An evaluation of a programmed intervention for caregivers of disadvantaged children with multiple disabilities.

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ABSTRACT

Many people in South Africa are aware of the need for intervention and rehabilitation of disabled children. The lack of resources in the state healthcare system has necessitated a move towards capacity building and empowerment of community members to reduce the burden of responsibility on the healthcare system. Such engagement of community members in healthcare initiatives also has the potential of re-integrating disabled people back into society.

The implementation of these strategies is undertaken largely by non-governmental organisations. One such NGO, the Child Development and Resource Centre (CDRC) provides a service to children with multiple disabilities and their caregivers for whom no other resources are available. In attempting to increase the range of its impact on disabled people in Kwazulu-Natal, a training programme was developed to deal with the needs of the caregivers.

The purpose of this study is to describe, evaluate and recommend changes of this nine module training course facilitated by the CDRC. The target population was the primary caregivers of disabled children living in peri-urban and rural areas and educare workers from non-profit organisations who were involved in service delivery to such families. The purpose of the training programme was to raise community awareness around disability, to sensitise and educate individuals to the needs of the disabled, and to empower caregivers in caring for disabled children in their communities.

The CDRC training programme was subjected to on-going evaluation and monitoring throughout the entire process. Based on an action research model, programme evaluation was implemented and data was gathered from three sources: observation notes on each of the nine modules, evaluation forms completed by the participants, and focus group discussions with the participants.

The pilot programme represents a valuable initial attempt at addressing the needs of this population. The main findings suggest that the content of the modules in the training programme were informative and useful. The composition and number of participants and trainers is argued to have influenced the impact of the programme. The study explores the complexities of action research design. Findings are discussed in terms of community empowerment literature. Recommendations for future programmes are made.

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Unless specifically stated to the contrary in the text, this thesis is the original work of the undersigned.

_____Davies_____

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As the candidate's supervisor I have / ~~have not~~ approved this thesis/dissertation for submission.

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The focus of this research is the issue of disability, and specifically disability in the South African context. Historically in South Africa, the issues of alienation and integration have been central to its history and transition. These issues have also been important in the area of disability. Like the national transition, there has been a similar shift in terms of recognition and awareness around disability issues. There has been a move from the alienation of people with disabilities to an attempt to integrate these people into society. This study describes an intervention that in acknowledging this previous alienation attempts to intervene in a constructive manner.

In this chapter, I will briefly explore the context of the research, definitions of disability, the prevalence of disability in South Africa and the provision of services for the disabled.

1.1 THE CONTEXT OF THE RESEARCH

There are two important issues which characterise the context of the research namely, the integration of previously alienated individuals and the decentralisation of health service delivery.

Kirk and Gallagher (1983) delineate four stages in the development of western society's attitude toward disabled individuals:
(i). During the pre-Christian era, the disabled tended to be neglected and mistreated; (ii) During the spread of Christianity, they were pitied and protected; (iii) In the eighteenth and nineteenth centuries - institutionalisation was established as a means of education and provision of care; (iv) In the latter part

of the twentieth century there has been a move towards accepting disability and integrating people into society to the fullest extent possible.

Health professionals and others in South Africa are aware of the desperate need for intervention and rehabilitation of disabled children in the country. In post-apartheid South Africa, health and social welfare services have not been able to contain and provide adequate services due to other pressing needs. The lack of resources in the health system in South Africa is evident (Philpott & McLaren, 1999). Thus, there has been a move towards capacity building and empowerment of community members to dilute the sole responsibility of a centrally-based health care system.

These two issues of integration and decentralisation are inter-related. In engaging the services of the community, it is hoped that people with disabilities are being integrated back into society and the resources of the health and social welfare services may become less burdened.

Non-governmental organisations have been part of this movement to alleviate some of the burden. The Child Development and Resource Centre (CDRC) in Pietermaritzburg, Kwa-Zulu Natal (KZN) is one such organisation. The CDRC, a registered non-profit organisation, was initiated in 1997, and was overseen by the South African National Epilepsy League (SANEL). On the same property there is a sheltered employment project for people with epilepsy and visual impairments.

The CDRC's vision was to provide a service to children with multiple disabilities and their caregivers for whom no other resources were available. This service consisted of providing a day care centre for children with multiple disabilities, to conduct assessments and make appropriate referrals, to place the children in appropriate educational facilities depending on their needs, and to provide

general support and awareness functions to the caregivers of these children. The centre also conducted community outreach work in various parts of KZN. One aspect of this was the weekly attendance to the Zenzeleni Community Centre, based in Mpophomeni, near Howick, KZN. Basic screening was conducted to identify children with disabilities and then referrals made either to the local clinic, or if more extensive assessment was required, a referral was made to the CDRC. Thus the CDRC works as part of a multi-disciplinary network, working closely with a wide variety of other organisations and resources.

In terms of the philosophical context of the CDRC, its aim was to empower the users of the centre. There was the awareness that offering a day care service for children with multiple disabilities could not reach all those children in areas further afield who were in desperate need of care. Thus the idea was conceived to empower and train participants so that they might return to their communities and train other interested parties.

It was agreed that a training course would be held at the CDRC on a monthly basis. A number of different peri-urban and rural communities were represented. In this programme, various aspects of care for children with multiple disabilities were presented by internal and external trainers. As a pilot project, a caregiver of a disabled child who was based at Mpophomeni was targeted to undergo the training programme at the CDRC and then to disseminate this information within her community. After each training session, she returned to Mpophomeni and repeated the training session with interested participants using the Zenzeleni Community centre as a base.

To date, various training manuals on caring for the disabled child in the community have been produced both nationally and internationally (Werner, 1988a.; Loveday, 1990). These have been aimed at the learner who has had some community-based rehabilitation training and experience and an adequate

level of literacy. However, these manuals did not seem suitable for the needs of the programme proposed above since the target group would have had limited education.

The CDRC's training course was conceptualised by the Director of the centre. She had had twenty years experience as a teacher, specifically with disabled children. The last two years of her work experience was with the CDRC. The training programme was initially aimed at the primary caregivers of disabled children living in peri-urban and rural areas, and educare workers from non-profit organsations who were involved in service delivery to such families. The purpose of the training course was to implement community awareness around disability, to sensitise and educate individuals about the needs of the disabled, and to empower caregivers in caring for disabled children in their communities.

In order to raise funds, the proposal for the training course was submitted to the Nelson Mandela Childrens' Fund. R22 000 was awarded to cover travel costs to Mpophomeni, training materials, photocopying and administration costs. It was unanimously agreed in the initial planning meeting that participants would not be charged for attending the course.

The following sections investigate more closely the nature of disability and its prevalence in the South African context.

1.2 THE DEFINITION OF DISABILITY

As reported in the White Paper on an Integrated National Disability Strategy, November 1997, there have been different accepted definitions of disability. Before outlining some of these definitions, it is important to provide the theoretical model in which many of these definitions have been embedded, namely the Medical Model.

According to this model, the causes of disability are attributed purely to medical conditions. Disabled people require treatment or else the alternative is to be hidden away. In this model, the disabled have impairments which implies they are always seen as inferior or inherently flawed. "The Medical Model of disability means that organizations for people with disabilities are usually controlled by non-disabled people who provide services to people with disabilities" (White Paper,1997, p9). A consequence of this is that disabled people and their families are often isolated from each other, their communities and mainstream activities. They very seldom have any influence in community activities and become dependent on state assistance. This model feeds into the disempowerment of disabled people and prevents them from equal political, social and economic rights. In terms of rehabilitation, the interventions have been to make disabled people "as normal as possible". These interventions have predominantly been run by white professionals who position themselves as the dominant and controlling experts, viewing disabled people as "passive objects in the rehabilitation process" (McLaren &Philpott, 1995, p2).

The Centre for Disability and Referral (www.isdd.indiana.edu) describes disability as a mental or physical condition that restricts an individual's ability to engage in substantial gainful activity. This seems to adhere to the Medical model of disability with disability being regarded as a 'condition' or illness.

Chinkanda (1987) uses the term disability interchangeably with that of mental retardation, handicapped and retarded. She uses the term according to the American Association on Mental Deficiency (AAMD) whereby "mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour, manifested during the developmental period" (Robinson & Robinson, 1976, p30). Such a definition builds on the ideas of normative development.

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Couper (2000) in her KZN – Manguzi study, uses the term 'disability' to mean "the restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being" or child. (Schuntermann, 1996, in Couper,2000, p19). This definition therefore focuses on activities and the way in which these may be constricted.

The Employment Equity Act, No 55 of 1998 builds on the ideas from the above definitions. It focuses on the effect of a disability on the person in relation to the working environment and not on the diagnosis. A person is viewed as disabled only if they satisfy all three of the following criteria: the disability has to be long-term or else recurring; the person has to have a physical or mental impairment; and this impairment needs to "substantially limit" the person. Thus for a person to be recognised as being disabled in the work place, there is a time frame, the medical model is a guiding principle and some external power will decide on the parameters of what counts as 'substantially limiting'.

The most comprehensive and inclusive definition of disability found for the purpose of this study is that provided by the World Health Organisation. It is the ICIDH-2 definition of disability:

> Disability covers any disturbance in functioning associated with a health condition. It can be applied to a disturbance at body, person and/or society levels ... It is always about the effects of a health condition and its interaction with environmental factors.... Disability and functioning are, thus, umbrella terms that are used to describe the three dimensions (Body structure and function, Activity and Participation) and their interaction with environmental factors (Schneider, WHO, 2000, p12).

This is therefore an interacting definition, considering the individual attributes and environmental factors.

The following diagram taken from the WHO classification of disability demonstrates that the interaction of concepts of ICIDH – 2 are multi-dimensional and complex (Schneider, WHO, 2000, p13).

Interaction of concepts

Health condition
(disorder / disease)

Body Function/structure ⟷ Activities ⟷ Participation
(Impairment)   (Activity Limitation)   (Participation restriction)

Environmental   Personal
Factors   Factors
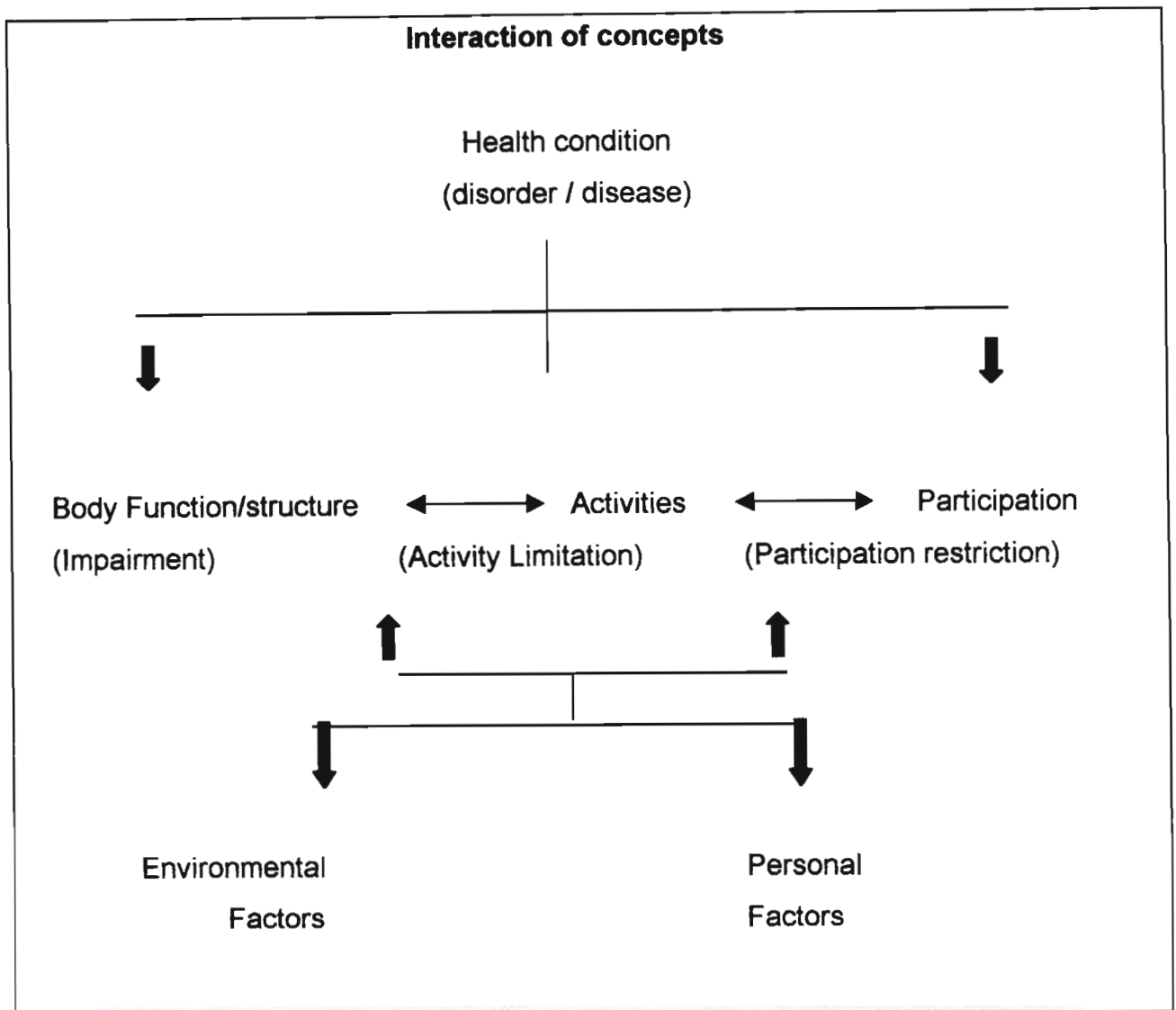
FIGURE 1.1: The WHO classification of disability

This diagram explains disability in terms of being a health condition which can be affected by body structure (eg amputation), and/or the activities one can engage in (eg unemployed due to positive HIV status), and/or to what extent one can participate (eg wheelchair bound). Thus there can be a physical

impairment, a limitation in one's activities or a restriction in terms of participating, or a combination of any three. Furthermore, all of these three areas are affected by environmental (extrinsic) factors and personal factors (the intrinsic character) in an individual's life.

Using the above diagram as a model of explanation for understanding disability, it becomes evident that the term disability cannot be restricted to only apply to those who have traditionally been seen as disabled. An example used by Schneider (2000) is that a woman in the latter stages of pregnancy who cannot climb steps in a public transport system would be viewed as experiencing a disability due to the inaccessibility of public transport. The model encourages equivalence across all health conditions – thus a psychiatric illness or using crutches can cause the same participation restrictions in terms of being employed. The model is also "neutral in terms of causality" (p 13). Thus the impairment of a body function may be due to a hijacking, diabetes or the use of thalidomide during pregnancy. The model is interactive and uses a biopsychosocial model since it recognizes the importance of the health condition as well as the environmental and personal factors that determine the outcome of a disability. If a person has a health condition and its effects on the person's functioning are negative, then it is understood as a disability, and the contextual factors (environmental factors - extrinsic, and personal factors – intrinsic) are as important to consider.

The principles of ICIDH - 2 definition are better supported by the Social Model of disability rather than the Medical Model. The Social Model "explains disablement as the result of any behaviour or barriers that prevent people with impairments choosing to take part in the life of society" (DART, 1997, p1). Thus the disadvantage of disabled people is not due to their impairments, but rather the circumstances and the discrimination they face as a result of societal structures. Such a definition emphasizes the shortcomings in society in terms of

society's failure to recognize and include the needs of disabled people as well as the actual capabilities of disabled people. In this model, disability and discrimination are therefore linked.

To present the entire and complex historical background around the disability movement in South Africa, does not serve the purposes of this particular piece of research. Yet, in saying this, certain developments have occurred that are useful in highlighting issues that have arisen out of the present research. These will be outlined below.

The shift from the medical model to the social model, which has been accepted officially by the South African Government, is largely through the establishment of organizations of disabled people or DPO's. "Central to the concept of the social model of disability is the principle of self representation by people with disabilities through DPO's" (White paper, 1997, p11). In 1984, Disabled People South Africa (DPSA) was established with 60% of the executive committee consisting of disabled people who had been injured due to shootings during the Soweto Rights of June 1976 (Philpott & Barry, 1997/1998, p18). Initially, the focus of the DPSA movement was urban but it has now expanded to include the vast rural population with disabilities.

1.3 THE PREVALENCE OF DISABILITY IN SOUTH AFRICA

According to the White Paper on an Integrated National Disability Strategy (1997), there is a serious lack of reliable information about the nature and prevalence of disability in South Africa. There has been a failure to integrate disability figures into the mainstream government statistical processes due to disability being viewed mainly within a health and welfare framework.

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Furthermore, the White Paper states that statistics have been unreliable due to the different definitions of disability, different survey technologies used to collect information, the negative traditional attitudes towards disabled people, the poor infrastructure for disabled people in underdeveloped areas and varying levels of violence in different times and places. All of these variables have restricted the collection of reliable data. Furthermore, society has tended to view people with disabilities as a single group, leading to people in wheelchairs becoming the most popular representation of disability. Thus the diversity and variety of needs required by disabled people as well as the effects on the family and community of disabled people, have largely been ignored.

In an October 1995 survey, the Central Statistical Service reported a disability prevalence of approximately 5% in South Africa. This approximation seems to be supported by the Health Systems Trust (HST) (1999) report that in 1996, there were 2 657 714 self – reported cases of disability calculated for the 1998 South African Health Review.

Couper (2000) in her paper on prevalence in Childhood Disability offers the following review of figures from studies that have been undertaken within South Africa.

TABLE 1.1: Prevalence rate of disability in various parts of South Africa

Areas of Study	Ages of children (years)	Reported Rate per 1000	Confirmed rate per 1000
Kwa-Zulu Natal - Ntuze	2-19	38	33
Kwa-Zulu Natal - Manguzi	0-9	83	60
Mpumulanga - Bushbuckridge	2-9		64
North West Province - Gelukspan	Under 9		52

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Couper differentiates between reported and confirmed rate in that the former refers to the number of children per 1000 population reported by the families to have a disability, the latter to those children who are reported by their families and are confirmed to have a disability by a professional.

The study conducted by Irlam (cited in Couper, 2000) in the Ntuze- Ongoye area of KZN, used the 'ten question' screening tool for children developed, by Thorburn, Durkin et al., (in Couper, 2000). Irlam found a childhood disability prevalence rate of 33 per 1000. Couper notes however, that no re-testing of the interviews was conducted and there were difficulties in following up children with a reported disability. Kromberg (in Couper, 2000) conducted a study in the Bushbuckridge area also using the validated screening tool, and found a confirmed rate of 6%. Corneljie (in Couper, 2000) did a study in the Gelukspan area without using the screening tool and reported results of 52 per 1000. Couper conducted her study in the Manguzi region and found a prevalence rate of 60 per 1000, similar to the findings of Kromberg and Corneljie. Couper includes the 0 to 2 years age group in her study and found that for this specific age-range, a prevalence of 2% disability was found.

Couper noted that in her Manguzi study, only one third of the disabled children are known to the health services in the area. She offers a breakdown of the prevalence rate in terms of specific childhood disabilities exclusively in terms of her Manguzi study.

TABLE 1. 2: Prevalence of specific disabilities in the Manguzi area of KZN

Specific Disability	Prevalence rate per 1000
Severe intellectual disability	6
Mild intellectual disability	17
Down Syndrome	2
Motor disability	28
Cerebral Palsy	10
Visual disability (mild to severe)	14
Hearing disability (mild to severe loss)	39
Speech disability (mild to severe)	24
Seizure disorders	9

It should be noted that when all the specific disabilities are combined, this gives an overall prevalence rate for childhood disability of 60 per 1000, or 6%. Furthermore, a child may have had multiple disabilities for example, they may be diagnosed as having cerebral palsy, but specifically would have seizure, motor and speech difficulties. These would be classified as three separate disabilities and this practice may affect the figures.

It is important to collect and collate this specific data in order to inform the planning of the types of services and facilities that are required in the prevention and /or rehabilitation of childhood disability. It is likely that to some extent the limited awareness of disability and the paucity of services available are partly influenced by the lack of reliable data collected in South Africa. Also, the lack of service provision in the Apartheid years is part of the historical legacy of racial discrimination.

1.4 THE PROVISION OF SERVICES FOR THE DISABLED

During the Apartheid years, there was limited provision of services for children with disabilities. Just as for general education, provision was determined by the race group of the learner, with provision for white learners being greater than for those of other race groups. Although whites made up 17.5% of the population, there were 64 specialised schools across the four provinces whereas for learners of all other race groups, there were only 34 comparative schools provided (Naicker,1999). Expressed as a ratio of the numbers of learners in a special school compared to those in mainstream, there were 1: 62 white learners compared to 1: 830 black learners (Naicker, 1999, p35).

There thus exists a serious backlog in service provision. The needs of many disabled people are neglected, particularly those from previously disadvantaged population groups. It was from such concerns, that organisations like the CDRC originated. The training course to be described and evaluated in this research project is an example of a response to the needs of caregivers in the context of very limited services being available.

1.5 OUTLINE OF THE THESIS

This chapter has presented the context in which this research project was conducted and highlighted the definitions and prevalence of disability. Chapter Two will explore the current literature around the issues faced by parents of disabled children. It will examine the theory of empowerment, and particularly parent empowerment. Literature around community based rehabilitation interventions will then be presented. Chapter Three justifies why a qualitative evaluation methodology was employed and explains the model of action research that provided the structure for analysing and presenting the findings. Chapter Four presents the findings of the research project and includes the

evaluation as part of this process. Chapter Five provides a discussion of the findings in the light of the literature and describes the strengths and limitations of this study. Chapter Six offers recommendations for future research and the concluding remarks.

Having outlined the need to engage caregivers more actively in the broader management of disability, this chapter explores the current literature around the ways that caring for a disabled child affects the lives of the primary caregivers. Furthermore, the diagnosis of disability in a child has implications for the caregiver. As Gregory (in Phoenix, Woollett and Lloyd, 1991) points out, the general message is that disability is unlikely, undesirable and to be avoided at all costs. Thus the implicit message is that it is the mother's responsibility to take all necessary steps to avoid it. The corollary is that if anything does go wrong, the mother may feel somehow to blame. In addition, the caregiving task falls primarily on the female caregiver rather than the male, particularly in the South African context. Ironically, the resources for caring for a child with multiple disabilites and the **support** of caregivers are more limited in the South African context than in more developed countries. This suggests that caregivers might be in the difficult situation of feeling erroneously responsible for the disability of their child at the same time as being underutilised in the management of their child's disability.

In the light of these presuppositions, the theory of empowerment, particularly parent empowerment, and community- based interventions are explored, since these are the principles which informed the interventions used in this research.

2.1 ISSUES FACED BY PARENTS OF DISABLED CHILDREN

Featherstone (1980), Ross (1964), Harris (1983) and Dyson (1996) all write about the effects of disability on the family. Featherstone (1980) writes "whatever their disabilities, handicapped children shape the lives of the families around them" (pi).

Literature presents the effects that having a disabled child can have on a family and the diverse variables that either compound or alleviate these effects. Robinson and Robinson (1976) argue that having a disabled child creates stress and emotional turbulence in the family. They list the following variables as impacting on the family functioning: the financial burden, a need for constant surveillance and supervision, social ostracisation and constraints, dietary measures, limited outings and activities, physical exhaustion of the primary caregiver, overprotection of the disabled child and the related overlooking of the needs of the remaining siblings. Harris (1983) supports these effects and includes feelings of depression, anger, guilt, sibling rivalry, and conflicts with extended family and judgmental strangers. According to Ross (1964), if parents' expectations are impeded by having a disabled child, their reactions of guilt, resentment and disappointment are "culturally relative" (p 101).

Ingalls (1978) describes the socio-economic status and educational level of parents as being significant in terms of their perception of disability. He feels that whereas a middle class family would perceive having a disabled child as a 'tragedy', a low-income family would perceive the same situation as a current crisis, something which impacts on their day-to day life events and in so doing, prevents them from regarding the long-term effects. Ingalls (1978) also considers the impact of parents' relationships on their perceptions of their disabled child. He reports that parents who are unhappily married and have personal problems prior to the birth of their disabled child, are less likely to accept that child than if they were a functional family. The reaction of parents to having a disabled child is also dependent on whether the child is a first born or not. Thomas (1978) cites Lowenfeld who argues that acceptance is more difficult if the disabled child is the firstborn since this is when parental expectations are highest.

In terms of the South African literature, Philpott and Barry (1997/1998) and Miles (1996) support these views. They write that when mothering a 'normal' child, parental difficulties will arise. However these difficulties are often compounded if the child is disabled. Feelings of guilt, resentment, bitterness, failure, protectiveness and love are experienced simultaneously with the additional stress of caring for a child with special needs. Furthermore, poverty, rejection from the community, and lack of facilities for their disabled children, enhances the isolation that many of these caregivers experience.

Donald, in Dawes and Donald (1994), reports that poverty and health risks are positively correlated and that the relationship between malnutrition and retardation is a prevalent concern. Furthermore, inadequate service delivery for the impoverished increases the risk of disability. Similarly, Bowley and Gardner (1980), compare the situation of how limited economic resources, poverty and malnutrition in developing countries impacts on disabled children versus those children in developed countries where the economic resources allow for medical, educational and scientific progress. Furthermore, they feel that perceptions and attitudes towards disability are further complicated by religious world views.

Chinkanda's (1987) study of 80 black South African mothers of disabled children cites the mothers as experiencing social stigma, adjustment difficulties that were related to family, friends and the community, the physical demands of child care and financial constraints, and inadequate service delivery facilities. She further argues that much depends on the mother's internal coping mechanisms and that these need to be supplemented by external support systems. According to Chinkanda's study, caregivers' greatest needs are for assistance in terms of financial support, practical assistance as well as emotional support in caring for their disabled child at home.

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Dyson's (1996) quantitative and qualitative research investigated the experiences of 19 parents and 19 siblings of school-aged children with learning disabilities. This study considered the effects of a disabled child in terms of parental stress, family functioning and sibling self–concept. She found that although the family functioning and self–concept of siblings was comparable to those families who did not have a disabled child, they did experience more stress. The stress was related to the excessive amount of time and energy expended on caring for their disabled child and the difficulties they had in accepting their child's disability. Furthermore, parents experienced guilt for investing more time in the disabled child than in their other non-disabled children. Parents also tended to put more emphasis on personal growth in their family compared to families without disabled children. The other source of stress was poor experiences in terms of professional support, assessment and placement of their children in appropriate educational settings.

Hemming (2001) conducted a phenomenological study investigating issues of concern to Zulu mothers of children with multiple disabilities in the Pietermaritzburg region of KZN. Her findings differ from those of Dyson (1996) in that the mothers had a better philosophical acceptance of their child's disability, yet they also found the role very demanding. This stress was compounded by financial constraints, and the lack of family, community and professional support systems. The lack of access to welfare grants, the unavailability of child care facilities/schools, inadequate service delivery in terms of educating them about their child's disability, and the need for more support from families and communities were evident in the results. Emotionally their responses to their child's disability varied, including "acceptance, blaming of others, being resigned or having hope" (p13).

Bowley and Gardner (1980) argue that in developing countries the extended family plays a large role but that males tend to consider disability to be the

domain of females. It is the females who are perceived to be responsible for the disability and this can lead to a sense of shame in the women.

In the light of this literature Philpott and Barry (1997/1998) state that "98% of parents of disabled children who live in the rural parts of South Africa are unemployed, semi-literate or uneducated single women" (p19). These caregivers, whether they are mothers or grandmothers often live in extreme poverty with very poor emotional, social, or economic support. In addition to this, the cultural and gender based ideologies also feed into the burden experienced by mothers of disabled children. Childcare is only one of the tasks expected of women living in rural areas. Other tasks may be collecting water, cooking, cleaning, washing – all of which are time consuming and labour intensive.

The breakdown of the traditional family structure and social support systems in certain South African communities, is related to a large number of variables. Historically, Apartheid and its migrant labour and forced removals destroyed many nuclear and extended family support systems. More broadly, factors like poverty and the HIV/AIDS epidemic continue to have a profound effect on these systems . Philpott (1992) made the assertion that "the system of lobola practiced in the black community has had profound implications for the institution of marriage in poor urban areas" (p5). This suggests that the conflict between traditional African and modern Western values may also impact on this breakdown. All of these factors contribute towards many mothers being single and having children from different fathers. The child is often cared for by the maternal grandmother so that the mother can search for employment. The fathers take very little or no responsibility in caring for a child. Particularly if the child is disabled, the father may not admit the child is his or else may use it as an excuse to leave the mother. Thus, embarrassment in the community and financial concerns fall onto the mother as the primary caregiver.

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Furthermore, the roles which professionals take may also be a disempowering agent to these families. By taking over decision-making powers and not acknowledging the role of the caregiver, the professionals' attitudes feed into further feelings of rejection and isolation.

> Countless numbers of non-disabled people are also victims of disability – their lives deeply altered by the disability of others....these are the caregivers, and they are almost always women. For them, caregiving usually means lost opportunities for education and for employment outside the home. Taking care of a disabled family member leaves little time for social and leisure activities and dims the lives of these sometimes reluctant, sometimes resentful but usually resigned caregivers.....they, too, need help. (Boylan, 1991, in Philpott, 1992, p4).

It is within this context that the DPSA (as mentioned in Chapter One) recognise the urgent needs of parents and have supported them to set up groups of their own. Support groups are one of the tools used to catalyse the process of empowerment, to be explored further in the next section.

2.2 EMPOWERMENT THEORY

Not only are some of the definitions of disability and interventions in disability disempowering, but also the caregivers of disabled people are disempowered. As noted above, the majority of caregivers are women, particularly in the South African context. In the past, politically, socially and economically in South Africa, as elsewhere, women have been oppressed and disempowered. The theory of empowerment will be used to draw a number of the principles that form the ideological basis of the purpose, design and implementation of the training course.

It has been suggested that empowerment theory is easy to define in its absence, but can be difficult to define positively due to its changing nature according to context. "Empowerment theory is an enigma" (Zimmerman, 1990, p169). In the absence of empowerment, one is left with alienation, hopelessness, and powerlessness, yet it "takes on a different form in different people and contexts" (Rappaport, 1984, p2). The process of empowerment can be located at various levels within the context of individual attributes, amongst a group of individuals, within an organizational setting, in an entire community or built into social policy. It is context based, culturally based, individually based and also differs across levels of analysis (Zimmerman, 1990).

At an individual level, the concept of empowerment has been equated with a set of attitudes, abilities, behaviours and even a kind of passion. Emener (in Sprague and Hayes, 2000) says, "to a greater extent, empowerment is a mind set" (p679). Vash (in Sprague and Hayes, 2000) explains it as "being centered in one's self and excited about one's purpose and meaning" (p679). In the same article, Beck (1994) describes it as having the courage to act despite the possibility that the consequences may be negative. As an individual attribute, empowerment includes participatory behaviours, motivations to exert control and feelings of efficacy.

At an organisational level, empowerment includes shared leadership, opportunities to develop skills, and effective community influence. The definition of empowerment used in the majority of literature studied, is the one offered by Rappaport (1987) who says "empowerment is a process, a mechanism by which people, organisations and communities gain mastery over their affairs" (p122).

Empowerment can have different intensities that change over time, "it is not an absolute threshold that once reached can be labeled as empowered" (Zimmerman, 1990, p170). Furthermore, Chavis and Wandersman (in

Zimmerman, 1990) found that the nature of empowerment is one that can result in individuals developing a sense of control, even if they do not perceive the group they belong to as having powers which change over time. As such, the authors distinguish between *empowering* organisations and *empowered* organisations. Empowering organisations, those that contribute to the development of empowerment of individuals, may not necessarily be empowered organisations, those that can influence policies.

Terms closely associated with the theory of community psychology are those of rehabilitation, prevention and empowerment. Within community psychology, Rappaport distinguishes between a 'phenomena of interest' and an 'exemplar' in the field. The phenomena of interest is the focus of the theory of community psychology, "it is what we try to define, understand, explain, predict, and create or facilitate by our interventions and policies" (Rappaport, 1987, p127). Rappaport feels that empowerment is the overarching goal of community psychologists, it is the focus of community psychology. According to him, an exemplar is the community's shared example of a problem solution; it is a strategy of intervention. As such, prevention would be an exemplar, it is an intervention used in community psychology.

Rappaport (1987) elaborates further that the nature of the theory of community psychology is ecological. The ecological approach provides a much "broader range of contextual understanding than is typically the case in a person-centered approach" (p134). Ecological theory is interested in the role of relationships, interactions and influences between people, programs, policies, professionals and their contexts. The concept of relationships is also intrinsic to the term of empowerment. One needs to understand what or who one has power over. Rappaport provides eleven guidelines, assumptions or hypotheses that he feels should be included into the Ecological theory of empowerment. These are briefly outlined in the table below.

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TABLE 2.1: Guidelines for an Ecological theory of empowerment

1. Empowerment is a multi level construct.
2. The size of the programme and the attention to the individual is not as important as the radiating impact of the one level of analysis on another.
3. The historical context in which a person, programme or policy is operating, has an important influence on the outcome.
4. There is awareness of the cultural context.
5. The longitudinal study of people, organisations and policies is seen as desirable, if not necessary.
6. "Empowerment theory is self-consciously a world view theory" (Rappaport, 1987, p140).
7. The conditions and degree to which members of a setting participate, has an impact on the empowerment of those members.
8. "Other things being equal, an organisation that holds an empowerment ideology will be better at finding and developing resources, than one with a helper-helpee ideology....where resources are seen as dependent on professionals" (Rappport, 1987, p141).
9. Prepackaged interventions and single solutions applied in a general way are less empowering than locally developed solutions.
10. Settings that are small enough to provide meaningful roles for all members, but large enough to obtain resources, are more likely to create the conditions that lead to empowerment.
11. Empowerment is not a finite resource that gets used up, but rather, once it is adopted as an ideology, it tends to expand resources.

According to these eleven statements, it becomes evident that understanding the process of empowerment is directly linked to the study of relationships within and between various levels of analysis from individuals, groups, organisations, communities and social policies. Rappaport feels that to focus purely on individual empowerment and to ignore the 'radiating impact' or unintended

consequences that empowerment can have, may be the largest damage that psychologists can do. He emphasises the importance of understanding the impact that an empowerment programme may have, prior to and subsequently to, its presence in a community. Thus research over a period of time is necessary in order to understand it. In addition, different individuals and contexts will bring a variety of cultural assumptions and diversity which need to be recognised.

According to Rappaport's point 6 in the table above, people who support this Ecological theory of empowerment acknowledge that they have certain presuppositions that are derived from their values, attitudes, beliefs and intentions. Furthermore, they need to acknowledge that there is mutual influence between the researcher and the participants. This implies that the people in the programme "are to be treated as collaborators; and at the same time, the researcher may be thought of as a participant" (Rappaport, 1987, p140).

In addition, Rappaport emphasises the importance of being aware of the language that we use, the connotative and denotative meanings that are communicated to the people with whom we work. "The choice of our language is seen to be very important as to what it communicates, and metacommunicates, not only to other researchers and policy makers, but also to the people being studied" (Rappaport, 1987, p141). Often the language between helper and helpee can lead to the trivialising of any positive observations that occur outside the control of the professional - any positive change that was not directly controlled is seen as 'the placebo effect' or 'spontaneous remission'. This language ultimately deprives participants of the opportunity to acknowledge and claim their own ability of self and mutual help. It leaves people with the sense that they are powerless rather than powerful, weak rather than strong. In using a

language of empowerment, changes and resources are seen as genuinely important in their own right and should not be explained away.

Point seven of Rappaport's hypotheses has direct implications for this research. He describes the results of three studies which examine the relationship between empowerment and participation. The results support the hypothesis that greater **participation** in community activities and organisations are associated with psychological empowerment (Zimmerman & Rappaport, 1988). Those who participate in decisions and activities that are meaningful to them are more likely to be empowered, and settings that have more opportunities for participation are expected to be more empowering.

Within the context of disability in South Africa, those from disadvantaged communities who are disabled, and those who care for them are in need of empowerment.

2.3 PARENT EMPOWERMENT

It is important to realise that empowerment, by its very nature, is not something one can 'do to' people, but rather something people do for themselves. Skogma, (1995) states that for parents of disabled children "outside forces cannot empower parents of disabled children. Empowerment is a process which the individual parent has to go through to gain more knowledge in meeting the needs of their own child in the home situation" (p24). For parent empowerment to occur, outside facilitators need to create situations whereby the parent can be involved in leadership, decision making and management processes whether at an individual, group, or organizational level.

Philpott and McLaren (1999) write that to understand empowerment one needs to address the rights and needs of people in relation to society. To only

recognise the rights of disabled people and their parents in terms of dignity, respect and equality, without meeting their basic needs of water, electricity and sanitation, is problematic. Likewise, by only focusing on what people are needing, may result in them feeling inadequate - thus Philpott and McLaren (1999) state, "an emphasis only on people's needs or deficits typically results in an unequal relationship, where professionals dominate" (p10). Thus the empowerment approach needs to "shift the base of power, so that professionals are not seen as 'experts', but as collaborators and partners, standing in solidarity with disabled children and their parents, working together to address disabling barriers in society" (Philpott &McLaren, 1999, p10).

Parents of disabled children have become disempowered due to issues of poverty, lack of self–confidence and the role that professionals who work in the field of disability, have played (Philpott & McLaren, 1999). Due to the lack of resources, together with the negative attitudes from society, and the resulting feelings of low competence and awareness, many parents of disabled children are left feeling powerless. In addition, the original focus on the medical model, which viewed disability as a type of impairment, allowed professionals to take control thereby undermining the role of parents in caring for their child. Werner (1988b.) writes that the steps of empowerment for parents include

- Bringing together people to discuss problems;
- Analysing the causes of these problems; and
- Formulating strategies to address them.

The facilitation of a group of mothers who can collectively discuss their personal difficulties of caring for a disabled child, suggests a recognition of these mothers, their disabled children and their families. This is a forum whereby the 'seed' of empowerment can germinate. In their evaluation of DICAG (Disabled Children's Action Group) Philpott and McLaren (1999) mention the following three aspects as being important for empowerment: training, building of

solidarity, and transformation. These three aspects emphasise the need for information and relationship in the empowerment process.

One also needs to be aware of the criticisms that have been levelled against the theory of empowerment. Riger (1993) illustrates how the assumptions and values underlying psychology promote the supposedly autonomous individual who is a product of Western social and belief systems. This belief in individualism, an individual's experience of power or powerlessness, may be unrelated to the actual ability to influence. "An increase in the sense of empowerment does not always reflect an increase in actual power" (Riger, 1993, p282). Riger continues by arguing that a sense of empowerment may be an illusion when so much of life is controlled by the politics and practices at a macro level. She feels that many efforts to empower people, to increase their power to act, for example by enhancing their self esteem, may do very little to affect their power over resources and policies.

> If interventions aimed to empower do not address these larger
> sociopolitical forces, they may be doomed to transitory or ineffective
> actions. On the other hand, attempts to address these issues may bring
> involvement in partisan politics which may put other constraints on
> psychologists' effectiveness (Riger, 1993, p283).

Furthermore, Riger highlights the issue that empowerment of underresourced people merely increases the competition for the same resources. The solution may be to balance empowerment with a commitment to the community that the people belong to, thereby strengthening both individuals and the community as a whole and reducing the competitiveness between the minority (the outsiders) and the insiders.

Riger argues that "paradoxically, situations which foster community may be the opposite of those which foster empowerment" (Riger, 1993, p288). Individuals

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who become empowered, and are able to control their own resources and speak out, may actually reduce the interdependence that produces a strong sense of community. Furthermore, there is also the danger that community empowerment becomes the goal when what people actually require is better jobs and more income. Riger feels that the challenge to community psychology is to articulate this relationship between individual empowerment and community empowerment, to simultaneously encourage a greater sense of community and to strengthen the ties that hold the community together and not promote certain individuals or groups at the expense of others.

Kaseje (cited in Philpott, 1992) warns that another danger of empowerment may be that communities may not expect it. Since they have received charity, or unelicited support for so long, many disadvantaged community members become passive and oppressed recipients. Thus empowerment should not be seen as simply adding another burden onto (in this instance) carers of disabled children, for example, expecting them to attend a weekly support group. Rather, in consultation with carers, it should be ensured and sustainable that they see actual tangible improvements in their lives. "Programs that attempt to impose additional tasks on women which are simply not feasible could even be considered as theft of the women's time, a commodity which is perhaps the most crucial constraint to reaching an adequate level of family subsistence" (Rogers, 1980, p94).

Rogers (1980) also refers to the concept of 'volunteerism'. She feels that the notion of people giving up their time in service for no tangible reward is largely a Western upper-class notion. To expect rural carers of disabled children to set up support groups, day care centers and become active in their community 'for nothing' is unrealistic and may be damaging in any community-based project.

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Thus, cautions in setting up a social programme include: being aware of not imposing western notions of individualism at the expense of community values; not misleading individuals into believing that because they feel more empowered that they will be able to make tangible differences in policies and over resources; that empowerment may not be what the community wants in the face of poverty and unemployment; and that the notion of volunteerism may not be appropriate for this South African context.

2.4 COMMUNITY-BASED REHABILITATION

Thus far, the issues faced by parents of disabled children have been presented, together with the importance of empowerment for disabled people, in particular the parents of disabled children. A third component that is useful to include in this literature review is that of community-based interventions.

The intervention of "early identification of disabilities and the provision of rehabilitation services" (McLaren & Philpott, 2000) aims to prevent disabilities or to limit the effects thereof. Levels of prevention occur at primary, secondary and tertiary levels. At a primary level, prevention consists of ways to prevent diseases, conditions or injuries that may lead to impairments or disabilities. In keeping with the social model for understanding disabilities, this would not mean simply immunization programmes for a child, but rather health education, safety promotion, and the adequate provision of health services for mothers.

The secondary level of prevention involves "early intervention in the treatment of diseases, injuries or conditions to prevent the development of impairments.....it also includes early detection through screening of potentially disabling conditions" (DoH, 1997, in McLaren & Philpott, 2000). Again, this includes not only medical treatment, for example treating diabetes before it results in a disability; but looking at teaching mothers to implement home programmes to

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assist in the motor, social and mental development of their child, or having community based rehabilitation workers doing home visits.

The tertiary level of prevention includes rehabilitation. McLaren and Philpott (2000) define rehabilitation as

> a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels.....Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function ......The rehabilitation process does not involve initial medical care (p80).

To achieve its aims, the rehabilitation process requires different kinds of services. Community based rehabilitation (CBR) is a philosophy and a strategy for providing rehabilitation services in a community in a sustainable and more appropriate way than institutionalised -based rehabilitation. The RDP Disability Programme recognized that "CBR should form the basis of a national rehabilitation strategy, with support from a continuum of secondary and tertiary rehabilitation services (McLaren & Philpott, 1995, p6). It was initiated at a time when many rehabilitation professionals began questioning the validity of their institution-based work due to the experiences and information gained from their outreach work.

There are many different types of community based rehabilitation programmes. Miles (1996) feels that most include the following aspects: the selection and training of 'village-based' CBR workers, the identification, assessment and appropriate referral of disabled people, the design and production of aids and appliances by local workers, the teaching of simple rehabilitative techniques to family members to use with their disabled child, awareness raising, counseling, community development and the promotion of integrated education. Miles also

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notes that CBR programmes differ in different cultures and different geographical locations.

Current literature on CBR describes a range of ways of working with disabled people and the ideal attitudes needed. Implementers of CBR programmes are increasingly recognising the importance of involving disabled people in the process and not simply regarding them as passive recipients of services. Other writers place more emphasis on the family of disabled people, rather than disabled people themselves. This is particularly important when it comes to disabled children since it is these children who are often unable to defend themselves, may be left alone and undervalued in their community, making them particularly vulnerable to physical, emotional and even sexual abuse. Their exclusion from 'normal' family and community life and the extra attention their special needs may require from the caregiver, may also affect their non-disabled siblings and the general survival of the family as a unit. Werner (1993) argues that not only should disabled people be **involved** in rehabilitation programmes but that they should be in **control** and that the families play an equally important role. He says "only when programmes *for* disabled people are led and controlled *by* disabled people (and/or their families) are they likely to help disabled persons gain self-determination and a respected, equal position in society" (pviii).

For the purpose of this research, it is important to note the different nature of the relationship between a CBR worker and disabled adults, and that of a CBR worker and children. Whereas the former would focus on empowerment and leadership roles, the latter relationship is framed as the CBR worker acting as a positive role model for the disabled child and 'doing' empowerment work with the child's caregiver/parent. O'Toole (1994, in Miles,1996) asserts that "the greatest resource in developing countries for helping disabled persons lead lives which are fulfilled and productive is a well advised and supported family" (p504).

In South Africa, Miles (1996) reports that parents as activists in terms of CBR programmes have primarily consisted of mother's groups and although they may have been effective in organizing support groups, they have not received the recognition or success that disability rights movements have achieved. She feels that parents do have an important role to play and cites an example of mothers being trained as CBR workers. McConachie and Zonkin (1995) go further and recognize that parents of children with disabilities play a critical role in the training of professionals. This affirms the experience and knowledge of the parent and enables professionals to gain valuable insight into the roles of parents and to challenge their 'expertise and experience'.

Yet again the danger of 'volunteerism' can arise. Philpott and McLaren (1999), in their evaluation of the Disabled Children's Action Group, describe a situation where mothers became aware of the needs of their disabled child and then set up a childcare center. Initially the mothers are willing to perform the childminding role in a voluntary capacity, but as they receive training, and become more active – they then 'expect' to be paid for the job. If this need is not met, the mother will naturally leave the programme and the process starts again. Thus to ensure the sustainability of a CBR programme, the mothers' efforts, expertise and time needs to be recognized, ideally, in a monetary fashion. Furthermore, the strain on the nurturing mother who takes on this leadership role, can lead to the danger of burn-out. Philpott and McLaren note the importance of mothers being personally supported as well as professionally trained. This also related to the importance of follow-up training and support by the CBR programme coordinators.

Another difficulty related to the training of support staff and community level workers is that there remains much debate regarding the levels and types of training, as well as their status and roles in the community and related to

professionals (McLaren & Philpott,1995). This is a result of the lack of regulated training courses, the lack of official recognition of the CBR workers and the lack of a comprehensive strategy for training rehabilitation staff. Earlier in this review, the views of Riger (1993) were explored, and the criticisms of empowerment in the context of Western individualism versus the African culture of collective consciousness were noted. Similarly, although the true essence of CBR does not conflict with this principle of prioritising needs of the community over the individual, Miles (1996) warns that CBR "has been packaged and marketed from a western individualistic perspective and there tends to be a strong focus upon correcting or minimizing the impairments of individual disabled people" (p503). She feels that to focus exclusively on the need of individuals would be counter-productive unless the basic needs of the community are addressed. Ideally, the CBR worker's role is to place value on the indigenous knowledge about disability and to sensitively balance this local expertise with that knowledge gained outside of the community.

The various issues that face parents particularly female caregivers have been described. Furthermore, the importance of the process of empowerment generally , and specifically, parent empowerment has also been discussed. Finally the intervention of rehabilitation, particularly community-based rehabilitation has been described and its criticisms highlighted. The aim is that this information will substantiate the arguments presented in the later discussion of this research.

CHAPTER THREE   METHODOLOGY

Chapters one and two explored how the definitions of and consequent
interventions in disability are in danger of further alienating individuals from their
personal and social realities. It was argued that the medical model of
conceptualising disability was disempowering on many levels and the literature
around empowerment was explored. This chapter explores the research
methodology used to evaluate an intervention done with the caregivers of
disabled, previously disadvantaged people.

Sections 3.1, 3.2 and 3.3. provide the theoretical justifications behind the
methodology. Section 3.4. looks at how these factors are incorporated
practically into the research study. Section 3.5 describes the planning of the
programme and 3.6. outlines the roles of the various participants.

A thesis speaks specifically to an academic or bureaucratic audience. One of its
purposes is to communicate the outcomes of an inquiry to an institution and as
such it needs to be presented in an acceptable form for these contexts. The
status of science in the modern world expects that universities and other
organisations should attempt to replicate the format required in experimental
scientific research. However, in so doing, significant information is lost. As
Stringer (1999) describes "they present it in a form that fails to adequately
represent the complexity and significance of events or to capture the agonies,
achievements, tragedies, and triumphs that constitute the reality of people's
lives" (p166). This is largely the challenge I faced in engaging in this research.

3.1 AIMS OF THE RESEARCH

The aim of this research is three-fold.

- To provide a descriptive account of some of the participants' experience of the training programme on caring for their child with multiple disabilities.
- To evaluate the training model used, the content and the process of the course.
- To inform future training initiatives on the content and the mode of delivery of training caregivers in the area of caring for disabled children.

In order to answer the research questions, the methodology outlined in this chapter informed the research design and data analysis to be undertaken.

3.2. THEORETICAL JUSTIFCATIONS: QUALITATIVE EVALUATION

The debate between the merits of qualitative versus quantitative research has been comprehensively presented by various writers (Patton, 1990; Clarke,1999; Banyard & Miller, 2000). It was decided that for the purposes of this study, a qualitative evaluation method would be the most appropriate and the various aspects of this method will be described in relation to the research undertaken. A brief outline is provided of how the values underpinning qualitative research and the theory of community psychology compliment each other.

3.2.1. Qualitative research and Community Psychology

Banyard and Miller (2000) put forward the rationale for advocating qualitative research methodologies by community psychologists: (1) Qualitative research methods are consistent with the core values of community psychology, (2) qualitative methods can lay the foundation for the development of culturally anchored quantitative methods, and (3) qualitative methods are a powerful set of

tools for understanding the subjective meanings people make of their experiences. Premises one and three are of direct relevance to this research.

The core values in community psychology presented by Banyard and Miller (2000) are related to diversity, context and empowerment. Diversity is appreciating the importance of studying the variety of contexts in which people live their lives. Culture, gender, race, religion and sexual orientation all shape the experiences of individuals and communities and thus are important aspects for community psychologists to study. The research tools of qualitative research such as in-depth interviews, focus groups and participant observation allow for the researcher to capture these "rich descriptions of this diversity and the specificity of human experience" (p490). In contrast to quantitative research methods which may use forced-choice answers, qualitative methods provide the platform to enable the researcher to understand the points of views of different participants at a societal and individual level. This then enlightens the researcher to new information that can be used to further develop new and /or revised theories and interventions. Furthermore, qualitative research helps us to "pay closer attention to the unique relationship of researcher and participant and also to provide space for a careful consideration of the researcher's individual standpoint and its impact on the research" (p493).

Banyard and Miller (2000) express concern about the failure of academic researchers to "adequately consider contextual factors that shape the behaviour of people in communities" (p494). They warn that this neglect of context frequently results in an overemphasis on individual determinants that can lead to the assumption that any failure or hardship is a result of the individual. Qualitative research methods allow for the rich descriptions of specific behaviours and *the settings in which they occur* and in so doing 'dissolve' the inferred blaming of the individual for which traditional research has been criticized. In their article, Banyard and Miller (2000) also highlight the value of

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empowerment in community psychology. They describe how qualitative research methods are not only tools "for gathering information, but for individual and group empowerment as well as action and social change" (p495). By using qualitative methods of open-ended interviews and focus groups, participants are given the opportunity to tell their own stories and this can be empowering, as a process in itself, on an individual level. The power of qualitative research tools can also be empowering at a community level:

> .....to document the truth of people's experiences, in their own words, becomes a source of empowerment by (a) affirming the reality of a community's historical experience and documenting that experience in written form ; and (b) facilitating the dissemination of these communal stories through publication and oral transmission to a wider audience, a process which can in turn draw greater attention and resources to the needs and concerns of the community (p496).

Mies (1983) and Benyamor (1991) cited in Banyard and Miller (2000), describe that when participants share their stories with other participants, it leads to collective support, a sense of shared circumstances, reduces self blame, raises group consciousness and helps individuals to understand the context of their circumstances – all of which are key elements in empowerment.

Quantitative methods are uniquely and ideally suited to identifying specific patterns of behaviour and change across time, particularly with large samples. Qualitative methods strive to reveal the subjective meanings that underlie and give rise to those behaviours – they address the 'why' of human behaviour. They allow the researcher to understand the meanings people make out of significant events in their lives.

The above points do not aim to diminish the value of quantitative methods but rather to highlight that both methods reflect distinct sets of beliefs about the

nature and the purpose of the research and the types of knowledge considered to be valid. I support the view that both quantitative and qualitative research methods reveal different aspects of the phenomenon under study and can complement one another. In support of Patton (1990), I advocate a "paradigm of choices" – in that I do not reject one methodology in favour of another, but rather choose "methodological appropriateness". The aim of this research is to make sensible methodological decisions by looking at the purpose of the research, the questions being investigated and the resources available. I recognize "that different paradigms are appropriate for different situations" (Patton, 1990, p39). As such qualitative evaluation techniques were seen as the best fit with this particular research, in that it is in the realm of community psychology, the theme of empowerment is important, and it allows the participants in the process to describe their experiences from which I can evaluate the purpose and process of the training course.

Any attempt to facilitate change in the world is a social intervention and if these attempts are planned and involve specific target groups, they become social programmes (Rossi &Freeman, 1993). Assuming by 'change', I mean to improve, the question arises of whether the people involved in the social intervention are actually accomplishing what they set out to, thus the social intervention needs to be evaluated. Patton (1990) uses the term evaluation to "include any effort to increase human effectiveness through systematic data-based enquiry" (p11). Evaluative research is judged by how useful it is in making human actions or interventions more effective and then disseminating that information to the people who need it so they may use it appropriately for its intended purposes.

3.2.2. Themes in Qualitative Evaluation

One of the first issues to clarify in programme evaluation is the goal of the evaluation - that is to distinguish between **summative** and **formative** evaluation. Summative evaluation is the assessment of the *outcome* of a

programme (Rossi & Freeman, 1993). This form of evaluation serves the overall purpose of judging the effectiveness of a programme. It usually uses both qualitative and quantitative research methods. Formative evaluations focus on assessing the *process* of carrying out a programme and are intended to offer suggestions for improvement in a specific setting (Rossi & Freeman, 1993). In this study, questions about the effects of the training course were produced using observations, content and process notes and participants' experiences of the course.

Patton (1990) provides a detailed description of 10 themes of qualitative inquiry. This research study incorporated these themes to varying degrees and those pertinent to the study will be outlined below.

The study was a **naturalistic qualitative design** in that it did not attempt to manipulate the research setting. It studied the impact of the training course on the participants as it unfolded – there were no predetermined constraints or limits on what the outcomes should be. The data of the evaluation included whatever emerged as important in understanding the setting whilst accepting the complexity of there being change and re-direction throughout the programme.

The study was **inductive** in that I attempted to make sense of the content and process of the training course without imposing pre-planned expectations. By becoming immersed in the data I used the findings from open-ended questions to discover important themes that emerged. "The inductive approach to evaluation means that an understanding of program activities and outcomes emerges from experience with the setting. Theories about what is happening in a setting........are not imposed through hypotheses or deductive constructions" (Patton, 1990, p44).

The research assistants who recorded the process, had **direct contact** with the people involved in the study in that they attended both the planning meetings and the training sessions. They were not directly involved in the programme activities but rather played the role of observers.

The evaluation was **holistic** in that each participant and their responses were not considered as standing alone, or simply as individually determined responses. Rather, the responses were viewed as a totality in which "the whole is understood as a complex system that is greater than the sum of its parts" (Patton, 1990, p49). The aim was to gain overall understanding of the caregivers' and the trainers' social contexts as well as the cultural and political contexts they came from.

This qualitative evaluation acknowledged that the training programme was **dynamic and developing** in terms of the number of participants, the nature of the participants, and the content and processes that arose during the course of the training sessions. The study needed to reflect how these dynamic processes impacted on all of the participants so as to provide information in terms of recommendations and improvements.

Patton describes **"empathic neutrality"** as the stance that qualitative researchers need to adopt. The issues of subjectivity and objectivity feed into the distinction between qualitative and quantitative research respectively. My aim in presenting the findings of this research is not to prove the training course as successful or not, but rather to try to understand the 'experience' as it was, to be true to the complexities and perspectives that arose and to report on the process. It is necessary that the inquiry methods and the stance taken by the research assistants is one that promotes empathy towards the responses of the participants. This aspect will be elaborated in Chapter 5.

All of the data collected was qualitative in that it consisted of **detailed, rich descriptions and direct quotations** of the trainers' and caregivers' experiences of the training course. The findings were considered within the political, social and economic context of South Africa.

In the design of the programme, cognisance was given to the need for **design flexibility**. Due to the naturalistic and inductive nature of the research, it was inappropriate and impractical to state testable hypotheses or finalise sample numbers. The design, to some extent, had to unfold as the data was being collected.

The above points aim to highlight the various themes that the researcher considered in presenting this qualitative evaluation of the training course. The next section elaborates on community-based action research, as the tool used to define the purpose of the research, and as the basis of the research design and presentation of the data.

3.2.3 Community-based action research

Stringer (1996) is supportive of the naturalistic, qualitative paradigms as described above, and agrees that the interpretive tools of such approaches "are useful in describing the historical, cultural and interactional complexity of social life" (p7). Yet he does feel that there is a weakness in these explanations of events in that they do not provide a link between theory and practice. According to Stringer, the emergence of the model of action research is based on this assumption that although recording events and formulating explanations is important, it is still inadequate in and of itself. Similarly Carr and Kemmis (1986) see action research as being concerned with developing a relationship between theoretical understanding and practice and with locating the discrepancies between them.

According to Louw (1982) action research distinguishes itself from conventional research in that it is not undertaken by highly trained experts with mastery in a chosen field.

> Action research does not rely on the superiority of the researchers in a particular field,.... but relies much more on the researcher's ability to stimulate dialogue and participation amongst those people he is working with, and his ability to understand the human condition in order to develop his empathy with individuals (p5).

One of the central goals of action research that Louw (1982) presents, which is also important in this particular study is that of autonomy - "the ability of groups to think and act independently in order to develop the general welfare of their people, as well as the personal qualities of individuals" (p8).

McNiff (1988) an author writing from an educator's perspective, states that action research "encourages a teacher to be reflective of his own practice in order to enhance the quality of education for himself and his pupils" (McNiff, 1988, p2). Action research is an increasingly popular movement in educational research which is being noted in educational communities as a real alternative to the more traditional theory-based approach to educational research. McNiff (1988) describes two aspects of the term "action research". Firstly, it describes the outcomes of an educator intervening in his /her own practice. There is "no hard and fast definition of what happens" (McNiff, 1988, p2). It is essentially an eclectic route into self-reflection that is aimed at educational improvement. The second aspect is that it provides a structure for methods and techniques, the systems that account for the anticipated improvement of the self-reflective practice. McNiff (1988) argues that action research is not simply teaching, but being aware and critical of that teaching and using this self-critical awareness to open up the process of change and improvement of practice. Action research is a "systematic enquiry made public" which distinguishes it as research. It aims to

develop theories and rationales for the practice and to "give reasoned justification for the public claims to professional knowledge" (McNiff, 1988, p6). Such an approach to research is appropriate to the current study because the programme to be evaluated was pscho-educational, even though it was not located in a formal educational setting. However, this is not to say the action research can only be based in an educational setting.

According to Stringer (1996), community- based action research is a derivative of the action research approach to inquiry. Historically, community -based action research is "related to models of action research that sought to apply the tools of anthropology and other disciplines to the practical resolution of social problems" (p9). He describes the dialogic, hermeneutic approach to evaluation which implies a "more democratic, empowering and humanizing approach to inquiry" (Stringer, 1996, p9) as being the ideological basis that community-based action research is based on. The fundamental premise of this approach to inquiry is that it starts with an interest in the problems of a group, a community or an organization. It is based on the assumption that the knowledge inherent in people's everyday, normal lives has as much validity and utility as knowledge linked to the theories of academic disciplines. Community-based action research acknowledges the "competence, experience, understanding and wisdom of ordinary people" (Stringer, 1999, p167). The following interpretive assumptions underlie community-based action research:

- Research is usually limited in context and focuses on particular issues or problems in a specific context.
- Researchers aim to empower participants by engaging them actively in all phases of the research project. "It has been described as research *of, by* and *for* the people" (Stringer, 1999 p167).

- The main purpose of the study is to extend the audience's understanding of an issue through providing rich and descriptive accounts that reveal the lived experience of the participants and their interpretations of the issue.
- Research aims to ensure tangible outcomes that directly benefit the participants. The participants' joint accounts form the basis of working towards a resolution of the issue or problem being investigated.

Thus the approach of community based action research is to use participatory procedures to enable people to systematically investigate their problems and issues, to formulate accounts of their situations and to devise a plan to deal with their difficulties. Briefly, the working principles of the approach are those concerning equal, harmonious and non judgmental relationships; empathic, sincere and attentive communication; encouraging, supporting and promoting active involvement and participation; and inclusion of all the relevant individuals, groups, and related issues.

The method of action research is described by McNiff (1988) as involving a "self-reflective spiral of planning, acting, observing, reflecting and re-planning" (p 7). Action research is never static but rather a continual process which demonstrates how one person's ideas develop and may be used by another to move his own ideas forward. Stringer (1996) writes about the community based action research model as - look, think, act. It is a recycling set of activities in which researchers/participants/ facilitators explore the details of their activities through a constant process of observation, reflection and action. At the completion of these set of activities, they will review (look again), reflect (reanalyse) and re-act (remodify their actions). Thus there are various formulations of action research which explain different ways in which the same set of activities are described. The model I used is taken from McNiff (1988) and diagrammatically the stages are presented as:
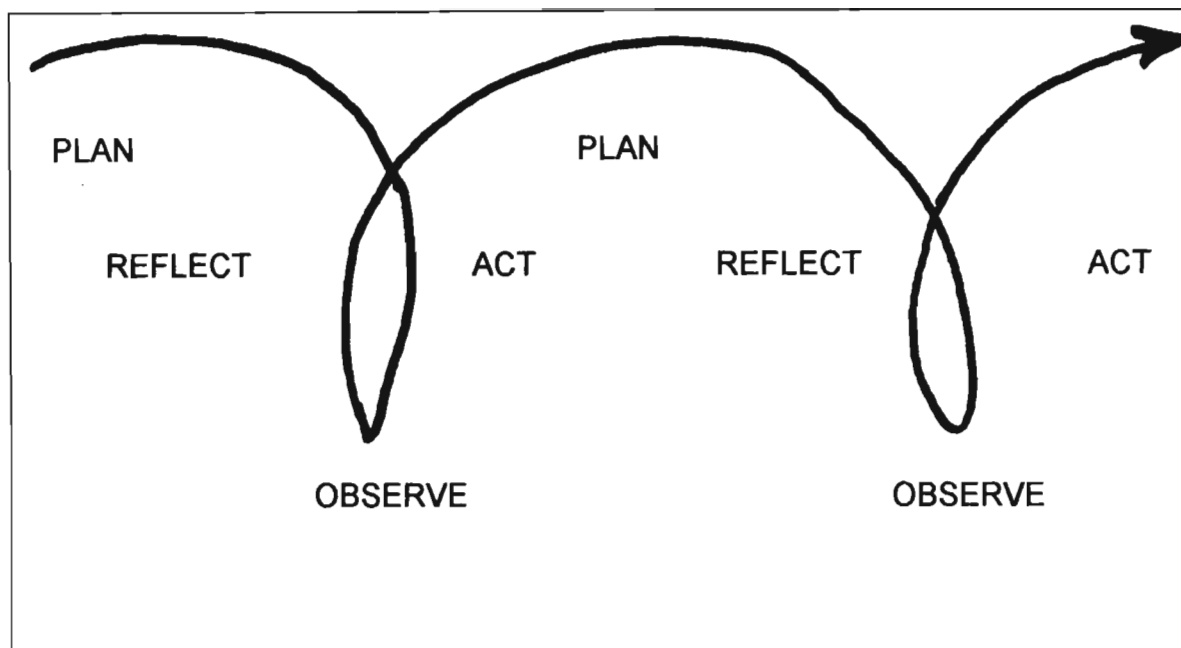
FIGURE 3.1: Action research Spiral

Planning: This describes the planning that went into each individual training session.

Acting: This is what happened in each training session, what the trainers and participants actually did during each session.

Observation: The observations that were made by the research assistant.

Reflection: This is when the observations are incorporated back in to the planning of the subsequent session.

I applied these four stages of analysis to each training session, with the goal of feeding the reflections of the preceding session into the planning of the subsequent session.

Thus far, the theoretical principles underlying this research have been discussed. The practical applications involved in the planning and implementation of the training programme will now be presented.

3.3 PRACTICAL APPLICATIONS

The section outlines the broader process of overall programme monitoring and evaluation. It will then describe the tools involved in the research process, the data and how it was analysed in more specific detail.

3.3.1. Programme Monitoring

In terms of programme monitoring, this consists of examining the coverage of the programme and the delivery of the service (Patton, 1990). The coverage is the extent to which the programme reached its intended target population and this will be elaborated on in subsection 3.4.3. The delivery of the service is whether the training was accessible to the target population. This will be discussed in Chapter Five. Furthermore, the researcher needed to consider other 'interfering events' (Rossi and Freeman, 1993). Shortly after the training course began, a mothers' support group was initiated (Hemming, 2001) due to many of the caregivers expressing their uncertainty and difficulty in participating in the course as fully as they wanted to. The question arises as whether this mothers' support group, providing the opportunity for mothers to share and ask questions, may have affected the intervention of the training programme.

3.3.2. Process studies and evaluation

The purpose of this qualitative evaluation of the training course was to see how effective it was in terms of training caregivers and other trainees in caring for children with multiple disabilities. To achieve this, the focus was on how the training course was run in terms of planning and implementation. Thus the focus was on the process of the course rather than the outcomes or results.

To evaluate the course, the data used were observation notes, focus group discussions and evaluation forms which allowed for rich descriptions. The observation notes were recorded by two research assistants, focussing on the

50

content and process of development. The data were primarily qualitative although parts were quantified (in terms of the attendance numbers). There was no attempt to generalise the findings outside of the setting of this course – the focus was purely on how effective this course was in its specific setting.

3.3.3. Sampling

In terms of specifying the target population for this study, certain criteria needed to be clarified. What was required was a clear definition of who the participants in the course should be. This could have involved strict inclusion and exclusion rules.

Originally, the selection of the target population was based on the "need and demand" idea (Rossi &Freeman,1993). The group was identified as requiring a psychoeducational intervention: viz. to facilitate the process in how to care for their child with multiple disabilities. What was not adequately established was that although this need may have been evident to the service provider, the degree of demand was not clearly investigated. Furthermore, although there was *sensitivity* of the selection of the target population – a group of caregivers of multiply disabled children who could be reached directly at the centre, there was no *specificity* in terms of excluding those people who did not have the same relevant needs. Thus theoretically, although the aim was to sample a homogenous group with a specific need, the study eventually used more "opportunistic sampling" (Patton, 1990, p179). The sample shifted as the data was collected.

3.3.4 Data Triangulation

The study used a mixture of data sources and investigators. Thus there was triangulation in terms of data and investigators. Three sources of data were used. This included (i) the content and process notes of each of the training sessions, (ii) evaluation forms completed by the participants at the end of each

training session – this exercise only began from session four onwards, (iii) focus group discussions that were held with certain of the trainers and certain of the caregivers at the end of the course.

3.3.5 Observation

The research assistants were not actively involved in the process as participants but rather sat to one side, observed and recorded the process of both the planning meetings and the training course. Their presence was never explained to the other participants and as such, their observations of the training sessions were rather more covert than overt.

3.3.6. Entry into the field

As indicated in the previous subsection, the research assistants' presence were never explained to the participants. They simply attended the sessions and observed. Their permission to enter the field was thus never sought. The neglect of this aspect in the initial negotiations of the research process will be discussed in Chapter Five.

3.3.7. Focus group discussions

Focus group discussions were conducted at the end of the training course with the director and the child development officer working at the CDRC, 3 of the trainers, 9 of the trainees from the CDRC course and 5 of the Mpophomeni trainees. Focus group discussions are a highly effective qualitative method for data collection. In order to gather productive and 'rich' data from this method, the researcher needs to monitor equitable participation, to promote communication in the group and to be a competent facilitator in the group setting.

3.3.8. Recording the data

The content and process notes were written by the research assistants and later typed out and kept in a file. The evaluation forms were handed out at the end of each training session, then collected up and kept in a file. This only occurred from session four onwards. The focus group discussions were tape recorded and later transcribed.

3.3.9. Interpreting the data – inductive analysis

Inductive analysis was employed in that themes emerged out of intensive reading of the data rather than being imposed prior to data collection and analysis. The qualitative method used to guide the structuring and analysis of the data was community based action research. The four stages of planning, action, observation and reflection was applied to the data and used to analyse and present the data in Chapter four.

3.4 PLANNING AND VENUE OF THE TRAINING PROGRAMME

This section describes the initial planning of the training programme. The training programme was to be run at the CDRC and then rerun at a community centre in Mpophomeni called Zenzeleni. The reader may refer to Chapter One for more information of these centres.

The initial intention while conceptualizing the training course was described by the Director of the CDRC. During her time at the CDRC, she realised through her contacts with the primary client group, that is mothers, grandmothers and other caregivers of children with multiple disabilities, that the vast majority had very limited information regarding the disability of their respective child. Although these caregivers had taken their children to clinics or possibly been referred to doctors, on arriving at the CDRC they were unsure about the difficulty

with their child and what the causes were. They would report that no clear explanation had been provided to them by the 'specialists'.

The Director felt that the CDRC could fill this gap in terms of building awareness, explaining the importance of early interventions, and empowering these caregivers by informing them about their child's disability and teaching them basic skills to assist the child. Furthermore, an underlying belief in Childrens' Rights and their right to an education, added to her commitment to intervene at this level. In addition, her interactions with the caregivers highlighted their heavy reliance on traditional beliefs and the idea that their child had been cursed. The director felt that these beliefs may inhibit a fuller understanding of the difficulties experienced by the child and thus prevent certain useful interventions from taking place.

Logistically, the director also realized that mothers could not access resources in town due to distance. By empowering them through training and encouraging them to return to their communities, there was the hope that this limitation could be solved.

The Director thus envisaged that the training programme would result in a:

> cohesive, dedicated group of trainees who would grow together during the course, to take back into their communities an awareness of childhood disability.

She hoped that an outcome would be that these trainees would then undergo trainer training so that they may be equipped to return to their communities and run courses there. Furthermore, she planned for the CDRC to then run specialised courses on childhood disabilities for hospitals, crèches, teachers and nurses.

The Director approached the Director of the Child and Family Centre (CFC), University of Natal - Pietermaritzburg, to assist in the development of this programme. They formed the 'core team' and made the decision to run and research a programme suited to their perceptions of the local situation. It was agreed in the planning of the training that an expressed principle would be that "blaming" the mother, in any way, would not be acceptable in terms of the process of encouraging people to accept new ideas and information. The aim of the training course content was not to be to replace people's beliefs and practices, but rather seen as alternatives that may be explored concurrently with their traditional beliefs.

Initially, the training course was to be held at the CDRC, on a monthly basis, in a two hour session. The CDRC sessions were to be held from 14h00 until 16h00. After session one at the CDRC, it was realised that the 2 hours were not sufficient. The times were then extended to 13h00 until 16h00, with a 15 minute break for tea.

Even with the extended time frame, various trainees felt that the time was still too short and that the sessions could have been held twice a month instead of once. Some of the trainers and caregivers commented:

- *I'm not sure what the trainees thought about the time, whether everything was covered in each module, but maybe time could have been increased.*
- *In the positioning, I know it took 2 modules, but you could see that not each and everyone got a chance to practise the skills, so I think it was a little rushed.*
- *Time was too short, because by the time we have finished, we still want to ask some other things.*
- *Time is a bit short, maybe twice a month instead of once.*

The research assistant made the observation that people were often arriving late and leaving early which was disruptive to the sessions. One of the criticisms of the course was that the course ended too late and so many people had transport difficulties. This point will be discussed again in Chapter five.

The CDRC seemed an appropriate venue in terms of accessibility to the trainers and it was also large enough to cater for the number of intended participants. However the regular trainees, who were mothers and other caregivers who usually attended the center felt it was inaccessible. They noted:

- *The CDRC is too far for us, we didn't have anything to bring us here.*
- *I think the workshop needs to be held in central town.*
- *We would like it to be moved because this place is too far.*

Another difficulty was that at times, children who attended the center would still be present during the training. This became problematic in that someone responsible for the caring of the children needed to be available. Since the staff of the CDRC were attending the course, the director sometimes assisted or else requested assistance from student volunteers or from employees of the sheltered employment organisation on the same property. This was not ideal since the children required specialized care in terms of their behaviour, and this could not be provided by these untrained volunteers. The result was that the training sessions were often disrupted by the behaviour of the children.

On the other hand, since the training course was about caring for the disabled child, it was also useful, particularly for modules 6 and 7.

3.5 THE ROLES OF THE PARTICIPANTS IN THE STUDY

The following subsection presents the various participants who were involved in the programme in differing capacities and roles. It is important to provide this information since it had a large impact on the process of the training.

3.5.1. Researchers

The role of the researcher in community-based action research "is not that of an expert who does research, but that of a resource person" (Stringer, 1996, p22). The researcher becomes more a facilitator or catalyst who works with the people to assist them in defining their difficulties, and supporting them to arrive at effective solutions. In this study, the role of the research assistant in an action research model was never explained or made explicit to the assistants. As a result, observations that were made and reflected on in the researchers' notes were never fed back into the process of planning the subsequent session. This is a crucial limitation which will be discussed in Chapter five.

My role in the study was to write up the findings from the raw data collected. During the time that the data was collected, I was employed as an intern psychologist at the CFC. I was assigned to the CDRC to administer educational assessments of some of the children and developed a good working relationship with the child development officers who were employed there. In addition, I participated in some locum work when the director of the centre was on leave. I attended two of the training sessions where my role was one of an observer in the workshops.

The data was collected by two research assistants who were completing their research internships. They were employed by the CFC. The first researcher collected data up to and including Session 4. Besides her involvement in attending all of these sessions, she went to the training meetings beforehand

and prepared agendas and completed the minutes of these meetings. She appeared to take a responsible role and related well to the director and the child development officers. She was extremely insightful in her observations and I found her notes very helpful. She was then moved to her second placement and a new research assistant replaced her.

This assistant did not attend module 6, the first planning meeting for module 7, and the first planning meeting for module 8. The director of the CDRC prepared the agendas for all the planning meetings. This research assistant's style and interaction with the centre appeared more formal, detached and less interested. Her observations were not as detailed as the previous researcher. This research assistant also conducted the focus groups with some of the trainers and trainees at the end of the training session.

The data generated by these two research assistants formed two of the sources of data for this study.

3.5.2. Trainers

The definition of trainers in this study are those who contributed to the content of a particular module. The trainers were volunteers who either had specialised knowledge in a certain area, or else had expressed an interest in training a particular module. Some were of professional status and others were people who had a certain amount of experience and interest.

The presence of the trainers during the course of the programme was an opportunity to allow these trainers to rethink their role in the community and their relationships with the caregivers of disabled children. A more implicit goal was, in a sense, for the programme to provide sensitivity training for the trainers as some of the professionals may have had difficulty relating to the realities of the mothers' lives. For example, in an underresourced area, realistic suggestions

for self-help needed to be made and suggestions that a mother living in a poor, rural community should have consulted a physiotherapist for her child's treatment, would have been met with resistance. Furthermore, such advice may also have negatively impacted on that trainer's credibility, leading to all her advice being viewed in a skeptical light.

It was decided in the original proposal that all material to be presented would be agreed on in the preliminary planning meeting for each module. The trainers would need to present their material in a participatory and non-judgmental manner. The trainers would circulate amongst groups during the group discussions to ensure they were being adequately facilitated and that during the feedback of the group discussion, any incorrect information or 'blaming' was to be dealt with tactfully. Finally, the feedback gathered from the group discussions in each session would be summarized, ensuring that the key concepts decided at the training meeting had been adequately covered and understood.

3.5.3. Facilitators

The facilitator in this study is the term used for those volunteers who did not actively develop or contribute to the material being presented, but had attended the preliminary planning meetings. Their role in the programme was to create a 'bridge' between the trainers and the trainees. Furthermore, they were skilled in translation between English and Zulu. Two of the facilitators were Child Development Officers employed at the CDRC, one was a childcare worker and one was a regular attendee at the CDRC and the mother of a hearing impaired child. This fourth lady was asked to be the trainer for the Mpophomeni based training programme. Although all four had extensive experience in caring for children with multiple disabilities, none were of a professional status. All four underwent a three hour basic training in facilitative skills run by the director of the center. Although the original proposal envisaged that the facilitators would

be consistent from session to session, providing continuity by their presence, this did not always occur.

The role of the facilitator was to ensure that everyone in the group understood the question or issue that was to be discussed. Furthermore, they were to ensure that everyone had an opportunity to speak with no one person dominating the discussion. The facilitator was to keep the group focused on the task at hand and any blaming of the mother was to be tactfully reframed. Each trainee's contribution was to be clearly summarised and ensured that it was understood by all of the group members. The facilitator could allow other participants to be the scribe.

3.5.4. Trainees

As previously mentioned, the trainees targeted to attend the training course were mothers and caregivers of disabled children and educare workers. The latter category included nurses, and creche and teacher assistants who work directly with disabled children. Some of the trainees were regular clients of the centre, whereas others were new and as such did not know the other trainees. Furthermore, the trainees were from different socio-economic, cultural and educational levels. This broad grouping resulted in trainees responding and interacting to different degrees.

The trainees also consisted of **professional** and **random** observers:
The professional observers were people who offered advice or assistance with the content of the course but did not participate in the delivery of the training modules. They attended the course as observers and participants.

The random observers were participants who simply showed an interest and arrived ad hoc. They were not invited to make any contributions to the content of the course, although they did participate in the proceedings.

In conclusion, this chapter has described why I chose the qualitative research methods to investigate the effects of the training programme for caregivers of children with multiple disabilities. It shows the appropriateness of qualitative research methods in the realm of community psychology and outlines various themes that were considered in implementing and monitoring this programme. Issues of sampling, triangulation, observation techniques and data collection and recording were presented. The model of action research is the inductive method used to analyse the findings and these will be presented in the Chapter four. Finally, the initial planning and the implementation of the training programme were described above.

4.1 INTRODUCTION

This study was designed to report on, evaluate and recommend changes in a training programme for caregivers of disabled children. These findings pertain to the **CDRC** based training programme. Section 4.7 describes the Mpophomeni based training programme. The study uses the model of action research to describe and analyse the findings. An integral factor of such a research design is that reflections from each session are used to inform the planning of the subsequent session.

As described in Chapter three, data triangulation was used. Firstly, there were the content and process notes of each session as recorded by the research assistant. Secondly, comments were gathered from evaluative worksheets that were completed by the participants after each session. Thirdly, there were the tape recordings of the feedback comments from focus group discussions held with the director of the CDRC, trainers and trainees. This information is compiled into a research document (Appendix A and B).

I have not recorded the evaluations as a separate section in this chapter, but rather incorporated them throughout the findings, in keeping with an Action Research model. This evaluative data is presented as verbatim comments taken from the focus group discussions and the worksheets. They are indicated by the use of italics throughout the chapter. I have selected a rich variety of material from the data collected. This thematically analysed work therefore represents a filtered version of the qualitative data. In the process, some of the responses have been omitted. Hull (1984) in Powney and Watts (1987) suggests that the researcher will interpret the data in the light of her "accumulated knowledge of

the participants' meaning system" (p192). This meaning system has been built up through the processing of the data within the context of the training programme. My responsibility is to use my integrity in communicating the participants' views as accurately as possible.

Furthermore, a Zulu translator was used in the focus group discussions for the sake of the English speaking research assistant. Many of the evaluative written comments were also translated from Zulu into English for the purpose of this study. As a result, there is the possibility that some meanings may have been changed to some extent during the process. In addition, many of the comments were from by participants who speak English as their second language.

4.2. TRAINING PROGRAMME

4.2.1. Planning of the training programme

The programme was originally designed to provide information and to develop awareness in primary caregivers of disabled children. The group includes caregivers living in peri-urban and rural areas and educare workers from non-profit organisations involved in service delivery to such families. The Director, through her extensive experience in childhood disabilities decided on the content for the nine modules. These were presented to and confirmed by a clinical psychologist based at the CFC, who had been working primarily in the area of child development and had played a role in the creation of the CDRC.

A meeting was then held in October 1998 with a variety of agencies who formed the network committee established by the CDRC over two years. Below is the list of agencies that attended this initial planning meeting:

TABLE 4.1: List of resource agencies involved in the initial planning of the course

Institute for Urban Primary Health Care
Child and Family Centre
South African National Epilepsy League
Peter Pan School
St Christopher's School
School Psychological Services
Association for the Physically Challenged
Thandanani
Edendale Hospital

Four mothers of children with multiple disabilities who attended the CDRC were also present at the initial meeting. The outcome from this meeting was that the original modules proposed by the director were agreed on, with some minor adjustments. Furthermore, those who were interested in undertaking the training in the different areas were recorded, and suggestions for other appropriate trainers were made and followed up. At this stage, there was a great deal of enthusiasm from all participants. A trainer, Barbara said:

> *(it was a)...great pleasure for me, as I had a goal in mind of helping other people, which I didn't know how or when, but when I was asked, I saw another Barbara, not this one I knew.*

This illustrates one of the trainer's initial responses to the planning and her excitement at being involved.

A professional trainee (dental hygienist) commented:

> *I do work with handicapped patients and I thought it would be exciting to know how to deal with them because you need to know how to communicate with them before starting to work on their mouths, to relax, calm them, so I though this would be ideal.*

This trainee expressed the need for learning how to relate to disabled patients.

A caregiver said:

> *I had a feeling of sharing my experience because I have a disabled child.*

This mother was indicating a willingness to share her story with other people.

The training course was advertised through a newspaper article, posters strategically placed at various community centers in the Pietermartizburg and Mpophomeni areas, and largely through word of mouth by CDRC and the network staff.

4.2.2. Content of the training programme

A list of the topics and the content decided on for each module in the training programme is outlined below.

Table 4.2: List of modules covered in the nine training sessions

Training Sessions	Topic	Content of training sessions
One	Awareness of Disability	What is disability? Newborn Child Pre school child School going child Prevention
Two	Acceptance and Basic Care	Hygiene Feeding Self help Toileting Dental hygiene Behaviour Management
Three	Communication	A model of Communication Barriers to Communication
Four	Purpose of Play and Stimulation	What is play? The senses and how to stimulate them Case studies
Five	Innovative Approaches – Toy and Equipment Making	Using what is around you – early stimulation ideas. Different toys for different disabilities Demonstrations Grading of activities and toys
Six	Handling and Positioning 1	The importance of positioning and handling in activities for daily living
Seven	Handling and Positioning 2	Positioning and cerebral palsy Recap of carrying position Sitting position for feeding Sitting position for playing Lying down position for sleeping
Eight	Use of music	What is music? Impact of different types of music Influence of rhythm on the body and brain Linking storytelling with music
Nine	Evaluation	Recap of 8 modules What are the skills/knowledge learnt from each module? What was your personal experience of the programme? How has this training changed your attitude towards disability? Recommendations for future programmes Barriers to sustainability.

These modules cover a comprehensive range of topics related to caring for a disabled child. The ordering of the modules progressed from general awareness raising, and information giving to more specific skills training. All of the modules were built on the underlying philosophy that a disabled child has potential that needs to be developed through stimulation.

4.3 DEMOGRAPHICS

To present the demographics in this study, certain terms need to be clarified. The roles of each were described in more detail in Chapter three. **Trainers/facilitators** were people who were either actively involved in presenting the material for each session, or else took on the role of facilitating small group discussions. They attended the training meeting to discuss the process and content, before the actual session. The **professional observers** were people who offered advice or assistance with the content of the course but did not participate in the delivery of the training. They attended the course as participants. The **random observers** were participants who simply showed an interest and arrived at a training module ad hoc. They were not invited to make any contributions to the content of the course, although they did participate in the proceedings. The targeted group or **trainees** were mothers, other caregivers, nurse assistants, teacher assistants and creche assistants.

There were fourteen participants who enrolled to attend the training programme. Eight of the participants were mothers of disabled children who attended the CDRC and the remaining six participants were educare workers. Of these 14 particpants (and the 25 who attended the Mpophomeni course) there was only one male. This seems to support the literature that the majority of people who fill the role of caring for the disabled child and who have a vested interest in this area, are female.

The levels of the participants' previous education are shown in Table 4.3 below. Three of the educare workers (creche assistants) were employed at a unit for cerebral palsied children, two were employed at a special school (teacher assistants), and one was a dental assistant employed at the local government hospital. Eleven of the participants were black and Zulu speaking, two were white and one participant was Asian. All fourteen of the participants were female. The medium of instruction was English with a Zulu-speaking translator present at all of the sessions.

TABLE 4.3: Educational levels of trainees

Educational level	Mothers	Educare Workers
Grade 3	1	
Grade 7	2	
Grade 8	1	1
Grade 10	2	2
Tertiary Level		3
Unknown	2	

The figure below is a graph showing the various categories of people attending the planning meetings for each of the nine training sessions.

Categories of people attending each training meeting

Legend: Professionals ■ Observers ■ Mother representative ■
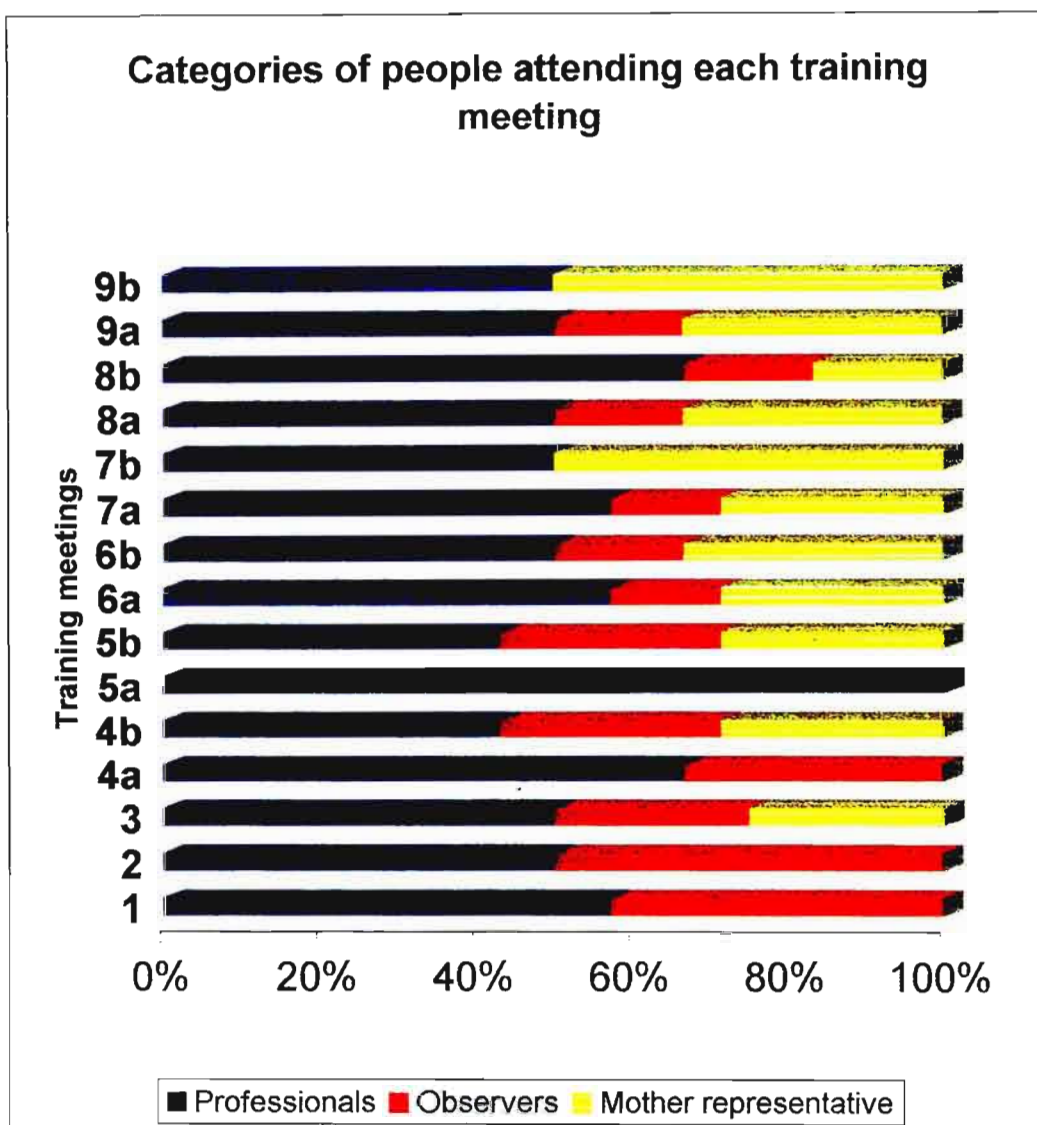
FIGURE: 4.1: Training meeting attendance

The vertical axis indicates the planning meetings for each module. From training session 4 onwards there were two planning meetings per training session, hence the labeling of 4a and 4b, and so on. Numerically, examples of the breakdown in attendance for session 1 was: four professionals and three observers; for session 3: two professionals, one observer and one 'mother representative'; for session 5a: two professionals and for session 5b was three professionals, two observers and one 'mother representative'. The reader can observe that the attendance at these meetings was largely dominated by people of professional status. Although a representative of the caregivers was present, she was also a facilitator and translator and was expected to be present since she was an employee of the CDRC. In terms of the perspectives from an actual caregiver – the target population for this course, there was no representation at all.

Thus any decisions regarding the content of the training modules or the process of how they should be delivered, was not discussed with the caregivers. The observers who attended the planning meeting were people who had some experience or interest in a particular module. Their attendance appears to decrease over time. This may be reflective of the decrease in enthusiasm and general participation as time progressed. Initially, all of the targeted population who wanted to attend the course needed to complete a registration form, stating their level of education and their reason for wanting to do the course. During the course of the training, other caregivers joined in at various points of the training. Although they did not complete a registration form, they were given the opportunity to participate. If they attended 7 or more sessions, they could receive a certificate.
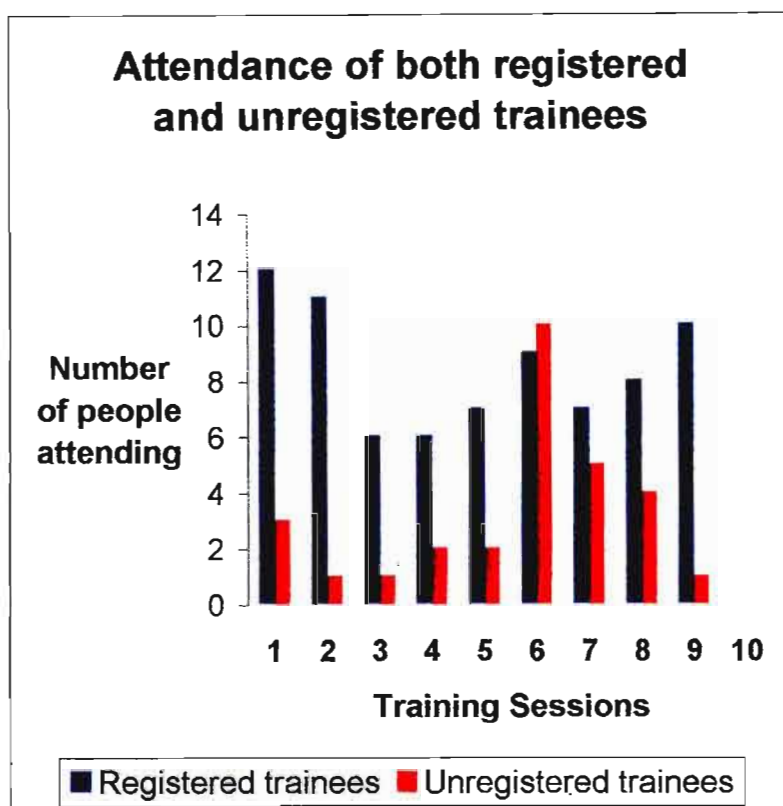
FIGURE 4.2: Attendance of registered and unregistered trainees

It is positive to see the gradual increase in 'other' (unregistered) caregivers who heard about the course via word of mouth, and started attending, particularly around modules six to eight. As mentioned in Chapter three, an 'interfering' event was the initiation of the mother's support group, from module four onwards. It was at this group, that many caregivers were encouraged to attend these modules, particularly Module 6,7, and 8 since a common request was for assistance with handling and positioning the children. Although the increase in attendance may not have been related to the actual training programme, but rather to this 'interfering' event, it was still a positive spin-off.

Below is a graph depicting the attendance of the nine sessions by the trainers, trainees (mothers/educare workers), professional observers and random observers.
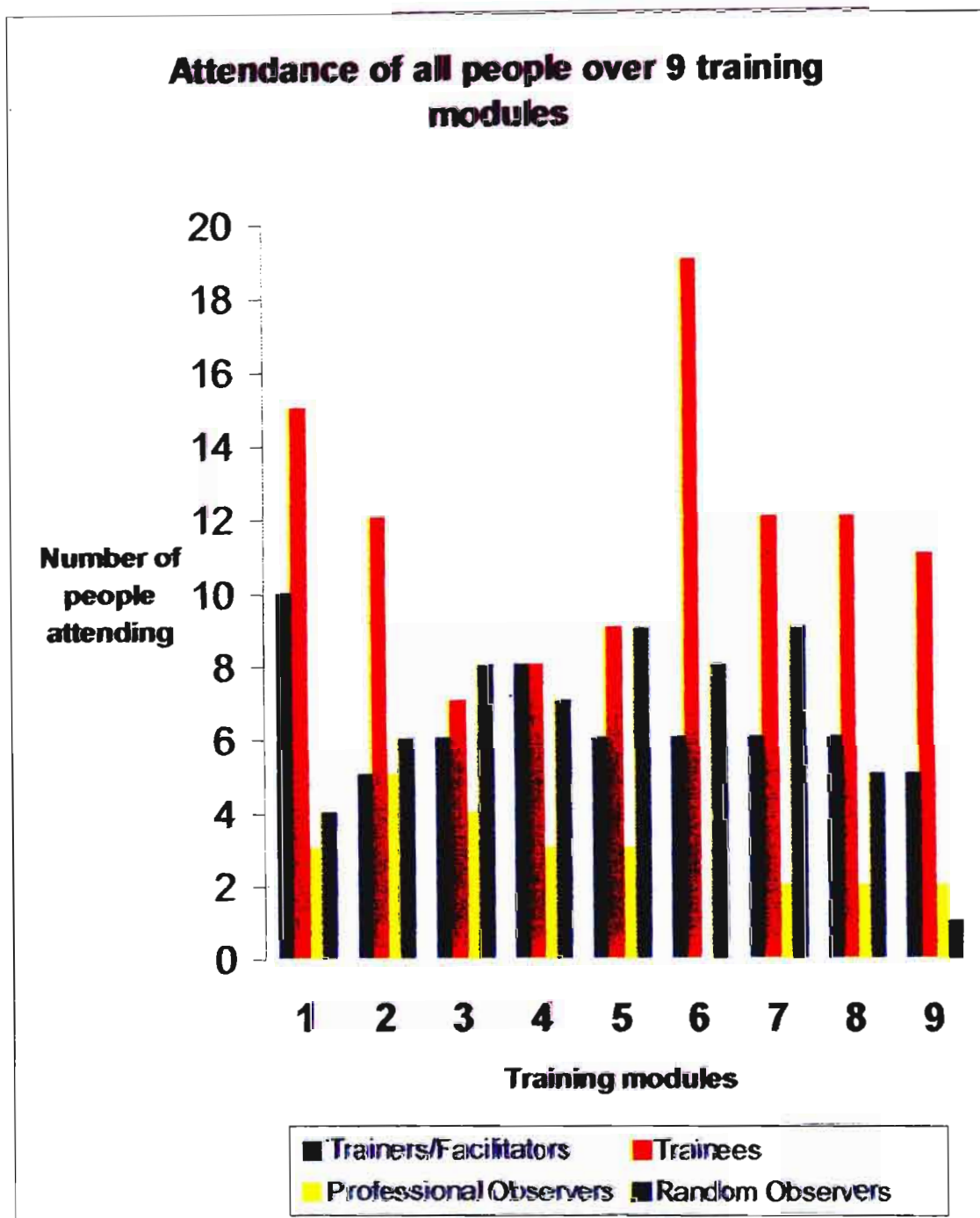
FIGURE 4.3: Attendance of all participants for the nine modules

In terms of the trainees, there was initially a high attendance, but this dropped around the middle of the course. From module 6, attendance again increased and this may be explained by the mothers support group and the general

increase in attendance demonstrated in Figure 4.2. The attendance of the trainers was initially very high, but then stabilized. The random observers' attendance increased and then slowly decreased, as did the numbers of professional observers.

A trainer made the following comment which demonstrates the difficulty in having such a wide range of different and constantly changing population of participants. She said

Also here (CDRC), the people attending changed, there wasn't a body of people that you knew would be there every week - new people came in quite a lot.

Another trainer, who delivered the training in four of the modules noted the same difficulty. She expressed this as:

I found it quite difficult because the range of people attending were at very different levels and I often felt that the mums, didn't get back the benefit because of dealing with this range of professionals and mums and some who had never had any direct contact with multi disabilities. So from a presentation point of view, I found it difficult to know which level one was working at, because my feeling was that one wanted to work with the mums, more than the others.

Another trainer supported this feeling of there being such a changing and diverse group of participants. She said:

I felt a little bit inhibited with all the extra people here. I think it was good for everybody to be here and we all learnt a lot, but I think you would get a much better response if the group was smaller.

For the sake of ease in recording the following findings, "professionals" will incorporate the trainers/facilitators, and the professional and random observers

The term "caregiver" applies to the actual mothers and caregivers who attended. "Participant" refers to the whole group. If we look at the professionals versus the caregiver population, we can see that there was an overwhelming dominance of these professionals compared to the actual targeted population – the caregivers, in all modules except number six.

Comparison of Professional 'others' versus Caregivers

Number of particpants (y-axis: 0 to 20)

Training Sessions (x-axis: 1 to 9)

■ Professional 'others' ■ Caregivers
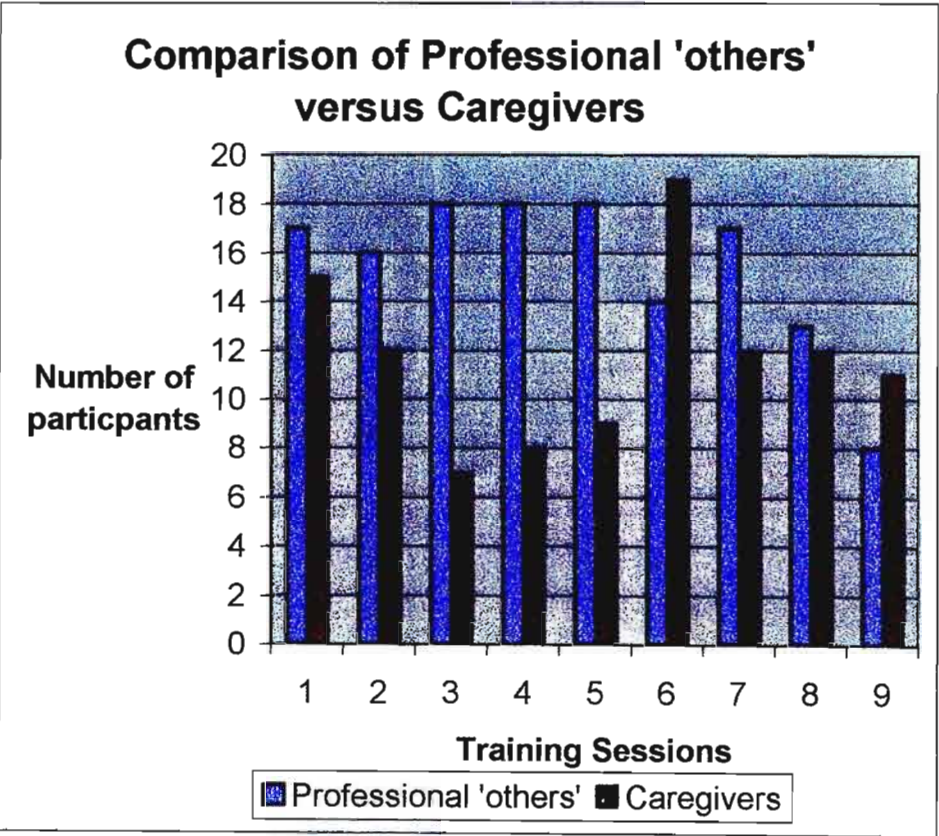
FIGURE 4.4:Comparison between the Professional others and the targeted population

It was only from Module 6 that there was a better balance between the two groups. A large criticism from the trainers and the director of the course was that these participants and the resulting splitting into groups during the training was always disproportionate according to the large presence of professionals 'versus' the caregiver trainees.

A comment made by the director from the focus group discussion displays her concern about the disproportionate numbers of professional versus the caregivers, and the effect she anticipated on their ease of participation:

We first started (CDRC) with our moms, and I think they were very unclear, they came in and we had many professionals who were interested in the course and I think the moms did feel a little threatened, a little bit uncomfortable in this company in the early part of the course.

One of the facilitators who was employed at the CDRC as a child development officer substantiated this concern in her comment:

......I picked this up early and spoke to them confidentially. As a concern it came out that maybe to speak to the mothers how they are feeling about the training itself, and it came out, it seems that the professionals are dominating everything, and so at times it's a little difficult for them to voice out everything they would like to say or else to ask anything because the majority of people seem to almost know some of the things that have been discussed in the course. So it came out that they thought the training was for someone else, not for them.

A trainer also felt that the imbalance in the 'nature' of participants affected the caregivers responses. She said:

Even if you have the number of people we had here - the parents and the caregivers, there weren't a lot of them. If you just had to have a discussion - not even in smaller groups, just to be open, it would make it easier for them to respond.

A random observer who attended one session also noticed the imbalance and she raised the point as follows:

Need to encourage more parents to attend as they are better teachers

Thus from an evaluative perspective the changing number and composition of the group was a problematic feature of the training programme.

4.4 FINDINGS FOR EACH MODULE

The following section presents the evaluative findings for each training module from one to nine. These findings are analyzed from the three sources of data referred to earlier, and follow the model of action research: planning, action, observation and reflection. Diagrammatically, the model will look like the following:

Plan

P   P   P   P   P   P   P   P

Reflect   Act   A   A   A   A   A   A   A
           R   R   R   R   R   R   R   R

Observe   O   O   O   O   O   O   O   O

Module 1	Module 2	Module 3	Module 4	Module 5	Module 6	Module 7	Module 8	Module 9
Awareness of Disability	Basic Care & Acceptance	Communi - cation	Purpose of Play & Stimulation	Toy & Equipment Making	Handling & Positioning 1	Handling & Positioning 2	Use Of Music	Evaluation
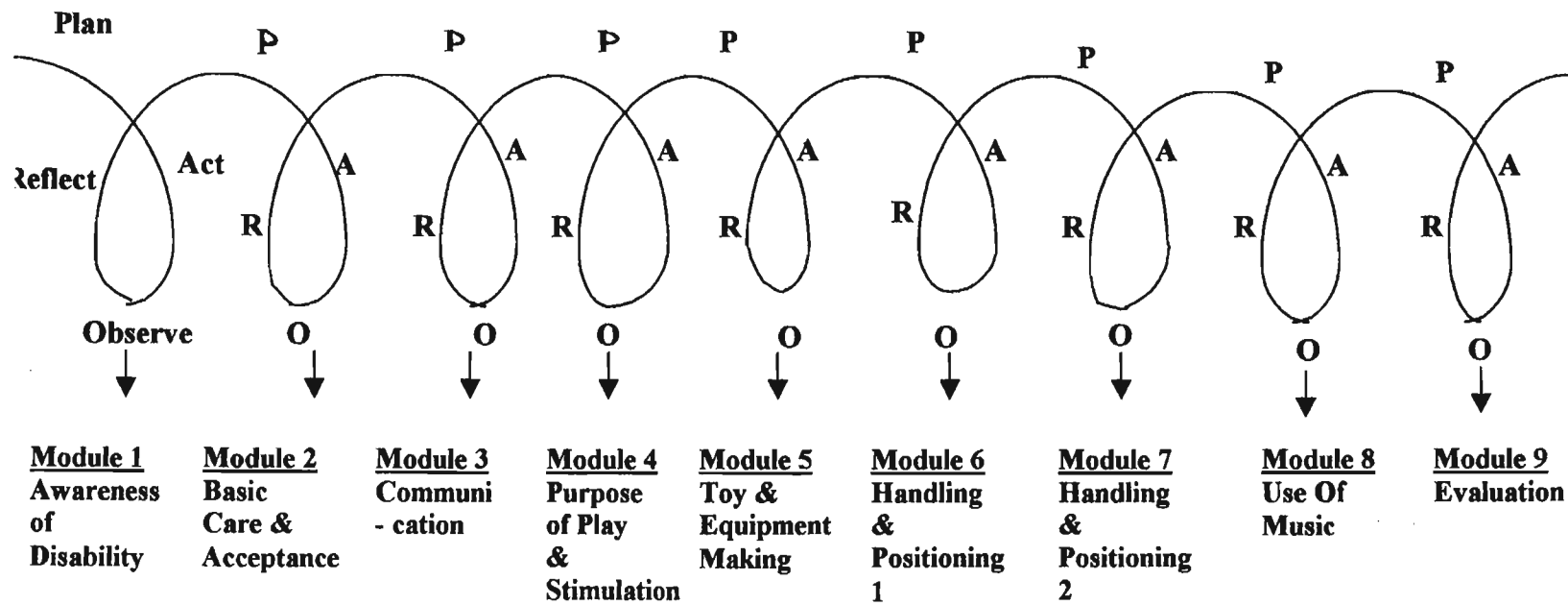
FIGURE 4.5: An Action Research Model applied to each Module

4.4.1. Module One: Awareness of Disability

Planning: This session was planned to begin with an introduction and that participants' expectations and goals would be explored. The goal of the session was to present the issues of recognition of disability, and some information on prevention and intervention. The issue of disability being seen as a curse was identified. It was agreed that a 'story-telling' technique would be used, with a disabled adult describing her personal experience, with the aim of breaking down stereotypes. The participants would then be split into smaller groups of two or three for discussions.

Action: The director introduced herself as the co-ordinator and then introduced all those present and asked people to make notes. An icebreaker was done and then the group was asked to split into smaller groups of two or three people to talk about their experiences of disability, with one person giving feedback. The trainers sat amongst the trainees and facilitated the discussion. A trainer asked for two important points from each group to be fed back, adding that the professionals and mothers should share equally. Feedback was provided by only one mother and six professionals. The trainer asked if there were questions from the participants. Four questions were asked by the professionals only.

In the focus group discussion, a trainer made the comment about the difficulty dealing with the diverse participants :

> *I think a more homogenous group would be easier, but at the same time it was quite nice to have the input because I think the professionals need to see the moms and where they're at. So it's quite tricky knowing how to deal with it.*

A trainer also commented on the high number of professionals that were present and their resultant effect on the participation from the caregivers:

> *I felt they (the caregivers) were receptive, ... but I think if there weren't*

so many specialists, I think that restricted them to a certain degree.

A resource list was then handed out to all participants. Two new trainers took over. They broke the group up by giving each of the participants a number and asked those with the same numbers to group together to discuss the causes and prevention of disability. After discussions, feedback was provided by three professionals only. A medical model for the prevention of disability was presented. There was general discussion. The organiser concluded the session by stating she felt another session should be done for orientation and that session one should be repeated in March.

With regard to the actual content that was provided, one professional trainee felt it was quite long but that it served mainly as a refreshment course for her. Other comments from the professional trainees were positive. A trainee said

I learnt that parents can have problems accepting their child, because for me, before, any parent accept any child automatically - but this isn't true - parents can be angry with themselves or the child.

Caregivers commented on how they enjoyed the experience of sharing freely.

- *When I found out that I'm not the only one with a disabled child I was relieved because I was able to share my experiences and difficulties with them freely and accepting my child.*
- *I feel so proud when we as mothers talk freely about our children.*

Observation: Although people were introduced, the goals and expectations of the participants were not explored. In the icebreaker the concluding positions of the participants did not allow for a good 'mix' of mothers and professionals. The 'natural evolution' in terms of breaking up into groups led to the formation of mainly separate groupings of mothers versus professionals. As such, although interactive discussion and equal participation was planned and encouraged, this

did not occur. Similarly, once the personal testimony was given, only four professionals responded, while there were no responses from the mothers. Some points made may have been too academic and theoretical. The content on prevention was presented in a very didactic, non-participatory manner with it being quite theoretically based according to the Medical model. No completed evaluation forms from the participants were found. Participants were asked to complete a three page worksheet which was then kept in a file at the CDRC.

Reflection: It may be useful to use this first session to give all participants an opportunity to share their personal experiences, to make the course more personally related to them and to provide a more informal forum whereby their expectations and goals could be discussed. More time could be allocated to allow for tea and late arrivals. A better mix between the professionals and the mothers is needed. This could be achieved through an icebreaker and will encourage the mothers to participate, as the professionals encourage the mothers by being interested in what they had to say. A didactic, non-participatory approach to relaying information should be avoided. This should be replaced by a more interactive discussion between the trainees and with the presenter. An evaluation is required after each session.

4.4.2. Module Two: Acceptance and Basic Care
Planning: It was agreed that the workshop times would be extended by one hour, with a longer break for tea. To ensure a better balance of professionals and caregivers in the groups, all participants would be assigned to one of three groups for the remainder of the course. Participants would be designated to their groups according to the colour of the name tags they received on their arrival. Each of the groups would have a facilitator. The director raised the issue of traditional beliefs needing to be discussed at an appropriate time and with sensitivity. Some discussion around this incurred and the other trainers agreed that once participants felt comfortable, they would naturally bring the issue up.

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Action: An icebreaker exercise was done with balloon-popping. The aim was to normalise feelings around having a disabled child and how to cope with everyday demands. The presenter touched on her own experience as being a mother of a disabled child, but mainly did a lengthy presentation of material in her role as a psychologist. The late arrival of participants and one trainer not arriving at all was disruptive. When a caregiver was directly asked to provide feedback, a professional intervened and cut her off. To cover the issue of traditional beliefs, a story was presented as a vignette. One professional asked a mother - "what were (the caregiver's) mistakes?" The director closed by adding that topics like positioning and behaviour management will be covered throughout the course. She asked that the worksheets were kept in a folder.

The trainer was aware of the lack of discussion and participation from the caregivers. She said

> *I did the module on acceptance. I think it went off well but would have liked more discussion from the parents.*

Observation: The presentation provided was very long and didactic, and although the trainer could have used her personal experience as a mother of a disabled child, she kept her presentation more focused on her professional work experiences. Once again, the feedback only prompted responses from the professionals. The professional's comment about the caregiver's mistakes had a negative, judgmental and critical tone. As soon as any notes were written on the flipchart, participants became absorbed in copying these down rather than participating in any discussion.

One of the trainees, excluding the caregivers found this module repetitive and long.

> *It was quite boring because it was something we'd already gone through. ..... mainly refreshment for me.*

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A facilitator commented that she thought the caregivers had found the module useful. She described her experience in one of the groups as:

I remember I was in a group - a white lady said she once kicked her child because of the stress she had, and one mother was helped. The mother said "I always thought white people don't touch their children, even if their child is wrong," so this helped her, because those are the things that really happen - it gave relief to her.

Another caregiver had commented:

It was good to know you are not the only one and to accept our children and not hide them or feel ashamed.

Reflections: The times do not appear to be convenient for all participants since people are arriving late and leaving early. Although an attempt was made for better integration of the two groupings, professionals still appeared to hold the dominant position in terms of speaking and providing feedback. Amongst trainees there appears to be a 'fear' of missing out on the written word. Some professionals present or ask questions in a tone that is judgmental.

A professional observer felt that it would be beneficial to both the trainers and the trainees if it was ascertained what knowledge the trainees already had and to give them credit for this. This may have encouraged the trainees to respond more if they felt recognised in their efforts.

I would like to have known from the mothers what they are already doing, so you're working from a known basis because we were giving information not knowing what people had already done, so it would be useful. Like feeding a physically disabled child - everyday they are getting food into that child, so its important to see what they are doing before you know what you need to help them with

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Trainees also requested more knowledge about dental care and nutrition. Two caregivers made the following suggestions:

- *I felt the dental hygiene part was sort of left out, so maybe in the future, we could get a dentist to elaborate on dental care.*

- *I was hoping they will include on what kind of food should we give our children because of the constipation they always have.*

The cultural perceptions around the causes and interventions of disability were not really 'opened up' for discussion as the trainers had hoped for in the planning. A facilitator said:

You know, I think because we are very believing in this Zulu thing that a sangoma can do something about a child, if maybe we can find a way of telling the mothers ..... they musn't waste much time waiting, rather they must do both. Even if plan 1(going to a sangoma) is not working and they won't feel plan 1 is not working, but plan 2 (doctor) is the real resource.

Another caregiver expressed her desire to discuss this issue more. She said:

They were suppose to emphasise on the cultural things.

4.4.3. Module Three: Communication

Planning: The trainer would give each designated group a function of communication (greeting, requesting information, and so on) to present to the larger group who would guess what the person was attempting to communicate. Another trainer would present a model of communication. This trainer would then lead a discussion about each mother's child - how does your child greet, protest, request. She would include a brief outline of the developmental stages of communication, but the ages at which certain stages are expected to be reached, would be left out since these may result in the mothers' feeling despondent regarding their child's progress. The participants would have a discussion around what function of communication is most important, the

barriers to the child communicating and any practical suggestions for overcoming these barriers. It was agreed that all of the caregivers need to be encouraged to see that their children do communicate in some way and that this should be recognised. If no practical suggestions or advice could be offered to the mothers, each group should act as an emotional support for that caregiver.

Action: Each person turned to the person next to them and took turns singing the customary Zulu greeting to one another. The purpose of this exercise was to demonstrate that communication is based on turntaking. A trainer then led a brainstorming session with the whole group on how disabled children communicate messages. She wrote the answers on the flipchart in English and Zulu. Mainly caregivers participated in this part of the session. The group discussion was around what the barriers are to a child communicating and how these can be overcome. Everyone participated in these.

Observation: It was noted that the session was largely an academic discussion around a model of communication. A trainer said in the evaluative focus group discussion that

> *I would like to have done more on communication and play because I think we didn't do much in the practical , we did more theory than anything else.*

Furthermore, the examples that were largely used as alternative modes of communication were in sign language. This became problematic since most of the children were physically disabled and were unable to sign. It appeared to 'delude' the caregivers that sign language was the answer to all communication difficulties they may have with their children.

It affected a caregiver to such a degree that she requested another separate module should focus purely on sign language. She commented:

> *It would be nice to have a separate module for teaching us sign language.*

Reflections: A mother requested advice on how to make her child sit without him falling over. Although this topic was not related to communication, it had obviously been of concern to the caregiver and she was distracted from any other task at hand. It was noted that it was important for these issues to be dealt with immediately regardless of their appropriateness to the current discussion, so as to show support and respect for the caregiver.

The trainer felt that the diversity of the participants in terms of their levels of education, personal experience and range of disabilities in their children was problematic for training. She commented:

> *Particularly with communication and play modules, the variety of disabilities, so you couldn't address the issues in any depth with particular parents.*

Two educare trainees expressed their enjoyment of this module .

- *I learnt a lot, especially about the deaf child who can't talk. The point I like a lot is if you approach somebody who can't talk, you can talk else they'll think you're also disabled.*
- *Most interesting for me is that communication is not only language, you can communicate if you don't talk. And children can show they are happy, sad, cry, smile - body language is also communication. And to help them to communicate with the body if they can't use their mouths.*

A caregiver felt very positive from what she gained in the session. It gave her a new sense of awareness in her child's potential.

> *I learn that when I am talking to my child, trying to make her laugh, she wouldn't respond. But now I know how to communicate with her and she laughs and she's able to do different things.*

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4.4.4. Module four: The purpose of play

Planning: It was felt that the Zulu connotations of 'play' should be explored. It was emphasised that the trainers cannot assume anything but that they need to ask the caregivers to describe what they think play is. An icebreaker was suggested whereby the trainees form pairs and then demonstrate a game they played as children. The trainer would conduct a brainstorming session around "what is play and why do children play?" The facilitator would then gather the participants into their three groups for a discussion on how they play with their children. Material would be presented on the senses and the trainer would develop various case studies for the trainees to discuss. It was agreed that the type and extent of disability would be decided on beforehand and specified to the mothers, to ensure there was diversity in the types of disabilities discussed.

At this point, it was also felt that the role of the facilitators needed clarification on the objectives of the group discussions. It was suggested that in future, any person responsible for the group discussions should prepare a brief for the facilitators on what they need to achieve in their groups. Written evaluation forms were developed and were distributed at the end of the session.

Action: In the brainstorming session of what play is, two professionals and a random observer answered, there was no response from the caregivers. The next trainer then thought she should be presenting her case studies, when in fact there was supposed to be group discussions around how to play with your child. As a result of the misunderstanding and the ensuing confusion, the trainer presented material on how to understand what category of disability a child fell into, in order to inform how best to play with a child. When she finished her presentation, it was suggested that the participants move into their three groups to discuss the original topic. However, once the groups were formed there was uncertainty as to what they were meant to discuss. The next trainer then

presented her material on the senses using a question/answer format. There was no participation from the mothers. She used pictures that she drew on the flipchart to illustrate her points about when certain senses are used and she used volunteers to effectively demonstrate the point about which senses certain games stimulate.

Observations: In the group discussions, there was confusion and uncertainty about what needed to be discussed. The facilitators were not consistent from the previous week and they were unaware of the outcome they were hoping to achieve from the group discussions. There was also confusion around the order of presentation and the content of the module was very information intensive.

This idea of written material and the strong presence of theory was problematic. A professional observer in her evaluation form, made the comment

> *Some of the written charts could be confusing. Need simpler descriptions of the formats and as much practical demonstrations/experience as possible.*

Once again, the diversity in the range of disabilities that trainers were attempting to cover in one session, did not allow for any specific difficulties to be addressed. A trainer noted her concern with this over inclusion of material by saying:

> *There wasn't much opportunity to give those parents much information to go home with.*

Due to the cultural differences with regard to the concept of play, it would have been useful to explore this more. A trainee made the comment that the concept of play is an unusual one in terms of her culture.

> *I didn't understand this one, because we South Africans don't see the importance of play, so I feel I needed more information on that.*

A caregiver also added that

> *(the play module) needs to be made simpler, I feel I needed another*
> *module on that.*

Caregivers did appear to find 'play' a new concept but they seemed to gain from this module and it appeared that they did learn a new awareness and skill from this module. Three caregivers made the following positive comments in their focus group discussions.

- *Before I did not see the reason to play with my child but after this module I am able to share anything with her, and to know she feels accepted.*
- *I didn't know how to draw the attention to my child until I know that there are toys you can put around or hang them or put on the child's wrist. That make it easy for the child to pick up a toy.*
- *To have knowledge that there is a need to play with a disabled child, it is not a waste of time.*

Reflections: The miscommunication and poor understanding of the order of presentation could be prevented if one person acted as a continuity presenter at each training session. This would have ensured that the training ran smoothly and could minimise any confusion on the part of the trainers and the trainees. The new material that was not incorporated into the planning should not have been brought into the delivery of the training, since this was confusing and information intensive. Furthermore, the facilitators needed to attend all the training meetings to ensure they are aware of what outcomes need to be realised from each session.

Once again, providing differing suggestions for a combination of disabilities became problematic from the trainer's perspectives. A trainer requested that the types of disabilities are separately looked at:

> *It may be useful to group children, like in play, if you have partially sighted children, to do particular things with them, so you can really focus on specific disabilities, like the very bright, little people with Cerebral palsy, and their movement is limited, you'd work with them differently.*

It was also felt that the session had focused on the individual child playing alone. A trainee recommended:

> *I would like to know how to teach children to play in a group, how to share ideas, toys. Many play alone and it's important for them to communicate in a group.*

A random observer, felt that the trainers needed to be aware of the terminology they were using. She said in her evaluation form:

> *Please don't say deaf and dumb.*

4.4.5: Module Five: Toy and Equipment Making

Planning: At the first planning meeting, there were no facilitators present. Since the previous module had brought up the importance of facilitators being aware of the outcomes intended for each session, another planning meeting was arranged. The planned outcome was to get trainees to generate ideas around which toys were suitable for various disabilities. An important suggestion was that in making the toys, consideration must be given to the level or extent of the disability and their appropriateness. Furthermore, it was important to consider the economic contexts of the caregivers. It was argued that it would be better if parents could be encouraged to bring in any materials that were familiar and available to them and their settings. The session was to be very practical and some of the children could be used to demonstrate the usefulness of the toys.

The trainer would facilitate a discussion around the grading of the activities and toys, ranging from simple to difficult.

Action: Everyone in the session was divided into four groups with at least one caregiver in each group. Each group had a facilitator who had four types of disabilities listed: visual impairment, auditory impairment, limited motor ability and good motor skills. Appropriate suggestions for toys were listed by the participants. Trainees were then asked to make toys for the children who attend the CDRC. It appears that many creative ideas were generated and that people enjoyed the exercise. Trainees were then given the opportunity to demonstrate their toys.

The director introduced each part of the session and moved around each group to ensure discussion was flowing. In ensuring that the facilitators were clear on their role, greater productivity emerged from the group discussions.

Observations: It seemed that the smaller groups ensured better participation from everyone and a more relaxed atmosphere. By having one person responsible for interacting with all the groups and guiding the process, there was better organisation. The session also had the spin off of encouraging caregivers to be more economical and creative by using waste materials. A caregiver came to realise the income generation aspect that could be learnt. She said:

> *Now, if you open your own playgroup and don't have money, you can make toys. I learnt that easy toys that you make can help a child. A child can develop from those toys and you don't have to throw everything away.*

From this module, three caregivers also expressed their desire to gain more knowledge and experience.

- *To learn how to make more complicated toys, if possible.*
- *I 'd like to add how to make chairs for the children, there are chairs that*

you can make with flour and paper, but I would like to be taught how to do that - perhaps a separate module.

- *I think they should have included some hand work for the mothers to sell and get something.*

4.4.6. Module 6 and 7: Handling and Positioning

These two modules were combined in content. Reflections are provided at the end of the planning, action and observation stages for both modules.

4.4.6.1.Handling and positioning 1

Planning: This module was originally conceptualised as being firstly on aids and equipment making (module 6) and handling and positioning (module 7). It was then decided that the two modules should be combined since they complimented each other, hence the session would be entitled Handling and Positioning 1 and 2. It was agreed that the primary focus should be on positioning during key functional activities. It was further emphasised that it needs to be clearly communicated to the participants that this workshop is not adequate in itself and that they still need assistance from professionals.

Action: The icebreaker was introduced. The trainer then pointed out that each child is different, with their own strengths and weaknesses. She added that therapy should not be done in isolation but rather in conjunction with practical daily living activities like feeding and dressing, and how important teamwork and other professionals can be. She stated that although there was no cure for the difficulties their child may experience, there were ways to prevent further deterioration. For the practical aspect of the training, the caregivers were all in one large group, with three trainers moving through them and showing correct positions for handling, sitting and lying down. In the feedback, the difficulties the mothers discussed were repeated questions like "why is my child like this?" and "the doctor didn't tell me anything". When asked what the mothers' biggest

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problem was when it came to seeking help, they all answered "money" in terms of not being able to take the child for therapy or special schooling.

Observation: During the planning meetings of these sessions, there was a disagreement between two of the trainers in terms of what content should be covered and how the training should be run. One of the trainers appeared to have the mindset that she was the expert/specialist and so her manner of teaching was more instructive. The other trainer, from a stronger community based training, felt the caregivers should be encouraged and recognised for the efforts they already have achieved and to rather share information. Due to the discrepancy, the latter trainer did not participate in module seven.

These sessions had been recommended to the regular caregivers who attended the CDRC, and to the other caregivers who attended the support group. Thus there was an increase in participation (Refer to Graph 4.2). With the one large group, different trainers, and two or three positions being demonstrated at the same time, this became confusing for the caregivers. Also a large amount of information was disseminated with no handouts.

4.4.6.2. Handling and positioning 2
Planning: The planning meeting for the second part of this module, raised the issue of it being more beneficial to have three groups instead of one larger group when it came to demonstrating and allowing mothers to practice the techniques. The three groups would allow everyone to be included and different techniques could be demonstrated according to different disabilities. Another issue of concern was that the trainers were being too professional rather than looking at things from the mothers' point of view. Furthermore the difficulty of mixed trainees, experienced people as well as mothers, was discussed since the trainers were not sure at what level to pitch the training.

The point was also raised that some of the mothers were feeling like things were rushed, with one mother feeling that her child had not benefited from the session. It was discussed that perhaps she felt this way since it was her first attendance to the course and that new mothers should join a new group.

Action: The discussions were brief and simple. The trainers demonstrated the various carrying positions using dolls. The trainees were then divided up into two groups, each facilitated by a trainer. The trainees sat on the floor, with the trainers explaining and demonstrating how to position the child for dressing and sitting. The trainees all unanimously asked to learn how to place the child in a lying down position. This was shown together with a demonstration of positioning the child in a standing position, using a built-up standing frame.

Observations: The trainees all appeared very attentive and participated well during the demonstrations and practice sessions. There was a good rapport between the trainers and the trainees and the interaction appeared a fruitful and positive one.

Reflections on both modules: Caregivers felt that they benefited from both of these modules. The practical demonstrations were successful in terms of teaching caregivers new skills. Two caregivers made these positive comments:

- *I learnt how to carry her on my back and talking to her.*
- *It was the most interesting module, doing the de onstrations. I learnt how to position a child who is stiff and one who is floppy and the importance of doing the correct thing because if you don't, the child can become more disabled.*

Another caregiver admitted she would still have problems but appeared more enthusiastic and hopeful after attending the module. She said:

I learnt how to position my child – I still have difficulties because my child

is too strong and she fights me, but I won't give up.

In module seven, dolls were used to practice the various positions. This was problematic and it would have been better to actually use the children on site. A caregiver commented:

> *We used teddy bears instead of other kids – that gave us a problem because the teddy can do anything you want.*

Again, a difficulty was in training diverse participants who had different levels of experience and education. It would be better to substantiate what level people were at and to divide the course into basic and advanced. Two of the trainees who were educare workers said:

- *We learnt how to handle and feed them, but we knew most of the things because (the 2 trainers) have taught us these things before - it was more revision.*
- *We want more complicated stuff in exercising their bodies, since it was for the beginners and we aren't really beginners, we're more advanced.*

A caregiver in her evaluation form expressed the following suggestion for future programmes.

> *I wish next time we can learn how we can help to prevent stiffness in our children.*

4.4.7. Module Eight: The use of music

Planning: Various ideas were discussed related to showing trainees how important music was for our moods and in daily living. The concept to be demonstrated was the effects of music on multiply disabled children and how music can be used. It was agreed that the presentations should be participatory. The caregivers would be invited to bring their children to this module. The trainer

would discuss the influence of rhythm on the body and brain and the activities that can be done to music which involve body movement. He would also cover how music can be used in such a way to encourage some basic cognitive effort from the child.

Action: With all the trainees in three groups, the trainer facilitated a discussion which focused on answering questions like "what is music?" and " what is the value of music?" "How can we use music to help us make better parents?" Different types of music (fast and slow) were played and trainees were required to draw according to how the music made them feel. The trainer spoke about the appropriateness of music since it would not benefit a very spastic child to play fast, vibrant music since this would make them stiffen. Alternatively, a child with low muscle tone would benefit more from fast music. The presentation covered how music can heal a child in terms of emotional calming and body tone.

Observations: The trainees actively participated and there was a constant flow of ideas and comments. The exercise appeared fun and the trainees seemed to enjoy themselves and participated enthusiastically.

Reflections: Caregivers really enjoyed this module and appeared to appreciate the usefulness of music. Two caregivers made the comment:

- *I learnt that music is very important and that it also helps in communicating.*
- *Music really reaches all kinds of people and unifies them. I thoroughly enjoyed it.*

A caregiver described in the focus group discussion how she used it practically once she returned home. This demonstrates a transference in skills that was useful. She said:

When I got home I sang to my child and she was moving and smiling, showing that she liked it.

Another trainee, a dental hygienist, commented how she hoped to incorporate this training into her place of work. She said:

Wonderful, it motivated me to use music in my workplace so I am considering that in the future.

The module also seemed useful in increasing professionals' awareness and appreciation in the cultural diversity of the target population. One noted:

Also, after that module, I realised that the Zulu culture is a very rich culture and we shouldn't diminish it and we should teach Zulu and English children both cultures.

4.4.8. Module Nine: Evaluations

The evaluative comments provided by the participants have been incorporated into the analysis of the findings, according to each module. The participants' feelings about the general running of the course will be elaborated on in the following section.

Planning: It was unanimously decided that an evaluation of the entire training programme should precede a discussion on how to ensure that the programme was sustained by the trainees. The rationale for conducting an informal evaluation was that an evaluation could highlight problems with the programme that may need to be remedied. Only once these problems were identified could the modules be changed accordingly. It was agreed that the evaluation would be broken down into three components:

* assessing the knowledge gained and the skills learnt from the modules.

*assessing attitudes towards disability both before and after the training programme

*assessing how the programme affected the trainees as human beings, how it impacted on them.

It was decided that after the evaluation, trainees should be given the opportunity to state whether they would like to continue with the programme the following year. Based on their responses, attempts could be made to hold another workshop to specifically target the question of sustainability.

At this planning meeting, some suggestions for future workshops were already being made:
* to change the time slot to a morning session.
* to keep the group membership of trainees consistent
* to have the same facilitator run the discussions with a particular group over the course of all the workshops.

Action: The Director of the CFC briefly mentioned what each module covered. The group then divided into three smaller groups and each group was asked to brainstorm the three components agreed on in the planning and listed above. Trainees gave feedback about what they had learnt in each of the modules and any future recommendations they thought should be considered. These comments were all noted by the research assistant and formed part of her content notes.

Observations: Although it was empowering for the participants to be involved in the evaluation, it seemed unclear how sincere the comments were. Asking the participants to verbally provide feedback within the larger group may have been insensitive and 'skewed' the responses to some extent. The caregivers appeared to be loyal to the CDRC and may not have wanted to sabotage their attendance to the center by making negative, albeit truthful responses. A follow up meeting regarding sustainability was never arranged.

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Reflections: The reflections associated with this module are included in the general evaluations of the whole course.

4.5 ATTITUDE CHANGES

A positive finding from the research was that there were various participants who reported how the programme had personally affected them in terms of their own awareness and understanding of disability. A trainee said:

> It has changed me because I was from a school who didn't do much with disability. I now try to accept people who have disabilities and understand them as human beings. I couldn't just eat in front of a disabled child because of the food coming out of the mouth, but now I can tolerate that. I sit and eat and feed them.

Although this may be a small change in tolerance, it contributes to the bigger realm of acceptance. The following quote, although extensive, shows an important shift in one of the educare worker's attitudes. It also demonstrates how effective a 'mix' of participants can be in certain situations.

> My attitude towards disabled children didn't change much, but it did towards disabled childrens' parents. Because I was with mothers and discussing it with mothers and then I realised that they want help and then we can help. I realised how little they know about their own disabled children, sometimes they don't know what is wrong with their child - he's just not normal, but he walks normal - and its amasing because the closest person doesn't know what to do with their child, so she comes to you and asks for help - so you must know, you must get a lot of knowledge, a lot of practice to help the mothers.

It would seem from comments such as these that the programme sensitised a number of the participants to the mothers' needs, as well as led to a greater tolerance of the disabled.

4.6 GENERAL RECOMMENDATIONS ABOUT THE RUNNING OF THE COURSE

The following section explores the evaluative comments provided by a variety of participants in terms of the overall running of the course. These comments were made with hindsight and there are comments on the outcome of the course. These thus form the summative evaluation of the training course.

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4.6.1 The appropriateness of the modules covered

It is important to consider the appropriateness of the material presented to the participants. A trainer commented on the overall programme:

>......*but as a pilot – it was very positive and a nice selection of modules.*

It would appear that the material covered in some of the modules was innovative and helpful.

When asked about her impressions of the overall programme, the director felt concerned that it was too information intensive and theoretical. She felt that the issue of awareness and identification of disability was of crucial importance for the caregivers. She said:

>*there was too much information, content, although it was handled with sensitivity and fun. There should have been more focus on awareness of disability, identifying the disability, the possible causes and possible prevention through hygiene, diet. There needed to be awareness at all levels of the community*

The director was therefore aware of the difficulty related to designing programme content to meet the needs of the participants and to develop awareness.

4.6.2. The manner of training

It was originally envisaged that the manner of training would be participatory and non-judgmental. Trainers were to work in pairs with a translator to translate their presentation into Zulu. The participants would be broken into smaller groups for their discussions. Trainers would circulate during these discussions to ensure they were being adequately facilitated. A trainer enjoyed the use of smaller groups. She commented:

> I enjoyed the grouping in all the modules, the smaller groups. It gave the opportunity to really discuss and get a lot of information from the participants, rather than the presenters giving all the information. Also the lovely response from the mothers – you could just see they had a new idea, something new to try with their kids.

Trainers in the course realised that the large number of professionals and the strong theoretical element restricted the caregivers from participating as fully as the trainers would have liked. The director made the following comment:

> I think it needs to be more experiential the next time round – I think I assumed wrongly that people did know more about specific disabilities, and I'm not just talking about people who haven't had any training, but even the people who have had training.

A trainer noted:

> I was thinking if you had shorter theory and more communication in the smaller groups because the parents can actually come up with some quite good ideas, and it's a learning curve for them as well, not just a top-down thing. So I would like to have more discussion, more things coming from the parents.

Only two of the trainers were able to communicate in Zulu. A translator was used in all of the sessions. This could be disruptive to the flow of training. As a trainer commented:

> In my case, I was limited because I can't speak Zulu and if we had been able to do everything in Zulu, it would have flowed easier. You tend to think and start talking and then you have to stop, and hang onto your thought while it's being translated, so you lose the message and the enthusiasm.

There is evidence that some caregivers were having emotional difficulties that content in the course catalysed, but no service or facility was offered in the running of the course. A caregiver reported that

> a mother said that they need counseling because some of them are having difficulties to accept and want to leave the situation of their kids.

This is an important caution to note when programme content might evoke emotional responses.

4.6.3. Outcome of the programme

Of the original fourteen participants who enrolled in the course, eight completed at least seven of the nine modules. A graduation ceremony was conducted where the graduates each received a certificate and a name badge indicating they had completed the programme. One caregiver became a voluntary helper who to date still attends the CDRC on a daily basis to assist with the children. Her own child has since been placed at a suitable educational facility. The other caregivers attend regularly with their children. They requested that another module was done on dental care and positioning and handling. The dental care element has subsequently been covered.

Another positive outcome from the course was the realisation and request from most of the caregivers to be able to share this opportunity of attending the course, with other people. The strong community spirit recognised in the African culture compared to the Western more individualistic attitude, was particularly evident in the following comments.

- *I think we must go out there and show other mothers its very easy to make your own toys at home and show them that you can save a lot of money.*
- *It can be a good idea to reach out to the community and teach parents without knowledge about ways of helping their children with disabilities.*
- *Let those who have knowledge reach out and help others who haven't got.*
- *I would be happy if this can be passed to others.*

In terms of the continuation of the course, numerous participants requested that the course continue the next year, that it be extended to others, and that those who did not attend seven modules be allowed to do 'make up 'sessions. This seems to highlight the genuine interest, enthusiasm and support for the programme. Unfortunately this does not necessarily mean the course will be sustainable, since the requests were that the course was repeated by the trainers, rather than the trainees suggesting that they carry the programme forward themselves.

A comment made by the director sums up the participants' feelings about the course being continued. She said:

I saw just last week the graduation party we had. I saw people had grown enormously. Also the friendships that have developed through the course and the reassurance to the trainees that it would go on, was incredibly well received. The applause and the cheer when we said it's not going to

stop. And those who don't have a certificate, can come and catch up and that has given me enormous confidence that we can go on with a group of dedicated trainees, friends, CDRC helpers to take the CDRC message further.

The director clearly felt encouraged by the relationships developed and the participants' enthusiasm for the work of the CDRC.

4.7 IMPLEMENTATION OF THE TRAINING PROGRAMME IN MPOPHOMENI

As mentioned in Chapter One, this training course was also held at Zenzeleni Community Centre in Mpophomeni. A caregiver of a disabled child who had been attending the CDRC since 1998, and living in Mpophomeni, was asked by the Director of the CDRC to become a community worker representing the CDRC. She was trained in facilitation and attended each module of the training programme itself. She then replicated the module at the community centre in Mpphomeni.

This course was not monitored by a research assistant and thus the breakdown in terms of an action research model was not possible. The following data was gathered from focus group discussions with the Director of the center, the community worker and 6 of the participants on the course. There was numerous differences between this course and the one based at the CDRC. These differences will be briefly outlined below.

4.7.1. Demographics:

Thirty community members applied to do the course and twenty five people graduated. One participant was male and one was physically disabled. There was a very different dynamic in that there was only one trainer who handled all aspects of the training although the director of the CDRC had oversight 'from a distance'. The director felt that this continuity and the fact that the trainer was

from the community was the deciding factor that made this course so successful. She said:

> ......*I think this is what held it, plus the fact that she was an inspired trainer and she had people visiting her home for extra training extra information. But it was community-based trainees from the community.*

This therefore indicates the potential for community development via empowered members of the same community.

4.7.2 Feedback regarding the specific modules

All of the participants interviewed gave very positive comments about the various modules. The research assistant conducting the focus groups was not known to them in any capacity, and there was no fear of being 'rejected' from the CDRC if they did make negative comments since they were not affiliated to it in any way. Some of the general positive comments made by the participants in terms of awareness of disability and acceptance were:

- *Not to believe in witchcraft or that you inherit it (disability) or that it is somebody's fault.*
- *I learn not to leave my child inside or hide her but to involve her in the community.*
- *As a disabled person, I feel accepted in the community after this.*
- *You can have an affair with a disabled, they can love and have relationships.*

In terms of the various skills the participants were shown, it appears they learnt a great deal.

- *For a disabled child to play, it helps for her to develop.*
- *You don't need to go to the shop to buy toys, but you need to make them.*
- *To hold a child in a good position can stop the damage to be worse.*

The weaknesses in the programme that the participants suggested related to the venue:

- *The place was fine but as a disabled person I had a problem with the door, it was too tight for me.*
- *The place was too small and we were disturbed by those people who were in and out.*

An interesting comment was that one participant did not like being taught in Zulu. She was thinking about how to use this training as part of her employment. She said:

> *Our trainer was teaching us in Zulu but we will have a problem if we go and work somewhere else.*

Most of the negative comments and requests for improvement were related to the course being more practical and the strong desire to visit day care centers and actively gain experience with disabled children. This is demonstrated in the following comments:

- *We were suppose to have the disabled children present just to see them and to practice.*
- *We would like to see those centers where the disabled children are.*
- *Its much clearer to learn something in front of us, like disabled children, special chairs, standing frames.*

A positive outcome that came from the training course was that many participants wanted to build a day care center in Mpophomeni. As a result of this, a committee was started involving some of the graduates, and a centre was developed in 2000. It was named after the 'original' community worker's disabled child. Three of the graduates started working on a voluntary basis. Understandably, since they attend everyday and generally run the entire center

they are currently requesting some form of monetary recognition. To date, the situation is that the center may close down unless these resources are found.

This chapter of the research project has intended to present and analyse the findings according to an action research model. The data came from three sources and three research assistants. This data was combined and provided a qualitative evaluation of the course, according to each specific module and to the overall running of the course. The final section presented the differences noted between the Mpophomeni course and the CDRC based course.

The following chapter will summarise and discuss these findings in the light of the literature presented in Chapter Two.

CHAPTER FIVE   DISCUSSION

The following chapter explores the findings that were presented in Chapter four and discusses them in the context of the literature review. Due to the nature of these findings, it proved more comprehensive to summarise and discuss them in terms of the strengths and limitations of the training programme and relate these various points directly to the literature presented. As such this chapter consists of two sections, namely: a discussion of the findings and recommendations for future training initiatives in the area of caring for disabled children. This chapter also responds to the final research question, viz: to inform future training initiatives on the content and the mode of delivery of training caregivers in the area of caring for disabled children.

At the outset, it is important to emphasise that the conceptualisation and delivery of the training programme arose out of a strong humanistic element on the part of both the director and the staff of the CDRC. They identified a need in the population with whom they had daily contact and they wanted to provide the appropriate intervention to meet these needs. This earnest and sincere response to a perceived need is commendable and deserves adequate recognition from the participants and the researchers involved. Their work gives us the opportunity for examining, reflecting and evaluating the nature of the intervention. It is hoped that such efforts will contribute to planning and undertaking interventions dealing with disabled children in South Africa, in ways that help to ensure more effective and sustainable support for disabled children, their caregivers and communities.

5.1 STRENGTHS AND LIMITATIONS OF THE PROGRAMME

This section presents the positive aspects of the training programme with regard to the philosophy behind it, the processes that occurred and other factors that proved successful. I will also discuss the weaknesses of the programme in terms of the modules presented, the process of implementation, and some practical applications.

5.1.1. Strengths of the programme

5.1.1.1. The programme

Firstly, the concept of training caregivers on how to provide comprehensive, practical and effective home based care to their disabled child or to other disabled children in their communities, is an admirable and necessary goal. It relates directly to the different levels of prevention discussed in Chapter two: primary, secondary and tertiary, with more of an obvious focus on the tertiary prevention. The presence of health professionals and service providers in the training programme also meant that the intervention may have influenced other levels of prevention.

The intervention is a response to a perceived need (in the CDRC). In responding to this need it recognises the need for capacity building and rehabilitative interventions proposed by the health and social welfare departments of the South African government. The intervention also demonstrates a general social responsibility towards those people who, in the past, have been marginalised and discriminated against. To some degree, it challenges the traditional focus by expert 'others' on the individual, and recognises that the disabled individual is a part of families and communities that have the capacity to offer useful, appropriate and sustainable support for the disabled person. It reflects the national objective of integrating disabled people back into society rather than isolating them. It also goes some way towards

decentralising the healthcare for disabled people, reducing the reliance on expert 'others' and distributing the care responsibilities in the community.

5.1.1.2. Evaluation

The evaluation in this study focussed on the process of the intervention, rather than the overall outcome. Although driven by goals (to improve the care of disabled children by their caregivers through providing training), the description and exploration of underlying group processes formed an integral part of the research. Qualitative research examines these processes. In terms of the objective of empowerment, it may at times have been more important to focus on the process of developing trust and relatedness in the group, and to encourage sharing rather than to focus on the content and delivery of the information prepared. This relates to the use of the ecological theory of empowerment, which, as discussed in Chapter two, is interested in the role of relationships, interactions and influences between people and their contexts. An example of this is the case of the participant who essentially interrupted a training process in order to ask a question about correct posturing for her child. It was judged to be important to respond to her request and pause the training, since it was implicitly believed that there was more to be gained from developing her relationship with the group and allowing her the experience of being heard.

5.1.1.3. Professional participation

The fact that professionals gave freely and enthusiastically of their time to attend the various planning meetings and deliver the training programme highlights the willingness and potential for cooperation in this area of work. The development of such supportive relationships has the potential to reduce the centralisation of resources and specialisation and enhance the quality of such interventions. It also reduces the risk of burnout by all involved professionals and caregivers.

5.1.1.4. Mothers' support group

The mothers' support group that developed out of the caregivers' discomfort in participating in the course, seems to have been beneficial to those caregivers and new caregivers coming into the CDRC system (refer to Hemming, 2001). Disabled People of South Africa (DPSA) acknowledge the important role that support groups for caregivers play and this has been reflected in the enthusiasm, discussion and positive results that have been born out of the establishment of this group.

This initiative asserts the importance of relationship and community over mere awareness-raising and education. In the literature review I outlined the various difficulties that impact on the caregivers of disabled children. These included social ostracisation, guilt, exhaustion, lack of support. According to Chinkanda's (1987) study and supported by Hemming (2001), caregivers' greatest needs are related to assistance in terms of financial and practical support, and largely emotional support from external support systems. The caregivers in this study seemed to learn and appreciate the skills that they learnt and there was a degree of emotional support from which they benefited. This support largely seems to have arisen out of the support group that was initiated due to the difficulties with the training programme. The support group helped to create a place where parents could develop relationships in which they could share freely without feelings of alienation.

Although this support group was not the focus in this particular study, and it might have been perceived as an interfering event (Patton, 1990), it provides us with important information. It represents willingness on the part of the organisers to engage sincerely with the participants, to find out about their concerns and to take the necessary action to address these concerns. This process required the ability to be self-critical, thus elements of action research were implicit. It also relates directly to the conditions of *empathic neutrality* on

behalf of the researchers and the ability of the director to be aware that the process was *dynamic and developing* (Patton, 1990, p 44), both being prerequisites for qualitative inquiry.

5.1.1.5. Content of modules

The content of the modules that the training programme included were innovative, creative and useful and appeared to encourage the participants to learn a wide range of important skills for more effective caring of their child. In the literature around parent empowerment, Rogers (1980) feels that it is of great importance that caregivers see tangible improvements in their lives. There does appear to be evidence of this in that caregivers did learn new skills which they put into practice at home, leading to transference of skills.

5.1.1.6. Sharing of experiences

Very importantly, the programme provided the caregivers with some platform to share their 'stories' and to gain awareness that they were not 'alone' in their difficult and at times, isolating experience. Although this did not occur as fully as was intended, the situation of the programme and the mothers' support group that developed simultaneously did allow this process to transpire. Both Werner (1988) and Miller and Banyard (2000) highlight the importance of bringing people together to discuss their problems with the result that it leads to collective support, reduces self blame and raises understanding of their circumstances.

5.1.1.7. Attitude change

If the reader refers to Chapter four, section 4.5, some of the comments made by participants shows their increased tolerance, sensitivity and a change in attitude towards people with disability. Furthermore, the manner in which the caregivers expressed the desire for the programme to continue, the request that they could complete 'make up' sessions and the desire for other caregivers to experience the programme, indicates that generally it was well received.

5.1.1.8 'Radiating' impacts

Related to the point above, although more appropriately within the realm of summative evaluation, the Mpophomeni based course seemed more successful than the CDRC based course. The fact that it was community based with there being only one trainer from the community, the large number of participants (25 graduated), and the seemingly resultant feeling of empowerment that arose from this course, led to a day care centre being established. This is a very positive 'radiating impact' that developed from the training programme.

5.1.1.9 Language

As reported in Chapter two, Rappaport (1987) asserts the importance of being aware of the language that people use with those with whom they work. It is significant to note the occasions in which the language used for disabilities was discussed in these training sessions. Participants suggested more neutral terms like "differently abled" or "challenged". The findings chapter gives an example of a participant who challenged the use of the words "deaf and dumb". These are important processes linking directly to the debate around what it means to be *disabled*, and whether it is fair to define this as an individual or a societal limitation, as discussed in Chapter one.

These factors are all positive contributions that fed into the course being a valuable intervention.

5.1.2. Limitations of the programme

This section outlines the weaknesses in the programme in terms of the practical implementation as well as the certain disempowering practices that were identified. It is recognised that the point of pilot initiatives is to identify limitations and to develop from this process.

5.1.2.1 Programme Design

The initial planning of the course and the implementation of the programme appeared to have the principles of action research implicitly embedded in it. In action research the researcher is not a passive observer, she/he is actively involved in the process being observed. However, in this study the researchers did not get explicit permission from the participants to conduct the research, their presence was not explained and they did not actively engage with the participants.

In action research, feedback from a process is used to inform subsequent processes. In this study, although the research assistant attended the planning meetings that were held before each module, and each module to observe the process and content, her reflections were not fed back into the planning. This meant that the function of the researcher in an action research model was not fully realised.

These omissions could be explained by a number of factors. It may be that the research assistants were never fully informed that this was the purpose of their attendance at each session. It may have been that they were not assertive enough to allow their suggestions and observations to be heard, or that they were heard but their opinions were never acted upon. Generally speaking, the research assistant had no influence over the process.

An example of this was the constant 'complaint' and realisation that there was never a strong participation from the caregivers. Even though this was identified early on in the process, it remained a continuous weakness. A mothers' support group was developed, smaller groups that allowed for a better 'mix' of participants were arranged, and verbal encouragement were given, yet this downfall was never fully resolved.

Community based action research was methodologically appropriate since it was implicit in the design and most importantly it provided a framework for recording the findings. However, it needed to be followed more explicitly for the programme to benefit from it. If action research had been followed more vigorously and explicitly, it would have improved the programme evaluation.

5.1.2.2 Participants

As noted in section 4.3 of the findings, and more specifically Graph 4.1, there was no attendance of the caregivers in the planning of the programme. In Rappaport's (1987) principles of ecological empowerment theory (see section 2.2.), he makes the point that the degree to which individuals participate in the decision making process has an impact on how empowered they feel. Although the intention of the course was capacity building and indeed empowerment of individuals, their absence in this major process of planning the course and its content would have negatively influenced how active and involved the caregivers felt. Furthermore, there was a sense of the professional 'other' 'taking over' in terms of their strong presence which dominated the modules. An example was cited of how a caregiver tried to respond to a question, yet she was overridden by a professional. This incident has the flavour of what Rappaport warns against: taking over decision-making powers and not acknowledging the role of the caregiver, feeds into further feelings of isolation and rejection for the caregiver. This would have affected their participation in the course as well as disrupted the process of individual empowerment.

Another difficulty in the light of empowerment theory, was that caregivers may have had the misconception that the CDRC was an **empowered** organisation (Chavis and Wandersman, in Zimmerman, 1990) – one that has influence over policies and larger resources. Although, the CDRC 's intention was to empower individuals, thus to work towards being an **empowering** organisation, it is not necessarily a particularly empowered organisation. Caregivers may have had

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the expectation that issues like disability grants and potential employment opportunities would be provided by their affiliation with to the CDRC. This was not the case and this may have 'disappointed' the caregivers to the extent that it impacted on their participation.

This concept of empowered organisations is one of the areas where the Mpophomeni based programme and the CDRC programme differed. In Mpophomeni, the participants appeared to have more realistic expectations of the training. This may have been related to the fact that it was community based with the trainer being from the community. It would seem that, this intervention ultimately delivered more. The participants went on to develop a committee within the community and lobbied for a day care centre to be established. It thus had elements of being both an empowering and empowered organisation.

The broad range in the composition of the trainees in terms of their educational levels, their theoretical and practical experience, and the personal contexts that people were coming from, was problematic for the trainers. The trainers became concerned about the 'level' at which they should pitch the training. Although the original conceptualisation of the programme was to be at a basic level, some participants made comments regarding the course being too simple, others found it complicated.

Furthermore, the needs of the various participants were different. Many random and professional observers participated simply out of an interest or else had been instructed by their organisations to attend the modules. Thus their reasons for attending may not have been as 'intense' as that of the caregivers. The large and continually changing numbers of the participants was also problematic since there was no continuity for the trainers.

One of the research assistants guided the focus group discussions. She was known as being affiliated to the CDRC, and as such there is the possibility that her presence may have inhibited some of the responses of the caregivers, since they may have feared sabotaging their continued attendance at the centre should they give negative feedback. The professional trainers did not appear to be affected by this dynamic.

5.1.2.3. Accessibility of the programme

As noted in Chapter three, section 3.4.2, accessibility is the ease with which the participants can be involved with the programme. The lack of consultation with the caregivers and the dominant presence of 'other' participants (refer to Figure 4.4) influenced the accessibility for the caregivers. It made them question whether the course was intended for them, inhibited their responses to speak out in the group for fear of seeming 'stupid' and the difference in culture and educational level may have restricted them. It was as a result of this discomfort, that the mothers' support group was established.

5.1.2.4 Delivery of training

The manner of training was at times too instructive, rather than facilitative, as was initially intended. The continuous change in trainers and facilitators from session to session also interfered with a strong rapport and cohesion developing within the group process.

Furthermore, an interesting comment was made in the findings regarding module two. A trainer suggested that the trainers should acknowledge that the caregivers have insight and experience and the trainers should allow the caregivers to claim this knowledge and be recognised as owning it. This raises the issue of language. Professionals' use of language may have left caregivers feeling powerless, thus depriving them of the opportunity of acknowledging that they do have resources.

In terms of the focus group discussions with the caregivers, a translator had to be used. The research assistant would ask the questions in English and these would be translated into Zulu. The caregivers would then respond in Zulu but these answers were not translated back into English. Thus, at various times, leading responses or unclear answers were given but these could not followed up by the assistant.

5.1.2.5 Content

Although the focus on the medical model in Module one, provided some information, it was not particularly useful in the light of the literature presented earlier in this study. The social model of disability would have contributed towards participants viewing disability in a more multi-dimensional context that included environmental factors. This would also have alleviated the 'guilt' feelings that some caregivers may have been experiencing.

Some of the trainers' material was too theoretical and information based which made it difficult for the caregivers to understand. This may have been frustrating for caregivers with more immediate, practical needs. The content of the modules, although comprehensive, was overinclusive. It left the trainers feeling that although they had covered a broad spectrum of psychoeducational material, none of it had been covered in great depth. Thus they were concerned about how useful the information actually was.

5.1.2.6 Logistics

The time was too short for all the material to be presented in a manner that allowed the participants to all 'practice' their new skills, for example in the handling and positioning modules. The fact that the course was held in the afternoon resulted in people often leaving early in time to catch their taxi's to their respective homes.

5.1.2.7 Follow-up

The area of disability and the issues faced by caregivers of disabled children is a sensitive and emotionally charged topic. At various times, caregivers underwent an emotional process and although this was sometimes observed and seen too, there was no formal structure of follow-up for those caregivers who perhaps needed additional support.

5.1.2.8 Volunteerism

Related to the point regarding empowered organisations and the negative impact this may have had on caregivers' expectations, a similar concern is that the caregivers receiving training would possibly have the long term hopes of conducting training themselves, as a form of income generation. In actual fact, this was one of the intentions of the programme. Without a formal structure of how this would occur, there was the danger that volunteerism was presupposed by the facilitators of the programme. Rogers (1980) criticises this mindset and sees it largely as a western ideology. The day care centre established at Mpophomeni was based on the expectation that caregivers would run it on a voluntary basis, and this has led to its sustainability being questionable.

5.1.2.9. Community-based rehabilitation

As mentioned in the previous section, tertiary prevention was an important component in this programme. McConachie and Zonkin (1995) state the critical role that caregivers of disabled children can play in training professionals. Although there were caregivers in this situation, they did not make full use of the opportunity to speak about their own experiences and thus provide valuable insight to other caregivers and professionals. Such sharing of expereinces may have been contributed to healing on many levels.

It is from these strengths and limitations above that information can be gathered and disseminated to the people who need it, so they may use it appropriately for its intended purpose. This leads onto the following section.

5.2 INFORMATION FOR FUTURE TRAINING INITIATIVES

In terms of evaluative research, the content and the process of the training programme was judged on how useful and effective it was in training caregivers of children with multiple disabilities. This evaluation was largely a result of the rich descriptions provided by various participants. The mode of delivery and content of the programme was also evaluated and certain strengths and limitations have arisen out of this analysis. It is from these strengths and limitations that that future training initiatives in this area can be recommended.

- The composition of the group of participants should be more controlled. The definition of the target population should have strict inclusion and exclusion principles to avoid the continually changing numbers and the 'nature' of participants. Diversity in a target population may be beneficial in terms of the knowledge and experiences that can be gained in such group processes. However this requires careful management and mediation. The disadvantage for the target population in terms of their resulting limited accessibility to the service and their consequent feelings of disempowerment, is great, and needs to be avoided.

- Clearer definition and a more homogenous target population would also assist in deciding on appropriate content of the training modules and that it is delivered at a level the trainees would understand, without fear of it being too elementary or too advanced. It seems more beneficial to include less content and to make sessions mainly practically based so that greater 'hands-on' experience can be gained.

- Time and venue is an important factor to consider. The later in the day and the more isolated the venue from convenient transport facilities, the greater the logistical difficulties may be if the target population is similar to the group in this study. Furthermore, the time allocated for any session must allow all trainees to participate as fully as possible, without being restricted by time.

- Structures should be in place to provide emotional support and follow-up counselling if individuals request it. Topics of training in the area of childcare may catalyse other emotionally charged issues, for example family structures, religious beliefs and cultural practices. Resources need to be available to contain any emotional problems that may arise. Similarly trainers/facilitators need to have 'empathic neutrality' and sensitivity in this regard.

- Expectations of trainees need to be thoroughly explored particularly in relation to what the training initiative means to them. If it is believed to become a potential income generating project or a recognised training qualification, suitable structures must be put in place so that these outcomes do occur and trainees do not feel misled.

- In support of Werner (1980), only if programmes for disabled people are led and controlled by disabled people and their families, are they likely to gain self-determination and a sense of empowerment. This highlights the essential point that it is vital that these people are included in **every aspect** of the training, from initial consultation, planning and implementation of a programme. This not only empowers the disabled people themselves, but also has the radiating impact of bridging the controversial gap between the 'expert' and the 'lay person'. In other words, the experience, competence and wisdom of ordinary people is given credibility and utility that the expert can learn from.

- Only one caregiver was targeted to be trained to return to her community and transfer her knowledge. In the light of the literature on community-based rehabilitation, future training initiatives may train more caregivers so that they

may amplify the impact of disability awareness across more communities and into more families.

- Although a resource list of service providers in the field of disability was provided to the caregivers, this exercise could have been expanded on. Caregivers could have visited these centres, hospitals, facilities and schools and been informed of exactly what services are provided; and may also have been introduced to a 'friendly' contact person should they have any queries. This list should also include culturally appropriate interventions.

- Future training initiatives may benefit from coordinating training and support groups in parallel. This process naturally evolved in this particular intervention.

- Modules that were requested for future training initiatives included dental hygiene, sign language and techniques of discouraging tight muscle tone.

The above points are not exhaustive although they do appear to be the central recommendations for future training initiatives that arose out of this particular research. The following chapter will briefly describe some recommendations for future research and provide the concluding remarks.

CHAPTER SIX   RECOMMENDATIONS & CONCLUSION

6.1 RECOMMENDATIONS

Through further research, close cooperation, and networking with all agencies in the field of disability, both nationally and internationally, more reliable and accurate statistics could be gathered. This is vital in terms of funding projects, particularly NGO based programmes, and in ensuring the appropriate provision of services. Furthermore, vested and responsible interest in this field will promote increased awareness, education and acceptance of children with disabilities. It is hoped that this study may contribute in some way towards these intentions. Below are some recommendations for future research.

- Although the role of the caregiver was acknowledged in this programme, the weakness in the process was that the caregivers should have been more involved in the entire process, in terms of decision-making, planning and implementation. This is an important consideration for all future research and interventions.

- The model of community-based action research seems to be a valuable tool for exploring, describing and reflecting on a process. Unlike this particular study, it needs to be made **explicit and followed vigorously** so that the researcher can use his/her reflections of each stage to inform the next stage. The researcher needs to be an integral part of the research and to engage participants in all phases of the study. In this study, the data was collected by 'other' research assistants and then analysed and written up by this researcher. Although action research was followed in terms of providing a structure for analysis and recording the information, it would have been more beneficial to the programme and for this study to have used action research more explicitly.

- Future researchers could also consider evaluating training programmes in a longitudinal study. This might provide useful information, for instance measuring attitude change and its relationship to the behaviour of caregivers towards their children. Issues of whether caregivers are feeding their children more nutritious diets and in a more effective manner; using toys and play to stimulate their child; and ensuring correct posture, could be explored. Thus 'parenting' or 'caregiving' techniques could be further investigated.

- A thorough needs assessment could be carried out in consultation with the target population to ensure the intervention is meeting their needs and not a perceived need of the facilitators of the training.

- An investigation of what existing resources and strategies are being used by caregivers of disabled children, including traditional interventions and 'western' interventions, could be undertaken. This would feed into individual empowerment since the researcher would be taking cognisance and valuing the decisions and experience these caregivers already have.

- A training-the-trainer intervention could be developed that involves supervision of the trainer, so that individuals may be developed personally and professionally as a resource for their community. This would involve more advanced training than this particular study described and could gather more representation of different communities. However, such initiatives would require funding, since remuneration for trainers should be a consideration.

6.2 CONCLUSION

This research study has examined, at the macro level, disability in South Africa; and, more specifically, an intervention aimed at integrating disabled children and their caregivers into KZN society. Through describing and evaluating a training programme for caregivers of children with multiple disabilities as well as other individuals who work in the field, there is the recognition and acknowledgment of these individuals as integral resources. Their interest and commitment to participating in the programme is reassuring to those of us who have the goal of raising awareness, acceptance and education of disability in society.

The research study provided a descriptive account of some of the participants' experiences of the training programme . It aimed to evaluate the effectiveness of this psycho-educational programme by applying a model of action research to analyse and present the findings. Out of these evaluative comments, it was hoped that future training initiatives in the area of caring for disabled children may be enhanced.

Disability, if viewed from the social model, cannot be attributed exclusively to the individual. When one acknowledges the impact of environmental factors have on how disability is regarded, it becomes clear that the families and communities of disabled children are very much intertwined. It is vital then for them to receive support, whether it be economically, practically or emotionally. To repeat a point made by O'Toole (1994, in Miles, 1996), "the greatest resource in developing countries for helping disabled persons lead lives which are fulfilled and productive is a well advised and supported family"(p504). This was the driving philosophy behind the CDRC's implementation of the training programme.

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APPENDIX A

Analysed content and process notes according to an

action research design

SESSION ONE: Awareness of Disability

PLAN:

The first training meeting was held on 13 January 1999. The aim of this was to discuss and prepare the material for Session one.

Present: An O.T. assistant, community worker, speech therapist, nursing sister, social worker, music therapist, community projects worker and the director of CDRC.

Logistics: It was agreed that the session would be 2 hours long with a 10 minute introduction, 20 minute presentation, and 1 ½ hours for group work. Presenters would work in pairs and time needed to be included for translating. It was agreed that practically there would be late arrivals and early departures and this should be considered in terms of planning times. Allocation of time towards tea and debriefing after the sessions should also be considered. Furthermore, it was felt that participants should not be overburdened with written materials.

Content: It was agreed that a disabled adult should describe her personal experience with the aim of breaking down stereotypes. The goal of the session was to present the issues of recognition of disability, prevention, and intervention (what action to take, what resources to access, how to deal with social reactions from family and friends). The issue of disability being seen as a curse was identified. It was suggested that participants expectations of the course and their goals need to explored and to be aware of the terminology used with regards to disability. An interactive discussion would be lead by the speech therapist about the participants own experiences of disability and what are the barriers that exist outside of people that may contribute to their disability.

Inherent Assumptions: By requiring applicants to complete an application form, there was the assumption that all participants should be literate. It was also assumed that the application form will screen out participants would may have had transport difficulties. The director stipulated that the course should be trainer-based " we need to develop our own training scheme based on our own ideas and what we think will work". It was assumed that all the participants will attend all the workshops, commit and eventually form a support group amongst themselves. The issue of sensitive issues coming up was "solved" with the assumption that the one facilitator, known to most of the participants, will be trusted enough for the participants to talk to.

ACTION:

Introduction: An apology was given by Ros for the change of venue due to the carpets being wet and due to 7 children of the mothers who were attending, being present. Ros introduced herself as the co-ordinator and explained that the purpose of the sessions were to conduct workshops in home care for the disabled, that these were for mothers/caregivers of disabled people, professionals and other interested community members. She hoped all would attend the nine workshops and receive their certificates. Ros then introduced all those present and asked people to make notes. 5 trainers and 21 participants were present of whom 13 were actual trainees the others were.....(confusion around - trainers, other on-

lookers and participants)

Icebreaker:
Content: The group was asked to split into smaller groups of 2/3 people to talk about their experiences of disability, with one person giving feedback. The group broke into 7 smaller groups in the following arrangements:

Group 1 - 3 professionals
2 - 3 professionals
3 - 2 professionals, 1 mother
4 - 3 mothers
5 - 2 professionals, 1 mother
6 - 2 professionals, 1 mother
7 - 2 professionals, 1 mother

The trainers sat amongst the trainees and facilitated the discussion. The speech therapist asked for two important points from each group to be feedback, adding that the professionals and mothers should share equally. Feedback was given by one mother and 6 professionals. Sarah spoke about disability in terms of within a person as well as barriers that exist outside a person which may add to their disability. She requested that the participants in their groups discuss what external barriers exist that contribute to an individuals disability. She did not ask for feedback on this. A translator then spoke about her experiences as the mother of a disabled person. The trainer asked if there were questions from the participants. Four questions were asked by professionals only.
A resource list was handed out to all participants. Two new trainers took over. They broke the group up by giving each participant a number and asked those with the same numbers to group together. After discussions, one person from each group was to feedback on the causes and the prevention of mental handicap. The trainer specifically asked the mothers of mentally-handicapped children to participate in the discussions. When the feedback started, an "on-looker" spoke about the importance of a shared language for talking about disability as some words - like "handicap", may cause offense. Feedback was provided by three professionals. A medical model for the prevention of disability was presented. There was general discussion. The organiser concluded the session by stating she felt another session should be done for orientation and that session one should be repeated in March. She asked for feedback to be given honestly so it could be used to develop the course. She also felt that the session should start early to allow time for tea. A translator assisted with the mothers giving feedback and completing feedback forms. Worksheets were also completed by the participants.

OBSERVE:

Introduction: Although people were introduced, the goals and expectations of the participants in terms of what they would like to learn from the course, was not explored. The participants were asked to make notes but paper and pencils were not provided.
Icebreaker: The concluding positions of the participants did not allow for a good ▯mix" of mothers and professionals.
Content: The ▯natural evolution" in terms of breaking up into groups saw mainly separate

groupings of mothers vs professionals. Furthermore, the actual population of the group was unbalanced with professionals making up the bulk of the participants. Emphasis was made for the mothers and professionals to share equally in terms of providing feedback. However, when it came to providing feedback on personal experiences of disability, only one mother shared. The other responses were from professionals. As such, although interactive discussion and equal participation were planned and encouraged, this did not occur. Similarly, once the personal testimony was given, only 4 professionals responded while there was no participation from the mothers. The point regarding "shared dialogue" may have been too academic and theoretical.

The second set of trainers achieved a better mix of professionals and mothers in terms of grouping. However, once again feedback was provided by professionals only. The content on prevention was presented in a very didactic, non-participatory manner with it being quite theoretically based according to the Medical model. No completed evaluation forms from the participants were found. They were asked to complete a 3 page worksheet which was then kept in a file at the CDRC.

REFLECT:

Introduction:
♦ It may be useful to use this time to give all participants an opportunity to share their personal experiences, to make the course more "personally related to them" and provide a more informal forum whereby their expectations and goals could be discussed

♦ .Pens and paper should be provided.

♦ Participants responses could be recorded on a flip chart and used as points of discussion. Furthermore, the points may reinforce/consolidate what knowledge has been gained from each session.

♦ More time could be allocated to allow for tea and late arrivals.

Content:
♦ A better "mix" between the professionals and the mothers is needed. This could be achieved through an icebreaker which encourages a better mixing. If the professionals and mothers are mixed together, perhaps a Zulu speaking professional can act as the facilitator for each group. A better mix will encourage the mothers to participate as the professionals encourage the mothers by being interested in what they had to say.

♦ After the personal testimony, the questions and discussions could have been recorded on a flipchart. Through sharing with others - whether mothers or professional, it may help toward normalising the experience of having a disabled child as well as highlight for the mothers that they too have knowledge to share with others which could be empowering for them.

♦ To substantiate that the organisations listed on the resource list are aware of the training course and that participants may be contacting them, what roles each organisation plays, and the name of a "friendly" person provided to assist with approaching each organisation.

♦ A didactic, non-participatory approach to relaying information should be avoided. This should be replaced by a more participatory discussion in the trainees are more involved in an interactive way with the presenter.

♦ An evaluation is required after each session.

SESSION TWO: Acceptance and Basic Care

PLAN: The second planning meeting was held on the 23 February 1999.

Present: The trainers present were an O.T. assistant, a mother, a school psychologist, and the Director of the CDRC.

Logistics:

♦ The workshop times were extended to 13h00 - 16h00, with a break for tea , to ensure that each module was completed. The director will spend 10 minutes doing an orientation to ensure everyone understands the goals of the course.

♦ To ensure a better balance of professionals and mothers, all mothers, educare workers and professionals will be assigned to three groups for the remainder of the course. Groups are formed on the colour of the name tags given to the individual on their arrival. Each of the groups will have a facilitator. (Ask the facilitators to ensure everyone in the group has an opportunity to feedback at some point to indicate how well everyone has understood the discussions.

The school psychologist will cover the issue of acceptance. The director raised the issue of traditional beliefs needing to be discussed at an appropriate time and with sensitivity. Some discussion around this incurred and the other facilitators agreed that as people feel comfortable, they will bring the issue up and thus "open" it for discussion. The O.T assistant and other facilitator would present on Basic Care. This would look at an holistic approach to the child and the difficulties around overprotection. Positioning and feeding techniques would also be covered. Feedback forms would be gathered after the module.

A break down of the programmed constructed is:

13h00	Orientation	10min
	Icebreaker	10min
13h30	Acceptance	15min
13h50	Groupwork	25min
14h15	Feedback	25min
14h40	Tea	20min
15h00	Basic Care1	15min
15h15	Basic Care2	35min
15h50	Feedback forms	10min

ACTION:

Introduction: An assistant hands out name tags of three colours as people arrive. Those who were not attending all the workshops were assigned a black tag and could join any of the three groups. People arrive late and one trainer has not arrived. The director welcomes everyone present.

Icebreaker: An exercise done in balloon-popping

Content: The aim was to normalise feelings around having a disabled child and how to cope with everyday demands. The presenter touched on her own experience as being a mother of a disabled child, but mainly did a lengthy presentation of material in her role as a psychologist. The three facilitators were introduced with each one being responsible for a

group. The break up is as follows: Green group: 1 mother and facilitator, 3 professionals, 1 educare worker, 1 volunteer.

Red group: 3 mothers, 2 educare workers, 2 professionals, facilitator

Blue group: 3 mothers, 3 professionals, 1 student

One person did not join any group.

There is group interaction around feelings of having a disabled child. In the red group, the facilitator is asked to take notes of the discussions for feedback. The groups then come together for feedback. Feedback is presented by 3 professionals from each group and then it is translated. In the Green group, one of the mothers is asked to provide feedback - she is encouraged with "you're a very eloquent speaker". As she is about to start, a professional stands up and gives feedback.

Tea is served from 14h30-14h45.

It is announced that one of the trainers will not be able to attend the session. During the next 20 minutes 6 participants leave independently, with one apologising for having to leave early. A mother arrives to join the workshop.

One trainer then presents a story that includes the issue of a traditional healer. Group work is carried out according to the colours. During the group work, a register is passed around. The groups then come together and each group has a speaker who provides feedback. This is translated into Zulu, or English. At 15h25, the director announces that the talk on Basic Care will be until 15h45 and that the feedback forms should then be completed. She also announces that the Zulu translation of the worksheet will be available for the mothers when they next attend the CDRC. A trainers then presents Basic Care material in English. This is translated and the main points are written on the flipchart. Another participant then takes over writing points on the flipchart. English versions of the worksheet are then handed out. All the mothers and caregivers (except one) write down notes off the flipchart in Zulu. When the next trainer begins her presentation, the mothers/caregivers are still copying notes off the flipchart. At 15h50 the director closes by adding that topics like positioning and behaviour management will be covered throughout the course. She asks that the worksheets are kept in a folde. She reminds mothers that only those who attend every module will receive a certificate. She thanks the presenters.

OBSERVE:

Introduction: The late arrival of participants and one trainer not arriving at all is disruptive.

Icebreaker: It is unsure of how appropriate the balloon popping exercise is and whether it ties into the theme of the session in anyway.

Content: The presentation on acceptance was long and didactic. Although the presenter could have used her personal experience of being a mother of a disabled child, she focused mainly on her professional work. Personal testimony that draws out the elements of the module would probably be an effective method of presentation. The groups could then discuss their reactions to the testimony, their own experiences and insights, and feed this back to the larger group. The presenter, in summing up the points from the feedback could then ensure that the learning objectives are adequately covered. During the groupwork, one facilitator is asked to take notes to feedback. Whilst this occurs, the discussion in the

group stops since everyone watches the facilitator take notes. When the feedback is presented, it is the professionals who provide the feedback. When a participant is asked to provide feedback, she is overridden by a professional. Participants leaving at various times becomes disruptive to the training process. To cover the issue of traditional beliefs, a story is presented. The story is not a testimony of a mother and so no one person's beliefs or actions are thought to be criticised by the group. One professional asks a mother "what were her mistakes?". This has a negative and judgmental tone. The passing of the register and feedback forms during the discussions is distracting for participants. As soon as notes are written on the flipchart, participants become absorbed in copying these down rather than participating in any discussion.

REFLECTION:

♦ The times do not appear to be convenient for all participants since people are arriving late and leaving early.
♦ Parts of the presentation are didactic, lengthly and non-interactive.
♦ Professionals appear to hold the dominant position in terms of speaking in the group and providing feedback.
♦ Note taking, passing around of registers/feedback forms is distracting for the participants. There appears to be a "fear" of missing out on the written word.
♦ Some professionals present /ask questions in a tone that is judgmental.

SESSION THREE: Communication

PLAN:

Present: The trainers present were a speech therapist, a students, the director of the CFC, and a child development officer from the CDRC.

(My reflections - none arose in the planning. The planning was very much academic discussion around a model of communication and what content to present.)

A break down of the programmed constructed is:

13h00 - 13h30 The speech therapist breaks the group into six smaller groups. Each group is given a function of communication (greeting/requesting information etc) to present to the larger group who will the guess what the person is trying to communicate.

13h30 - 13h50 The student will present a model of communication and build on the experience of being motivated to communicate but not having a means to communicate.

13h50 - 14h10 Tea

14h10 - 15h00 The speech therapist will lead a discussion about each mother's child - how does your child greet, protest, request. She will include a brief outline of the developmental stages of communication. The ages at which we expect certain stages to be reached, would be left out since these may make the mother feel despondent regarding their child's progress.

15h00 -15h45 The participants will break back into their three groups (according to their colours and have a discussion around what function of communication is most important, what are the barriers to the child communicating, any practical suggestions for overcoming these barriers.

15h45 - 16h00 Feedback forms

It was agreed that all mothers need to be encouraged to see that their children do communicate in some way and that needs to be recognised. If no practical suggestions/advice can be offered to mothers, each group needs to act as an emotional support for the mother.

ACTION:

Introduction: The director of the CDRC did not join the training since she was looking after the children. The child development officer who usually cares for the children, joined the training for the first time. A new participant from outside joined the group. The three educare workers were not present and neither was one social worker. Three mothers were not present. Thus 9 mothers, 8 professionals, 3 facilitators were present. The speech

therapist welcomed everyone in Zulu.

Icebreaker: The group turned to the person next to them and took turns singing the customary Zulu greeting to one another. The purpose of this exercise was to demonstrate that communication is based on turntaking.

Content: The CDRC officer divided the group into 5 smaller groups. Each group was given a message that had to be communicated to the larger group without speaking. Each group was given 5 minutes to decide who was going to present the message and how they were going to communicate it (without speaking). The groups could each decide what disability and the extent of the disability each presenter had.
In groups 1,2,3: all members of the group presented the message through sign language.
In group 4: only two members of the group presented, using sign language.
In group 5 : Only one member presented the message, also using sign language.
The groups could decipher the messages without difficulty.
The student then presented a model of communication. She would ask questions and then get the group to answer. She used illustrations of Makaton signs to demonstrate the types of messages that could be conveyed. These signs were then verbally translated into Zulu and demonstrated. The speech therapist then led a brainstorming session with the whole group on how disabled children communicate messages. She wrote the answers on the flipchart in English and Zulu. 6 mothers, 1 facilitator and 1 professional participated in this part of the session.
At 14h20 , tea was served. A demonstration was done with three children to show that all children are attempting to communicate with their mothers.
At 15h00, the group was divided into their usual 3 groups based on the colour of their nametag. The group discussion was around what the barriers are to a child communicating and how these can be overcome. The discussion was lead by the trainers and not the ususal facilitators. Everyone appeared to participate in the group discussions.
At 15h25, feedback was provided by the facilitators of the red group and the blue group and translated into English. Feedback was presented by a mother of the green group and translated.
Some discussion continued in response to a mothers request for help on teaching her child to sit without falling over.
The speech therapist then thanked everyone for attending and encouraged the mothers to go home and see how their children were communicating. They all sang a turn-taking song. Evaluation forms were handed around and the participants were requested to complete them.

OBSERVE:

Introduction: *One of the mothers who is also a trainer for Mpophomeni course had made up notes on communication. There is concern that the Zulu training in Mpophomeni is not consistent with the training at the CDRC.*
There is not a lot of consistency with those attending.
When each group was given a message to "communicate" to the larger group, they could decide what disability and the extent of the disability each presenter had. This became

problematic since all the groups chose to use sign language, and most of the children are physically disabled to the point that they would be unable to sign. Furthermore, it gives the impression that if one can teach the child to sign, they will be able to communicate, without taking into consideration that a strong cognitive element is required.

In the brainstorming session, the speech therapist facilitated some discussion from the mothers but the use of flipcharts can be overwhelming and distracting.

When the mother asked about assistance in teaching her child to sit without falling over, it was obviously a burning issue, which was not related to communication but was worrying the mother.

REFLECT:

- ♦ To assign the type and extent of disability to each group to ensure a good mix of experience and that all various disabilities are considered.

- ♦ In place of using a flipchart to make notes, the facilitator could encourage participation and discussion from all of the mothers by individually asking them how each of their children conveys different types of messages. Although it may be more time consuming, it would guarantee fuller participation.

- ♦ For all participants to decide that should any question be asked, regardless if it is central to the current discussion, that it is answered and respected. The participant would not be able to continue participating if she was otherwise requiring information.

SESSION FOUR: Purpose of Play

PLAN:
The first training meeting for this module was held on 19 April 1999.

Present: The director of the CFC, the director of the CDRC, a student.

The director of the CFC felt that the trainer for the Zulu course in Mpophomeni should be attending these meetings so that she gains as much grounding in the areas as possible. It was also agreed that the Speech therapist should be involved in this module. It was agreed that the previous module had gone well due to a good blend of practical and theory. The director of the CDRC reported that the flipchart was used in Mpophomeni and that it had been useful and that the mothers were meeting at the trainers home to complete their worksheets which were being taken very seriously.
The feedback from the Mpophomeni group had been positive. A request was made that an outside Psychology student should attend one module so that an objective view may be given.

It was felt that the Zulu connotations of the word "play" should be explored..

A second training meeting for this module was held on the 26 April 1999.

Present: The director of the CFC, a teacher, a student, a speech therapist, the trainer from Mpophomeni, the child development officer from CDRC, a trainer.

A brief summary from the previous meeting was provided. It was emphasised that the trainers cannot assume anything but need to ask the mothers to tell us what they think play is. The speech therapist agreed to present an overhead on the senses. An icebreaker is suggested whereby the mothers from pairs. They then demonstrate games they played as children. The student would then lead a brainstorming session around "what is play and why do children play". The facilitator would then get the participants into their three groups for a discussion on how they play with their children. The speech therapist would then present material on the senses. Finally the trainer would develop case studies. It was agreed that the type and extent of disability would be laid out for the mothers.

The director of the CFC then discussed the role of the facilitators. It was felt that the facilitators need clarity on the objectives of the group discussions. She suggested that in future, any person responsible for a group discussion should prepare a brief for the facilitators on what they need to try to achieve with their group.

The research assistant and the director of the CFC, discussed the importance of training the facilitators before any training had begun on what their role is in general and then to ensure that they are properly prepared for what their role is in each specific discussion in every module.

A break down of the programmed constructed is:

13h15 - 13h30 Icebreaker.
13h30 - 13h55 Brainstorm in the large group around what is play and why do children play
13h55 - 14h20 Three group discussion - how do you play with your child.
14h20 - 14h40   Tea
14h40 -15h10   Presentation on the senses and how to stimulate them
15h10 - 15h35 Three group discussion looking at three case studies with varying disabilities
15h35 - 15h45 Questions and conclusion
15h45   Evaluation forms

ACTION:

Introduction: At 13h30 a shopping list game was started. The director of the CDRC interrupted this to make two special introductions of people who had decided to join the training for the day. A Zulu speaking Psychology Masters student also joined the training to observe so that she can evaluate whether the Mpophomeni was consistent with the CDRC training.

Icebreaker: The director of the CFC introduced the icebreaker. People turned to the person next to them and had to decide on a game they played as children to present to the group as a whole. The participants laughed and appeared to enjoy this.

Content: The student then lead a brainstorm session on what is play. Two professionals and the visiting volunteer offered responses. No mothers gave any answers. The student asked why do children play. Again only trainers and professionals answered, but there were no answers from the mothers. The student tried to place responses in the categories of biological, intrapersonal, interpersonal and sociocultural. When requesting that the mothers name these categories in their own words, there was no response and so she named them herself.

Next one trainer thought she should be presenting her case studies, when in fact there was suppose to be group discussions around how to play with your child. As a result of the misunderstanding and the ensuing confusion, the trainer presented material on how to understand what category of disability a child fell into, in order to inform how best to play with a child. When she finished her presentation, it was suggested that the participants move into their three groups to discuss the original topic. However, once the groups were formed there was uncertainty as to what they were meant to discuss. One group only had one mother in it which made discussion difficult, while another group had four mothers in it. Feedback was presented by one professional, and two trainers.

Tea was served at 14h40.

15h00 - the speech therapist presented her material on the senses using a question/answer format. There was no participation from the mothers. She used pictures she drew on th flipchart to illustrate her points about when certain senses are used and she used volunteers to effectively demonstrate the point about which senses certain games stimulate. She produced English notes which will be translated into Zulu for the mothers.

15h20 - The trainer was introduced who had written up the case studies so that the groups

could refer to them during their discussion. However, she presented material that had not been covered at the two training meetings. Facilitators were different in this group discussion. Feedback was provided by two professionals and one trainer.

The session was concluded with the Director of the CDRC saying that English worksheets for the previous module on communication would be made available as soon as possible. The Zulu worksheets had already been completed. The next module date was moved forward due to Election Day.

The "standard" facilitators have been asked to attend the training meetings to ensure they are able to effectively facilitate the group discussions, although it is not intended that they are involved in the actual training at CDRC.

OBSERVE:

Introduction: A game not discussed in the training meetings were introduced. New people/onlookers appeared for this one session.

Content: The opportunity was provided for mothers to say what they think play means, yet no responses were offered by mothers at all. Furthermore, the student gained no input from the group as a whole in terms of labeling her categories. The value of the exercise in terms of outcome was questionable. In terms of large group brainstorming, the mothers seem reticent and unwilling to speak up.

There was a great deal of confusion around the order of presentation and general chaos. The forming of the groups did not allow for a balanced mix of trainers, professionals and mothers. Feedback was only ever provided by professionals or trainers and never by the mothers themselves.

The presentation on the senses did not arise any response from the mothers.

When the case studies were presented, material was included that had not been discussed at the previous training meetings. Although the material dealt with the principles on which play as stimulation is based, it added more content to a module that was already quite information intensive.

The facilitators were often unaware of the outcome they were hoping to achieve from the group discussions.

REFLECT:

Introduction:
♦ The outcome of the brainstorming session was to bring about discussion around the functions of play. The value of this is questionable and perhaps the outcome could be more to simply explore the mothers perceptions and understanding of what play is (Western notion may be different to an African notion).

♦ Larger group brainstorming does not appear to encourage responses or participation. The presenter needs to actively encourage the mothers to participate or else the smaller group break down might be more productive to ensure maximum participation.

♦ The miscommunication and poor understanding of the order of presentation could be prevented if one person (the Director of the CDRC) acts as a continuity

presenter at each training session. This will ensure that the training runs smoothly and minimise confusion.

♦ The extra "new" material that was added to the case study part was very information intensive. Perhaps this could be excluded at this level of basic training.

♦ The facilitators need to attend all the training meetings to ensure they are aware of what outcomes need to be realised at each session.

**FINALLY START SEEING SOME INCLUSIONS OF
SESSION 4 REFLECTIONS INTO SESSION 5'S PLANNING.** NEW ASSISTANT - DID
NOT MAKE OBSERVATIONS/REFLECTIONS

SESSION FIVE: Toy Making

PLAN: The first training meeting was held on the 24 May 1999. A new research assistant
replaced the former one.

> **Present:** The trainers present was the director of the CDRC, and a principal of a Special
> School.
> The facilitators were not present at the training meeting.
> It was decided that before proceeding onto Module 5, the training session should first
> commence with a recap of the previous module with the parents. It was agreed that the
> parents should be divided into 4 groups, each which would be engaged in a discussion
> around the appropriate toys/activities which could be used for the different disabilities.
> Thereafter, the parents would become involved in making toys which are suitable for the
> needs of the child. It was mentioned that there would be a need for tables/trestles at which
> parents could work.
> There was discussion around the fact that there was a limited choice in the type of toys that
> could be made, depending on the material available. An important suggestion was that in
> making the toys, one should take into consideration the level or extent of the disability, as
> well as whether the toys made would be useful to the parents in their rural communities.
> It was argued that it would be better if parents could be encouraged to bring in materials
> themselves, which were familiar and available to them, to use to make the toys.
> It was decided a second training meeting would be necessary to formalise the content and
> process for this module, and to assign various tasks to the people who would be involved in
> planning the workshop.

The second training meeting was held on the 4 June 1999.
> **Present:** The director of the CDRC, a school psychologist, the principal of a Special
> School, three facilitators.
> ♦ The three facilitators were present.
> ♦ The facilitators would actively encourage the mothers to participate through
> breaking them into smaller groups so that there is more participation.
> ♦ The facilitators were briefed that their role/outcome they need to achieve would be
> to get the trainers to generate ideas around what toys are suitable for different
> disabilities

The session would begin with an icebreaker. It was suggested that an "untangling hands"
icebreaker would be used. The trainees would tangle their hands and then attempt to untangle
them. The purpose was that out of chaos comes order.
The workshop would begin at 13h30. A list of the required and appropriate materials was
discussed and listed.

A break down of the programme constructed for the 9 June 1999 is:

13h30	A brief introduction by the Director of the CDRC
13h35	Recap of the previous workshop on different disabilities done by the Speech therapist.
13h40	Icebreaker of "untangling hands" introduced by the Speech therapist.
13h50	Commencement of small group task where mothers will be divided into three equal groups. This task will take the form of a brainstorming session, in which the trainees are encouraged to talk about the different toys that can be made according to different disabilities. The trainees will be advised to perceive the child as a whole. The role and outcome that needs to be achieved by the facilitators was highlighted.
14h10	A feedback session to the larger group will be conducted by the School psychologist.
14h30	After the feedback session there will be a exhibition/demonstration by the trainers of the toys which have been made previously.
14h45	Tea
15h00	The smaller groups are involved in a workshop of actually making the appropriate toys with the material provided and with the assistance of the trainers.
15h30	Feedback to the larger group. Trainees are given the opportunity to demonstrate how useful/appropriate the toys that they made are, according to different disabilities. It was decided that some of the children could be used to demonstrate the usefulness of the toys.
15h50	The speech therapist will facilitate a discussion around the grading of the activities and toys, ranging from simple to difficult. The types of toys would depend on the nature and the extent of a child's disability
15h55	Feedback forms and close

ACTION:

There were 25 people present including all the trainers and facilitators.

Introduction: The Director of the CDRC welcomed everyone present. She explained that the workshop would revolve around making toys for children with different disabilities.
Recap: The last workshop material was revisited. The speech therapist emphasized that

the trainees need to look with "new eyes" at the things thrown away and that they can be resourceful.

Icebreaker: Everyone was divided into 6 groups and instructed to tangle their hands. They were then asked to try and get loose. There was a lot of laughing and talking. Once everyone broke loose, there was a round of applause and much laughter.

Content: Everyone was divided into 4 groups with at least one parent in each group. The school psychologist explained that the trainees had to think of toys that children with different disabilities could use. The categories were visual impairment, auditory impairment, limited motor ability and good motor skills. Each group had a facilitator who had a form on which each of the four types of disabilities were listed, and underwhich they had to jot down suggestions made by the participants. All the groups appeared actively involved. Some people in the groups were more vocal than others.
The Director of the CDRC initially moved from one group to another to supervise and guide the process. Eventually all the discussions were running smoothly and independently. The school psychologist asked for feedback from each group separately. The facilitators in each group listed the different toys/activities that could be used for the different types of disabilities. A variety of suggestions according to the different disabilities were noted and shared amongst the larger group.
During tea, the parents were told they were welcome to view the materials on display.

The speech therapist and school psychologist showed the trainees the various items that had been made out of different materials and demonstrated how to use them. Materials were then laid out on trestles. Trainees were asked to make toys for the children who attend the CDRC. Everyone was very engrossed in the activities with a great deal of laughing, sharing ideas and talking. It appeared like many creative ideas were generated and that people enjoyed the exercise.

Trainees working at each table were then given the opportunity to demonstrate their toys. After this feedback session, trainees were asked to complete their feedback forms which aimed to elicit their feelings about the workshop.

As the conclusion to the workshop, the speech therapist spoke about grading the toys. She emphasised the importance for parents to see at what level the child was functioning, so that appropriate toys could be made. The Director of the CDRC concluded the day by thanking everyone for attending. She mentioned the content and date of the next training session.

OBSERVE: **MINE OWN:**
  Having a structured plan where everyone attended the training allowed it to run more smoothly.
  Outlining the outcomes to the facilitators ensured they achieved what was intended.

Smaller groups ensured better participation and more relaxed atmosphere.
One person responsible for interacting with all the groups and guiding the process,
allowed there to be better organisation.

REFLECT:

SESSION 6 AND 7 - AIDS AND EQUIPMENT MAKING

PLAN: The first training meeting was held on the 13 July 1999.

Present: The trainers present was the director of the CDRC, the Director of the CFC, 2 occupational therapists, an O.T. assistant, the three facilitators, and the research assistant.

The initial discussion revolved around changing modules 6 (Aids and Equipment making) and 7 (Positioning and exercise) around. However, it was eventually decided that both modules should be combined, since they complimented each other. It was agreed that the primary focus in both sessions should be on **positioning** during key functional activities (such as dressing ,eating). It was also agreed that **stretching, handling techniques, training on answering questions like "why can't my child sit?▯, and harmful situations** need to be covered in the training.

It was further emphasised that it needs to be clearly communicated to the participants that this workshop is not adequate in itself and that they still need assistance from professionals. Furthermore, that they could prevent their child▯s situation from getting worse by consulting processionals as soon as they discovered their child had a problem.

The second training meeting was held on the 22 July 1999.
Present: The director of the CFC, two occupational therapists, 2 facilitators, one student.
It was agreed that the overall theme would be on the importance of positioning and handling your child correctly during activities of daily living.
A break down of the programme constructed for the 4 August 1999 is:

20min	An icebreaker conducted by the student of movement as an agent of change.
10min	What you as moms can do to prevent your child from having more problems. This will be conducted by the Director of the CFC.
30min	The group is divided into three smaller groups. The aim is to brainstrom what the mothers' problems are in relation to issues like bathing, dressing, feeding. Secondly to look at positioning in terms of carrying, sitting, lying down. This part will be conducted by one of the O.T's
14h15	Tea
14h30	Group discussions. The group is broken down into three smaller groups. The importance of positioning is discussed and practical examples are demonstrated and practiced by the mothers with their children.

15h55   Handouts on the professional resources available are given.

ACTION:

There were 16 mothers, 7 other participants, and 9 facilitators and trainers present. The training session was held on the 4 August 1999 at the CDRC.

Introduction: At 13h30 the Director of the CDRC welcomed everyone present and introduced the trainers/facilitators. The Mpophomeni trainer then opened the session with a song.

Icebreaker: At 13h35 the student introduced the icebreaker, with one of the facilitators interpreting. The group was asked to stand in a circle. One person was asked to go outside the room. Whilst she was outside, another person would be asked to change the rhythm of clapping. The first person, on returning, had to watch the participants and try to find out who had instigated the change in rhythm.

Content: At 13h45 the Director of the CFC firstly thanked the O.T. for her input into this training module and for assisting the group in appreciating the care which must be taken when dealing with physically disabled children. She pointed out that each child is different, with their own strengths and weaknesses. She outlined that advice around positioning would be the theme of the days session. The O.T. added that therapy should not be done in isolation but rather in conjunction with practical daily living things like feeding, dressing etc.

At 13h55, the O.T. addressed the mothers of physically disabled children. She stressed the importance of teamwork and working with other professionals. She stated that there was no cure for the problem of the child but that there were ways to prevent deterioration and ways to improve a child's problem.

At 14h10, the participants split into three groups with a facilitator in each group. There were 5 mothers in each group plus 2 or 3 other participants. The facilitators had been briefed about the main theme. The groups were asked to discuss issues like the history of the child, when did the problem start, what were the main problems. The three O.T's walked around and listened/advised where necessary. The student and the Director of the CFC were participating in different groups.

At 14h25 the groups returned to the larger group. Facilitators were asked to provide feedback. The children were discussed freely with repeated questions being "why is my child like this?" and "the doctor didn't tell me anything". When asked what the mothers biggest problem was when it came to seeking help, they all answered "money" in terms of not being able to take the child for therapy, special schooling.

At 14h40 Break for tea. The group was asked to return at 15h00 since there was still much

work to be covered. The O.T. promised some important positioning techniques after tea.

15h00 The participants returned to the big group. Mothers were asked to show how their child was positioned when sitting, lying etc at home. Each child was demonstrated on and moms were asked to try the correct positions. During the session the moms moved around and appeared interested in things relevant to their own child.

15h50. The O.T. then spoke to the group emphasising he importance of the child attending school and being treated as much like "normal" children as possible. The Director of the CFC thanked the mothers and trainers for participating and helping with the course. She addressed the mothers saying she understood their problems and the difficulty in arranging schooling but that the CDRC's role was to act as a stepping stone in getting better facilities for their children.

The director of the CDRC then took mothers back to the taxi rank. The facilitator handed out feedback forms and told trainees of the next date.

OBSERVE:

Introduction: The song that was used as an introduction was enjoyed greatly by the mothers and the other trainees.

Icebreaker: The purpose of the icebreaker was to recognise movement as an agent of change and to stress the importance of positioning and handling your child correctly. This was not explained and the link is quite obscure. Although participants appeared to enjoy the exercise, none of the mothers actually volunteered to be "in".

Content: When the O.T. addressed the participants, she stated many important factors , factors which those who work with children take for granted, but which are important and new pieces of information for mothers. It seemed that there was too much information given and that perhaps handouts would be a better option.

At 15h00, the group returned to a larger group since there was too little time to break the group into three. Due to this, there were two or three positions/advise being demonstrated at the same time by the different O.T's and this was confusing for the mothers.

REFLECT:
NO REFLECTIONS WERE OFFERED BY THE RESEARCHASSISTANT

SESSION 7 - HANDLING AND POSITIONING

PLAN: The first training meeting was held on the 16 August 1999.

Present: The trainers present was the director of the CDRC, the Director of the CFC, a student, an OT. and two facilitators.

The content of this meeting was to evaluate the previous session, to decide on the title of module 7, who the trainers were and what key concepts would be covered in the session.

The meeting started with people debating as to whether there should have been three groups instead of the one larger group when it came to demonstrating and allowing mothers to practise the techniques. It was agreed that three groups are better provided that everyone is included and that there are differently disabled children in the groups so that different techniques can be shown. Furthermore, that the three groups should have continued after tea to cut down on the confusion.

A recurring problem is that the trainers did not conduct the module as had been previously arranged and that too much extra information was being included which could again confuse the trainees. It was agreed that there are many aspects to one topic and that all could not be dealt with in one session.

Another issue of concern was that the trainers and presenters were being too professional rather than looking at things from the mothers point of view. Furthermore, the difficulty of mixed trainees of experienced people as well as mothers was discussed. The focus of the presentation should be on dealing with caring for the child with a disability and not purely the mother/child approach. The training course has been designed for people who wish to care for disabled children in their community and not necessarily only mothers. This needed to be stressed to the mothers and that the course may not necessarily help their particular child but that what they learn could assist other children in their community. Furthermore, that the course is not seen as the only resource.

The idea of forming a CDRC training task team was agreed on. This would consist of professionals who have the skills and the sensitivity of keeping in perspective where the parent/caregiver is coming from. It was agreed that these members would be elected and not volunteer themselves as had been done in the past.

It was suggested that vital information for the modules be documented in a guide, that one person should present one module instead of 3 or 4 modules, and that the trainers must not be overcritical of themselves.

An issue of concern was that the mothers were feeling like things were rushed. There was also a situation where a mother kept asking about her hyperactive child and was being ignored. It was agreed that this particular mother would be seen at the end of the session.

Another mother was feeling that her child had not benefited from the session and asked if her child would benefit from the other modules. It was felt that perhaps the mother felt this way since it was her first attendance to the course. It was thus suggested that new mothers should join a new group.

The question arose as to whether the module should be repeated. It was agreed that this next module (Module 7) would be more practical and that both module 6 and 7 are introductory programmes for caregivers. It was agreed that the title of the module would be Handling and positioning during everyday living activities. Furthermore, that the 3 □specialist" trainers should each work with one group. The key concepts to be explained would be simplistically what is cerebral palsy, the importance of correct positioning and practical aids to assist correct positioning.

The second training meeting was held on the 24 August 1999.
Present: Two of the occupational therapists and 2 facilitators.
The one O.T. suggested that before the training begins, posters are put up around the room to highlight essential information about the definition, type and causes of cerebral palsy. These posters would be translated into Zulu and available to be photocopied and given to the participants for future reference.

A break down of the programme constructed for the 1 September 1999 is:

13h30	Welcome by the Director of the CDRC
13H35	A specific icebreaker conducted by the student was not decided on.
13h40	A discussion with the large group would follow. The aim would be to discuss the surrounding posters so that the trainees are provided with some theoretical knowledge of CP. It was reiterated that it is important to keep the discussion simple and not to try and "overeducate" the trainees.
14h00	The trainees are divided up into three smaller groups, with one trainer/expert assigned to each group. This activity will recap the carrying position that was taught in the previous module. The trainees would need dolls to practice this. The training would be guided by answering the following questions: "how do you carry a child?", "what is the best way to carry a child?".
14h30	Tea
14h45	The second component of the small group activity would involve a discussion and demonstration of how the trainees manage a child during different activities. The group structure would remain. Initially it was felt that a number of routines could be demonstrated, however it was eventually decided that this would be too much for the trainees to absorb in one session. As a result, only three positions were chosen. The rationale for choosing these particular positions were that they were usually the ones the child spent the majority of their time in. The trainers will demonstrate these

positions using dolls, explaining how the child should be placed in that particular position and why it is important. The trainees will then be given the opportunity to practice what they have been taught. It was emphasised that "gentleness" needs to be stressed since a child's body should not be forced into a position since injuries could result.

15h45   Feedback

16h00   Close

ACTION:

There were 3 facilitators,2 trainers and participants present. The training session was held on the 1 September 1999 at the CDRC.

Introduction: One of the facilitators welcomed everyone present.

Icebreaker: The student introduced the icebreaker, with one of the facilitators interpreting. The icebreaker involved having to talk to the person next to you without showing your teeth. The trainees broke out in laughter during the explanation of what had to be done. The trainees were good sports and enthusiastically participated, and had tears rolling down their face since it was so comical.

Content: With all the trainees in one large group, the O.T. discussed CP in as simple a way as possible. The information was translated by a facilitator. The discussion was brief and simple. The trainees appeared to be quite attentive during the discussion.

The two O.T's demonstrated the various carrying positions using dolls. The trainers explained and demonstrated how to position the child in different ways. The trainees stood up and practiced the various carrying positions. They appeared to concentrate and actively participate in the demonstrations. They did not have any questions.

The trainees were then divided up into two groups, each facilitated by a trainer. The trainees sat comfortably on the floor, with the O.T.'s explaining and demonstrating how to position the child for changing nappies and clothes, and for sitting. The trainees followed the instructions of the trainers and emulated the positions demonstrated.

There was a break for tea.

The participants returned to the big group. The trainers demonstrated how to position the child whilst holding them on their laps and whilst feeding. The two O.T's went on to demonstrate how to position the child whilst the caregiver is busy/working. The trainees all unanimously said that they place the child in a lying down position. Hence, a demonstration followed for a lying down position. Trainees practiced these positions using dolls, while

some used their own children. It was emphasised that the child needs to be kept occupied in this position, with a toy. Finally there was a demonstration of positioning the child in a standing position, using a build-up standing frame.

OBSERVE:

Icebreaker:.The icebreaker was unrelated to the overall theme of positioning and handling. It was greatly enjoyed by the participants.

Content: The trainees all appeared very attentive and participated well during the demonstrations and practise sessions.
There was good rapport between the trainers and the trainees and the interaction appeared a fruitful and positive one.

REFLECT:

NO REFLECTIONS WERE OFFERED BY THE RESEARCH ASSISTANT

SESSION 8 - USE OF MUSIC

PLAN: The first training meeting was held on the 10 September 1999.

Present: The trainers present was the director of the CDRC, the speech therapist, an O.T a student, and two facilitators.

Content: Various ideas were discussed of ways to show trainees how important music is to our moods and daily living. It was agreed that presentations should be participatory. The concept to be demonstrated was the effects of music on multidisabled children and how music can be used. The mothers of children would be invited to bring their children to this module. There would be an exhibition of instruments.

The second training meeting was held on the 27 September 1999.
Present: One occupational therapist, a clinical psychologist, a student, a speech therpaist,2 facilitators and the research assistant.

A break down of the programme constructed for the session is:

Welcome by one of the facilitators.

The icebreaker was related to music by people making a rhythm and then saying their name.

Small group discussions being lead by the clinical psychologist. All present would be divided into three groups. The session will be a brainstorming session that intends to elicit discussion about music from the trainees. Questions will be posed to the groups to encourage them to brainstorm.

The groups will return to the larger group to provide feedback and summarise what has been discussed.

A drawing task is set whereby the trainees are required to draw how they feel when different kinds of music is played for them. The assumption is that drawing to different kinds of music will produce different kinds of drawings.

The speech therapist will then engage a discussion about the impact of different types of music on the child both emotionally and physically.

Break

The O.T. will discuss the influence of rhythm on the body and brain. She will discuss the number of things that can be done to music which involve body movement. She will also cover how music can be used in such a way to encourage some basic cognitive effort from the child. Trainees will hum, and wait to see if the child responds (turn-taking exercise).

Linking story telling with music. A facilitator will sing some Zulu songs each of which tell their own story, and both children and trainees will be required to move their bodies and hands according to the beat and rhythm.

The finals part of the session is aimed at giving trainees the opportunity to share their ideas about some of the songs that can be sung to children (storytelling songs)

ACTION:

There were 4 trainers present. The training session was held on the 6 October 1999 at the CDRC.

Introduction: One of the facilitators welcomed everyone present.

Icebreaker: The student introduced the icebreaker, with one of the facilitators interpreting. The icebreaker involved everyone present to click their fingers and clap their hands, in keeping with the music that was played in the background. Once a clicking and clapping rhythm had been achieved, each person said "My name is ....", in keeping with the rhythm that had been set. Everyone participated and a steady rhythm was established with people calling out their names in time to the beat.

Content: With all the trainees in three groups, the psychologist facilitated discussions which focused on answering questions like: What is music/ what is the value of music? How can we use music to help us make better parents? It was emphasised the importance of generating as many ideas as possible. The trainees actively participated and there was a constant flow of ideas and comments.

The psychologist facilitated the feedback session. All the ideas and comments that were generated during the discussions were read out by a group representative and written on the board. These were translated by a facilitator.

The O.T. then put on different types of music (fast/slow) and trainers were required to draw according to how the music made them feel. There were significant individual differences in the drawings.

The speech therapist spoke about the appropriateness of music as it would not benefit a very spastic child to play fast, vibrant music since this would make them stiffen. Alternatively, a child with low muscle tone, would benefit more from fast music. It was presented how music can heal a child in terms of music and body tone.

The O.T. did an exercise waving a scarf to music. Different tempos of music was played and trainees had to actively participate by waving scarves in keeping with the music. The idea was that the child could respond to the music by waving a scarf. It was discussed how a child could be educated/taught using educational songs that are repeatedly sung to the child. It was told that one did not need expensive instruments to use music and household

goods could also be used.

The facilitator sang some songs which told stories and were educational. The idea was to demonstrate to trainees that songs can be used to encourage imagination and creative thinking.

OBSERVE:

Icebreaker:.The icebreaker was related to the overall theme of use of music. It was greatly enjoyed by the participants.

Content: The drawing exercise appeared fun and the trainees seemed to enjoy themselves.

REFLECT:

NO REFLECTIONS WERE OFFERED BY THE RESEARCHASSISTANT

SESSION 9 - EVALUATION

PLAN: The first training meeting was held on the 21ˢᵗ October 1999.

Present: The director of the CFC, a student, a counselling psychologist, a clinical psychologist, two facilitator and the research assistant.

Content:. It was unanimously decided that an evaluation of the entire training programme should precede a discussion on how to ensure that the programme is sustained by the trainees. The rationale for conducting an informal evaluation is that an evaluation could highlight problems with the programme that may need to be remedied. Only once these problems are identified, the modules changed accordingly, then the issue of sustainability can be considered. It was agreed that the evaluation would be broken down into three components:
* assessing the knowledge gained and the skills learnt from the modules.
*assessing attitudes towards disability both before and after the training programme
*assessing how the programme affected the trainees as human beings, how it impacted on them..

It was decided that after the evaluation, trainees should be given the opportunity to state whether or not they would like to continue with the programme the following year. Based on their responses, **which is likely to be in favor of sustaining the programme,** attempts can be made to hold another workshop specifically targeted at the question of sustainability.

The second training meeting was held on the 26 October 1999.
Present: The Director of the CFC, a clinical psychologist,2 facilitators and the research assistant.
At this planning meeting ,some suggestions for future workshops were discussed:
* that the time slot be changed to a morning session.
* keeping group membership of trainees consistent
* having the same facilitator run the discussions with a particular group over the course of workshops.

10 min	The clinical psychologist will facilitate an icebreaker. This will involve each person singing their own song all at the same time. The aim is that eventually everyone sings the same song.
5 min	The Director of the CFC would briefly summarise the titles of the various modules, which would serve to remind the trainees about what each module entailed.
30 min	Trainees would break up into three groups. This will be a brainstorming session in which there will be discussion around: the knowledge and skills learnt from each of

the modules.
Personal and group growth
Attitudes towards disability.
These questions will be posed to the three groups and a representative of each group will record the comments being made.

15min	The Director of the CFC will facilitate a feedback session on each of the three questions.
10min	Tea
25 min	Small group discussions will continue around the level of commitment to carry on, and what are the barriers to staying involved, and what assists you to stay committed. A facilitator will introduce this session. The trainees will be divided into three groups and discuss these two questions. A facilitator will record the responses/comments.
15min	The feedback of the previous discussion will be facilitated by the two facilitators.

ACTION:

The training session was held on the 3rd November 1999 at the CDRC.

Icebreaker: The psychologist asked the trainees to think of a song they would like to sing. The trainees were then requested to sing their songs all at the same time as loud as they could. Then they were asked to sing the same song together. There was silence as none of the trainees initiated a song which could be sung by all of them. Eventually , the trainer asked one of the trainees to lead everyone in song. The trainees followed her eagerly.

Content: The Director of the CFC briefly mentioned what each module covered.
The group then divided into three smaller groups and each group was asked to brainstorm the three questions agreed on in the planning. A representative from each group read out the responses/comments made by the trainees. The comments made were as follows:
Module 1 - the trainees felt they were able to use the knowledge gained to help disabled children.
Module 2 - they learnt to involve mothers in the process of caring for the child.
- learnt to help people to accept their children
- learnt to be sensitive to disabled children and to respect how they are feeling
- learnt they don't have to pity the children, only respect them
Module 3 - learnt that both able-bodied and disabled children have skills/talents that are unique
- learnt to acknowledge our own limitations in communicating with a disabled child.
- learnt to talk to the child
- noticed the receptiveness of the child
- learnt that disabled children communicate through signs, sounds and movement of

the body.

Module 5 - learnt to be more economical and resourceful

Module 6 / 7 - these modules are helpful

- Learnt how to position the child for eating and bathing
- how to teach a child to stretch independently
- learn to talk to the child and let the child know what is happening
- learnt the importance of positioning the child correctly

Regarding their personal experience of the workshops, the following comments were made; Sharing views with other mothers of disabled children makes the mothers not feel alone. They learnt to be more professional and resourceful. They realised that their children are a blessing (it was God□s will). They learnt not to care what others have to say about the disabled child and learnt to love the child more. In terms of their attitude towards disability, they learnt to change their beliefs and the existing myths around disability, that disability is not a curse and the disabled child is not bewitched. They no longer feel afraid of disability. Recommendations for future programmes were that medical professionals could be included in the training sessions who could explain the causes of disability to them. That it was important for the child, mother and health care worker to work together in a team so that the child may be viewed holistically and that dental care could be included for future programmes. The comments regarding barriers to sustainability of the programme were time - having to leave work early and getting home late; that transport to and from the CDRC was problematic and that the venue was nor accessible to everyone.

OBSERVE:

Icebreaker:.The icebreaker was related to the theme of group relations. The purpose was to demonstrate that one person should not dominate a group, that every member of a group cannot talk/share simultaneously, and that different voices need to be respected. The group seemed unable to take the initiative to decide on one song and needed a "leader" to encourage them.

Content: The aim of the recap of the modules was to encourage the participants to reflect on the content covered and to prepare them for making comments about each of the modules *Many comments were made but it felt like the "right" things to say were being said. A critical, objective viewpoint was not conveyed.*

REFLECT:

NO REFLECTIONS WERE OFFERED BY THE RESEARCH

ASSISTANT

APPENDIX B

Evaluative comments from focus group discussions

CDRC

EVALUATIONS:

The following section present the evaluations of the training course. The source of the data comes from focus group discussions held by the research assistant with the various participants involved.

Director/coordinator of the programme:

COMMENTS ABOUT THE OVERALL TRAINING COURSE:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Director/coordinator of the programme:	"When I first thought the course was a good idea, I put a lot down on paper and it all seemed a fairly easy process. What I realized in putting it into action, it's amazing how much can grow out of that contact, and not only between mothers and mothers, but people who come onto the course from outside of the direct field of disability". "I learnt a lot putting together this course" "I learnt, not just about disability, but about the personal aspects of caregivers"	"I think it needs to be more experiential the next time round – I think I assumed wrongly that people did know more about specific disabilities, and I'm not just talking about people who haven't had any training, but even the people who have had training." We first started (CDRC) with our moms, and I think they were very unclear, they came in and we had many professionals who were interested in the course and I think the moms did feel a little threatened, a little bit uncomfortable in this company in the early part of the course

		message and the enthusiasm". "I felt a little bit inhibited with all the extra people here. I think it was good for everybody to be here and we all learnt a lot, but I think you would get a much better response if the group was smaller - like the Mpophomeni group. "Also here (CDRC), the people attending changed, there wasn't a body of people that you knew would be there every week - new people came in quite a lot"
Trainee dental hygienist	"The icebreakers were hilarious and fun" "It was good to have a mixed group because you get an idea from the mothers, the trainees ,the health workers, and put it all together so that the play, the care, anything you do with the patient in a hospital setting, you reinforce it at the home setting. As a	"Initially I was nervous with the icebreakers but once you get the hang of it and become friends with everyone in the group, then you don't feel so awkward"

| therapist, child care worker(faciltator) | rather than the presenters giving all the information. Also the lovely response from the mothers – you could just see they had a new idea, something new to try with their kids"

"Viva CDRC" | have the input because I think the professionals need to see the moms and where they're at. So it's quite tricky knowing how to deal with it"

"I was thinking if you had shorter theory and more communication in the smaller groups because the parents can actually come up with some quite good ideas, and it's a learning curve for them as well, not just a top-down thing. So I would like to have more discussion, more things coming from the parents"

"In my case ,I was limited because I can't speak Zulu and if we had been able to do everything in Zulu, it would have flowed easier. You tend to think and start talking and then you have to stop, and hang onto your thought while it's being translated, so you loose the |

		attendance improved. Also in Mpophomeni 25 people graduated here not that much because people just came in, anybody maybe just for one module
Three trainers (provided professional content to the course) – A school psychologist, a speech therapist, child care worker(facilitator)		
Trainee	"when working in the health field, you see the patient just as a patient and now after this course, you start seeing the patient as a person and you can respond otherwise. You don't just go on and start with your work, you can spend 2 minutes touching, smiling, exercising them and most will respond"	

COMMENTS ABOUT THE MANNER OF TRAINING

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS /RECOMMENDATIONS
Three trainers (provided professional content to the course) – A school psychologist, a speech	" I enjoyed the grouping in all the modules, the smaller groups. It gave the opportunity to really discuss and get a lot of information from the participants,	"I think a more homogenous group would be easier, but at the same time it was quite nice o

| Facilitator: | | "It was stressful at times trying to contact the trainers and at times they were not punctual"

I picked this up early and spoke to them confidentially. As a concern it came out that maybe to speak to the mothers how they are feeling about the training itself, and it came out ,it seems that the professionals are dominating everything, and so at times it's a little difficult for them to voice out everything they would like to say or else to ask anything because the majority of peole seem to almost know some of the things that have been discussed in the coyurse, and so it came out that at least during some of the days that the mothers are attending, that we just redo the stuff. So it came out that they thought the training was for someone else, not for them. Also the attendance, at first it was not that much, but after discussing this |
| --- | --- | --- |

| | the tension that you get, I was glad to be able to tell the mothers – yes, it may be difficult now, you can see the difficulties only, but we must please bear with our children, because for sure, it doesn't end up like this – there is a good thing behind this pain"

I remember I was in a group - a white lady said she once kicked her child because of the stress she had, and one mother was helped. The mother said "I always thought white people don't touch their children, even if their child is wrong," so this helped her, because those are the things that really happen - it gave relief to her. | |
|---|---|---|

Trainee	Positive Comments	Negative Comments
Dental hygienist	"Mainly refreshment for me"	
Teacher asst	"I learnt how to take care of a disabled chil, not to think for him or her but let her show you what she is capable of doing"	
Teacher asst	We had knowledge of this basic care, but little things like feeding and carrying, it's always	It was quite boring because it was something we'd already gone through

	accept her.	
Trainee - caregiver	When I found out that I'm not the only one with a disabled child I was relieved because I was able to share my experiences and difficulties with them freely and accepting my child	
Trainee - caregiver	I feel so proud when we as mothers talk freely about our children.	

Module Two:

Trainer	Positive Comments	Negative Comments
	"The module on acceptance, parents maybe looked at their children in a different way and maybe found it easier to accept them and to look as their children as people, and not as a liability	"I did the module on acceptance. I think it went off well but would have liked more discussion from the parents"
	I was very happy to do this module on acceptance because I found myself in a very difficult situation of accepting my child. If it wasn't for my father who made me accept my child, I don't know. But knowing that there is a way of dealing with	

can't afford it, 6 pe person, 7,10 per person, so we must be taught how to work in a group.

- a mother said that they need counseling because some of them are having difficulties to accept and want to leave the situation of their kids.

IMPRESSIONS OF THE SPECIFIC CONTENT OF THE MODULES:

Trainee	Positive Comments	Negative Comments
Dental hygienist	"It was more refreshment for me"	"It seemed rather long to me, but because it was more refreshment in my mind"
Teacher asst	"I learnt how to accept and treat you child, not to be frightened"	
Teacher asst	"I learnt that parents can have problems accepting their child, because for me, before, any parent accept any child automatically - but this isn't true - parents can be angry with themselves or the child." "I liked the shared experience because people were open"	
Teacher asst	"I mustn't be afraid of disability, I must stand up and help them".	
Trainee - caregiver	"I had a problem of what to do with my child's disability but I was able to get the knowledge and to accept her as she is and for the family and community to	

	mother knows what to do and vice versa - this helps to stimulate the child much more."	

General Recommendations:

TRAINERS;

"I think its good to talk about culture, that we look different, we may come from different cultures but basically we all become frustrated, we all love our children, there are day's when you don't love them as much, we all have our guilt feelings and dreams."

"We need to be culturally open - we had a variety of people, the white English person, the white Afrikaans person, Indian, Zulu - speaking ,urban,rural - a wide variety and we all look at things in a different way, but we all feel the same emotions. We express and deal with them differently, but we all feel the same - get frustrated, guilty, overwhelming love, protectiveness."

"Even if you have the number of people we had here - the parents and the caregivers, there weren't a lot of them. If you just had to have a discussion - not even in smaller groups, just to be open, it would make it easier for them to respond.

"TRAINEES:

"I would like a medical doctor to teach us what is happening with a child who is born normal and then after that, they become disabled. Because some moms say 'no, I went to the hospital and the docor said no the babies O.K. We need a doctor to explain what the causes are of disability, not just that the child is disabled - moms need to know so they can prevent it for the second baby".

"I want some modules for teachers or people who work with children in a group, on what activities and to bring 5 or 6 children and we do activities with them because to spend time with one child, we

	good to be reminded.	
Caregiver:	It was good to know you are not the only one and to accept our children and not hide them or feel ashamed.	

Recommendation for Module Two:

TRAINER:

You know, I think because we are very believing in this Zulu thing that a sangoma can do something about a child, if maybe we can find a way of telling the mothers – you can't say, 'look you must stop, just don't go there' – but that they exercise it but knowing very well that if my plan 1 (sangoma) doesn't work there is room for a plan 2. But they mustn't waste much time waiting, rather they must do both. Even if plan 1 is not working and they won't feel plan 1 is not working, but plan 2 is the real resource."

" I would like to have known from the mothers what they are already doing, so you're working from a known basis because we were giving information not knowing what people had already done, so it would be useful. Like feeding a physically disabled child - everyday they are getting food into that child, so its important to see what they are doing before you know what you need to help them with."

TRAINEE:

"I felt the dental hygiene part was sort of left out, so maybe in the future, we could get a dentist to elaborate on dental care"

"I was hoping they will include on what kind of food should we give our children because of the constipation they always have"

"They were suppose to emphasise on the cultural things"

Module Three:

Trainee	Positive Comments	Negative Comments
Dental hygienist	"This was excellent as it helps you to not see the patient as only a patient, but as a person as a whole that you need to relate to"	
Teacher asst	"I learnt a lot, especially about the deaf child who can't talk. The point I like a lot is if you approach somebody who can't talk, you can talk else they'll think you're also disabled"	
Teacher asst	Most interesting for me is that communication is not only language, you can communicate if you don't talk. And children can show they are happy, sad, cry, smile - body language is also communication. And to help them to communicate with the body if they can't use their mouths.	
Caregiver	I learn that when I am talking to my child, trying to make her laugh, she wouldn't respond. But now I know how to communicate with her and she	

	laughs and she's able to do different things	

Recommendation for Module Three:

TRAINER: I would like to have done more on communication and play because I think we didn't do much in the practical , we did more theory than anything else" TRAINEE: "It would be nice to have a separate module for teaching us sign language"

Module Four:

Trainer	Positive Comments	Negative Comments
	"Still it was very positive as it was an opportunity for parents to see other people who have children with disabilities and that there are really things one can work on.	"Particularly with communication and play modules, the variety of disabilities, so you couldn't address the issues in any depth with particular parents. There wasn't much opportunity to give those parents much information to go home with."

Trainee	Positive Comments	Negative Comments
Social Worker		"I didn't understand this one, because we South Africans don't see the importance of play, so I feel I needed more

		information on that"
Dental hygienist	"It gave me new ideas"	
Caregiver	Before I did not see the reason to play with my child but after this module I am able to share anything with her, and to know she feels accepted.	
Caregiver	I didn't know how to draw the attention to my child until I know that there are toys you can put around or hang them or put on the cgild's wrist. That make it easy for the child to pick up a toy	
Caregiver	To have knowledge that there is a need to play with a disabled child ,it is not a waste of time.	
Caregiver	A child knows you better by playing with her	
Caregiver		

Recommendation for Module Four:

TRAINER

"It may be useful to group children, like in play, if you have partially sighted children, to do particular things with them, so you can really focus on specific disabilities, like the very bright, little people with Cerbral palsy, and their movement is limited, you'd work with them differently"

TRAINEE

"It needs to be made simplier I feel I needed another module on that."

"I would like to know how to teach children to play in a group, how to share ideas,toys. Many play

alone and it;'s important for them to communicate in a group."	

Evaluation worksheets :MODULE 4

Particpant	Positive Comments	Negative Comments
Caregiver	To learn to play with my blind child using different toys around me to talk to her	
Random Observer		Please don't' say deaf and dumb
Random Observer		Need to encourage more parents to attend as they are better teachers
Professional Observer	Discussion in the groups after the presentations	Some of the written charts could be confusing. Need simpler descriptions of the formats and as much practical demonstrations/experience as possible

Module Five:

Trainee	Positive Comments	Negative Comments
Teacher asst	"Now, if you open your own playgroup and don't have money, you can make toys. I learnt that easy toys that you make can help a child"	

	"Making toys is play for children, they learn, while they are making toys and they enjoy playing with them too, because they touch, smell, they stick they cut, so it teaches them a lot of skills.Also you learn not to throw anything away, it gives you new ideas on how to use materials that we meet everyday.	
Caregiver	A child can develop from those toys and you don't have to throw everything away	

Recommendation for Module Five:

TRAINEE:
"To learn how to make more complicated toys, if possible"
"I 'd like to add how to make chairs for the children, there are chairs that you can make with flour and paper, but I would like to be taught how to do that - perhaps a separate module"
"I think they should have included some hand work for the mothers to sell and get something

Evaluation worksheets :MODULE 5

Participant	Positive Comments	Negative Comments
Trainee		Perhaps to write down ideas and have as a hand out

Module Six and Seven:

Trainee	Positive Comments	Negative Comments
	"It was the most interesting module, doing the demonstrations. I learnt how to position a child who is stiff and one who is floppy and the importance of doing the correct thing because if you don't, the child can become more disabled."	
Teacher asst	"We learnt how to handle and feed them, but we knew most of the things because (the 2 trainers) have taught us these things before - it was more revision"	"We want more complicated stuff in exercising their bodies, since it was for the beginners and we aren't really beginners, we're more advanced"
Caregiver	I learnt how to position my child – I still have difficulties because my child is too strong and she fights me, but I won't give up	
Caregiver		We used teddy bears instead of other kids – that gave us a problem because the teddy can do anything you want.

Recommendation for Module Six and Seven:

TRAINEE:
"We want more complicated stuff in exercising their bodies, since it was for the beginners and we

aren't really beginners, we're more advanced. Exercise techniques ,like physiotherapy for teaches so you can touch the child and decide what exercise the child needs, because sometimes there are no physiotherapists around or she is too busy to help"

Evaluation worksheets :MODULE 6 AND 7

Participant	Positive Comments	Negative Comments
Caregiver	I learnt how to carry her on my back and talking to her	
Caregiver		I wish next time we can learn how we can help to prevent stiffness in our children
Trainee	The good thing is the demonstrations and practical advise	

Module Eight:

Trainee	Positive Comments	Negative Comments
Dental hygienist	"Wonderful, it motivated me to use music in my workplace so I am considering that in the future"	
Teacher asst	It was more theoretical for me – the dynamics of music is energy, that's the main point, and now I understand why we can use music - it gives us energy too. Also, after that module, I realised that the Zulu	

	culture is a very rich culture and we shouldn't diminish it and we should teach Zulu and English children both cultures -	
Caregiver	I learnt that music is very important and that it also helps in communicating	
Caregiver	When I got home I sang to my child and she was moving and smiling, showing that she liked it.	
Caregiver	My child makes some sounds when we are singing and she tries to move	

Evaluation worksheets :MODULE 8

Particpant	Positive Comments	Negative Comments
Trainee	Music really reaches all kinds of people and unifies them. I thoroughly enjoyed it	

Module Nine:

ATTITUDES TOWARDS THE TRAINEES BY THE TRAINERS:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Three trainers (provided	"Each individual, they felt it was	"I felt they were receptive, a lot of

professional content to the course) – A school psychologist, a speech therapist, child care worker(facilitator)	part and parcel of their problem,... but since they were here, they find out even those people who are so high up and trained, they have experienced some of these things, so it gives them some release"	them were taking notes, but I think if there weren't so many specialists, I think that restricted them to a certain degree"

ATTITUDE TOWARDS THE TRAINERS BY THE TRAINEES:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Dental hygienist	"Very professionally doing their things and doing their best". "Felt it was very professionally done, yet the people were approachable - very informal but professional"	
Teacher asst	"They are professionals in their field and they are very motivated and no-one force them to do extra work, but they do it because they seem to lie this work. But the impression is they are very motivated"	
Caregiver	We were trained well	
Caregiver		The lady who was teaching about looking after teeth didn't have enough time to teach us will

PERSONAL EXPERIENCE::

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Trainee - social worker	"It has changed me because I was from a school who didn't do much with disability. I now try to accept people who have disabilities and understand them as human beings. I couldn't just eat in front of a disabled child because of the food coming out of the mouth, but now I can tolerate that. I sit and eat and feed them"	
Trainee - dental hygienist	"It increases my tolerance level a lot, like sometimes I know with my own daughter, I not so patient but by doing this course, using for example music, jumping around with her, it makes her feel so much closer to me and me to her, then she's relaxed and I can go and do my thing." "My attitude towards disability, I wouldn't say it has changed as when you work with people, you tend to be more receptive and tolerant but it definitely increased my tolerance and acceptance.	
Teacher asst	It changed me a lot, before I used to, especially if I saw a disabled person, I used to get a fright, I felt	

	like running away - now if I see somebody who is disabled, I think how I can help - I feel stronger than before.	
Teacher Asst	My attitude towards disabled children didn't change much, but it did towards disabled children's' parents. Because I was with mothers and discussing it with mothers and then I realised that they want help and then we can help. I realised how little they know about their own disabled children, sometimes they don't know what is wrong with their child - he's just not normal, but he walks normal - and its amazing because the closest person doesn't know what to do with their child, so she comes to you and asks for help - so you must know, you must get a lot of knowledge, a lot of practice o help the mothers.	
Teacher Asst		"For me it's a challenge, to go out there and to help those who don't know, but it's only that I'm stuck, I don't know where to start. I'm willing to go out there, but I'm stuck"
Caregiver	I learned that a disabled person, a	

	child or adult, is a human being like us	
	I learned that disability can be caused by diseases not that you are born with it	
	I used to say shame when I see a disabled person asking myself what causes it – but now I don't say it.	
	I am able to visit people who have disabled kids.	
Facilitator	It is easy to say ,yes, I accept things and I can work with these kinds of disabilities, but its another thing when everything is laid on the table, to see whether you can eat this or not. My mind was opened and to know how, if I meet this kind of a child, I can do this and this and this. Yet before , in the past, I would wait for someone to ell me what to do, how to refer to the right person – so it has helped me	
Trainer	Keep it up, it's empowering us	

TIME FACTOR:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Trainee - Social worker		"I'm not sure what the trainees

		thought about the time, whether everything was covered in each module, but maybe time could have been increased"

"In the positioning, I know it took 2 modules, but you could see that not each and everyone got a chance to practise the skills, so I think it was a little rushed. |
Trainee:Teacher asst		'I liked the way they were running it but the problem was the time for us to log off work and then to come here in time"
Trainee:Teacher asst		Time is a bit short, maybe twice a month instead of once.
Trainee; caregiver		Time was too short, because by the time we have finished, we still want to ask some other things
Trainee; caregiver		If the time for trainer can be enough because some of them didn't have enough time
Trainer		Also one always runs out of time, but as a pilot - it was very positive and a nice selection of modules

Evaluation worksheets

Particpant	Positive Comments	Negative Comments
Trainee		We need more time , three

		hours is not enough for a person like me. At least six hours a month would be fine

VENUE FACTOR:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Teacher asst		The CDRC is too far for us, we didn't have anything to bring us here.
Teacher asst		To organise transport, like a mini bus to collect
Caregiver		We would like it to be moved because this place is too far
		I think the workshop needs to be held in central town

SUSTAINABILITY:

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Dental hygienist	I missed out on three modules, and feel very sad as the one's I missed were the main gest of the course and I would like to have make-up sessions" 'It was a wonderful learning expereince ,when I saw it in th newspaper, I was so excited and came over and each month looked forward to it. If there was an advanced course, I would be interested and my colleague would	

	also like to participate.	
Teacher asst	"I think I would miss this course because it was habit to go there once a month and I want them continued"	
Director/coordinator	After the modules they said it was useful and they were willing to continue training should it happen again in the future. The confidence they had after the training course and the improvement in the way they felt that they could help someone in their community. I saw just last week the graduation party we had. I saw people had grown enormously. Also the friendships that have developed through the course and the reassurance to the trainees that it would go on, was incredibly well received. The applause and the cheer when we said it's not going to stop. And those who don't have a certificate ,can come and catch up and that has given me enormous confidence that we can go on with a group of dedicated trainees, friends, CDRC helpers to	

	take the CDRC message further	
Caregiver	I wish this training can be taken further into coming years	

DESIRE TO SHARE KNOWLEDGE FURTHER:

Trainee	Positive Comments	Negative Comments
Caregiver	I would like to help other people outside	
Trainee	I think we must go out there and show other mothers its very easy to make your own toys at home and show them that you can save a lot of money	
Trainee	It can be a good idea to reach out to the community and teach parents without knowledge about ways of helping their children with disabilities	
Trainee	Let those who have knowledge reach out and help others who haven't got	
Caregiver	To tell other parents of disabled children to bring them to places like the CDRC	
Caregiver	It's important to pass what we've learnt to others who don't know	
Caregiver	We need to see other parents	

	who don't take notice of their children to stand up and do something	
Trainee	This course should be extended to outside parents who are having disabled children	
Caregiver	I would be happy if this can be passed to others	

APPENDIX C

Evaluative comments from focus group discussions
Mpophomeni

MPOPHOMENI EVALUATIONS:

GENERAL COMMENTS ABOUT THE OVERALL TRAINING COURSE:
The Mpophomeni committee was developed after the training course. It came out of the first outreach. We met Thandi and she became our Community outreach worker. I said " I can't make decisions for you, it is important for you to make decisions and with people in your community and that's how it developed. I think Thandi called from her trainees for people who would volunteer to come onto the committee. She has a small committee, Philile is the CDRC representative. I think she only has mothers of disabled children on her committee. What is planned for next year is that she does get some community leaders, teachers, clinic sisters, so it is more representative of the community and not just disability.

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS
Director/coordinator of the programme:	There was a huge difference between this course and the CDRC course	
Facilitator:		
Three trainers (provided professional content to the course) – A school psychologist, a speech therapist, child care worker(facilitator)		

COMMENTS ABOUT THE MANNER OF TRAINING

PARTICIPANT	POSITIVE COMMENTS	NEGATIVE COMMENTS /RECOMMENDATIONS
Director	We started off with applications and we selected 30 people and 25 people graduated from the course. It was a very different dynamic, we had 1 trainer, which was quite daring, but we selected Thandi to attend the CDRC to do her training. I oversaw it from a distance, reports wer brought to me, but everything was handled by Thandi. I think this is what held it, plus the fact that she was an inspired trainer and she had people visiting her home for extra training extra information. But it was community-based - trainees from the community. We first started (CDRC) with our moms, and I think they were very unclear, they came in and we had many professionals who were interested in the course and I think the moms did feel a little threatened, a little bit uncomfortable in this company in the early part of the course	

IMPRESSIONS OF THE SPECIFIC CONTENT OF THE MODULES:

Module One:

Caregiver	Positive Comments	Negative Comments
	I learnt what disability was all about.	
	I learn how you get a disability, that alcohol or unhealthy food can cause it	
	Not to use drugs if you are pregnant	
	Not to believe in witchcraft or that you inherit it or that it is somebody's fault	
	That to immunize your child can cause it	

Recommendation for Module One:

What causes a normal person to be disabled I needed to know

Module Two:

Caregiver	Positive Comments	Negative Comments
	As a mother of a disabled child I used to be rough on my child, but I learn to accept her and to be nice to her.	
	I learn how to look after her	

	As a disabled person, I felt accepted by the community	
	I learn not to leave my child inside or hide her but to involve her in the community	

Module Three:

Caregiver	Positive Comments	Negative Comments
	I learnt how to communicate with the deaf or blind	
	I learnt to talk to my child whenever I do something	
	I learn that it is not difficult to communicate with the disabled	
	As a disabled person, I learn to communicate with a normal person	

Recommendation for Module Three:

Sign language should be included

Module Four:

Caregiver	Positive Comments	Negative Comments
	I learnt that I can play with a disabled child and not to hide her	
	For a disabled child to play, it helps for her to develop	

	Not to force a child to do something	
	A disabled child needs to have her own time.	
	You need to clean them and make them smell nice	

Recommendation for Module Four:

"We were suppose to have the disabled children present .just to see them and to practise"   "We would like to see those centers where the disabled children are"

Evaluation worksheets :MODULE 4

Participant	Positive Comments	Negative Comments
Trainee	We must be more serious about this course so that we will be able to help the disabled after all	
Trainee		More Trainers for this course
Trainee	Our trainer is very good in teaching and explaining clearly to us	
Trainee		We would like to learn all this practically
		I would like to see different kinds of disabled children

Trainee	I suggest we start a day care center at Mpophomeni	

Module Five:

Caregiver	Positive Comments	Negative Comments
	You don't need to go to the shop to buy toys, but you need to make them	
	I learnt what kind of toys you make for a different disability	
	You don't have to throw away the waste, you can use some of it	

Recommendation for Module Five:

We need more skills in learning how to make toys

Evaluation worksheets :MODULE 5

Participant	Positive Comments	Negative Comments
	To keep things like cooldrink 2 litres because we can use it to make toys	
		We would like to see a disabled child involved in our training
		I want to do what we learn with children practically
		We'd like to have a disabled

		day care center
		We'd like to visit disabled institutions

Module Six and Seven:

Caregiver	Positive Comments	Negative Comments
	I learnt that you don't have to put a child in one position or to put a child where there are no surroundings	
	How to carry a child in a proper way and how to put her when changing the nappy or feeding her	
	To massage a child each time you change her	
	To hold a child in a good position can stop the damage to be worse	
	I liked that the physiotherapist visited our center to show us exercises	

Recommendation for Module Six:

'I was hoping that a disabled person to be present when we were told about self help"

"We were hoping for a practical thing especially the children

Evaluation worksheets :MODULE 6 /7

Participant	Positive Comments	Negative Comments
		To have different kinds of

		disabilities for training
		We need to make things like special chairs for our children
		To do things practical in order to base it in mind
		Its much clearer to learn something in front of us, like disabled children, special chairs, standing frames etc.
	It's very good to have people like Kari to come and help us with our training	
		We need to learn to help a child who can't swallow
	The worst thing is using dolls for our training	

Module Eight:

Caregiver	Positive Comments	Negative Comments
	I learnt that music can relax the muscle of a stiff child	
	Il earn that you play a different music according to the disability	
	You can communicate with your child through music	
	The guy who was showing us	

	was great	

Recommendation for Module Eight:

I wanted to see the stiff and floppy child present while playing music to see exactly what does music do

Evaluation worksheets :MODULE 8

Participant	Positive Comments	Negative Comments
		We need a day care center because of our skills
		We need another music workshop
	I learnt to play music to give love and hope	We need more play therapy workshops
	Music can be used as an energiser	

PERSONAL EXPEREINCE / ATTITUDE CHANGE:

Caregiver	Positive Comments	Negative Comments
	I used to ignore a disabled person but I communicate with them	
	I used to feel sorry for them but now I accept them	
	As a disabled person, I feel accepted in the community after this	
	I used to hate eating in front of a	

	disabled person	
	I got rid of the fear to help a disabled	
	You can have an affair with a disabled, they can love and have relationships	

VENUE:

Caregiver	Positive Comments	Negative Comments
		The place was fine but as a disabled person I had a problem with the door, it was too tight for me
		The place was too small and we were disturbed by those people who were in and out
		We need a bigger room for training

TRAINING

Caregiver	Positive Comments	Negative Comments
		Our trainer was teaching us in Zulu but we will have a problem if we go and work somewhere else
	Our trainer was very patient with us	
	Having a break in between sessions was good	

Recommendation for overall course:

We would like to see all different kinds of disability to be present at all the sessions.

We would like to visit the centres