the amount of funds needed to continue their project.

- **Minimising the cost of the project** as much as possible while at the same time maintaining a good quality of service at a level which can be afforded by local resources.

This strategy is currently being experimented in the CBR programme in Alexandria but its success will only be evident after a few years.

Project sustainability is not easy to achieve; it has to be solicited, planned and worked for from the initial phase of the programme implementation. Project initiators have a major role in planning and structuring their intervention to ensure the sustainability of the project after their withdrawal.

"The direction of the first step is crucial in reaching the right destination".

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A DESCRIPTION OF COMMUNITY-BASED REHABILITATION

(Helander 93)

Community-based rehabilitation (CBR) is a strategy for enhancing the quality of life of disabled people by improving service delivery, by providing more equitable opportunities and by promoting and protecting their human rights.

It calls for the full and co-ordinated involvement of all levels of society: community, intermediate and national. It seeks the integration of the interventions of all relevant sectors - educational, health, legislative, social and vocational - and aims at the full representation and empowerment of disabled people. It also aims at promoting such interventions in the general systems of society, as well as adaptations of the physical and psychological environment that will facilitate the social integration and the self-actualisation of disabled people. Its goal is to bring about a change; to develop a system capable of reaching all disabled people in need and to educate and involve government and the public. CBR should be sustained in each country by using a level of resources that is realistic and maintainable.

At the community level, CBR is seen as a component of an integrated community development programme. It should be based on decisions taken by its members. It will rely as much as possible on the mobilisation of local resources. The family of the disabled person is the most important resource. Its skills and knowledge should be promoted by adequate training and supervision, using a technology closely related to local experience. The community should support the basic necessities of life and help the families who carry out rehabilitation at home. It should further open up all local opportunities for education, functional and vocational training, jobs, etc. The community needs to protect its disabled members to ensure that they are not deprived of their human rights. Disabled community members and their families should be involved in all discussions and decisions regarding services and opportunities provided for them. The community will need to select one or

more of its members to undergo training in order to implement the programme. A community structure (committee) should be set up to provide the local management.

At the **intermediate level,** a network of professional support services should be provided by the government. Its personnel should be involved in the training and technical supervision of community personnel, should provide services and managerial support, and should liaise with referral services.

Referral services are needed to receive those disabled people who need more specialised interventions that the community can provide. The CBR system should seek to draw on the resources available both in the governmental and non-governmental sectors.

At the **national level, CBR** seeks the involvement of the government in the leading managerial role. This concerns planning, implementing, co-ordinating, and evaluating the CBR system. This should be done in co-operation with the communities, the intermediate level and the non-governmental sector, including organisations of disabled people.

APPENDIX II

A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS

This questionnaire deals with your feelings about a child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide true (T) or false (F). answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all of the questions.

1. _____ doesn't communicate with others of his her age group.   T   F

2. Other members of the family have to do without things because of _____ .   T   F

3. Our family agrees on important matters.   T   F

4. I worry about what will happen to _____ when I can no longer take care of   T   F
him her.

5. The constant demands for care for _____ limit growth and development of   T   F
some one else in our family.

6. _____ is limited in the kind of work he she can do to make a living.   T   F

7. I have accepted the fact that _____ might have to live out his her life in   T   F
some special setting (e.g., institution or group home).

8. _____ can feel himself herself .   T   F

9. I have given up things I have really wanted to do in order to care for _____ . T   F

10. _____ is able to fit into the family social group.   T   F

11. Sometimes I avoid taking _____ out in public.   T   F

12. In the future, our family's social life will suffer because of increased   T   F

responsibilities financial stress.

13. It bothers me that _____ will always be this way.   T   F

14. I feel tense whenever I take _____ out in public.   T   F

15. I can go visit with friends whenever I want.   T   F

16. Taking _____ on a vacation spoils pleasure for the whole family.   T   F

17. _____ Knows his her own address.   T   F

18. The family does as many things together now as we ever did.   T   F

19. _____ is aware who he she is.   T   F

20. I get upset with the way my life is going.   T   F

21. Sometimes I feel very embarrassed because of _____ .   T   F

22. _____ doesn't do as much as he she should be able to do.   T   F

23. It is difficult to communicate with _____ because he she has difficulty   T   F
understanding what is being said to him her.

24. There are many places where we can enjoy ourselves as a family when   T   F
_____ comes along.

25. _____ is over-protected.   T   F

26. _____ is able to take part in games or sports.   T   F

27. _____ has too much time on his her hands.   T   F

28. I am disappointed that _____ does not lead a normal life.   T   F

29. Time drugs for _____ , especially free time.   T   F

30. _____ can't pay attention very long.   T   F

31. It is easy for me to relax.   T   F

32. I worry about what will be done with _____ when he she gets   older.   T   F

33. I get almost too tired to enjoy myself.   T   F

34. One of the things I appreciate about _____ is his her confidence.   T   F

35. There is a lot of anger and resentment in our family.   T   F

36. _____ is able to go to the bathroom alone.   T   F

37. _____ cannot remember what he she says from one moment to the next.   T   F

38. _____ can ride a bus.   T   F

39. It is easy to communicate with _____ .   T   F

40. The constant demands to care for _____ limit my growth and development.   T   F

41. _____ accepts himself herself as a person.   T   F

42. I feel sad when I think of _____.   T   F

43. I often worry about what will happen to _____ , when I no longer can take care of him her.   T   F

44. People can't understand what _____ tries to say.   T   F

45. caring for _____ puts a strain on me.   T   F

46. Members of our family get to do the same kinds of things other families do.   T   F

47. _____ will always be a problem to us.   T   F

48. _____ is able to express his her feelings to others.   T   F

49. _____ has to use a bedpan or a diaper.   T   F

50. I rarely feel blue.   T   F

51. I am worried much of the time.   T   F

52. _____ can walk without help.   T   F

Appendix III. Family Support Scale

by
Carl J. Dunst, Vicki Jenkins, and Carol M. Trivette

Listed below are sources that of tentimes are helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

(N.B. In the study, the questionnaire were administered and completed by the two examiners).

	Not Available	Not at all helpful	Some-times helpful	Gener-ally helpful	Very helpful	Extre-mely helpful
1. My parents	NA	0	1	2	3	4
2. My spouse's parents	NA	0	1	2	3	4
4. My spouse's relatives/kin	NA	0	1	2	3	4
5. Husband or wife	NA	0	1	2	3	4
6. My friends	NA	0	1	2	3	4
7. My spouse's friends	NA	0	1	2	3	4
8. My own children	NA	0	1	2	3	4
9. Other Parents	NA	0	1	2	3	4
10. Co-workers	NA	0	1	2	3	4
11. Parent groups	NA	0	1	2	3	4
12. Social groups/clubs	NA	0	1	2	3	4
13. Church	NA	0	1	2	3	4
14. My family or child's physician	NA	0	1	2	3	4
15. Professional helpers (social workers, therapists, teachers, etc.)	NA	0	1	2	3	4

16. Professional agencies (public health, social services, mental health, etc.)	NA	0	1	2	3	4
17. School/day care centre	NA	0	1	2	3	4
18. Early intervention program	NA	0	1	2	3	4
19. --------------------	NA	0	1	2	3	4
20. --------------------	NA	0	1	2	3	4

Appendix IV Judgement rules for counting 'Teaching Related Activities' (TRA).

Family Involvement is taken to be reported positive interaction between the child and another family member which aims toward the acquisition of skills needed for child independence

For example:

> any sort of training assistance to the child such as **allowing more time** to do a daily living task, or direct training such as demonstrating, physical prompting etc.

> **positive management** of an incident of problem behaviour

> encouragement to **communicate**, or express self more clearly, or increase language understanding

> asking child to help in a household activity, or verbally prompt to carry out self-care task, if this is part of their stated **priorities**, or the **teaching targets** given recently

> where there is an **unexpectedly** high level of interaction, e.g. father plays with child with toys for some time

Judgement rules:

1   Because of the effect of including a training task which is frequently repeated, such as toilet training, washing hands or spoon feeding, It was decided to count these a maximum of 3 times in one day.

2   If a parent describes that someone else was with the child, and she was not present, and can only assume what happened, then do not count. Do count if the parent does seem to know exactly what took place.

3   Likewise, do not code what is described as generally the case, only what is reported to have happened on that particular day.

4   We distinguish between teaching of understanding, non-verbal expression and verbal expression. Therefore, count more than one (even if it is contained in one episode of time) if described as separate parts of what took place.

Appendix V. Post hoc comparisons of parent attitude scores between the groups taken in pairs at the three separate time points.

		Pre-Intervention			End of First Year			Follow up (18-20m.)		
		CBR			CBR			CBR		
Outreach	Total Scores	-			-			-		
	Child Competence	***			-			-		
	Family Stress	-			**			-		
	Future Anxiety	-			-			-		
	Parent Adjustment	-			-			-		
		CBR	Out-reach		CBR	Out-reach		CBR	Out-reach	
MCH	Total	***	***		***	***		***	***	
	Child Competence	***	***		***	***		***	***	
	Family Stress	-	***		***	-		**	-	
	Future Anxiety	-	-		-	**		-	-	
	Parent Adjustment	**	***		***	**		***	**	
		CBR	Out-reach	MCH	CBR	Out-reach	MCH			
Control	Total	-	-	***	***	***	-			
	Child Competence	-	**	***	***	***	-			
	Family Stress	-	**	-	***	***	***			
	Future Anxiety	-	-	-	-	-	-			
	Parent Adjustment		-	**	***	**	-			

** $p < 0.01$.

*** $p < 0.001$.