THE EVALUATION OF THE IMPACT OF INTERVENTIONS BY A PHYSIOTHERAPIST ON INTELLECTUALLY IMPAIRED AND PHYSICALLY DISABLED CHILDREN AND THEIR CAREGIVERS IN TWO COMMUNITY GROUPS IN PERI-URBAN CAPE TOWN

Janice Behr

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ABSTRACT

Physiotherapy services for disabled children and their families have conventionally been received at a hospital or school for children with special educational needs in the main towns and cities of South Africa. Community-Based Rehabilitation (CBR) programmes were proposed and established as an additional approach to Institutional-Based Rehabilitation to address the need for accessible resources for these families.

In this study the author evaluated two CBR programmes for disabled children and their main caregivers in two separate low socioeconomic peri-urban areas of Cape Town. The programme, a weekly group meeting, included physiotherapy interventions to assist the development and functional ablities of the children by means of activities that the caregivers could include in daily home care. They handled their own children following demonstrations and correction of handling skills by the author. The majority of the caregivers were mothers. Their children, less than 13 years old, were severely intellectually impaired. Some with concomitant physical disabilities.

The author implemented the interventions of the CBR programme and she required to understand the impact on the particpants in a study using qualiative research methods. In the pilot programme the attendant members were individually interviewed, after her withdrawal, for their opinions of the outcomes. Evaluation documentation of their children and CBR programme records were related to the caregivers' responses. From the pilot study experiences the author felt that additional methods of data collection would result in a greater understanding of the impacts of the interventions. Expanded methods of research were utilised in the study of the second group.

During the interventions at group meetings the author used field notes to record observations. Participant observation allowed the author to analysis the responses of the participants. Focus group interviews assisted in understanding external factors influencing the participants as well as their needs. Individual interviews, after the closure of the CBR programme, allowed the participants to express their views of the interventions. Documentation of the individual evaluation of each child was related to the views expressed by the caregivers. Common meanings and themes were explored in the analysis of the various data collected.

Analysis revealed that interventions of education and training for the caregivers improved their knowledge and understanding of the impairments and disability of their children. The children benefited functionally from their families increased skills and knowledge. Through discussion with other families at group meetings, the caregivers had an understanding of other disabilities in children and developmental outcomes possible for their own child. The caregivers were more confident to address the negative perceptions of disability in their communities.

It is recommended that physiotherapists implementing any interventions for disabled children should ensure that the caregivers are partners in planning and selection of interventions and that their needs are addressed. Community participation in Community-Based Rehabilitation programmes was required for the participants to become self-reliant and solve their own needs as well as for the programme to be sustainable. This was demonstrated in only one of the programmes.

From this study it can be concluded that the physiotherapist who initially facilitates the community participation and decision making cannot achieve the community goals without active participation by the community. Group discussions and demonstration of functional activities as well as individual interventions impacted on all caregivers at the CBR meetings to sustain the future care and development of their children.

The author hereby declares that this whole thesis, unless specifically indicated to the contrary in the text, is her own original work.

Janice

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LIST OF ABBREVIATIONS USED IN THIS STUDY

CBR	Community-Based Rehabilitation
IQ	Intelligent Quotient
ICIDH	International Classification of Impairment, Disability and Handicap
NDT	Neurodevelopmental Therapy
NGO	Non-Governmental Organisation
PHC	Primary Health Care
RDP	Reconstruction and Development Plan
WCCPP	Western Cape Community Partnership Project
WHO	World Health Organisation

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION TO STUDY

The study for this thesis was selected because rehabilitation for children with disabilities and their families has been the main focus of the author's physiotherapy career for the past 25 years. This experience has been gained in children's hospitals, schools for specialised education and as a volunteer with NonGovernmental Organisations (NGOs) for children with intellectual and physical impairment.

The author's entry to community-based programmes for disabled children was via two routes. The first was the teaching of the rehabilitation of children in the academic undergraduate programme for physiotherapy students, a course which included Community-Based Rehabilitation (CBR). The undergraduate clinical practical teaching, supervised by the author, was executed at daycare centres for profoundly disabled children with multiple impairments. Here the undergraduate students were instructed in the interventions a physiotherapist could use to maintain or optimise the habilitation of these children. The author realised that to maintain any achievements obtained by children attending these centres it would be necessary to include the caregivers of these children in any planning, something that was not occurring at daycare centres.

The second entry route was the invitation extended to the author to be seconded, twice a

week, from an academic department to community-based programmes for families with disabled children in the Western Cape towns of Paarl and Worcester. The author was able to include individual caregivers in the interventions for their disabled children at community-based programmes and shared advice and handling skills for their disabled children with the families which could assist in daily care. A limited number of community members from these towns were trained to assist in the daily community-based programmes. Previous experience and working with physiotherapy students, staff and children at daycare centres enabled the author to select appropriate interventions and include the families as key members in the community programmes. As a consequence of the author's secondment, undergraduate physiotherapy students assisted her in various stages of the CBR process.
As a result of the author's involvement in community-based programmes, she was asked to facilitate a community programme for children with disabilities in Mfuleni township near Cape Town. It was this involvement in Mfuleni which led to the pilot study for this thesis.

Families with disabled children in Mfuleni had expressed the need for their children to learn to walk and to go to school. In September 1992 a group of health professionals, including the author, met to consider the needs of the disabled children in this community. Following consultation and the participation of the families concerned, a CBR programme was implemented to share ideas between the families and the health workers in the daily home care of the disabled child. The parents were taught different ways to manage, develop and exercise the disabled child at the weekly group meetings. The CBR programme was facilitated by a team consisting of an enrolled assistant community nurse representing the health centre, a physiotherapist from the Department of Physiotherapy at the University of the Western Cape (the author) and a social worker from the Association for the Physically

Disabled. These team members liaised with all health workers in this community. The community health committee was the strategy through which information and agreement on the formation of the CBR programme was communicated to the Mfuleni community.

The CBR programme commenced with the families of disabled children younger than 15 years who were not attending school or creche, an age limit set to preclude too great a discrepancy in the needs of the families and their disabled children. (Follow up of the families with disabled children attending school or of an older age was undertaken by physiotherapy undergraduates separately from this programme.) The families were asked to participate voluntarily at the weekly CBR group meetings which were held at a central venue, the community centre. The understanding was that the main caregiver of the disabled child would attend as regularly as their circumstances and needs permitted. The CBR programme meetings were open-ended in attendance. During the 18 months of the author's association with the Mfuleni CBR programme a total of 32 families participated in the programme. Three community members, themselves mothers of disabled children, were given limited training as CBR workers for disabled children. They continued to facilitate the CBR programme with the assistance of the other families after the withdrawal of the health team members.

The author soon realised that the Mfuleni CBR programme had been an opportunity to plan a pilot programme of suitable developmental interventions for disabled children from it's inception and to monitor other intervention's required for the CBR programme. The impact of the interventions by the physiotherapist on the disabled children and their families needed to be understood. At the end of the author's constant association with the Mfuleni CBR programme the caregivers' perceptions on the outcome of the interventions were obtained by conducting interviews for the pilot study. These views were compared with documentation of attendance and the progress of individual children recorded during their 18 months' association with the Mfuleni CBR programme. In 1994 a similar programme was instituted in Delft near Cape Town for families with disabled children to evaluate the outcomes of physiotherapy interventions for this study.

1.2 BACKGROUND

- The partnership of the Government
- The apaltete era

In South Africa social and economic barriers imposed by the apartheid structures restricted the resources available to black families with disabled children in both the rural and urban areas. The unequal distribution of health care and educational facilities has been of a greater disadvantage to disabled children and their families from the rural communities than to urban disabled children and their families. The repeal of government laws restricting living areas and employment opportunities in 1985 resulted in large numbers of parents bringing their disabled children to the cities and towns for schooling and medical treatment (Loveday, 1991a). This migration has caused an increase in the number of these children in peri-urban areas in South Africa as well as an increase in demand for urban housing with resultant overcrowding and the continued growth of informal settlements. The lack of basic facilities in overcrowded environments has been demonstrated to be a high-risk factor for health problems, violence, social and educational problems (Wilson and Ramphele, 1989). Donald (1994) discussed studies which suggested that disabled children in these communities will be expected to be intellectually and physically impaired as a result of postnatally acquired conditions associated with poverty.

In South Africa disabled children have traditionally received physiotherapy treatment either at a hospital or in a school for children with special educational needs in the larger towns and cities. The caregivers and their charges have been required to undertake long journeys on public transport - often with three changes - to reach the hospital for medical care and therapy. The numbers of disabled children living in peri-urban areas exceed the available places at the limited schools for special educational needs or other special care facilities. Many communities are without resources to assist disabled children and their families. In order to address the needs of disabled children and their families Community-Based Rehabilitation programmes for children were established (Loveday, 1991a). This study evaluated the impact of interventions by a physiotherapist on the disabled children and their families at two sites of CBR programmes.

1.3 COMMUNITY-BASED REHABILITATION

An alternative approach was required to expand existing institution-based rehabilitation services. A service that was accessible, affordable and acceptable, yet practical and scientifically sound, was required (O'Toole, 1991). Experts at an international rehabilitation meeting in 1969 recognised that the Primary Health Care philosophy proposed by the World Health Organisation (WHO) could be an additional delivery service (O'Toole, 1991). Rehabilitation was recognised by WHO (1978) as an integral part of Primary Health Care services. Mpofu (1995) argues that CBR is not an alternative but an additional approach to institutional-based rehabilitation as the two approaches are interdependent.

Primary Health Care can be defined as a philosophy aimed at maintaining optimal health in the population through the promotion of health and the prevention of health problems for all members of the community. Community participation and the involvement of all sectors in the community are required to focus on community development for optimal health. The components of economic improvement, improvements in nutrition and literacy as well as health have to be addressed through a national policy formulation in the Primary Health Care concept. The Declaration of Health for All by the Year 2000 (WHO, 1978) acknowledged the Primary Health Care approach as the most effective way of achieving this goal.

In South Africa this is being addressed through the Reconstruction and Development Programme (RDP, 1994), a programme conceived by the African National Congress Party as a means to redress the inequalities inflicted on the majority of the South African population by the previous apartheid system. Community participation and involvement of the people in their development was envisaged with the assistance of RDP funding. Previously disadvantaged communities would be assisted to obtain equitable services in health, education and housing. Economic growth was anticipated to alleviate the shortages of employment opportunities.

According to Helander (1989), the assumption is that the improvement of access to health services can be expected to increase the survival of children with acquired and congenital disability. This will in turn increase the prevalence of disability even though the incidence has decreased and rehabilitation will be required for the disabled section of the community.

The CBR concept utilises non-professionals with limited training to provide assistance for disabled persons, a principle which had been resisted by many health professionals (O'Toole, 1991). Undergraduate curricula of health professionals have to be reviewed to prepare them for additional CBR responsibilities. Health professionals are required to change values and attitudes to prepare themselves for the CBR approach (Bowerbank, 1994), which is a partnership between the community and all those involved in promoting the health of the population including those with disabilities. Intersectoral collaboration is required which involves not only health workers but all community members, workers and professionals involved in the development of the community (Mpofu, 1995). An incorporation of the individual together with the involvement of the community is part of the CBR process (O'Toole, 1991), which aims to use and build upon available community resources to provide services and training for disabled persons. Provision of these services within the community is achieved by knowledge and skills about disability being shared with disabled people and their families as well as non-professional community members (Helander, Mendis, Nelson and Goerdt, 1989). The CBR approach involves the community together with the disabled persons in the planning, decision-making and evaluation of programmes. CBR requires institution-based rehabilitation for referral and assistance of problems which cannot be managed at community level (Mpofu, 1995).

CBR occurs in the community and does not require the families of disabled children to travel distances to institutions for rehabilitation. The inclusion of all community members in CBR programmes should assist in their sharing opportunities and taking responsibility for the needs and health of the disabled, as well as others. Social integration could make the community more aware and accepting of the disabled persons through being involved in the planning and implementation of CBR programmes (O'Toole 1991).

The physiotherapist thus needs to be a facilitator and trainer with knowledge of and acceptance by the community. Kemp (1991) states that in South Africa a CBR service needs professional health workers for the continued support, supervision and further training of the CBR worker. From the author's experience community-based group meetings for disabled children and their families form part of CBR and have a specific role in the stimulation of the child to achieve its maximum potential as well as emotional support and training for the parents.

1.4 DISABILITY

The majority of the children attending the CBR programmes with which the author was involved were severely intellectually impaired and physically disabled.

The International Classification of Impairment, Disability and Handicap (ICIDH) of the WHO (1980) was devised as an attempt to standardise the concepts and definitions of impairment, disability and handicap. The ICIDH focused on the disability and the consequences of disease. It has been suggested that this complex classification required further updating to make it more accessible and less cumbersome (Katzenellenbogen, 1991).

An impairment is defined as "any loss or abnormality of psychological, physiological or anatomical structure or function" which may or may not result in a disability (WHO, 1980). Intellectual impairment is the inability to function at the level of the chronological age both socially and intellectually, with the child performing at a developmental level significantly below its actual age. The degree of intellectual impairment varies from mild, moderate, severe to profound and is classified by assessment of developmental delay or by psychometric testing using one of the standardised tests (Wagner, 1991). In different countries intellectual impairment, other than that classified as mild, is termed mental impairment, mental handicap, mental retardation or a severe learning difficulty. A physical disability is "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980). A handicap is "a disadvantage for a given individual, resulting from an impairment or 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" (WHO, 1980). This can be as a result of the difficulty that the individual has in interacting with the environment (WHO, 1980). Dekker (1995) expressed the opinion that the medical diagnosis, which focused on the pathology or the disease, was insufficient information for a physiotherapist. He stated that it is the consequences of disease which are important to a physiotherapist and the consequences are the impairment and the disability. Dekker stressed that the consequences of disease on the quality of life, the handicap in the ICIDH, should not be neglected in evaluation nor rehabilitation.

The World Health Organisation (WHO) in a 1968 report stated that a prevalence of 4 per 1 000 people in the average population are mentally handicapped with an Intelligence Quotient (IQ) under 50. Op't Hof (1987) has found a prevalence of 6 to 7 per 1 000 people in South Africa with an IQ under 50. A study by Allen, Behr and Hendricks (1995) appeared to support Op't Hof's findings on the numbers of children mentally handicapped with an IQ under 50 in the population of the peri-urban area of Paarl-East in the Western Cape. Loveday (1991b) commented that from her experience in peri-urban townships in the Western Cape with predominately African[1] populations, it is difficult to determine the actual numbers of mentally handicapped and physically disabled children. She pointed out that the African population is not stable because many people return to rural homes in the Eastern Cape throughout the year after seeking employment or health care for children in the cities. Many surveys have indicated a prevalence of disability of about 10% of the population in industrialised countries (Helander, Mendis, Nelson and Goerdt, 1989). From numerous studies it was concluded that between 7% to 10% of the population in developing countries is disabled. People with disabilities living in developing countries have a shorter life span and as a consequence the prevalence of disability is lower in developing countries. For this reason it can be assumed that 10% of the population of children in the peri-urban areas would be disabled. Donald (1994) was of the opinion that in South Africa the factors of poverty and disadvantage will perpetuate the incidence of disability in children. He considered that the extent of disability in children is substantially greater than the 10% which had been reported in studies concerned with the special educational needs of disabled children.

1.5 NATURE OF THE PROBLEM

Disabled children and their parents in South Africa have in past years been referred for treatment by doctors from their home towns to specialised hospitals in the nearest large cities. The medical staff of the specialised hospitals would, if possible, refer a disabled child

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[1] *The author is aware that racially constructed terms are offensive but in some sections of this thesis it has been necessary to use these terms to discuss cultural differences, past history and restrictions created by apartheid. The terms for population classification of African, referring to black African, coloured and white have been used in this study. The term black refers to African and coloured persons.*

for physiotherapy at the most accessible hospital, special clinic or special school. At present in South Africa, these facilities are still available only in the large cities, which are not necessarily the children's home town. Physiotherapists working in these institutions required the disabled children to attend treatment sessions two or three times a week, often necessitating lengthy and complicated travel arrangements.

Physiotherapists are members of the health teams treating the disabled children. The child with impairments of movement and posture resulting from neurological conditions would be treated by physiotherapists using the principles described by Bobath and Bobath[2] (1984; 1985). Irwin-Carruthers (1989) stated that the physiotherapist is a practitioner of the science and art of therapeutic movement. This principle formed the therapeutic basis of physiotherapy treatment of disabled children in the large towns of South Africa, where the majority of therapists are concentrated. Each child would be treated individually by the physiotherapist to improve movement and function. Often other aspects of development, which included speech, cognition and social skills, would be left to other members of the health team or ignored after a long physiotherapeutic session. The planning and selection of the therapy was effected by the physiotherapist. It has been suggested that physiotherapists did not consider the needs of the family and the child in the therapeutic approach. The family and the child were not being involved in the rehabilitation process.

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[2] *The Bobath Concept for children with neurodevelopmental impairment has been based on a hierarchial model of motor control. The hierarchical model suggests that the maturation of a series of ranked organised reflexes and reactions within the central nervous system forms the basis for the acquirement of postural stability. Alteration of postural tone and inhibition of primitive and postural reflex patterns are important parts of Bobath treatment. In recent years this approach to treatment has become more dynamic and functional in its approach (Campbell, 1991).*

Wolf (1993) stated that the importance of the role of the parents in the care of their child and their crucial role in the rehabilitation of their disabled child had been overlooked. The parents were totally forgotten or were never included as being part of the team by many doctors and physiotherapists during the medical and therapeutic treatment of the child. According to Molteno (1992), the parents have to be contracted into playing their role in the rehabilitation of their child. Molteno pointed out that in America, formal documents are signed to enforce the contract, a point which has reinforced the fact that the medical teams were ignoring the role of the parents and thus parents were not part of the rehabilitation of their child.

Physiotherapists have realised in the last few years that treatment approaches need to be reviewed and directed at the therapist becoming part of the team which includes the parents (Kolobe, 1991). The argument is that the physiotherapist will use her knowledge to assess the total requirements of the child, train the parents and refer to other team members to maximise the full potential of the child. This means that the physiotherapist will have to learn a new means of service delivery through workshops, literature and discussion with other professions and colleagues. Sanctions against South Africa for its apartheid policies had resulted in limited knowledge of the CBR concepts reaching many therapists involved in government service. Developing countries and rural areas of South Africa are similar in many respects to First World communities but the approaches required will differ from the community programmes described in First World reports and journals. As argued before, physiotherapists have to be members of the Primary Health Care teams in CBR through which they will have an additional approach to the treatment of the disabled children and not deliver a therapeutic service in a hospital only.

Physiotherapists are part of the Primary Health Care team through their role in Community-Based Rehabilitation. Rehabilitation involves intervening in the environment and society as a whole to facilitate the social integration of people with disabilities and handicaps, and to reduce the impact of disabling and handicapping conditions (WHO 1981, 1982). In CBR the role of the physiotherapist is no longer only therapeutic but requires additional knowledge of cultural beliefs and practices, health promotion, environmental awareness and facilitating community participation. This knowledge enables the physiotherapist to be able to plan and implement suitable interventions to meet the needs of each community. CBR is multisectoral in approach and requires the participation and involvement of the community, who should be encouraged to be responsible for their own rehabilitation (Mpofu, 1995). The role of physiotherapy in CBR programmes for disabled children has been suggested by O'Toole (1991); however, the author did not find records of evaluation of the impact of physiotherapy interventions. Mpofu (1995) comments that CBR programmes are reported in newsletters, reports to influence donors or on the termination of projects rather than evaluation studies. Mpofu states:

> " Most of the literature on CBR comprises instructions on implementation and people's experiences of it" (1995:40).

The assumption is that at all times the community and parents of the disabled child are expected to be partners with the physiotherapist in the CBR process (Loveday, 1991a; O'Toole 1991). The physiotherapist shares the skills of rehabilitation principles as a trainer and educator of parents of disabled children in accessible community programmes. CBR workers are selected by the parents attending the programmes for disabled children and their families. The selected persons, who might be the parents of a disabled child, are trained by the physiotherapist to continue the CBR programme in that community (Loveday, 1991b;

O'Toole, 1991). CBR programmes ensure that physiotherapy services are available to the people where they live and work instead of physiotherapists working in large centres and at institutions or hospitals only.

1.6 RATIONALE

This thesis sets out to evaluate interventions by a physiotherapist on disabled children and their caregivers attending two community group programmes. Two peri-urban communities of a low socioeconomic status in Cape Town were used in this study from which the author hoped to gain an understanding of the role and the outcomes of the interventions by a physiotherapist on community groups for disabled children. The community, the disabled children and the author would benefit from a better understanding of the impact of such interventions. Physiotherapy concepts and paradigms might be altered following this study.

1.7 AIMS AND OBJECTIVES

1.7.1 Aim:

To evaluate the impact of interventions by a physiotherapist on intellectually impaired and physically disabled children and their caregivers attending two community groups in the Western Cape.

1.7.2 Objectives:

To establish the outcomes after physiotherapy interventions on the caregivers of disabled children.

To establish whether the group programme interventions could impact on the daily home management of disabled children.

1.8 DEFINITIONS OF TERMS

1.8.1 Group meeting

The term group meeting will be used in this study for all weekly meetings which included interventions by the physiotherapist to a group of disabled children and their families attending the Community-Based Rehabilitation programme.

1.8.2 Caregivers

The term caregivers has been used for the family member who is the main caretaker of a disabled child. This caregiver attended the group meetings with their disabled child. The caregivers were either mother or father, grandmother, aunt or foster mother of a child with a disability.

1.8.3 Intervention

An appropriate action undertaken by the physiotherapist to address the impairment or disability, the consequences of which affect the quality of life of that child and its family. The interventions are determined by the evaluation of the child and the expressed needs of the family or caregiver and are planned by the physiotherapist in consultation with caregivers and children.

1.8.4 Intellectual impairment

Intellectual impairment is a below average general intellectual functioning with deficits in behaviour and attainment of life skills. In South Africa the term mental handicap is generally used for intellectual impairment measured on the intelligence scale of an Intelligence Quotient below a score of 50. The assessment of the younger child who has been scored at a level for gross motor function, fine motor function, speech level and social development level and who, when compared to the chronological age, has scored below expected levels is also termed mentally handicapped (Wagner, 1991). In this study the term intellectual impairment is used rather than mental handicap as the intellectual impairment was not always a handicapping impairment but, rather a disabling impairment.

1.8.5 Delayed development

Delayed development is a global delay in all domains of the child's development compared to that expected to be attained by a child of that age. This term is used when the child is too young to determine the degree of intellectual impairment.

1.9 OVERVIEW OF CHAPTERS

This document is organised into five chapters. The following brief overview of the chapters provides an explanation of their content.

Chapter One discusses the background to children with disability in South Africa and the physiotherapy services available for disabled children. CBR programmes are proposed as an additional approach to the treatment of disabled children and assistance to their caregivers. It is argued that the physiotherapist would be required to obtain additional knowledge with the establishment of CBR programmes.

Chapter Two discusses views from the literature which will give an understanding of the relevance of this study. The concepts of CBR, Primary Health Care and community participation are key principles in the interventions. Interventions used by the physiotherapist in the individual rehabilitation of the disabled child in this study are examined. Factors that could affect child rearing in a low socioeconomic status community, cultures and the presence of a disabled child in the family are considered. Interventions that could be implemented by a physiotherapist and the premises governing interventions of movement impairment are presented.

Chapter Three describes the methodology and choice of methods used in the research strategy for this study.

Chapter Four reports on the results of the interventions by the physiotherapist and the effects that these had on the caregivers and their disabled children.

Chapter Five consists of the discussion by the author on the outcomes of the study. The effects of the interventions of the physiotherapist on the disabled children and their main caregivers are discussed and the consequences of participation by the community members for CBR programmes are considered. Conclusions and recommendations are made in this chapter.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Many diverse factors affecting disabled children and their caregivers attending CBR programmes have to be understood as they could influence the interventions planned for the disabled child and their family by physiotherapists. In this chapter the literature with special relevance to this study will be reviewed and will consider concepts of the care of disabled children, physiotherapy contribution to such care and community intervention in the following sections:

- Primary Health Care, Community-Based Rehabilitation, community development and community participation
- Factors influencing community intervention for disabled children
- Physiotherapy interventions to assist the development of disabled children and the coping skills of their caregivers
- Play and child development
- Meeting the holistic needs of the disabled child and the caregiver
- Evaluation of CBR programmes.

2.2 PRIMARY HEALTH CARE, COMMUNITY-BASED REHABILITATION, AND COMMUNITY DEVELOPMENT

The influences and links between CBR, Primary Health Care and community development will be explored in this section. CBR is recognised as being part of the Primary Health Care approach. CBR has used models of community development to obtain community involvement and assist the development of communities. Community development cannot be discussed without consideration of the effects of political policies on the community, the individual and the resources of the community. The term community is required to be understood by workers involved in CBR and Primary Health Care.

2.2.1 Primary Health Care

The Alma-Ata conference on the topic of Health for All by the Year 2000 promoted the strategy of Primary Health Care for community development, to meet the demand for an integrated and community-based approach to development in all areas of the world. Prior to this conference people had questioned the traditional medical model of health care which focused on disease and curative measures rather than encompassing the socioeconomic factors that contributed to poor health in many communities. Inequalities between the health status of developed and developing countries was found to be unacceptable (Dennill, King, Lock and Swanepoel, 1995). Following the Alma-Ata conference it was assumed that the Primary Health Care approach was aimed at prevention of disease and promotion of optimal health in all sectors of the population. Achievement of these goals required community self-reliance and participation which were a common intent with those of community development programmes. Health professionals would not be the only educators of the community but agriculturalists, engineers, economists and educationalists would be involved in the development of the community and required to collaborate together with the community to obtain the required health status (WHO, 1978; WHO, 1979; WHO, 1982).

Primary Health Care can be expressed as a philosophy aimed at maintaining optimal health in a population through promotion of health and prevention of health problems for all members of the community. A national policy formulation of the Primary Health Care philosophy would have to address the components of economic improvement, improvements in nutrition and literacy, provision of housing with clean water and affordable health services and would include community involvement. The community, through their participation, would be required to control their own health status in conjunction with a healthy environment (Bowerbank, 1994; Jacobs, 1991). Werner (1985) expressed the opinion that repressive governments have never allowed Primary Health Care to succeed. He stated that the social change involved with community participation and self-reliance was a threat to governments and those in control.

The National Health Plan formulated by the South African government in 1986 was based on the Alma-Ata principles. The plan was initially to be implemented through partnership between the state and the private sector (Dennill, King, Lock and Swanepoel, 1995). In 1991 the South African National Health Service Delivery Plan was proposed as an intention to provide and develop affordable, community-orientated and participatory Primary Health Care. Dennill, King, Lock and Swanepoel (1995) were of the opinion that the previous South African government had made progress in attaining some of the goals of the National Health Service Delivery Plan. However, they felt that lack of available information and needs identification, especially in the rural areas, resulted in inefficient planning of health services. The other major problem was the need to train and educate health personnel to the primary health care, community-based approach as well as for traditional education in the curative, institution-based approach. The Health Policies of the new South African government require that the country adopts the Primary Health Care approach as appropriate to meet the needs of the whole population (RDP, 1994). This approach will require time for adjustment from the previous service delivery of a medical, curative approach to health care. The development of partnerships in the PHC approach is an empowering process which will require the change in attitudes of both the community and the health care team members.

Jacobs (1991) mentioned that the adoption of the good Health for All principle did not define how the health of children could be enhanced. In 1983 UNICEF, WHO and international specialists met in the United States of America to address the issues of child health. This meeting evolved a strategy to address child health issues and child deaths from preventable diseases using affordable technology included in the Primary Health Care approach.

The view of numerous medical and health professionals that Primary Health Care is an inferior service has been perpetuated. The misconception of a complex service that is not just a matter of medical systems has to be understood by health workers in the resistance to the move away from Tertiary Health Care to Primary Health Care (MacPherson and Midgely, 1987). Health professionals need to realise that community work requires a high level of confidence and security in one's own skills (Kemp, 1994). The challenge is highlighted in the following statement by Craig, Derricourt and Loney that

> "community work is frequently seen as providing a radical alternative to other forms of social intervention, an opportunity to tackle the causes rather than bandage the symptoms" (1982:1).

MacDonald (1982) discussed the Primary Health Care strategy and stated that it would seem to be a new model, in urban and rural areas, to meet the health care and health needs through education but he commented that community development models have been available for many years within professions allied to medicine.

2.2.2 Community-Based Rehabilitation

Primary Health Care is comprehensive health care which integrates preventive, promotive, rehabilitative and curative care. To ensure that rehabilitation resources are available to the community, CBR is recognised as part of the Primary Health Care approach (Bowerbank, 1994).

It is suggested that rehabilitation services, to serve all the disabled children in the country, can more practically be met through CBR programmes (O'Toole, 1991). The training of CBR workers to assist health professionals in providing services for a larger population and in the concept of Health for All have proved to be effective in many developing countries 9 throughout the world (Lagerkvist, 1992; O'Toole, 1991).

Adaptation of the WHO model for CBR to the individual requirements of each community has resulted in a variety of models throughout the world today (Kisanji, 1995). The community has to be participatory to learn to be self-reliant and trained to manage the CBR programme (Werner, 1985). The CBR process utilises many of the concepts discussed in community development and is linked to the Primary Health Care philosophy.

It is suggested that the word community has many definitions and thus the individual group of participants will determine the definition of the community in each CBR programme (Rifkin and Cassels, 1990). A major objective of CBR programmes is to develop positive community attitudes towards people with disabilities. Such people are unable to perform functional skills which will affect their daily life. Mitchell, Zhon, Lu and Watt (1993) found that people in communities where CBR programmes were operative had a more favourable attitude towards people with disabilities than in communities without CBR programmes.

No organisations concentrating on community rehabilitation for impairment, disability or handicap were listed in the study of community organisations by Matiwana, Walters and Groener (1989) in the Greater Cape Town area for the period 1980 to 1988. From this study CBR appeared to be undeveloped in Cape Town though home-based nursing services provided by NGOs were mentioned. Fuller (1991) observed, from a survey of the developing world, that physical and occupational therapy community services for disabled children during 1987 were therapeutic clinics consisting of exercises and instruction to parents. Education sessions for the parents to create an awareness of prevention of disabling conditions was observed by Fuller to have been added to most community clinic sessions. Community rehabilitation was stated by Kemp (1991) to be a new concept in South Africa and therapists had to understand their role in implementing CBR and altering their attitudes towards the service delivery of CBR. Physiotherapists have to realise that their role in the community is as important as in the special school and hospital. The advantages of CBR are that the physiotherapist transfers knowledge and skills to parents and CBR workers to ensure that there are resources available to large numbers of parents and disabled children. As a facilitator the physiotherapist has to obtain multisectoral collaboration with participation and decision-making by the parents, disabled children and their communities to improve their own quality of life and health status (Mpofu, 1995). CBR workers are community members living in that particular locality and in many programmes the parent of a disabled child is chosen by the community to be trained as the CBR worker (Loveday, 1991b). The CBR workers are trained in basic skills of rehabilitation to maintain the support of the disabled persons in their community and are part of the CBR team. The physiotherapist, with knowledge of the community culture, can evaluate the requirements of the child in the home and community together with the CBR worker. The child is at an advantage in a familiar environment and not distraught after lengthy travel for therapy. Education of parents is a major factor in the rehabilitation of disabled children and cannot be overlooked in CBR as the parent is part of the team (Myezwa, 1994).

Kemp (1991) stated that in South Africa a CBR service definitely needs professional health workers for continued support, supervision and further training of the CBR workers and for their professional expertise.

2.2.2.1 Community-Based Rehabilitation workers

A person from a specific community will have knowledge of the community needs, attitudes, customs and threats to the community and is the ideal person to train as a CBR worker. The worker will be the authority on the community and a major resource for the trainer of lifestyles and attitudes. The result will be a sharing of knowledge between the worker and trainer. CBR workers will be required to assist in motivating the community with the democratic participatory approach to growth and knowledge of the community as well as the roles of advocacy and support of the disabled children and their families (Lagerkvist, 1992;

Rifkin and Cassels, 1990; Tumwine, 1989).

A secure job and salary structure are required for the community workers, with continued understanding and support from the trainers. The trainer will have to motivate government for policy changes to ensure a career structure for the community worker as volunteers will not remain permanently in a project and the socioeconomic status of many communities will necessitate the creation of job opportunities (MacDonald, 1982; RURACT, 1990).

2.2.3 Health education and health promotion in Primary Health Care and CBR

The Alma-Ata conference and documentation shifted attention from curative medicine to the social interaction of health and ill health. The shift away from medicine changed the education on health. Health education had until then been perceived as an intervention of talks or posters placed on walls of clinics and hospitals. According to Macdonald (1982), posters and talks are termed health information. He stated that education, in contrast to information, necessitates the understanding of the behaviour and attitudes of the communities by the educator and the participation of the community in the education programme. This is a statement which has to be considered in CBR for effecting health prevention and promotion to maintain health in the community.

To effect a change in a community through participation in health education, the community needs to be prepared to adapt themselves to the changing situation and understand the means of attaining the goals. The appropriate health behaviour choices of the individual required to effect a change have to be considered. The political, economic, social, cultural and environmental aspects of the community of which health education is a strategy are considered in health promotion (Reddy and Tobias, 1994). Community participation with awareness and understanding of the disabled members of a community requires a change in behaviour and attitudes towards the disabled. Kok (1988) suggested that changes in behaviours could only be implemented if problem analysis, determinates of the behaviour, motivation for change, behaviour intervention and evaluation of the effect of the intervention are used in combination. The felt needs of the community must be addressed and the community worker or facilitator has both to understand the community, its beliefs and attitudes and to listen to the community in order to gain community participation in health promotion and attitude change programmes (Cornielje, Ferrinho, Coetzee and Reinack, 1993; Macdonald, 1982; Rifkin, 1986).

2.2.4 Community

The word community has been used to qualify any grouping of people. It has been suggested by numerous authors that the word community could have many interpretations. A group of people living in a defined area can be a community. Subgroups of this community form their own communities linked by commonality of language, religion, disability or interest. The community could be linked by common interests and not confined to an geographical area. Lombard stated that

> "The community is the unit in which all community-related activities take place" (1992:62).

She commented that there are endless definitions of the concept of community. Furthermore, each definition had to be considered from the various disciplines involved in defining the concept. She mentioned that one classification does not exclude another. Each community consists of subsystems, within a social or ecological system, which interact with each other (Lombard, 1992).

According to Jewkes (1994) community is a word used by outsiders - non-members- to categorise people. She is of the opinion that the non-members do not have the same construction of communities as their members. An important consideration overlooked by non-members is that all communities are not heterogeneous (Jewkes, 1994).

2.2.5 Community development

The experiences and implementation of community development models have influenced the planning of CBR (Clarke, 1980). Kraushaar and Schmitt de Torres (1982) and Marsden and Oakley (1982) stated that community development programmes during the 1950s concentrated on education of the people to an industrialised or urban lifestyle in Europe and America but in the developing Third World countries a new political entity had to be addressed with the emergence of self-government following rule by a First World country. These authors were of the opinion that in the 1960s community development was attempting to reach the population with the lowest socioeconomic status and achieve some degree of equity. A major change in community development models started in the 1970s with emphasis moving away from individual participation to community participation. The community programmes at that time had self-reliance and self-determination, a result of community initiatives. Marsden and Oakley (1982) criticised community development and commented on the ways in which it had covertly been used in many developing countries to exploit disadvantaged people. An example is the separate development policies of the previous South African government.

NGOs who, with the relief agencies and international voluntary organisations had been charity organisations until that time, changed the emphasis of their work in the late 1960s. The NGOs in all areas of the world changed the focus of their work from relief to education, the emphasis of which was community awareness of the causes and nature of poverty and active community participation in decision-making for each community (Marsden and Oakley, 1982).

2.2.5.1 Community participation

Participation of a community, whether a focused community group or the total community of an area, will encompass the principles of power sharing, decision-making and influencing policy decisions and the implementation of any programmes (O'Toole, 1991). Lombard explained that through involvement, people can problem solve together, receiving support and have a sense of belonging. Finding a "community" enabled people to add some meaning to their lives. People who participated developed their abilities together with other people. Once the participation has been facilitated and the community has developed, the facilitator can gradually be withdrawn and increasingly the community will accept the responsibility (Lombard, 1992). Monitoring community participation by incorporating participatory evaluation into programmes in India has been described by Feuerstein (1993). She has found that this resulted in community members being responsible for initiating community ventures from skills gained in the participatory evaluation experience. Malinga (1990) expressed the right of disabled people to participate in matters concerning their own health and to plan a practical programme of action in consultation with professionals. Parents and disabled children also have these rights. Primary Health Care encompasses the encouragement of people to be part of all events that affect their lives and determine their basic rights (Werner, 1988). Participation is a common component of both CBR and community development projects which enables the process of people realising their own potential for equatable social development (Cornielje, Ferrinho, Coetzee and Reinack, 1993; Werner, 1988). Fernando (1985) emphasises that community participation should be in collaboration with all sectors impacting on decisions for that community.

2.2.5.2 Political policy

Matiwana, Walters and Groener (1989) commented that in South Africa voluntary associations proliferated in the late 1970s, at the time of social crisis in response to group consciousness and the philosophy of democracy. Community struggles and protest against the unequal education systems and apartheid impacted on the social change, resulting in an increase in community work and therefore community development.

NGOs and Community-Based Organisations, generally with international funding, have been the major role players in community education in South Africa but were repressed by the government in the 1980s (Matiwana, Walters and Groener, 1989). The previous government in South Africa viewed NGOs as politically motivated. The government's reason for attempting to suppress NGO work was that community workers were community activists working for democratically consented social change. The community development at this period had a socio-political content (Matiwana, Walters and Groener, 1989). Nakajima

(1989) said that most authorities have seen disability in the community as a minor problem and rehabilitation as a luxury left for charitable institutions to control and handle. Community work has been perceived by welfare and health sectors in most countries to be an alternative and second rate or inferior intervention (Marsden and Oakley, 1982). In an attempt to redress the unequal spread of services, the new South African government policy has emphasised the Primary Health Care approach to health care as stated in the Reconstruction and Development Programme. The re-addressing of the orientation from high technology curative health services, centred in the major cities and towns, towards Primary Health Care in the communities is at present being undertaken through the RDP policy and planning of the national and provincial government structures in South Africa (RDP, 1994).

CBR is a multisectoral approach which will involve co-ordination and co-operation of all government sections at national, provincial and district levels (Helander, Mendis, Nelson and Goerdt, 1989). Bowerbank (1994) discussed the additional skills of negotiation and facilitation that would be required by a physiotherapist to enable the shift of practice from the expertise of the physiotherapist and the interaction with an individual client to community participation and policy making. The role of the physiotherapist in CBR will also include participation and lobbying in the reconstruction of the policy for health care and rehabilitation in the new South Africa (Bowerbank, 1994).

2.2.5.3 State policy in South Africa

In South Africa the effects of apartheid on poverty and stress factors for the disadvantaged community cannot be neglected. Turton and Chalmers (1990) have argued that South Africa is similar to other developing nations as regards economic and social problems but that the policy of apartheid has increased these problems for black people. Apartheid has produced a barrier for advancement which has increased the numbers of indigent people and thereby the stress of poverty.

Historically, South Africa was divided into areas of dwelling for racially segregated groups. The Group Areas Act of 1950, which ensured that ethnic groups were separated by laws, was implemented by the government of that time. This Act forced black persons to move and resettle in new designated areas (townships) on the outskirts of Cape Town. Many people had to give up family homes occupied for generations and move to these townships. In the 1960s these areas were, as yet, undeveloped and communities who had been living in the central Cape Town area of District Six were scattered among the various townships (Sparks, 1991). All but the white population were moved further away from the central business district of Cape Town. The separation of the races has resulted in a bitterness about the losses suffered through resettlement or forced removals and a loss of pride among disadvantaged black communities (Wilson and Ramphele, 1989).

The majority of the homes in these townships consists of subeconomic houses rented from the municipality of Cape Town. Facilities such as indoor piped water, indoor toilets and electricity were not present in the majority of the homes at that time and persists even today. Services of refuse removal and street sweeping occurred less often than one sees in the more affluent areas (Wilson and Ramphele, 1989). The townships are situated at a distance from the central business and industrial areas. Transport services are inadequate, necessitating people leaving home very early in the morning and returning 12 or 13 hours later. The main hospitals and business areas of Cape Town had been clustered around the mountain and the new settlements were sited in the areas of the sandy Cape Flats, away from the central facilities. One large state teaching hospital was built near the new settlements north of Cape Town.

The repeal of the Group Areas Act in 1990 has seen the return of all races to many areas of greater Cape Town. The families of low socioeconomic status will be unable to afford to move from the townships as the house prices are higher in the more central areas of Cape Town. They will remain disadvantaged by inadequate public transport and the distance of the townships from the employment centres.

In South Africa Influx Control, the law restricting migration of rural populations to the cities, was scrapped in 1985. As a result, migration to the Western Cape from the poverty-stricken rural areas increased after this date. The opportunity to find employment in the Western Cape was minimal at this time as the economic growth of the region was depressed (Matiwana, Walters and Groener, 1989). At the time of this research study (1993 to 1995), employment opportunities are still limited in the Western Cape and unemployment figures are high.

New policies have been formulated by the South African Government since 1994. The Reconstruction and Development Programme proposed by the government has drafted ways in which the unequal distribution of health and all services, education and economic improvement can be addressed with community participation (RDP, 1994). Aranes (1995) discussed the implications and implementation of the policies included in the RDP in the Western Cape. He said that the people who will benefit are the most marginalised communities but that the region's economy must be sustained and given a boost to create the jobs required to fulfil the basic needs of these people.

Most authors emphasise that chronic poverty has subjective or psychosocial implications to people and communities resulting from restrictions placed on access to social institutions and services, the constrictions on life choice and the subjection of the individual to control by others (McLloyd, 1990). In a study by Clarke (1980), the attitudes of clinic and hospital personnel, shopkeepers, civil servants and church workers towards the poor are sited as perpetuating the hopelessness and despair of poverty.

The preceding section has considered community development and the relationship and influence on CBR philosophy. Factors that form part of any CBR programme and that could influence the final goal of community ownership of the project were discussed. The following section will consider the community and the disabled children.

2.3 FACTORS INFLUENCING COMMUNITY INTERVENTION FOR DISABLED CHILDREN

The environment in which the child is reared will have to be considered in the selection of appropriate interventions by the physiotherapist. Language, cultural practices and values, socioeconomic status of the community and family have to be acknowledged in any planned intervention so as to be appropriate for that community programme. Child-rearing practices and the stresses of poverty on the child and caregiver are important considerations to be recognised by the physiotherapist. The consequences to the family of caring for a child with a disability and the stresses on the caregivers could affect the participation of disabled children and their families in community intervention programmes. The assumption that these factors will influence community interventions for disabled children and will have to be understood by the physiotherapist is reviewed in this section.

2.3.1 Communication

Insensitivity and a lack of awareness of cultural values by health workers have been negatively perceived by caregivers in studies by Brookins (1993) and Kalyanpur and Rao (1991). Both these studies stated that with recognition of the different values, support and collaborative relationships, community workers will gain the trust and participation of the community. These studies have relevance to the South African population where many different cultures and traditions are to be found. The influence of traditional healers, beliefs and practices in African population must be respected and a Western, First World approach of intervention must be adapted to recognise the different values (Donald, 1992).

Physiotherapists must understand the cultural values of the people with whom they are working if they wish to be understood. Different values, attitudes and customs impact on how people express themselves and on how they interpret information received. Kwetting (1991) stressed that therapists should not see culture as ethnicity and race. The community could be similar in ethnicity, housing and socioeconomic status but the lifestyle, power structure and religious beliefs in each individual family would alter the way in which the individual will demonstrate stress. Even siblings reared in the same home environment can demonstrate individual socially acquired lifestyles. The therapist must be sensitive to the habits, morals, and customs of each person; this will include an understanding of the individual attitudes, beliefs and values (Kwetting, 1991).

Identification of the individual dimensions in each family group will facilitate interaction between the therapist and the family and thereby enhance the development of the child within that environment. The therapists must reduce their own personal bias in the interaction through an awareness and recognition of their own cultural beliefs and values (Sparling, 1991).

A sensitivity to the other's frame of reference, in respect of interpretation of communication and the emotional expressions within the caregiver's lifestyle, is required for trust and communication (Meadows, 1991). The caregivers, unable to understand English, may supply an incorrect response or be unwilling to volunteer that they lack comprehension. The community-based therapist will therefore be required to communicate without English. Non-verbal cross language communication will be key words and phrases used by the therapist, which Meadows (1991) stated would be appreciated as a sign of interest, especially in a community setting.

Community-based health workers must have a meaningful communication system and understanding of the cultural diversity and not merely a translation of instructions (Meadows, 1991). An understanding of differences in language, beliefs and customs will assist in the active participation of caregiver and child together with the therapist in the programme.

The communication between all family members is necessary for the correct information to be delivered to influence the development of the child. Stress from uncertain information shared by only one family member can thus be avoided (Frey, Greenberg and Fewell, 1989).

Physiotherapists were found to be one of the most frequently seen service providers and perceived as the most helpful by caregivers in a study by Sloper and Turner (1992). To meet the needs of the caregiver the community physiotherapist should have the ability to advise on most aspects of child care. A knowledge of appropriate referral procedures for further assistance is required by the community physiotherapist. The community-based physiotherapist should be seen as an ally, enabling the family to articulate its needs with supportive relationships and acceptances of differences especially in lifestyle and behaviour which will build trust. The acknowledgement of the parents' competencies as equals is important for empowerment of the community (Kalyanpur and Rao, 1991; Sloper and Turner, 1992). Involvement and participation of families together with physiotherapists in CBR programmes have been discussed elsewhere as a means of facilitating their development.

2.3.2 Poverty, the child and the caregiver

Richter (1994) stated that the effects of poverty on the lives of South Africans cannot be discussed without the overlap of poverty, culture and population group. She mentioned that many studies have examined the changes in black family life in adaptation to apartheid and in response to the changes to urban life, but there have been few studies on the effects on family life.

The child's development in a community will be dependent on the nature of the neighbourhood and the environment. Overcrowded dwellings with large families and the female-headed or single parent families are all factors to be considered in child-rearing practices, but have little adverse effects on the child's development (Richter and Griesel 1986a, cited in Richter, 1994). Richter mentions that in a low socioeconomic status community the distinction between married, single and separated marital status has little meaning or implication for the child.

The stress of poverty plays a role in undermining the quality of child care. Many families have limited or no financial support from fathers who work on contracts away from home and are isolated from family support networks (Richter, 1994). The caregiver has been found to have a diminished capacity for consistent, supportive and child-centred parenting and to have a higher incidence of depression when poor. Social support is said to assist in protecting the individual from the negative consequence of stressful circumstances and determines the individual parenting patterns (McLloyd, 1990). The increase in poverty is noted to result in neglect and abuse of children, occurring more often by single mothers who have been isolated from social support (Gelles, 1992).

The social class of the child has not been found to be a determinant of the child's developmental outcome, but the quality of learning experiences available and the mother's interaction and support of the child have been shown to be predictors of the child's development (Richter and Grieve, 1991).

2.3.3 Disability

Low socioeconomic status of the family has been found to be related to a higher incidence of disabling conditions. As this study was conducted in two peri-urban townships of low socioeconomic status, the following section will review literature which demonstrates the link between poverty and disability in children.

Stein and Susser, quoted by Donald in Childhood and Adversity, in a survey of the evidence on the epidemiology of mental retardation, concluded that in Third World countries:

> "post-natal damage to the brain is more common than in more developed countries [including] infections such as tuberculosis and acute bacterial meningitis, and the encephalopathies that occur with measles, whooping cough, and with electrolyte imbalance and dehydration following gastroenteritis" (1994:138).

The assumption is that postnatal brain damage will be more prevalent in areas of low socio-economic status in South Africa.

Diseases of poverty resulting in intellectual impairment and physical disablement of children have been illustrated in a number of South African studies.

An investigation into head injuries in child pedestrian traffic accidents by Cumpsty and Theron (1986) revealed that the majority of victims were unaccompanied children under the age of eight. The long-term outcomes were not followed up for the children in this study but it can be assumed that a proportion will have had cognitive and neurological impairment. Road traffic accidents in peri-urban areas are also cited, by Donald (1994), as causes of disability to children. The relationship between low socioeconomic status parents requiring to work and lack of child-minding facilities and risk of disability or impairment was commented upon by Donald (1994).

Arens, Deeny, Molteno and Kibel (1987) established that 52% of children with cerebral palsy,[3] as a result of tuberculous meningitis, were also severely to profoundly intellectually impaired. The relationship between postnatally acquired cerebral palsy and postnatally acquired intellectual impairment (mental handicap) could be linked with the poor socioeconomic circumstances of the communities concerned (Arens and Molteno, 1989; Molteno, Roux, Nelson and Arens, 1990).

Limited antenatal care facilities or lack of antenatal care and maternal malnutrition have been found to be a factor for low birthweight babies especially in the context of poverty. Allen, Behr and Hendricks (1995) found that regular attendance at an antenatal clinic was 47 % in a survey of mothers of disabled children in a peri-urban environment. It is suggested that further research into the link between the poor antenatal attendance and the high incidence of intellectually impaired children in this community be conducted.

The Primary Health Care strategies for optimal child and infant care by monitoring child health and development have been implemented in South Africa. Immunisation of infants together with maternal education and infant monitoring have assisted in reducing infant

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[3] Cerebral palsy is a term used to describe disorders affecting movement and posture due to a nonprogressive brain lesion. Cerebral palsy is often associated with impairments of intellect, vision, hearing and speech (Scrutton, 1984).

mortalities and improving child health in impoverished communities. These strategies could assist in the prevention of pre- and postnatally acquired disabling conditions of children in the low socioeconomic status population (Kibel, 1988).

The prevalence of mild intellectual impairment (IQ 50-70) may appear to be lower than expected in certain communities as this impairment is unrecognised in disadvantaged communities with limited educational opportunities (Molteno, 1990). As infant mortality rates are high in such communities from lack of health services, children with impairments and disability in disadvantaged communities are more likely to die as a result of the associated problem of their conditions. Molteno stressed the need to prevent intellectual impairment through identification and prevention of known causative factors. Chromosomal abnormalities and inborn errors of metabolism, infections of the pregnant mother (syphilis, rubella, toxoplasmosis), disorders of pregnancy affecting blood flow, and the effects of drug and alcohol ingestion are causes of intellectual impairment with no social class bias. The perinatal causes of intellectual impairment are asphyxia of the full term infant and the complications of prematurity (Molteno, 1990). Molteno commented that mild intellectual impairment was more common in disadvantaged communities due to the environmental deprivation and insufficient postnatal stimulation. The intellectual impairment associated with brain damage and physical disability has been discussed previously. Molteno mentioned child abuse as a known cause of physical and intellectual impairments resulting from injuries to the brain.

2.3.4 Disability and caregiving

The studies discussed previously show that the highest incidence of disabled children would be expected in communities of low socioeconomic status due to postnatally acquired disease or injury. One can conclude that with the low socioeconomic status of a family the probability of a disabled child in that family is increased. In this section the discussion will be on the effects of caring for a disabled child in association with poverty.

Lea (1990) in a literature review of parents of children with mental handicap stated that there is contradictory evidence relating to the stressing factors of families with handicapped children. Lea noted that mothers have been the main focus of the studies and fathers less often. Lea commented that little research has been directed at the effect of the handicapped child on the siblings and suggested that the nature of these effects should be investigated.

The effects of a handicapped child on the marriage and the family have contradictory research findings and more vigorous research is required to reveal all the factors influencing the results (Lea, 1990). Factors which influence the natures of the families' reactions to a handicapped child, as reviewed by Lea, are religious conviction, the personal characteristics of the handicapped child, the social support available to parents and the coping resources parents employ. The influence of socioeconomic status on the stress and coping of a family with a handicapped child was indicated to be unclear due to contradictory research findings. Dyson (1991) commented that for many professionals a handicapped child equals a handicapped family but in fact the problems of raising a handicapped child are no different from raising a normal child. Lea (1990) suggested that a paradigm shift from the medical model of abnormal and negative aspects of the family towards the strengths of these families and their position in a social, political and economical context is required by professionals. The expressed needs of the handicapped person and their families must be acknowledged.

The different perspectives of the handicapped persons and their families are the results of a historical and social process. These require appropriate services for the real needs of the handicapped in each community (Dyson, 1991; Lea, 1990; Sloper and Turner, 1992). Glidden (1993) supported the assumption that insufficient studies have been undertaken on the positive factors and capability of families which include disabled children.

2.3.5 Meeting the needs of the families

Sloper and Turner (1992) found that in their study of service needs for families of children with severe physical disability three unmet needs emerge, the greatest of which were the lack of information on services, the availability of services and the lack of information on the child's condition. Strain from other life events, such as unemployment, and a higher proportion of the use of passive optimism as a coping strategy for the outcomes to a disabled child, made these families more vulnerable to stress and disempowerment. Grieve and Mphelo (1994) found similarly that parents, irrespective of age, education or socioeconomic level, desired knowledge and information. This was found to be inadequate at the outpatient clinics of large peri-urban hospitals in South Africa (Grieve and Mphelo, 1994). CBR programmes could be more appropriate and accessible for caregivers and their children to receive frequent advice and assistance (Loveday, 1991b).

The majority of caregivers in studies of home intervention programmes have stated that service providers, who visited individually and at unspecified times, was disruptive to the family life and perceived as an imposition (Kalyanpur and Rao, 1991).

2.3.6 Coping

Studies on responses from parents of children with disabilities state three main goals which should be addressed by health workers to assist in the parents' adaptation. Health workers should determine the needs of the parent for their child. They should listen to the parents. Families should be facilitated in coping with the child with a disability (Johnson-Martin, Goldman and Gowen, 1989; Sloper and Turner, 1993).

Community participation through advocacy and facilitation is the key factor in CBR programmes with self-reliance as an anticipated outcome to assist in parent coping. South African parents have been found to have a tendency to be passive and allow recipient services, leaving the professionals to assume responsibility and decide for them about the child (Joubert, 1988). The health professionals should facilitate the parents to identify major issues and the means of addressing them (Sloper and Turner, 1993). Parents should be encouraged to act independently without the health professionals. Communities should support the parents in finding solutions for coping with disabled children (Kalyanpur and Rao, 1991; Rifkin, 1986). Sternisha, Cays and Campbell (1992) found, from 11 primary research studies, that acknowledgement of the family in planning for the management of the disabled child by the health professional and knowledge on all available resources had a positive effect on adaptation and coping skills of families of disabled children.

2.4 PHYSIOTHERAPY INTERVENTIONS TO ASSIST THE DEVELOPMENT OF DISABLED CHILDREN AND THE COPING SKILLS OF THEIR CAREGIVERS

How can physiotherapists assist families to cope with disabled children? An understanding and knowledge of the needs of the disabled children and their families will be necessary to determine the appropriate intervention. To enable the disabled child to function at the maximal level of independence, the physiotherapist will have to identify the impairment and disability. This will determine the selection of the intervention (Campbell, 1991).

It is suggested that a comprehensive evaluation of the child will guide the therapist in the skills required by the parent or main caregiver to be trained to implement the rehabilitation of the child (WHO, 1982; O'Toole, 1991). A therapeutic programme of exercises performed by the therapist and instruction to the parent has traditionally been given to children with disabilities in the clinic and hospital setting. The therapist would base the treatment from an evaluation and analysis of the impaired posture and movement skills of the child (Campbell, 1989). According to O'Toole (1991), CBR programmes differ to the therapeutic approach in that they are planned from the needs of the children and the needs of the parents for the children. The intervention goals are prioritised by the child, parent and therapist together. Community group meetings for disabled children form part of CBR and have a specific role in the stimulation of the child to achieve maximum potential as well as emotional support, education and training for the parents (O'Toole, 1991).

2.4.1 Impairment of postural control and movement

An impairment in the control of posture against gravity or movement will prevent the exploration of the environment by the child and limit the opportunities to interact with people and objects. As a result of the delayed interaction with the environment the disabled child will not obtain the necessary sensory inputs to alter the posture or movement and the problem- solving abilities required for normal development (Bobath and Bobath, 1984).

The process of development enables the infant to use a pattern of movement selectively and discriminately. During the development of motor skills the child combines several movement patterns directed to solve environmental problems and thereby acquires new information. The co-ordination of actions linked to cognition, posture and movement are functional movements (Campbell, 1989).

General developmental delay as a result of intellectual impairment delays the rate of acquiring posture and movement as well as other skills. Neurological conditions such as cerebral palsy impair motor co-ordination and delay the acquiring of postural and movement skills (Bobath and Bobath, 1982). Children with visual impairment acquire postural skills at the same time as children without impairment but show delay in acquiring movement skills (Van der Velde, 1989).

The link between motor function and social, cognitive and emotional growth is mentioned by Campbell (1989) as a resource for the child's motor behaviour. Should an impairment of motor function be present then the development and growth of the other skills of the child will be affected.

Impairment in posture and movement may be contributed by a discrepancy in muscle tone. Bobath described muscle tone as an "ongoing physiological adaptation - a condition of readiness" (1985:5). Muscle tone is the degree of tension in the muscles of the body. Brazelton described tone as:

> "a resistance of parts of the body to passive movement - a summary assessment of motor responses as evaluated when at rest and is confirmed by handling and testing the motor response when handled" (1984:34).

The tone can range from low to high, that is decreased to increased, though this can alter as the child grows older or with effort of movement. Many intellectually impaired children, such as the child with Down Syndrome, have decreased tone all their lives (Nelson, 1990). Differences in tone have been used for diagnosis, assessment and the neurodevelopmental therapy approach emphasises the modifying of tone. Kathrein (1990) commented that tone is difficult to assess accurately and no standardised methods of testing tone were available.

Co-ordination of movement patterns are acquired through the repeated practice of the infant to establish an automatic motor sequence (Bobath and Bobath, 1982). These co-ordinated movement sequences are difficult for children with neurological impairment and result in a disability of function and in time an associated handicap for that child (Campbell, 1989). The inability to achieve the necessary postural alignment after movement results in an atypical alignment. Gravity may also influence the incorrect alignment. Movements that do occur may be co-ordinated but lacking the full range of movement. Atypical compensatory postural alignment results from the loss of movement range. These atypical patterns become practised and habitual. The restricted patterns of movement result in change in muscle length, as well as in joint and soft tissue structures. The muscle and soft tissue changes which occur reinforce the abnormal movement patterns through an inability to achieve the normal pattern. As a result contractures and deformities will occur (Campbell, 1991). The neurologically impaired child motivated to move reinforces these atypical patterns with exploration and the child with associated intellectual impairment has gravity reinforcing the pattern from positioning. The child with physical disability and intellectual impairment will not attempt to explore the environment, due to the lack of initiative, delaying development and allowing the reinforcing gravity induced abnormal postural alignment (Campbell, 1989).

2.4.2 Intervention for posture and movement control

Intervention to improve posture and movement will be directed towards the required outcome, the age of the child, the severity of the disability, the person implementing the intervention and the needs of the caregiver.

Cognition has to be linked with posture and movement to achieve the self- directed purpose of functional movement. The severely intellectually impaired child has been found to be limited in the initiation of purposeful movement. Intervention approaches will differ dependent on the evaluation of the individual child as a whole and analysis of the underlying components of impaired movement (Lunnen, 1991).

Campbell (1989) stated that the physiotherapist is said to be aware of the postural alignment, co-ordination of the movement and components of the movement. Appropriately, the physiotherapist will correct the movement sequence to improve the performance. Whereas the parent or caregiver will focus on the achievement of the developmental function required, for example walking, without correcting the movement sequence. Campbell (1989) holds the view that all the child's activities require equal emphasis on correct positioning and the performance of that skill. Lunnen (1991) observed that this approach will differ with the severely intellectually impaired child who will neither be motivated to move nor understand the task. The achievement of a functional movement with atypical alignment may be all that can be achieved with the severely intellectually impaired child.

An inability to move against the influence of gravity is commonly found in children with motor impairment resulting in physical disability. Function can be improved by strengthening exercises and re-education of the motor skill when motor impairment is caused by paralysed muscles. Alternatively, the child may require an alternate means of mobility with support of orthotic appliances or wheelchairs. Children with neurological impairment resulting in changes in muscle tone, for example cerebral palsy, will also require intervention directed towards the abnormal muscle tone. Positioning and exercises to normalise the muscle tone will improve the function of these children (Scrutton, 1984).

The weight shift of the body facilitates movement in any directional plane within the physical space of the body. This involves a degree of postural realignment. The shift of body weight is necessary to facilitate the required movement. If the initial body position is out of alignment, the weight shift necessary to allow the spacial movement in that plane will be extremely difficult and any movement may be fearful to the child. The postural malalignment results in abnormal patterns of movement occurring to compensate for the lack of weight shift. An example of this is the child with a physical disability who initiates movements with extension of the neck. Another example is the child with intellectual impairment, decreased muscle tone and postural fixation of the trunk who moves in one plane (Bobath and Bobath, 1984; Campbell, 1989). Exercises and activities to elicit the weight shift and retraining of the motor pattern would be a necessary intervention in the daily routine of the disabled child and specific exercises dependent on the person performing the task (Campbell, 1989). Correct positioning will not assist the child to gain movement without active intervention with an adult and child moving together in a correct alignment. The profoundly handicapped child will be re-positioned periodically throughout the day and enabled to move with the assistance of an adult. Positioning will help to prevent the atypical postures which result in changes in muscle length, joint and soft tissue structures (Nelson, 1990). Positioning changes, preformed for the child unable to move, will assist in preventing respiratory problems. Rib cage deformities from malalignment, retention of secretions in the lung and poor respiratory expansion are due to incorrect positioning which result in respiratory impairment (Lunnen, 1991).

2.4.3 Impairment of oral control, speech and communication

Neurologically impaired children may have difficulty with oral motor control which causes feeding problems and difficulty in production of sound required for speech. Drooling and respiratory problems are associated with inco-ordination of respiratory and oral motor movements. Aspiration of food is caused by a lack of oral control (Simmons, 1990). The hypersensitivity or hyposensitivity of the areas around the mouth of the child, together with an aversion to certain food textures or a feeding substance, will inhibit the intake of food.

This could result in nutritional deficiencies and the inability to brush teeth for dental care. Facilitation of sounds for communication will also be inhibited by changes in oral sensitivity (Dercksen, 1994).

Children presenting with Down Syndrome and associated hypotonia have been found to have a resultant delay in speech acquisition (Harris and Shea, 1991). Horstmeier and Tingey (1989) emphasised that all children with language problems should be tested to ensure that a hearing impairment is not an underlying cause.

The social interaction of children with poor oral control, demonstrated by the behaviours of drooling and messy feeding, was noted by Lunnen (1991) to be low as these behaviours are offensive both to the caregivers and the community.

Children with intellectual impairment have delayed language development due to cognitive deficits which may or may not be associated with neurological problems (Lunnen, 1991). The child unable to communicate will have limited social interaction and cannot convey their needs clearly to others. The caregivers become as frustrated as the child with the inability to communicate (Horstmeier and Tingey, 1989). Communication problems of the child have been found to be associated with poor maternal adjustment to the disabled child when maternal-child interaction is limited. General development of the disabled child is affected by the poor child-caregiver communication and interaction (Conway, 1991; Frey, Greenberg and Fewell, 1989; Sloper and Turner, 1993).

2.4.4 Intervention for oral control, speech and communication

The caregiver is trained to promote the correct eating patterns of the child. Positioning of the child for optimal oral control during meal times is taught. A positive attitude by both child and caregiver towards meal times is essential for feeding to be enjoyable. Desensitisation and oral therapy techniques required to assist the development of feeding patterns are taught to the caregivers though preferably not performed at a meal time. Drooling will also be controlled by reinforcement of lip closure and swallowing (Fraser, Hensinger and Phelps, 1990; Simmons, 1990).

The child with impaired motor control may require assistance to allow the hand to mouth activity of feeding. The therapist could assist in the goal of self-feeding through the intervention of suitable modification of feeding utensils and supportive seating positions for feeding. The caregivers will be trained in the implementation of this intervention, which must be acceptable to the lifestyle of both the disabled child and the caregiver (Fraser, Hensinger and Phelps, 1990). The intellectually impaired child without motor impairment capable of self-care may have to be motivated to eat and drink independently.

Feeding problems have been shown to affect family life as feeding the more severely disabled child will be very time-consuming for the mother. The difficulties of leaving the child with other people restricts the socialisation of the mother as often only she can cope with the feeding procedure of her child. The limitation of the mother's own lifestyle due to time spent feeding the disabled child impacts on the family, especially the father, and this was found to be a significant risk factor for poor adaptation of the father to the disabled child (Sloper and Turner, 1993). Intervention measures to assist with feeding problems and training other carers to assist with feeding as well as training the child to allow other persons to feed them are key intervention measures in feeding intervention.

Intervention for communication will be directed toward incorporating language skills in daily dialogue with the child through training the caregiver in strategies of communication with the child. The latter learns to communicate through gesture and will observe and understand this even when the receptive language is unclear (Oosthuizen, 1990). Vision is therefore an important part of communication and children should be positioned in a manner to enable vision to assist communication. The intellectually impaired child has to be facilitated to recruit vision to assist in interacting with people and expressing their needs (Horstmeier and Tingey, 1989).

There are numerous alternative means of communication available for the child unable to speak which have to be selected to meet the needs and resources available to each individual child. Selection of the appropriate alternative communication means will be dependent on the motor control of the child and the level of intellectual impairment. Mime, hand signs, Bliss symbolics and a variety of communication boards have been suggested as means of assisting the child to communicate (Horstmeier and Tingey, 1989; Lunnen, 1991). The assumption is that physiotherapists should be conversant with the interventions and alternative resources to assist the communication of children with impairment of speech.

2.4.5 Inappropriate behaviour and self-care

Habilitation is more applicable to the intellectually impaired and severely physically disabled child than rehabilitation as they will not be restored to full independence (WHO, 1981). One hopes that an ability not previously possessed might be acquired by the child and family and that the lives of the family and caregivers are normalised (Fuhrer, 1987).

The self-stimulatory behaviours such as mouthing objects or body parts, head banging and rocking are inappropriate behaviours which restrict the social interaction of the severely intellectually impaired child (Montgomery, 1981). Distractibility and inappropriate social responses by a disabled child limit integration with the community and placement in schools.

The acquisition of self-care skills is necessary for independent functioning but would be obtained to the highest functional level of the disabled child. Parents reinforce dependence through inappropriate behaviours of self-care which are not age appropriate. The parents of disabled children have been found to be most concerned that the disabled child develops the independent skills of eating, dressing and toileting (Allen, Behr and Hendricks, 1995). As the acquisition of self-care skills are culturally bound, the intervention should take cognisance of the family traditions.

2.4.6 Intervention for inappropriate behaviours and self-care

Behaviour modification is directed to task analysis and to understanding the cause of the behaviour. Montgomery (1981) suggested that sensory overstimulation or understimulation could result in frustration to self- stimulate. In contrast to the usual practice of limiting the behaviour she suggested that altering the sensory stimulus would reduce the behaviour. Higher functioning intellectually impaired children can be trained in self-care and appropriate social responses with behaviour modification programmes which reward the correct behaviours (Montgomery, 1981). Lunnen (1991) suggested an approach to behaviour modification where the target behaviour is selected. The specific responses that are desired are selected and defined. Reinforcement of the correct response will result in the target behaviour objective being acquired. All workers involved with the disabled child, including the family, must reinforce the target behaviours for the intervention to succeed (Lunnen, 1991).

Various interventions to assist in the habilitation and development of function of the child with impairment and disability have been discussed. The underlying theory and assumptions for many interventions have been the basis of physiotherapeutic approaches to the disabled child. The relevant approaches for this study will be discussed in the following section.

2.4.7 Approaches using specialised intervention

Physiotherapists have used a variety of intervention methods to design appropriate evaluations and interventions for the disabled. Newton (1990) suggested that therapists should be flexible in the approach to evaluation and treatment of disabled persons as each person has a multidimensional motor response. She also stated that recent research had improved the understanding of motor control problems as well as explaining the reasons for different therapy approaches having similar observable motor changes. A problem-orientated approach to intervention for any disability will require the selection of the components of the methods most efficient for the needs of the disabled child (Umphred and McCormack, 1990). These authors stated that though therapists using a specific intervention still maintain assertive boundaries and paradigms on the effectiveness of that method, there are many more commonalities than differences in the intervention approaches. The result of overlapping treatment methodologies and management is said to have resulted in multisensory models.

Integrated holistic approaches to the individual needs of the child and the individual differences of the therapists should determine the intervention rather than focusing intensely on the motor impairment (Nelson, 1990; Umphred and McCormack, 1990). Palisomo (1995) in a review of sensorimotor literature suggested that the goals and techniques should reflect a broader perspective than the professional perspective and impairment only. Therapy intervention should be included in the child's play and address the parental needs. Gans (1984) mentioned that the demands and stresses of the approach on the child and family, and relationships within the family and with the local community, must be considered in planning the intervention.

The relevant aspects of theoretical interventions of neurodevelopmental therapy, sensory integration therapy, developmental movement and a multisensory curriculum are discussed as applicable interventions to be incorporated in the theoretical basis of a community-based programme for disabled children and training of the caregivers and CBR workers.

2.4.7.1 Neurodevelopmental therapy

The Neurodevelopmental Therapy (NDT) approach to the management of sensorimotor disorders seen in children with cerebral palsy is based on various concepts derived from the work of Dr and Mrs Bobath. The NDT approach emphasises the inhibition or integration of primitive postural patterns and promotes the development of normal postural control against gravity and the normalisation of tone (Bobath and Bobath, 1984). The facilitation of movement and postural responses incorporating the work of others in the field of neurological impairment are included in the NDT approach, which is used for all children with neurological impairment and not only children with cerebral palsy (Lunnen, 1991).

Bobath and Bobath (1984) acknowledged the influences of techniques developed by others on the NDT concept. Proprioceptive stimulation (from work of Knott and Voss) may be utilised to build up tonus in NDT. Tactile stimulation (from work of Rood) may recruit muscle activity. The specific preparation of the child with inco-ordination that assists in the function for daily life is incorporated into NDT from the work of Peto. Preparation for future functional skills or improving the skill which is abnormally performed is included in the treatment principles. Dynamic movement sequences and the training of parents in daily home activities are important concepts in the NDT approach (Bobath and Bobath, 1984).

Physiotherapists, occupational therapists and speech therapists enrich their knowledge in the shared training on post-basic courses of NDT to the benefit of intervention for the holistic development of the child - this shared post- basic training enables each therapist to understand the other therapy disciplines. Kemp (1994) expressed the opinion that NDT trains therapists to select the key factors which affect the child's progress and in servicing a disadvantaged community the practical application of the NDT concepts of problem solving and caregiver training are essential to the therapist. The debate surrounding quantity versus quality care in the different approaches of intervention and not the "hands on" one-to-one therapeutic approach is addressed by Kemp in the statement that:

> "without compromising this basic knowledge and training, NDT is also capable of addressing the undoubted need of many therapists in South Africa and throughout the world to apply these skills in conditions of underdevelopment" (1994:12).

2.4.7.2 Sensory integration therapy and motor control and motor learning

Ayres (1976) developed a theoretical model of sensory integration therapy for use with children with a dysfunction in organisation of sensory information for functional use to produce an adaptive response. Ayres believed that this ability is essential for perception. The child who cannot receive or organise sensory input will not be able to perform the correct motor response due to a dysfunction in the learning process of the sensorimotor experiences. Unlike other approaches requiring the mastery of specific tasks or skills, sensory integration therapy aims to improve the brain's ability to perceive, to remember and to plan the required motor activity.

Lunnen (1991) cited studies that have found that the sensory integration therapy approach was effective in increasing eye contact, vocalisation and postural responses in children with severe intellectual impairment. Montgomery and Richter (1977) concluded that neuromotor development in severely intellectually impaired children is improved more effectively by facilitation of postural responses than motor skill practice technique.

Tal and Dikla (1995) argued that a perceptual experience on the position and movement of limbs and the environment is kinaesthetic sense and Ayres used proprioception and kinaesthesia synonymously. They inferred that kinaesthetic sense was important but not crucial to motor control but rather to motor learning. Motor learning intervention has been said to have a limited role in the intervention practice of children with severe intellectual impairment (Montgomery and Richter, 1977).

Croce and DePaepe (1989) critique therapeutic interventions with reference to the motor learning theory. These authors explained that motor control and motor learning are based on the assumption that activities are purposeful and that the individual is assisted to improve the ability and obtain the achievement of the goal. Retraining and rehabilitation use the skill of learning. Motor learning requires a step-by-step task analysis and breakdown which is practised with effective communication and feedback to the person performing the movement in response to the specific task presented. The problem solving approach is incorporated to maintain the ability to control the motor function. Progression will be to combine patterns of the movement and improve co-ordination resulting in a motor pattern relearnt and an automatic execution of the skill. To be able to perform the relearning task sensory motor pathways need to be intact. Disabled children with neurological and intellectual impairment have problems with receiving environmental information due to concomitant sensory impairments. These children therefore have insufficient information to develop adequate correct motor responses. The sensory functioning needs to be maximised but not overloaded with sensory inputs. The child with multiple impairments cannot select relevant information from the environment or from an overloaded sensory stimulation. Feedback with praise or correction is an essential component to movement of any motor learning intervention (Croce and DePaepe, 1989).

2.4.7.3 Effects of central nervous system dysfunction in childhood model

Campbell (1991) proposed that a model should be developed for the effects of central nervous system dysfunction based on clinical observations and human experience with persons with neurological dysfunction. She suggested that outdated neurophysiologic theories of stimulus and response nature be abandoned and commented that there have been insufficient research studies on the theories and practice of neurodevelopmental therapy. The model proposed by Campbell for spastic cerebral palsy syndromes is based on the dysfunction which she states "results in three primary problems: abnormal movement, deprivation and compensatory reactions in sensory systems, and disturbed pattern of social interactions" (1991:11). She proposed that research and testing to support or refute her hypothesis is required.

Recent research cited by Campbell shows that muscular atrophy and disuse weakness, or lengthening weakness from excessive elongation, from co-contractions of overactive antagonists for prolonged periods produce deformities. Physiotherapists should therefore assist muscles to work within normal ranges, with normal force and repetition to improve the mechanical efficiency of movement. This will assist in preventing increased abnormal tone, reduction in muscle length and other compensatory responses of posture, contracture and deformities. The model suggested by Campbell has been adopted by some therapists working in America and Canada. The emphasis of therapy intervention has shifted from the focus on negative difficulties to strengths of achievement of function by the disabled child (H. Larin, personal communication, 14 September 1995).

More normal movement will prevent sensory deprivation, increase motivation and aid a better quality of life. The severely handicapped child with cerebral palsy is unable to move alone but requires assistance to maintain postural alignment and muscle length.

Campbell (1991) used the hierarchy of levels of The International Classification of Impairment, Disability and Handicap to produce an evaluation format which differs from that previously used by NDT therapists. She commented that this evaluation format could be used as a clinical data base collection for research into evaluation in efficacy of various treatment approaches. The format focuses on the problem solving approach to the specific neurological dysfunction of the child. The consideration of the whole child and family in planning the intervention are not precluded but form an important part of the evaluation format and intervention planning. A simplified format could be useful in CBR worker training programmes which follow the problem solving approach to impairment and disability.

2.4.7.4 Linking a multisensory approach to the disabled child and developmental movement

Sherborne (1993) believed that in order for satisfactory development the child must relate to self and to others. The underlying theory on which Sherborne has based her work is Laban's analysis of human movement which developed personality, potential and enabled people to experience and understand all types of movement.

The disabled child who has restricted movement cannot communicate nor explore the environment. Sherborne (1993) described an approach in which the participation of disabled children in body awareness programmes using touch, music and movement with a partner involves the learning of trust, caring and relationships. Severely disabled children have little control of the weight-bearing parts of their bodies. They lack the awareness of their own bodies and have an inability to maintain an anti-gravity posture (Sherborne, 1993).

All sensations of movement received by a disabled child with minimal movement control are from the caregiver's handling. Contact and handling should therefore be as pleasant and as acceptable as possible to the children (Sherborne, 1993). Longhorn (1988) and Sherborne both commented on the inability of disabled children to escape or to complain or praise the quality of touch and handling by other persons. These authors emphasised the importance of training the caregiver and therapist to be sensitive to the handling of these children.

Body awareness and weight bearing will be prompted by tactile development. The child will start to explore objects with the hands and begin to use the mouth and tongue. Tactile programmes are included with posture and movement intervention. Tactile tolerance of the facial and mouth area can assist in improving feeding patterns. The senses of touch and smell are developed by contact with different smells and textures of people and the environment through body contact in movement and other experiences. The sense of taste is linked to the sense of smell, both of which are thought to be poorly developed in the severely disabled child from lack of exposure to the environment. The acceptance of different food flavours and textures is enhanced by the child's exposure to a variety of tastes and smells in daily encounters other than at feeding times (Longhorn, 1988).

The lack of movement restricts the exploration of tactile situations and investigation of the environment. The child therefore has to be assisted to understand touch, tactile experiences and weight bearing of the whole body (Longhorn, 1988). Longhorn has found that the multisensory approach enables the child to break the barrier of the handicap through using all the senses to communicate with others. Movements in contact with another person, as described by Sherborne (1993), have been included in Longhorn's programme to the benefit of all children but particularly those less profoundly intellectually impaired. Music, movement of the children and singing linked together with the words, actions of body parts including tactile stimulation and sensory awareness were found to benefit the children and the parents (Hallman, 1984, cited in Longhorn, 1988).

2.5 PLAY AND CHILD DEVELOPMENT

Play is a natural part of children's lives by which they learn to interact with the environment. It has been suggested that children achieve much of their early learning through play. Caregivers support the development of the child through interaction in play into which many daily activities are incorporated. The physiotherapist can use play to gain specific goals in interventions planned for children. Some therapists use play as a basis of the process of all interventions.

Richter (1994) discussed her own and other studies which have shown that the availability of play materials and the mother's conscious attempts to support the child's development have been the best indicators for the developmental outcomes of children. The stress of the woman having to manage the home and raise the children, and in many incidence maintain full time employment, in an overcrowded home environment have been studied. The lack of play facilities in an inadequate urban environment was found to be a major stress factor which could be addressed if the women were shown how to occupy the children and child care facilities in the community were available (Dixon, Johnson, Leigh and Turnbull, 1982).

An increasing number of mothers are working. In addition the need for child daycare has arisen through lack of family support systems with influx of rural families to the cities and households moving away from the city centres to newly developed areas (Donald, 1994). A deprived and stressed environment of the caregiver together with a child with difficulty interacting with the environment has been discussed as resulting in less than adequate child care (Richter and Griesel, 1986a cited in Richter, 1994).

Play is a learning experience in which the child interacts with both new and familiar objects, people and the environment. The disabled child is handicapped in the social attainment of play through motor or sensory or intellectual impairment or any combination of these impairments. Social skills acquired through interaction and communication in play are delayed in disabled children. The parents have to be trained to provide the stimulation for these developments to occur and the therapist can use play to achieve goals of intervention (Tingey, 1989). Kwetting (1991) commented on the cultural implications of play in formal testing tools for standardised assessments and tasks required of children from different cultures. Toys used by First World families are not always affordable nor culturally appropriate in all communities.

2.6 MEETING THE HOLISTIC NEEDS OF THE DISABLED CHILD AND CAREGIVER THROUGH CBR PROGRAMMES

Glidden (1993) studied the resources and stress of families with children with disabilities and queried stress from the implementation of a physiotherapy home programme requiring one hour daily of exercise and training with the disabled child. The stress was found to vary depending on the lifestyle of the caregiver or parent. Generally, the demands on the caregiver's time for a specific programme were resented by fulltime homemakers (Glidden, 1993). Cherry (1989) discussed how the improved daily management of a disabled child, however small, was a freedom for the overworked caregiver and lessened the care-giving demands. The therapist should be aware of the individual family stress and coping responses to facilitate adaptive behaviour, coping and improved interaction with the health workers. Cherry found that playgroups benefited both the child and the caregiver with the availability of social interaction and building of social support networks which assisted in relieving caregiver stress.

Cherry (1989) cautioned therapists not to overemphasize developmental milestones, such as walking, that will never be achieved and will disappoint the caregiver and be stressful to them. Small attainable goals should be taught and incorporated within the daily management to meet the needs of the child and caregiver. Calhoun, Rose, Hanfil and Sturkey (1991)