PARENTAL PERCEPTIONS OF FAMILY - CENTERED CARE /INTERVENTION FOR CHILDREN WITH DISABILITIES

By

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ABSTRACT

This study examined the dimension of family-centered intervention for children with disabilities using the measures parental perceptions of care and its relationship to parental satisfaction and goal achievement.

The sample consisted of 79 parents of children with disabilities of the total (272) caseload who were enrolled in Cheshire Community-Based Rehabilitation (CBR) program. The children ranged in age from 1.75 to13.75 years, the mean chronological age of the children was 4.16 years and <u>*SD*</u> *= 2.28.*

All of the children had disabilities, out of which 45.57% had developmental delays. Three measures including the Measure of Processes of Care (MPOC), Clients Satisfaction Questionnaire (CSQ-8) and Question on Goal Achievement were administered.

The findings support the hypotheses that when parents perceive the intervention program as being family- centered they are more likely to satisfied with care and perceive their goals as being met, and have positive attitudes toward the care.

CHAPTER ONE

1. Introduction

1.1 Background of the Study

With the global human rights movement becoming prominent, many changes have followed in the filed of disability rehabilitation. These included the "Independent Living Movement" which supported the concept of "empowerment" of persons with disabilities and the planning of interventions directed at the community where persons with disabilities lived. The main objectives of Community-Based Rehabilitation (CBR) movement among others are: the enhancement of the daily-life and activities of persons with disabilities, the creation of awareness in the community of equal rights and the potentials of persons with disabilities, the provision of barrier-free environment, the utilization of local resources as well as the active participation and inclusion of persons with disabilities in the community (Thomas & Thomas, 2001 cited in Tirussew, 2005).

Along this line, one of the most fundamental changes in the health care system during the past twenty years is the shift from expert-oriented care to one that seeks to involve clients' families in ways that are respectful and supportive (Ahmann, 1994; Letourneau & Elliott, 1996; Wharf, 1992).

In the traditional focus of early childhood intervention it was the role of the therapist to identify the areas of difficulty for children with special needs and to develop a treatment strategy based on this information. While family participation was crucial to the success of such an endeavor, the family typically assumed a relatively passive role in the family-professional relationship. To address the imbalance in this relationship, family- centered intervention is now being used by many Community-Based Rehabilitation (CBR) practitioners and health care professionals.

Family-centered care focuses on the family that is described as comprising of interdependence of members (Dunst, Trivette & Deal, 1994). They stated that if a family is strengthened and supported, they will be better able to meet their needs as well as their child's needs. The help-giver takes a proactive approach that promotes and enhances already existing family strengths. In other words, a partnership is formed allowing the family to identify their needs, strengths and resources, and the family and caregiver together decides what is necessary to promote positive changes in the function of family and the caregiver decides what is necessary to promote positive changes in the function of the family and the care of the child.

Dunst, Trivette, Davis and Cornwell's (1988) study illustrated that if service providers (health care professionals) use the attitudes, beliefs and behaviors that are consistent with family-centered care, families will be empowered and positive outcomes will result from the care they receive. The families sensed more control over the care of their children and were able to engage in the therapeutic process more fully. Branspach (1986) found that when parents perceived control over their children's program activities, they felt more satisfied with the therapy programs. Bass and Leavitt (1963) and Latham and Locke (1979) showed that when professionals set goals collaboratively with clients, goals could be successfully met.

In Ethiopia, the advent of the idea and importance of early psycho-social intervention gained impetus in the beginning of the last decade. In 1989, early intervention for psycho-social development of infants and young children was jointly initiated by the Department of Psychology, Addis Ababa University and Centre of International Health University of Bergen, Norway. The early psycho-social intervention program was based on the principles of medicated, learning experience which focuses on the identification and enhancement of caregiver adult-child interaction (Klein et al., 1987 in Tirussew, 2005). Child-focused international and local organizations operating in the country expressed increased interest in different types of early intervention programs, particularly in early child care and development. Around the same period, local non-governmental organizations, (e.g., Cheshire Services Ethiopia /Cheshire Home Foundation) started to emerge with CBR programs and thus brought a momentum for undertaking home-based, school-based and community-based early intervention programs in the country (p. 33).

The literature on family-centered care/service provision indicates that there may be a number of barriers to the implementation of family-centered care/ services, including terminology used by professionals, the inability of service models to incorporate parents' views, and parents' lack of skills or information of how to become involved (Arango, 1990; Brown, Pearl, and Carrasco, 1991). Even though a system, in this case, a children's rehabilitation agency, may set out to provide services according to a certain model, outcomes may or may not reflect the principles of the model.

This paper has presented the theoretical, experiential and exploratory background of a family-centered care/intervention to delivering services to children with disabilities and their family. A family-centered care is grounded in the research and theories of social system and an ecological paradigm and shares many of the values and principles of early intervention and family support programs. Specific implications and application of the key components of a family-centered guided model, principles and values, focusing on relationship, parental satisfaction and goal achievement and linkages would be explored and discussed in-depth in this study.

1.2 General Statement of the Problem

Around the world, too many young children experience developmental health problems due to poverty, prematurity, low birth weight, infectious diseases, exposure to toxic substances, and other risk factors. Children with established disabilities, such as an autism spectrum disorder, motor disability, communication and language problem, behavior disorder, or hearing and visual impairments, also need early and swift support. For all of these children and their families, co-occurring environmental threats or limited caregiving abilities often further compromise growth and development (Mickael Guralinck, 2007).

Providing effective early intervention programs for vulnerable children and their families constitutes one of the most important challenges for contemporary societies. State-of-the-art intervention requires the contributions of specialists from many disciplines, the construction of programs that are firmly rooted in biomedical and behavioral research, a program development component that is capable of incorporating emerging research findings, and advocates and administrators to ensure that funding, personnel, and related resources and policies are available and consistent with the knowledge base and goals of early intervention (Mickael Guralinck, 2007).

In Ethiopia, both governmental and non-governmental service providers respond to the needs of children with disabilities. Among the millions of the children with disabilities, however, only very few have access to treatment centres. Community-Based Rehabilitation (CBR) Centres, operating through non-governmental organizations (NGOs), have started door-to-door, home-based early intervention programs. But the vast majority of children with disabilities in the country do not have access to such services. They either engage in begging and looking for alms or live out of public view. They constitute the poorest of Ethiopia's poor. Also, it is uncommon to find in the urban centres people (children) with out disabilities who generate their daily income by having individual with disabilities beg for alms. This can be referred to as "double dependency syndrome" (Tirussew, 2005).

Several researches have affirmed that this serious problem could be solved using family-centered care/intervention model. The use of family-centered care model in programs designed to help families with children who have special needs has been associated with outcomes such as accelerated rates of progress by children, acquisition of skills by parents (Care & Derevensky, 1991), and empowerment of families (McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993) as well as increased parental satisfaction (Cleary & McNeil, 1988; Styba, Ellaschunk, Jesse & Cote, 1992). The family-centered model of intervention includes focusing on needs that are of direct concern to families. By taking this focus into account, interventionists can develop a trusting and collaborative relationship with families and assist them in achieving their goals (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell & Helm, 1986; Garshelis & McConnell, 1993). The literature suggests that when the family-centered care model is used, family goals can be successfully achieved (Adubato, Adams & Budd, 1981; Dunst & Trivette, 1987; Schriebman, O'Neil & Koegel, 1983).

In general, this study is aimed at highlighting the need to work within family-centered context, and ensure that parents are fully aware of how the information will be used. and how this information can help identify family strengths and needs in order to design appropriate service provision policies and programs.

To this end, in this study I looked at the relationships between three variables: parents' perceptions of the extent to which the care they receive is family-centered; parental satisfaction with the program; and parents' perceptions of their goals being met in attending the CBR Program. The literature suggests a positive relationship between the family-centeredness of a program, parental satisfaction, and goal achievement. None of the relationships has been studied extensively in Ethiopian context, but the literature supports continuing research in this area.

Research Questions

Grand Tour Question

"Do parents of children with disabilities (who have long-term health care needs) perceive the practices of Cheshire Services Ethiopia-CBR Centre's program as reflecting the family-centered care/intervention philosophy and principles?"

Sub-questions

1. Will parental perceptions of care received in attending the Cheshire Services Ethiopia-CBR/Intervention program, facilitate family-centered care model as measured by the Measures of Processes of Care (MPOC) using an 8-point rating scale?

2. Will parental perceptions of care received in attending the **Cheshire** CBR/Intervention program as measured by the MPOC be positively correlated with level of satisfaction with the CBR program as reported by the parents using the Measure of Satisfaction/Client Satisfaction Questionnaire (CSQ) using a 4-point rating scale?

3. Will parental perceptions of care received in attending the **Cheshire** CBR program as measured by the MPOC be positively correlated with parental perceptions of Goal Achievement as measured by a Single-Question using a 7-point rating scale of Goal Achievement?

1.3 Purposes of the Study

The study was designed to provide useful information to the practitioners of the family-centered care/intervention who work directly or indirectly with children with disabilities and their families, managers who direct children's treatment centres/institutions/agencies and programs, and policy-makers who make decisions about program and funding strategies. More specifically, the purpose of this exploratory study is to determine from the parents involved with the Cheshire Services Ethiopia-CBR/Intervention Projects/program how well the family-centered care/intervention model facilitates the provision of family-centered services/care coordination, as perceived by parents of children with disabilities (long-term health care needs). Accordingly, the central purposes for this examination of family-centered care/intervention strategies for children with disabilities are as follows:

1. To describe innovative, effective family-centered care/intervention programs and strategies for serving young children and their parents/families and contributing to assuring that participants(clients) are prepared for success when they enter elementary or higher schools,
2. To analyze key factors in the design and implementation of family-centered care/intervention programs,
3. To describe how .agency policies support or inhibit successful management and front-line service strategies, and
4. To provide recommendations to the practitioners, managers, and policy-makers of family-centered care/intervention on how to create more high quality programs.

1.4 Significance of the Study

The researcher would begin the study with conviction that better understanding of family-centered care model, policies and principles can improve the lives of children with disabilities, their families; enhance support for and ease the burdens on the practitioners and contribute to stronger families and communities. The researcher believed that this study contributes to a more complete, balanced, and grounded image of how family-centered intervention model programs work in the present policy structure. And the researcher also believed that more accurate understanding of the interplay of agency funding and policies, programs, local management, staff capacity and motivation, and responses of families and communities will lead to more constructive and successful agency policy and program formulation and implementation in accordance with the model, principles and values of family-centered care. The researcher trusted that wider appreciation of the diversity of the family-centered service consumers' community, the subtleties of practice, and the dynamic effects of policy, program and management will lead to renewed efforts to help young children with disabilities develop to their fullest potential. In specific, the significance of the study is as follows:

1. It helps:
   - to enhance the child's development (i.e., strategies to promote child development),
   - to provide support and assistance to the families (i.e., strategies to Serve and involve families),
   - to maximize the child's and family's benefit to society, and
   - to policy effects in local agencies.
2. Since a study of this kind is scanty (probably none) it would contribute to the existing literature at least in Ethiopian context.
3. The study would help as a stepping stone for those interested in the field and for those who would like to make an in-depth study.

1.5 Limitations of the Study

The limitations of the study are as follows:

1. Care must be taken when generalizing these results to other situations because they are based on a single program.

2. Since only self-report instruments were used to measure the variables studied the results are representative of the cognitive and emotional state of the respondents at the time of completion of the measures.
3. This is a correlational-survey study so that only descriptions of relationships can be made. No causal inferences can be made.
4. Even though data were collected from nearly half of the total caseload in urban setting in a relatively medium demographic area, care must be taken when generalizing these results to rural setting..

1.6 Delimitation of the Study

It is difficult for the student researcher to make an extensive study of all the Cheshire Services Ethiopia (CSE) - CBR where the CBR are found throughout Ethiopia- in the cities of eight Administrative Regions. It is also found unmanageable to the student researcher in terms of finance, effort, time and the wide geographical location of the CSE-CBR in the country. Further, it would be cumbersome to include the total caseload of the CSE-CBR program from these wide geographical areas in the study. Thus this survey study is delimited to one of the CSE-CBR of Addis Ababa branch, four sub-cities: Kolfe Keranio, Addis Ketema, Gulelle and Arada sub-cities.

1.7 Operational Definition of Key Terms

Parent: Biological parent, a common law spouse, or legal guardian such as a foster parent, adoptive parent, step mother or step father of a child.

Family: A primary group whose members assumes certain obligations for each other and generally shares common residences. Child care and child socialization, income support, long-term care, and other care-giving are among the functions of family life (Barker, 1995).

Family-centered philosophy: Recognized that the family is central in a child's life and should be central in the child's plan of care. Family-centered care embraces diversity in family structures, cultural backgrounds, choices, strengths, and needs. The philosophy of family-centered care calls for partnership between parents and professionals that support parents in their central caring role (Ahmann, 1994).

Family-centered care: Family-centered care is the name of a set of beliefs, attitudes, and principles which have been applied to the care of children with special health care needs and their caregiving family. The philosophy of family-centered care is based on the promise that the family is the enduring and central force in the life of a child, and has a large impact on his/her development and well-being (Bruder, 2006).

Rehabilitation: The field of rehabilitation is a broad one indeed. The United Nations World Program of Action Concerning Disabled Persons (1983), adopted by the U.N General Assembly in December, 1982, cited Sharon and Roy (1992), defines the term as follows: Rehabilitation means a goal-directed and time-limited process aimed at enabling an impaired person to reach optimum mental, physical and/or social functional level, thus providing her of him with the tools to change her or his own life (p.3).

Intervention: The term "intervention" is used here in a generic sense to define any program or activity prescribed for a child on the basis of assessment results. Intervention thus encompasses treatment and habilitation/rehabilitation activities in clinical/medical, as well as educational, settings. Frequently used terms for treatment therapy or intervention, such as "Individualized Family Service Plan (IFSP)", "Individualized Program P lan (IPP)," "Individualized Education Plan (IEP)," "Individualized Habilitation/Rehabilitation Plan (IHP or IRP)," are used interchangeably. (Bjorck-Akesson, Granlund & Simeonsson, 2000; Simpson & Fiedler, 1989; Turnbull & Turnbull, 1990 cited in Rune & Susan, 2001).

Early Intervention: refers to a set of actions that has the intent or effect of altering the course of, coming between, or interrupting future activities or process (Haggerty et al., 1996 in Tirussew, 2005). More specifically, early intervention is an attempt to prevent or minimize the physical, cognitive, emotional, and resources limitations of young children with biological or environmental risk factors (Blackman, 2003 in Tirussew, 2005).

Family-Centered Practice: Family-centered practice is based on the premise that children's abilities to learn and develop are "inextricably intertwined" with the strengths, needs, and philosophies of their parents and other families members. A guiding principle of family-centered practice is the belief that parents are the experts regarding their family's needs and priorities (Singer & Powers, 1993). An equally important principle is that families who have a member with a special need or disability have more in common with families who do not have a child with special need or disability than they have differences (Mahoney, O'Sullivan, & Robinson, 1992).

Health Care Needs: An infant, toddler, or child aged 0-6 years who has been identified to benefit from pediatric rehabilitation services due to prematurity, or a congenital or acquired condition.

Person /Child with Disability: The definition of eligibility for Disability Support Services assistance used by Ministry of Health, New Zealand (1998, p.28 cited in Trevor & Pat, 2001), states:

> A person with a disability is a person who has been identified as having a physical, psychiatric, intellectual, sensory, or age-related disability (or a combination of these)which is likely continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.

CHAPTER TWO

2. Conceptual Framework and Literature Review

2.1 Conceptual Framework

2.1.1 Family-Centered Care

The model of family centered intervention that is used in this paper is that of Dunst, Trivette & Deal (1994). The model is based on two theoretical perspectives: *Human Ecology Theory* and *Social Systems Theory*. *Social Systems Theorists* postulate that, "different social settings and their members are interdependent, and that events and changes in one unit reverberate and produce changes in other social units" (Dunst, Trivette & Deal, 1994, p.2). The family is viewed as a growing and always changing social unit that has its own structures, resources, functions and interactions (Bailey, 1987). Social systems theory sees the goal of intervention as being to identify family needs, to locate the resources and supports for meeting these needs and to help families use existing capabilities as well as learn new skills in order to mobilize needed resources (Dunst & Trivette, 1987) with in the family's own system and social context (Bailey, 1987). This form of intervention helps a family to be more competent and better able to mobilize resources, which leads to family empowerment (Dunst, Trivette &Deal, 1994).

The major focus of family-centered assessment and intervention is to empower families to make them more competent and better able to mobilize resources. Researchers have indicated that family-centered assessment measures in an intervention program provide information on the family's resources, priorities, concerns, and unique characteristics, identify the programs and services that would be most beneficial to children with disabilities and their families, help professionals evaluate the effectiveness of their intervention, ensure that the intervention program (e.g., IFP/IFSP) accurately reflects family goals, help in the evaluation of services, and ultimately lead to greater benefits for the child (Bailey & Simensson, 1988; Dunst, Trivette, Davis & Cornwell, 1988; Garshelis & McConnell, 1993; Olson & Kwiatkowski, 1992; Whitehead, Deiner & Toccafondi, 1990). Three conditions need to exist for empowerment to occur (Dunst, Trivette & Deal, 1994). First, the health care giver must believe that people are competent or have the capacity to be competent. Second, enablement must be fostered, which refers to creating opportunities for competence to be learned or displayed. Third, family members must be able to attribute their behavior change to their own actions in order to acquire a sense of control necessary to manage family affairs. Thus the empowered family will be able to exert influence on its social and environmental situation in a manner that will be beneficial.

Shelton and Stepanek (1995) list eight elements of family-centered care which include:

- family is the constant;
- coping and support is tailored to the family;
- peer networking is encouraged and facilitated;
- families are appreciated as families;
- information is exchanged in a complete and unbiased manner;
- family diversity is recognized (e.g. ,cultural);
- family-professional collaboration occurs at all levels of care; and
- services are supportive, flexible, accessible and comprehensive.

A review of the literature conducted by McBride, Brotherson, Joanning, Whiddon and Demitt (1993) revealed three major principles of family centered practice that is believed to encompass current values and practice. These are:

1. Establishing the family as the focus of services. The concerns of all family members should be the basis or establishing intervention outcomes, and

the strengths of all family members should be considered as resources for implementing interventions.

2. Empowering families to make decisions regarding their child and family. This fosters their sense of control and provides a basis for partnership in parent-professional relationships.
3. Providing services that strengthen the family's ability to meet their needs and those of their child. This is accomplished by providing support that enhances and promotes family capabilities and family functioning.

Bronfenbrenner's (1979) theory of ***Human Ecology*** stresses the importance of looking at the growing person, the changing environment and the interaction between the two. The family is seen as constituting the ecological context in which the child functions (Bailey & Simeonsson, 1988). Each family is embedded within other larger systems in society, such as neighborhoods and social attitudes, and these systems are mutually interdependent and influence one another (Bailey, 1987). All of these systems need to be considered in order to understand the family's roles and their ability to function. The child is seen as a part of the family system and the child both influences and is influenced by the family (Bailey, 1988).

The approach to helping grows out of the premise that human beings can be understood and helped only in the context of the intimate and powerful human systems of which they are a part (Hartman & Laird, 1983). From the *Ecological Systems Theory* (Germain & Gitterman 1980) point of view, the primary mission of the family-centered practitioner is the enhancement of the quality of life and the adaptive balance between human beings and their ecological environments (Shelton, Jeppson, & Johnson, 1989). As Shelton and Stepanck (1995) noted earlier, the 8 key elements of family-centered care, identified by these authors also reflect this view:

1. Recognition that the family is the constant in the child's life while the service system and personnel within those systems fluctuate;

2. Facilitation of parent/professional collaboration at all levels of health care;

- care of an individual child;
- program development, implementation, and evaluation and
- policy formation;

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner;
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families;
5. Recognition of family strengths and individuality and respect for different methods of coping;
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems;
7. Encouragement and facilitation of parent-to-parent support;
8. Assurance that the design of the health care delivery system is flexible, accessible, and responsive to family needs (p. 71).

A ninth element was added in 1992 by the family-centered care committee of the Eastern Canadian site (Letourneau & Elliott, 1996).

9. Implementation of appropriate policies and programs that are comprehensive and provide emotional support to meet the needs of staff.

The first eight elements are likewise described by others (e.g. Brown, Pearl & Carrasco, 1991; Cormany, 1993; Korteland & Cornwell, 1991; Mahoney, O'Sullivan & Dennebaum, 1990).

King, Rosenbaum, Law, King and Evans (1997) condense the same principles into three basic assumptions:

1. Parents know their children best and want the best for their children.

2. Families are different and unique.
3. Optimal functioning of family members occurs within a supportive family and community context; all members are affected by the stress and coping of other family members.

Parents know their Children best and want the best for their Children

The first premise promotes the view that parents are competent in caring for their children. Pecora, Whittaker and Maluccio (1992) state that, "parents and children are regarded as active and striving human organisms who are basically motivated to grow and achieve competence" (P. 51). The premise reflects the values of the client-centered approach, or humanistic theory, as described by Carl Rogers, among others (Rowen, 1986). This is a shift away from emphasizing pathology or deficits when dealing with families, which is still prevalent in health care (Ahmann, 1994; Brickman, Rabinowitz, Kazura, Coates, Cohn & Kidder, 1982; Fiene & Taylor, 1991; Mahoney, O'Sullivan & Dennebaum, 1990).

Power in decision-making becomes an issue under the premise of competence. Delaney and Weening (1995) write about the need for organizations to develop partnership models with parents. In a collaborative partnership, all partners exercise power in the decision-making process. The collaborative partnership involves polling of resources, information and labor to meet shared objectives. It means working with groups and/or individuals who bring insight and experience to the table (Barter, 1996; Delaney & Weening, 1996). This is in line with the shifting paradigm from what Schriver (1996) refers to as binary or competing and oppositional terms, such as "we-they", to cooperative and inclusive terms, such as "us".

According to Yjosvold's interdependence model of collaboration, as described by Barter (1996), four key elements are a prerequisite to a successful collaborative effort:

1. common wishes and goals,
2. shared values and attitudes,
3. joint tasks and rewards,
4. fair distribution and exchanges.

The collaborative model is compatible with the key elements of family-centered practice principles in that collaboration is expected to take place on all levels of intervention, from worker-family to administrative levels. Sharing of power and resources, mutual problem-solving and operating from a common value base are features of a collaborative framework that fit with a family-centered practice (Barter, 1996; Shelton, Jeppson & Johnson, 1989).

The goal of family-centered practice is to assist participants to develop knowledge, attitudes and skills to be effective as parents. The family becomes an equal partner in the service provision network, and is treated with *respect* and dignity (Cardoso, 1991). Proper information enables parents to participate in the decision-making process (Hartman & Laird, 1983).

Dunst, Trivette and Deal (1988) provide a description of help-giver and help-seeker activities based on Brickman's helping Models (Brickman et al., 1982), expanding to an Enabling Model, which de-emphasizes help-seekers' responsibility for causing problems, and emphasizes help seekers' responsibility for acquisition of competencies necessary to solve problems, meet needs, realize personal projects and attain desired goals (Dunst, Tivette & Deal,1988). The services provider experiences a shift in his/her role from an expert to an ally who enables the family to articulate what they need (Kalyanpur & Rao, 1991). Letourneau and Elliott (1996) summarize the key elements of family-centered care as those that promote self-determination, decision-making capabilities, control and self-efficacy. All these components reflect an enabling rather than a medical model of helping.

Families are different and unique

The second premise states that families are different and unique (King et al., 1997). The very definition of family changes over time with changes in family structures in society. Family-centered care embraces diversity in family composition, cultural backgrounds, choices, strengths and needs (Ahmann, 1994; Johnson, 1990; Harthman, 1992; Letourneau & Elliott, 1996; Shelton, Jeppson & Johnson, 1989).

Schriver (1996) claims that, the traditional and dominant world view is shaped by "the dimension of whiteness", which is defined by patriarchal/masculine values. Public decision and policy-making arenas are controlled by these values, also referred to as Eurocentric. Alternative Paradigms offer a view that is based on the inherent worth and dignity of all humans, recognizing especially the benefits of human diversity.

Hardy and Laszloffy (1994) address two issues related to diversity. The language and terminology used by professionals tends to be based on the dominant white middle class societal values. Secondly, professionals tend to marginalize issues related to race, gender preference, or other issues of diversity. The authors add that two major movements, the postmodern and the multicultural movements, offer a potential challenge to the Euro-centricity.

The feminist view parallels the family-centered model as it promotes diversity, creativity, alternative views and personalized outcomes. The emphasis of intervention is more on the process than the end result (Korin, 1994; Wheeler & Chinn, 1991). Korin (1994) elaborates on the ways in which the larger context of social inequalities contributes to an imbalance of power in therapeutic relationships. She discovered in her clinical practice that she inadvertently encouraged dependency, or "chronic patient hood", among those who live within a continuous cycle of oppression. She used Freire's ideas (as in Korin, 1994) about critical consciousness to educate her clients. The goals of the therapist was to demystify knowledge, eliminate arguments based on authority, and generate a redefinition of hierarchies of power in clinical relationships, allowing the client to be active and exercise control over the process. The use of similar principles is an absolute necessity when dealing with families of children with disabilities, in order to implement family-centered principles.

Schriver (1996) states that "inclusive perspectives allow us to more readily gain access to and understand the strengths of others" (p. 57). The strengths perspective is consistent with a collaborative model, and compatible with the family-centered principles. Saleeby (in Schriver, 1996) lists six basic assumptions that guide a strengths perspective:

1. Respecting client strengths,
2. Clients have many strengths,
3. Client motivation is based on fostering client strengths,
4. The social worker is a collaborator with the client,
5. Avoiding the victim mind set, and
6. Any environment is full of resources (pp. 58-59).

Dunst, Trivette and Deal (1988) define certain qualities associated with family strengths. They categorize them in two major themes:

1. Family strengths and capabilities represent intrafamily resources that are often mobilized as one way to meet needs.
2. Family strengths and capabilities are the competencies that families employ to mobilize or create extra-family resources (p. 26).

Families accomplish the above in their own unique way, depending on their qualities and their own functioning style.

Optimal functioning of family members occurs within a supportive family and community context

The third premise emphasizes the importance of the support of family and community to the optimal functioning of the client. Shelton, Jeppson and Johnson (1989) state that, family-centered care goes beyond the child's health care needs. It strives to recognize and to promote healthy family functioning by enabling the child and family to meet normal developmental tasks. These include the ability to maintain employment, normal social relationships with relatives, friends and neighbors, normal routines, and to have the family members' needs met, including the individual with disabilities, through normal, generic programs (Slater & Wikler, 1986).

The Family Systems Theory proposes that family members need to be physically and mentally healthy to be able to take care of the children in the family. For that reason, the intervention in the family-centered approach does not necessarily need to be directed towards the identified child in order to be beneficial (Rolland, 1988).

The impact of the chronicity of a child's condition is felt by the entire family. The family members may experience increased amount of stress, social isolation or financial strain (Bernier, 1990; Kazak, 1986; Marchenko & Smith, 1992; Rosenbaum, 1996; Slater & Wikler, 1986). The lack of ability to function spontaneously as a family unit is one of the major issues for families who have a child with long-term health care needs (Diehl, Moffitt & Wade, 1991; Fiene & Taylor, 1991; Jackson, Finkler, & Robinson, 1992; Marchenko & Smith, 1992; Slater & Wikler, 1986). Marital difficulties and issues with sibling adjustment are common, and caregivers struggle to balance their time between the demands brought about by the illness or disability and the needs of other family members.

Bernier (1990) postulates that families experience recurrent grief and crisis. He states that their ability to manage the circumstances depends on the supports available, coping abilities unique to the family, and on the nature of the disability.

The family itself is a natural helping system and an instrument of change (Hartman & Laird, 1983). A family shares specific characteristics with all other type of systems: for instance, every member of the family plays a part in the working whole. If one member of the system is affected, it has an impact on all other members of the system (Brown, Thurman, & pearl, 1993). The impact of a child's disability or illness on a family can be examined through the Family Adaptation Model (Patterson, 1988).

Interventions are directed towards establishing a balance between the demands on the family and its adaptive capabilities. The demands are created by stressors, such as an initial diagnosis or normal events in the life cycle, such as starting school: and strains, which are accumulating demands, associated with the disability, such as financial problems, day-to-day care giving stress, etc. Adaptive capabilities are comprised of resources (personal and family and community system) and coping abilities. A practice based on family-centered principles regards human problems, needs, and conflicts as adaptive tasks providing the client with opportunities for growth, mastery, and competence development (Pecora, Whittaker & Maluccio, 1992).

The family's ability to assist a child who has disabilities (long-term health care needs) depends on the internal coping mechanisms of the family, as well as on the formal and informal resources and supports available to the family (Bernier, 1990; Knoll, 1992; Pecora, Whittaker & Maluccio,1992). The shift in service planning over the past decade or so has been from expert provided services to accessing community resources and encouraging family-to-family support (King et al., 1997; Knoll, 1992, Winton & Bailey, 1997).

2.1.2 Perceptions of Care

Parent involvement is a key component in empowering parents and returning to them a sense of control over the outcome of their child's life (Dunst et al., 1988). To actively involve parents it is necessary to understand and respond to their needs. Parents and families have needs and resources that directly affect the functioning of their children (Mahoney, O'Sullivan & Dennebaum, 1990). When programs provide services that deal directly with family needs and resources, children and families benefit the most from the program (Dunst, 1985). Parents need to be given the opportunity to give feed back on all aspects of program delivery.

Maddison (1977) stressed the importance of seeking the opinions of health care consumers and believed that parental opinion is important since it reflects the care that their child received. Ledwith (1988) stated that consumer surveys are useful and emphasized looking at more than just consumer satisfaction. King, Rosenbaum and king, (1995) also supported consumer input and felt that measuring parents' perceptions of care-giving is a useful method of evaluating activities to improve services. Bailey, Buysse, Smith and Elam (1992) also stated that perceptions of consumers are essential and they explored two barriers to consumer involvement. First many professionals may resent parental viewpoints since they feel that decisions related to programming are ultimately theirs. Secondly, health care professionals may feel that consumers have inadequate knowledge to participate in this process.

The shift to a family-centered approach warrants the assessment of parental perspectives on services for their child and their family (Able-Boone et al., 1990). Able-Bonne et al. (1990) provide two rationales for acquiring parental perspectives on early intervention services. First, they state that studies have shown that parents wants to share their perceptions to services rather than have professionals make assumptions about whether their families' needs were met. Second, they state that parents' views on the best implementation strategies are required to ensure that effective services are offered.

Other studies used quantitative research methodologies to examine parental perceptions of care in early intervention programs. Mahoney, O'Sullivan and Dennebaum (1990) used the Family-Focused Intervention Scale with 503 mothers who had handicapped children ranging in age from birth to 6 years. Mothers who received high levels of family-centered care reported significantly greater benefits from the intervention. The findings also indicated that programs with home-based components had a substantially greater family-orientation than programs that were primarily centre-based. Parents expressed their greatest needs as learning how to utilize the early intervention system and identifying other community resources to assist them in the care of their children. Trivette, Dunst, Boyd and Hamby (1995) found that sources of variation in 208 American parents' assessment of help-giving practices and their personal control appraisals were related to differences in program models and not parent or family characteristics. Rating scales were used to identify the program model used. Program models included professionally-centered family allied, family-focused, and family-centered. The family-centered model was considered to be more effective and resulted in more parental control of their children's care.

Similar results have been found by studies examining parental perceptions of care received while their children were in hospital-based programs and habilitation centres. Ball, Glasper and Yerrel (1988) used a questionnaire to look at many aspects of pediatric nursing care. They showed that parents' perceptions of receiving adequate information and evaluating staff as being competent related strongly to their respect for clinical staff. Similarly, Baine, Rosenbaum and king (1995) measured 22 components of care perceived as important by 213 Canadian parents of children with long-term disabilities.

The components of care covered a broad range of activities conducted by health care professionals, organizational features of treatment facilities and philosophical approaches to caregiving. All of the components of care were ranked as important: however the parents ranked parent involvement, education/information, treatment accessible and available care continuity, consistency, coordination, and family-centered care as being most important. BjÖrck-Akesson and Granlund (1995) studied parents' perceptions of family involvement in the habilitation process. The sample consisted of 73 Swedish parents. Using rating scales, parents ranked 4 dimensions of family involvement. They found that parents perceived substantial discrepancies between how they are currently involved in early intervention and how they think that they should ideally be involved. Parents wanted to be more involved in decisions regarding their child's assessments, team meetings, and the generation of family goals and services.

In the family-centered model of providing care practices are consumer driven, in those families' needs and desires determine all aspects of service delivery and resource provision (Dunst, Johnson, Trivette, & Hamby, 1991). The aims of programs are to promote family decision-making and competencies and to strengthen a family's capacity to build both informal and formal networks of resources to meet their needs. Although the studies that have been cited have been conducted with different populations (e.g. different disabilities, age groups, countries); different programs (e.g., early intervention programs, habilitation centres, hospital-based); different methodologies (e.g. qualitative, quantitative); several common elements have emerged. Parents want to be involved (Baine, Rosenbaum & King, 1995; BjÖrck-Akesson and Granlund, 1995; Summers, Dell' Oliver, Turnbull, Benson, Santelli, Campbell & Siegel-Causey, 1990). This involvement is reflected in their desire for more informants in (Able-Boone et al., 1990; Baine, Rosebaum & King, 1995; Ball, Glasper & Yerrel, 1988; Mahoney, O'Sullivan & Dennebaum, 1990), and to be the primary decision-makers in their children's care (Able-Boone et al., 1990; BjÖrck-

Akesson & Granlund, 1995; Katz & Scarpati, 1995; Summers et al., 1990). The parents also want comprehensive and consistent care (Able-Boone et al., 1990; Baine, Rosenbaum & King, 1995; Chisten, 1991; Summers et al., 1990) and health care providers who are caring and respectful (Chisten, 1991; Summers et al., 1990). These studies suggest that when parents perceive programs as having the characteristics of family-centered care, then parents perceive the programs as being more effective and in turn provide them with the control they need to ensure that their family's needs are met (Mahoney, O'Sullivan & Dennebaum, 1990; Trivette, Dunst, Boyd, Hamby, 1995).

2.1.3 Satisfaction

2.1.3.1 Client Satisfaction

One measure of the effectiveness of health care services is the extent to which the consumers are satisfied (McWilliams, Lang, Vandiviere, Angell, Collins & Underdown, 1995). Client satisfaction is an important indicator of the quality of treatment received and is also an important goal of service providers (Hill, Bird, Hopkins, Lawton, & Wright, 1992; Kopec-Schrader, Marden, Rey, Touyz & Beaumont, 1993). Client satisfaction surveys provide very useful information. They provide information about the acceptability of different interventions (Sabourin, Bourgeois, Gendreau & Moval, 1989). They are a good predictor of the client's compliance with treatment, premature termination of services and future help-seeking behavior (Kaplan & Ware, 1989; Sabourin et al., 1989; Ware & Davies, 1983). They are also moderately related to the client's view of treatment outcome (Sabourin et al., 1989; Ware & Davies, 1983).

Consumer satisfaction has been found to be related to factors that include: client socio-demographics, physical and psychological status of the client attitudes and expectations concerning medical care (Cleary & McNeil, 1988), characteristics of the provider or organization that made the care more 'personal' such as good communication skills, empathy and caring (Cleary &

McNeil, 1988; Kaplan & Ware, 1989), and structure, process, and outcome of care (Cleary & McNeil, 1988). Structure refers to the physical setting and resources available and includes accessibility and continuity of care. Process refers to the way in which the service is delivered and includes technical and interpersonal aspects of care, and outcome is the end product of the process.

Client dissatisfaction is usually related to concerns regarding communication, empathy, time, accessibility, and the attitudes of health professionals towards care their clients (Hill et al., 1992). Plapp and Rey (1989) stated that satisfaction and dissatisfaction are mutually exclusive since it is possible that a person may be generally satisfied with something but still have a number of specific dissatisfactions with it.

2.1.3.2 Parent Satisfaction

Though similarities exist between client and parent satisfaction it is important to examine parent satisfaction as a separate concept. Measuring parent satisfaction is an essential component of the evaluation of early intervention program (Bailey & Simeonsson, 1988). Parents have the major responsibility of their child's development and their decisions concerning success and failure should have primacy (McNaughton, 1994). Parent satisfaction measures are important because they give families a sense of ownership and control over the services made available to them, and may increase parent participation in programs (McNaughton, 1994). Information about parent satisfaction and dissatisfaction can be used to develop better services for families (Bailey Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell & Helm (1986); McNaughton, 1994). Data collected regarding parent satisfaction may also be used to convince people of the usefulness of a particular program (McNaughton, 1994).

Where attempts have been made to identify correlations between reported satisfaction measures and objective measures of achievement, the focus has been on the child receiving the services (McNaughton, 1994). Marfo, Browne, Gallant, Smyth and Coribett (1991) reported a low correlation (r=0.20) between parent satisfaction and child progress as measured by the rate of the child's development during satisfaction and child progress as measured by the rate of the child's development during intervention. Upshur (1991) observed a low correlation between fathers' satisfaction and their children's development of cognitive skills (r= 0.22) and no relationship was found between mothers' satisfaction and measures of children's progress. Plapp and Rey (1989) found that 70% of parents were satisfied with the treatment their child received and a similar proportion reported improvement in their children's skills. Kopec-Schrader et al. (1993) conducted a study in a private hospital for children with eating disorders and found that most parents were satisfied with the services provided and about the same proportion reported that their child was functioning better yet felt that they were not given enough information and support. These studies suggest that there may be a weak relationship between parental satisfaction and their child's development of skills.

The literature also suggests an important link between parental perceptions of participation in programs and satisfaction with the care received (Cleary & McNeil, 1988). In a survey of parental satisfaction of parents who were fully involved in all aspects of their child's stay in hospital, Jackson, Bradham and Barwall (1978), found that all parents reported that they were satisfied with the care child received. Similarly Styba, Elaschuk, Jesse and Cote (1992) confirmed that parent expressed a high degree of satisfaction with being able to be completely involved in all aspects of their child's care. Caro and Derevensky (1991) evaluated a family-centered home-based intervention model with 16 families having infants with moderate or severe disabilities and found high levels of parental satisfaction. These studies suggest that when a program has the characteristics of being family-centered, parents report that they are satisfied with the care their children received.

Parental perceptions of the characteristics of the staff providing the program are also related to feeling satisfied with the care provided. Similar to the literature on client satisfaction interpersonal elements of care such as understanding, warmth and sincerity were identified as being valued by consumers of health care. A number of authors have found these qualities to be related to parental satisfaction with care (DiMatteo, 1979; Doyle & Ware, 1977; King et al., 1997). Similarly, in a study looking at parental satisfaction with the transition from early intervention programs to kindergarten, it was found that parents who felt supported and had explanations provided to them felt more satisfied (Hamblin-Wilson & Thurman, 1990).

McWilliams et al. (1995) found that parents' satisfaction was related to their perceptions of having access to services, developing Individualized Family Service Plans (IFSPs) and coordinating services. However, they also found that priorities vary for different families. For example, Latino families included information and support, socialization for the child and help with separation from their children as goals. Philadelphia families wanted to be well educated about their children and prepared for transitioning to school. They also found that fathers and mothers have differences in their perceptions of satisfaction but both agree on what is beneficial to their child and family.

The potential benefits of collecting information on parents' satisfaction with early intervention services are frequently cited in the literature (Bailey & Simeonsson, 1988; Mahoney O'Sullivan, Dennebaum, 1990). Information on parent satisfaction with early intervention services can help develop better services (Upshur, 1991; Wolery, 1987) enhance parental participations in programs and provide support for the usefulness of a program (McNaughton, 1994). The literature reviewed also suggests that there may be a relationship between parent perceptions of being involved in programs that are family-centered and their level of satisfaction with the program. The characteristics most cited as linked to satisfaction include feeling supported, receiving clear explanations of care, being fully involved in all aspects of care, and the feeling that the staff are being understanding and sincere. These characteristics are all part of the model of family-centered care.

2.1.4 Goal Achievement

Reviews of research conducted on setting goals have concluded that parents are typically passive recipients of information rather than active decision-makers (Brinckerhoff & Vincent, 1986). Witt, Miller, McIntyre and Smith (1984) stated that the parental role preferred by most professional team members is of a passive participant. Salisbury (1992) reported that goals have often been completed by staff prior to meetings with parents, and that participation has meant listening to professionals and approving the goals already prepared for their review. Katz and Scarpati (1995) found that staff use their professional roles and influence to change family goals by redirecting, suggesting and encouraging families to adopt certain interventions.

In order to set goals that are meaningful and important to the child and family, it is necessary to work together with them. A team approach is necessary in early intervention and families are essential members of the team (McGonigel & Garland, 1988). Studies have found that parents who want to be involved in all aspects of their child's program have the ability to develop and implement goals when encouraged by staff (Katz & Scarpati 1995). Bass and Leavitt (1963) and Latham and Locke (1979) support that "ownership" of goals, which is only possible when a person is meaningfully involved in setting their own goals, is the most effective way to ensure that goals are successfully met. By focusing on needs that are of direct concern to families, interventionists can develop a trusting and collaborative relationship with families and assist them in achieving their goals (Bailey et al., 1986; Gashelis & McConnell, 1993).

There is some research that demonstrates that parents can be reliable sources of information and that they can be accurate assessors of their child's abilities

(Beckman, 1984). Models that stress enabling and empowering families and respect for their beliefs and values are based on the assumption that family priorities are paramount and are to be respected (Minke& Scott, 1995). These models stress that disagreements should be resolved through negotiation and families must retain final control over decisions.

Several studies have illustrated the benefits that result when families set the goals for intervention. Adubato, Adams and Budd (1981) studied aspects of training a mother and father in child management techniques with their six years old severely developmentally delayed son. The parents chose the goals of improving their child's dressing, skills and a partnership was formed between the therapist and the mother to work collaboratively. There were four significant results from this study: the mother learned to implement the training procedures and communicate them successfully to the father; parents showed generalization of skills; child improved with dressing skills; and a two years follow up indicated that parents retained their knowledge of skills thought, continued to use the procedures and rated the training as helpful to teach self-help skills.

Schriebman, O'Neill and Koegel (1983) conducted a study to investigate the effectiveness of a generalized training program of siblings of autistic children. The goal of improving the child's behavior was generated by the family and then the therapist worked to gather with the siblings to improve the behavior of the child with autism. The result showed that the siblings learned to use the behavioral procedures proficiently, and developed a more positive attitude towards their sibling with autism. The behavior of the children with autism also improved. These studies illustrate the benefits that result when parents generate treatment goals that are important to them and their families. In these two situations the therapists used the family-centered model of care to achieve the outcomes that resulted.

The literature suggests that when partnerships are formed between professionals and parents so that goals of intervention are collaboratively set, positive outcomes will result. Working towards goals that are important to the family and the child are characteristics of the family-centered care model.

2.2 Literature Review

2.2.1 Description of Models

A number of features are common to programs that operate within the family-centered service philosophy. The family of the child with disabilities is central to service delivery and takes on the primary decision-making role (Korteland & Cornwell, 1991). Family-centered programs use strengths based, empowering approaches. Parents are treated as experts on their child's condition (Powell, 1996). Collaboration is expected not only between worker and family but also beyond agency boundaries. These models promote one-stop access to services, regardless of whether services are provided by one agency or a number of agencies. Collaboration and team work between professionals are essential in order to ensure coordinated services. Some family-centered programs promote the identification of a service coordinator. The role can be taken up by a professional or a parent or other caregiver (Cormany, 1993). The assessment and care plan address both child needs and those of the family. Interventions are tailored to family needs, skills, competencies and values. In addition, linkages with other families and referrals to other resources will complement the plan. Evaluations of family-centered programs are based on individualized outcome (Boone, Moore, & Coulter, 1995; Brown Pearl & Carrasco, 1991; Brown Thurman & Pearl, 1993; Cormany, 1993; Dunst, Trivette, Gordon & Starnes, 1993; Fiene & Taylor, 1991; Jackson, Finkler, & Robinson, 1992; Kaufman, 1992; Korteland & Cornwell, 1991; Mahoney, O'Sullivan & Dennebaum, 1990; Rosenbaum, 1996).

2.2.2 Implementation of Family-Centered Practice Models

Implementation of a family-centered intervention model has been found to result in high levels of parental satisfaction, accelerated rates of progress by children with moderate or severe disabilities, and acquisition of skills by families (Caro & Derevensky, 1991). Outcomes of empowering individuals and families include: a positive self-concept, personal satisfaction, self-efficacy, a sense of mastery, a sense of control, a sense of connectedness, self-development, a feeling of hope, social justice, and improved quality of life (Gibson, 1991). Empowering families to make-decisions fosters a sense of control and provides a good basis for partnership in parent-professional relationship (McBride Brotherson, Joanning, Whiddon & Demitt, 1993).

Families have stated their preference for family-centered practices (Able-Boone, Sandall, Loughry & Frederick, 1990); however, the family-centered model is not widely used. On a questionnaire that consisted of 22 components of care, Rosenbaum, King and Cadman (1992) found that although family-centered care was highly rated by parents, it was rated much lower and infrequently offered by health care professionals. Brotherson and Goldstein (1992) conducted focus groups with 21 family members who were involved in early intervention programs in Kentrucky. The families indicated that they would like professionals to consider their unique family environments are routines as well as to be respected as competent, contributing members of the team with knowledge to share. They also found that the more family-centered intervention services mothers received, the more they perceived their intervention programs as benefiting their families and their children. In looking at a sample of 503 mothers who had handicapped children who were enrolled in intervention programs throughout the United States, Mahoney, O'Sullivan and Dennebaum (1990) found that families had greater needs for family-centered services than were currently receiving. These findings are consistent with those of Mahoney and associates (Mahoney & O'Sullivan, 1990; Mahoney, O'Sullivan & Fors, 1989). They found that the most predominant model used was the family allied model, where professionals develop goals and interventions for parent feedback and approval. Mahoney, O'Sullivan and Dennebaum (1990) also found that the most common services provided in family-centered early intervention programs involved providing families with information about their children and helping parents and families become involved in the early intervention system. They found that different types of care were provided depending on the age of the children and whether there was a home-based component. Mothers of children age birth to 3 years and programs with home-based components that have Individualized Family Service Plans (IFSPs) tended to have a greater family-centered orientation. In a qualitative study on parent-professional relationships in early intervention, Minke and Scott (1995) found a higher degree of staff control than parent driven intervention in three early intervention programs, even though these were described by the staff as being family-centered. For example, staff tended to reserve decisions regarding estimation of progress on goals and the design of intervention strategies for themselves.

The use of family-centered practice is supported by theory and research (Turnbull, Summers & Brotherson, 1984). Parents have also stated their preference for family-centered practice (Mahoney& O'Sullivan, 1990; Mahoney, O'Sullivan & Fors, 1989; Rosenbaum, King & Cadman, 1992). Evaluation of family-centered outcomes as perceived by parents seems to be the logical next step in the provision of family-centered services (Washington & Schwartz, 1996).

The publication of the key elements of the family-centered care by the Association for the Care of Children's Health (Shelton, Jeppson &, Johnson, 1989)set forth a motion that has been gaining acceptance in health care and children's services ever since. Even though widely implemented, Letourneau and Elliott (1996) found in a recent survey of health care professionals that family-centered care is more difficult to put in to practice. Even though, health care professionals generally support and respect the philosophy of family-centered care, many experience conflict in their helping styles, based on the medical model, and the expectations for practice according to the family-centered principles. Specifically, the support needs of families are not consistently recognized as intervention tends to focus primarily on the child (Dunst and Trivette, 1987; Korteland & Cornwell, 1991; Shelton, Jeppson, Johnson, 1989).

Boone, Moore and Coulter (1995) assessed family-centered practices in infant and toddler programs. They reviewed Individual Family Service Plans (IFSPs) to determine quality indicators reflecting family-centered practices. Both parents' and professionals' perceptions of family-centered practices were assessed. They found that the IFSPs were primarily child-centered, focusing on facilitating the child's development. The majority of written outcome statements addressed child-centered concerns (67%). Only 22% of global family concerns and 23% of child related family concerns were addressed in the outcome statements. Both parents and professionals had higher expectation for ideal services. According to this study, parents and professionals in rural areas perceived greater family-centered practices in current service delivery than in urban areas.

Diehl, Moffitt and Wade (1991) surveyed the needs of parents of children with medically-complex needs. The most overwhelming concern reported by these parents was the stress on the family structure created by the complex needs and time demands that the disability placed on the family, and the impact of it on all family members. The needs expressed by the parents were not the ones addressed by most service delivery systems. Mahoney, O'Sullivan & Dennebaum (1990) polled mothers of children with disabilities who received early intervention services. Their findings concur with the above view that the components of family-focused intervention are not consistent features of the services provided to them. Brown, Pearl and Carrasco (1991) report that intervention activities are mainly child-focused or concentrate on discharge planning. Tucker and Roberts (1990) state that holistic care is still regarded as a future issue in the service provision for children with long-term health care needs. Slater and Wkler (1986) propose that professionally provided services tend to substitute families rather than support them.

Arango (1990) notes that family-centeredness is a buzz word these days but wonders how many health care and educational programs truly are based on these philosophical principles. She questions the family's role in the decision-making process, whether they receive emotional support, and easily the service fits in to all aspects of a child's and the family's life. To promote a true parent professional partnership, Arango (1990) encourages parents to become involved, and organizations to accept parents as advisors, board members, and support for other parents. She emphasizes the need to become much more culturally, racially, and geographically diverse in order to represent a true family-centered point of view.

2.2.3 Barriers to Family-Centered Practice

Often parents and professionals are operating within limited models, which prevent them from living up to the family-centered philosophy (Brown, Pearl & Carrasco, 1991; Boone, Moore & Coulter, 1995; Jacono, Hicks, Antonioni, O'Brien & Rasi, 1990; Letourneau & Elliott, 1996; Mahoney, O'Sullivan & Dennebaum, 1990). Parents may be unaware of their unique and important role in the early intervention process (Boone, Moore & Coulter, 1995; Winton & Bailey, 1997). Social policies and agency mandates, may view children as separate from their families (Hartman & Laird, 1983). Family members may not be seen as important partners in the provision of health care and rehabilitation services (Ahmann, 1994). From the medical model's perspective, the family is often viewed as an extension of the patient rather than the patient as an extension of a family unit (Jacono et al., 1990). Family members are seen as resources for the child with disabilities, whereas the resource needs of the families go unrecognized (Slater & Wikler, 1986).

Cardoso (1991) points out that a barrier to family-centered care is the reluctance of care providers to see parents as competent. Summers et al. (1990) conducted a qualitative study that focused on the Individualized Family Service Plans (IFSPs) process in early intervention. In a summary of the responses generated by a focus group, the most frequently mentioned theme was the importance of sensitivity to families. Respondents mentioned the need for staff to be supportive of families who experience a wide range of emotions, and to be accepting and non-judgmental. Other comments generated by the study underscored the importance of the family as the ultimate decision-maker, the need to respond to diversity and individual family preferences, the importance of providing clear communication and consideration for the whole family, including its natural support networks (Summers et al., 1990, P. 85). Winton & Bailey (1997) agree that the family-centered vision in service provision is the desired direction by both families and professionals. Families often do not know how to assume the central role and professionals lack the skill and means of developing collaborative partnerships with them.

2.2.4 Research in Family-Centered Care/Intervention

There have been a number of published literature reviews that have evaluated or summarized the effects of early intervention programs, including reviews that have focused on the effects of early education interventions on cognitive development and academic achievement (e.g., Karoly, Greenwood, Everingham, Hoube, Kilbum, Rydell, Sanders, & Chiesa, 1998; Ramey & Ramey, 1994; 1998), antisocial behavior and delinquency (Karoly et al., 1998; Yoshikawa, 1995), and parenting practices and economic self-sufficiency (e.g., Karoly et al., 1998; St. Pierre, Layzer, & Barnes, 1995) [all are cited in Perloff , Butter ,Berry & Budetti, 1998).

The complexity of delivering a program that focuses simultaneously on child and parent/family; that begins before birth and carries on until the child is well into elementary school; and that is designed to affect all developmental domains is great. The lack of an adequate body of research on these collaborative, multifaceted, intensive, comprehensive programs is the most serious limitation of the literature to date (Schultz Lopez, & Hochberg, 1996).

Research on client satisfaction has been hampered by a lack of awareness that users of the service may have suggestions which could improve service delivery, by a lack of standardized measures for collecting this information, by low response rates to satisfaction surveys (Kopec Schrader et al., 1993) by poor psychometric properties in existing satisfaction surveys (Sabourin, et al., 1989) and by the high levels of reported satisfaction (Larsen, Attkisson, Hargreaves & Nguyen 1979). High levels of reported satisfaction can be explained in several ways (Larsen et al., 1979). These ratings may be due to the client's desire to give positive comments to avoid repercussions or these ratings can be accepted at face value. It is difficult to find a meaningful comparative basis for interpreting client satisfaction findings since levels of satisfaction in absolute terms and in isolation from other data are meaningless. The sample may not be a representative sample of the client population due to low return rates, patient dropout from programs, and perhaps only satisfied persons reply. Another influence is the halo-effect, which refers to the tendency to rate people one likes positively (Tuckman, 1994). This causes the scales to simply measure the general positiveness of the rater's/client's perceptions of the staff rather than satisfaction with the program. Despite the fact that concerns have been identified with client satisfaction surveys, it is still important to measure client satisfaction. If the client's perspective is not taken into account the evaluation of services is incomplete and biased towards the provider's perspective (Larsen et al., 1979).

Bailey and Simeonsson (1988) noted that the measurement of parental satisfaction has received limited attention in the past and therefore little information exists to guide the collection and interpretation of satisfaction data. In a review of 20 early intervention studies published between 1975 and 1983, Marfo and Kysela (1985) reported that only 2 studies included a measure of parent satisfaction with in the early intervention program. However, as the emphasis on client empowerment and family-centered care in health care is growing parent satisfaction is gaining credibility as an important outcome measure (Unwin & Sheppard, 1995).

Several studies have examined parental perceptions of intervention programs four of which used qualitative methodologies. Chisten (1991) explored the perceptions of 8 parents in Arizona using interviews, participant observations and document analyses. Parents identified communication across the program, comprehensive program services, and caring qualities of the staff, as being of critical importance to them and their children. Able-Boone et al. (1990) interviewed 30 families in Colorado. Parents emphasized their need to become knowledgeable about their child and about available services as well as the importance to professionals' relaying information and empowering families to become their own decision-makers. Summers, et al. (1990) examined family preference of how services are delivered and how practitioners interacts these families in early intervention using nine consumer focus groups. The results showed the need for practitioners to be sensitive to parent's needs and perceptions including giving positive feedback being flexible and being responsive to rapid changes in the family. Summers et al. (1990) emphasized the importance of acknowledging the family as the ultimate decision maker and the family's desire to be more actively involved in setting goals and designing the intervention program. Katz and Scarpati (1995) used an ethnographic approach to determine how members of an early intervention team in New England state involved nine families in the development of Individual Family Services Plans (IFSPs). Parents perceived early intervention programs as being more child focused than family-focused even though there was a significant degree of family involvement. In this program, the professionals maintained the belief that they were the primary decision-makers responsible for the final development of goals and the source of professional judgment.

Despite the increased call for adoption of family-centered models and approaches in the early intervention [(e.g. Able–Boone, Sandall, Loughry, & Frederick, 1990; Dunst, Trivette, and Deal, 1988b, 1994b; McGonigel, Kaufmann, & Jonson 1991) heath care (e.g., Brewer, McPherson, Magrab, & Hutchins, 1989; Shelton & Stepanck, 1995), and other human services (e.g. Hutchinson & Nelson, 1985; Nelson, 1990; Pizzo, 1990) all are cited in Trivette, Dunst, Boyd & Hamby, 1995] fields, relatively little research has been developed to the influences and consequences of family-centered practices.

Many articles addressing family-centered care or service coordination in early intervention are descriptive in nature (e.g., Cormany, 1993; Fiene and Taylor, 1991; Rothman, 1991; Brown, Pearl & Carrasco, 1991; Boone, Moore & Coulter,1995; Jacono et al., 1990; Letourneau & Elliott, 1996; Mahoney, O'Sullivan, Dennebaum, 1990; Hartiman & Laird, 1983; Slater & Wikler, 1986; Cardoso, 1991; Summers et al., 1990; Winton & Bailey 1997). Netting (1992) provides a word of caution to the fact that service coordinators in early intervention can become gate keepers, especially during the era of fiscal constraints and limited resources. Cormany (1993) acknowledges similar concerns referring to some problems with program related service coordination involving the rationing of services in some direct manner by matching consumer needs, vendor priorities, and available funding. Fiene and Taylor (1991) note that scarcity of resources and environmental barriers are of concern to families living in rural and remote regions.

Family-centered care is not always the most resource efficient. Frequently, coordinated care results in higher and a wider range of costs and at least initially, increased usage of resources (Marchenko & Smith, 1992; Smith, Layne, & Garell, 1994). Service coordinating, however, strives for cost effectiveness (Cormany, 1993; Fiene and Taylor, 1991; Rothman, 1991), creating a potential conflict between family-centered care and effective care management/coordination.

Rosenbaum (1996) describes the measure of processes of care (MPOC) questionnaire that his research group specifically developed to evaluate parents' perceptions of family-centered services in pediatric rehabilitation settings. King, Rosenbaum & king (1995) conducted a number of surveys at various children's rehabilitation settings for the purpose of the validity and reliability studies when developing the measure of processes of care questionnaire. The emphasis of these studies was to develop an instrument to measure the degree of family-centeredness. Letourneau and Elliott (1996) studied professional's perceptions of family-centered service practices at a children's hospital. Concerning this issue, no Ethiopian articles were found that addressed specifically a dimension of family-centered care intervention approach for children with disabilities at an outpatient facility, such as children's treatment (CBR) centre.

Jackson, Finkler and Robinson (1992) evaluated a pilot project and found that a family-centered early intervention program can be effectively implemented in a hospital setting, the process being highly satisfactory to parents. Marchenko and Smith (1992) conducted a pre-and post-test study and discovered that family-centered early intervention services improved maternal life satisfaction, but the needs of all family members were not met. For instance, siblings of children with disabilities continued to have difficulties in coping. Smith, Layne & Garell (1994) concluded that care coordination was readily accepted by families and resulted in increased services, but the evaluation proved to be challenging. Outcomes like empowerment and family congruence are not easily quantifiable outcomes, which makes measuring them difficult with quantitative methods. The complexity of family systems and the lack of appropriate definition of early intervention /care increase the difficulty of determining the impact of intervention and the attainment of goals. In addition, self-selection and a small size of the sample were identified as areas of concern.

Several articles describe models of family-centered intervention, care, or service programs (Brown, Pearl & Carrasco, 1991; Fiene & Taylor, 1991; Kaufman, 1992; Boone, Moore & Coulter, 1995; Jacono, et al., 1990; Letourneau & Elliott, 1996; Mahoney, O'Sullivan & Dennebaum, 1990; Ahmann, 1994; Slater & Wikler, 1986; Cardoso, 1991; Summers, et al., 1990; Winton & Bailey, 1997) but do not involve an evaluative component.

Dunst et al. (1993) investigated the extent to which different relationship-related help-giving attitudes and behaviors vary among caregivers/service provides. The findings demonstrate that there is a link between caregivers' practices consistent with family support principles, and the practices presumed to being family-centered. In brief, better family outcomes are related to care/ service provider helping styles that are consistent with the intent of family support principles.

CHAPTER THREE

3. Methodology

3.1 Design of the Study

As indicated in the literature review, even when certain type of service philosophy is identified with an agency or a program; it does not automatically mean that services are implemented in accordance with the principles and values of the model. Before further analysis and postulations are possible regarding the family-centered care/service coordination model, it was necessary to find out whether the parents involved with the Cheshire Services Ethiopia: Community-Based Rehabilitation (CBR) Program for children with disabilities actually felt that they were receiving services that were congruent with the family-centered intervention values and principles. With no control group available and without a proven theoretical framework, an exploratory design was chosen.

In the case of this particular research it is not possible to evaluate the services of the Cheshire CBR/Intervention Projects for children with disabilities before the parents become involved with the services of the program. For that reason, a pre-test was not feasible. The survey research was conducted as one-shot case study, or post-test only one-group model or design (Leavitt, 1991)

A cross- sectional - personal interview format was chosen as a method of data collection.

3.2 Study Population

The total caseload of the Cheshire Services Ethiopia: Community-Based Rehabilitation (CBR) program, excluding the waiting list, was surveyed. The CBR projects' catchments area includes the four sub-cities (Kolfe Keranio, Gulelle, Addis Ketema and Arada sub-cities) of Addis Ababa. All of the families residing within the city of Addis Ababa and receive services in their own home and communities on a weekly consultation basis out of which nearly half of the total caseload were included in the survey project.

All children in the Cheshire CBR/Intervention program are categorized in 6 major disability areas. They have motor disorders/motor developmental delays, mentally challenged/mental retardation, physical disability, hearing impairment, visual impairment and multiple disabilities. The children may receive one or several services, such as physiotherapy, occupational therapy, social work etc. The frequency of intervention may vary from less than once a week through once a week to once a month. A number of modalities are used such as individual or group therapy, mediated therapy and consultation.

The survey was limited to parents/families receiving services from the Cheshire CBR Centre's staff /social workers. This limitation was imposed due to the dramatic decline in contact between parents and professionals once services are provided through different venues, such as the school and health settings.

Among the two hundred and twenty nine total caseload of Cheshire Services Ethiopia-CBR program, about three-fourth (N=172) children were identified as eligible to participate in the survey, excluding the recently discharged and waiting list. Using stratified random sampling, a sample of eighty one (n= 81) parents (families) of children with disabilities who participated in the CBR program from 6-24 months or more was studied. All of these parents (families) agreed to participate in the study. Four types of questionnaires were administered to each parent /family already selected for the research study, and each of them completed the survey package. All of the eighty one (n=81) responses were returned and this was what makes the response rate 100%. Two of the returns were discarded due to insufficient data. The data analysis is based on seventy nine (n=79) completed questionnaires.

3.3 Instruments

The instrument employed in this study was a questionnaire using an interview format. Items for the questionnaires and interview came from the literature in the field of family-centered care/intervention and parental perceptions of care from previous studies used to measure: Parental/familial perceptions on processes of care/intervention, Clients'/parents', and families' satisfaction with care taken, services given and parental/familial perceptions of goal achievement. The questionnaire were constructed in accordance with guidelines by [Wiersma, 1991; Backstrom & Hursh-Sesar, 1981; Berdie & Anderson, 1974]. According to these authors, one of the fundamental rules in constructing questionnaire is to ask clear, unambiguous questions, avoiding jargon and terminology that may be unfamiliar to the respondents.

Being that participants or respondents were not scattered throughout the country and limited to the city of Addis Ababa, 4 sub-cities: Kolfekeranio, Addis Ketema, Gulelleand Arada sub-cities, Questionnaires in an interview format were selected as the principle instrument to acquire data for this study. Because the accuracy of self-reported data is controversial and questionable, a substantial amount of literature has been generated concerning validity and reliability of data collected with self-reporting instruments (Kaufman & Rasinki, 1991; Wentland & Smith; 1993). Studies of self-reported data, however, generally conclude that respondents {clients} where relatively a good source of information, and that self-report accuracy is affected more by the way questions are asked, the specific information sought, and the characteristics of the clients in the study (kaufman and Rasinki, 1991). In a meta-analysis of 245 survey questions, Wentland and Smith (1993) found evidence to support these conclusions. They stated that respondents generally desire to be truthful, and inaccuracy is due more to item construction and item characteristics than respondent's motive. Taking these crucial issues in to account the following instruments were chosen by the researcher for this survey study.

3.3.1 The Measure of Processes of Care (MPOC) Questionnaire

Parents' /families' perceptions of the extent to which intervention workers used family-centered care model were measured with the Measure of Processes of Care (MPOC) Questionnaire (Appendix 5). Permission to use the tool was obtained from its developers, the Neurodevelopmental Clinical Research Unit (NCRU) of McMaster University and Chedoke-McMaster Hospitals (1995). The Chief Executive Officer of the Cheshire Services Ethiopia- CBR authorized in writing the use of their CBR projects' caseload as the survey population

The MPOC is self-administered questionnaire containing 56 items across 5 scales which was developed to measure parents' perceptions of the care/services they and their children receive from rehabilitation/treatment centre. The authors of the questionnaire state that the measure is viewed as "tapping the important features of family-centeredness" (King, Rosenbaum & King, 1995, p. v).

The MPOC consists of five scales: Enabling and partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care for the child and family, Respectful and Supportive Care.

The questionnaire consists of a number of statements related to activities at the Cheshire Services Ethiopia -CBR Projects/ program. Statements are rated by the respondent on a scale ranging from 0 (not applicable) through 1(never) to 7 (to a great extent). Thus, items are scored on an- 8 point scale (7= to a great extent, 4 = sometimes, 1= never, 0= not applicable). A scale score is the average of the items' ratings for the scale, and scale scores ranged from 1 to 7. If items are rated 0, they are eliminated from the scale, and each scale has an upper limit of 0 scales that are acceptable before the scale must be eliminated.

The reliability and validity studies of the MPOC measure are based on four data sets (1) the pilot testing study (n= 653), (2) a field testing (n=151), (3) a test-retest reliability study (n= 29), and (4) a validation study to assess social desirability response bias (n= 14) (King, Rosenbaum & King, 1995). A brief overview of these studies follows:

Reliability

The internal consistency of MPOC-56 scales was assessed by Cronbach's Coefficient Alpha. The MPOC- 56 scales have good internal consistency, indicating that items in each scale measure a unique underlying theme (Cronbach's alphas across scales varied from 0.63 to 0.94 in the reliability study (n= 29) that is, all values, except for the third scale in the smaller sample (n= 29). Providing Specific Information about the Child (= 0.63) were above the minimally accepted criterion of 0.80 and from 0.81 to 0.96 in the pilot study (n= 653)], and good test-retest reliability (intraclass correlation coefficients (ICCs) for the 5 scales ranged from 0.78 to 0.88 (n=29)).That is, the stability of the scales over time was assessed with data collected in a test-retest reliability study. Parents answered MPOC questionnaire the same way after an interval of 3 to 4 weeks. The Intraclass Correlation Coefficient (ICCs) was used as a reliability coefficient, ranging from 0.78 to 0.88, suggesting good stability over time.

Validity

Content validity: Through the development of MPOC, the domain of care-giving was systematically reduced to aspects determined by parents to be of more relative importance. Parents also participated in generating the items for the aspects of care-giving and health care providers examined the draft version to determine if the content reflected how care might be experienced by parents in the treatment centre where they worked. All items retained in the MPOC were rated as highly important with item means ranging from 2.20 to 2.96 on a three point scale (King, Rosenbaum & King, 1995, p.42).

Construct validity: Evidence is presented by the research group that the 5 MPOC scales are distinct and represent meaningful aspects of care. The data to support these findings were derived from the four data sets mentioned above. The MPOC was initially developed for the purpose of exploring how the processes of care giving relate to parents' psychosocial well-being. A single question on stress was created to investigate any association between the MPOC and a preliminary assessment of parents' mental health. Two versions of the stress question have been used during the development of the MPOC. Correlations of MPOC with this stress variable were tested, with a hypothesis that higher levels of stress on MPOC scale score would be associated with lower levels of stress on all scales. The results of these testing showed statistically significant negative correlations between all MPOC scales and stress.

The MPOC scales correlate positively with a measure of client satisfaction (Client Satisfaction Questionnaire by Larsen et al., 1979).The authors note that "the correlations between MPOC scales and satisfaction show particularly that the interpersonal (rather than informational} aspects of care are highly related to satisfaction" (King, Rosenbaum & King, 1995, p.47).

The MPOC scale scores do not react to demographic characteristics of the family and child, and aspects of service delivery. In preliminary studies no significant correlations were found between MPOC scale scores and community types (urban, small urban, rural), family type (single-, two- parent), gross family income, mothers' education, fathers' education (Spearmen Rank, r), and child's gender (eta coefficient). These findings provide evidence for discriminant validity.

The developers of the instrument predicted a negative relationship between a child's age and some of the scale scores. Enabling and Partnership (-0.13) and

Coordinated and Comprehensive Care, (-0.16) showed negative correlation (Pearson r coefficient) with child's age.

Paired t-tests were conducted to assess social desirability bias. The findings provide supportive evidence that parents are reporting their true experiences.

The authors of the instrument make a particular point of noting that since the MPOC has been developed quite recently, more validity and reliability studies need to be conducted in the future.

Comments from parents on the questionnaires indicate that the issues being addressed in MPOC are relevant, the questions are well formulated, and that the work is worthwhile (King, Rosenbaum& King, 1995, P.42). The instrument seems acceptable to parents and appears to measure what it purports to measure.

Suitability for Current Study

The MPOC was developed in Ontario, Canada, and has been successfully used in Ontario Children's Treatment Centres, and it also suitable for the purposes of this research. It was specifically developed to measure parents' perceptions, making it compatible with the focus of this research. The questions are designed to describe services that parents and their children receive from children's treatment centre. The questionnaire was developed with extensive input from parents. The five scales are based on the aspects of care that parents viewed as important (King, Rosenbaum& King, 1995). Although new, the MPOC is an established instrument to measure the extent of family - centeredness of service providers.

The intent service/care coordination, case management, or intervention is to provide continuum of care, to coordinate and link service systems, and to maximize and enhance informed decision-making processes in the client

(Greene, 1992). Berkowitz, Halfon & Kllee (1992) proposed four indicators of service/care coordination, case management, or intervention effectiveness: comprehensiveness, continuity, duration and coordination of care.

The items in the Coordinated and Comprehensive Care for Child and Family scale of the MPOC reflect behaviors that "encompass the holistic needs of the child and family, and that provide service in a way that is continuous and consistent over time, settings, and people" (King, Rosenbaum, King, 1995, p.25). This scale especially can be seen as one measuring elements of service coordination. Family- centered services/ care coordination is based on the systems theory framework, and in the case of children with disabilities (long-term health care needs), planning takes place within the context of the family (Bernier, 1990; Pecora, Whittaker & Malusccio, 1992). Ensuring continuum of care and coordination and linking of service delivery systems are primary functions in family centered intervention (Greene, 1992; Rothman, 1991).

3.3.2 The Mesure of Satisfaction/Client Satisfaction Questionnaire

The CSQ-8 is a one-dimensional 18-item instrument to assess global patient/Client satisfaction (Attkisson & Zwick., 1982). They found the CSQ to be substantially correlated with treatment dropout, number of therapy sessions attended, and with change in client-reported symptoms. Nguyen, Attkisson & Stegner (1983) later developed a shorter, 8-item version of the CSQ. This shorter version of the CSQ-8, had the same construct validity and internal consistency reliability as the longer version (Nguyen, Attkisson & Stegner, 1983; Chan, Sorensen, Guydish, Tajima & Acampora,1997). The CSQ-8 was translated into Dutch by De Brey (De Brey, 1983). In this study, the Dutch version was demonstrated to have similar high internal consistency (Cronbach's $\alpha = 0.91$) as the original English version (Cronbach's $\alpha = 0.93$). Thus, the CSQ is a standardized scale used to assess client's satisfaction with a program (Larsen et al., 1979). It consists of 8 questions with a 4- point response scale.

The questions ask about various aspects of the program. The response scale scores vary with '4' representing high satisfaction and '1' representing low satisfaction. A comment section is included at the end of the questionnaire. This questionnaire has a reading level of grade seven. No information is available on test-retest reliability. Therapists' estimates of how satisfied they believed their client to be correlated at 0.56 ($\rho<0.01$) with client's CSQ scores illustrating adequate concurrent validity. The scores obtained on this questionnaire are always very high.

3.3.3 Question on Goal Achievement

One item using a 7-point rating scale was used to determine parental/familial perceptions of goal achievement. It was: "Did the Cheshire Services Ethiopia-CBR/children's Treatment program meet your goals?" The scale scores consisted of: 1-none, 2- very few, 3- few, 4- some, 5-quite a few, 6- most, and 7- all.

3.3.4 Demographic Questionnaire

In order to describe the participants, a demographic questionnaire was constructed and added to the other 3 types of questionnaires: the MPOC, the CSQ-8 and the Single Question on Goal Achievement (Appendix 4). The *descriptive variables* were chosen for the demographic questionnaire from similar questionnaires used in pilot- studies. Some questions were chosen on the basis of the literature review. For instance, parents' perception of services or care may be influenced by the number of services being received. Also, individuals with higher level of education tend to respond to the administered questionnaires in an interview format more often than individuals who have less formal education. The researcher was also interested in finding out that the respondent (care giver) saw as the main service or care coordinator for the child's health care needs. This question was of interest to the researcher in order to explore care/service coordination component of the service model. The agency of family service coordinators was assigned the care coordinator role when the family-centered intervention model was implemented. However, parents can also choose to appoint a community advocate or coordinate the resources themselves.

For the purposes of this research, the MPOC, the CSQ, the Single Question on Goal Achievement and the Demographic Questionnaires were reviewed by the Family Advisory Committee of the Cheshire Services Ethiopia - CBR as well as the Ethiopia Evangelical Church of Mekane Yesus – centre for Mentally Challenged Children (EECMY- CMCC) The Committee was comprised of family representatives, clinical, and administrative staff. The consensus of the Committee was that the instruments were appropriate in terms of their intent and language for a parent survey.

3.4 Procedures

Consent was given for the researcher to administer three measures: the MPOC, the CSQ and the single question on goal achievement, and the family and the child background questionnaires. These measures were part of standard program procedures and the researcher administered them to the participants in co-operation with the CBR team coordinators. The brief survey package consisted of 81 questions (56 MPOC, 8 CSQ, 1 Goal Achievement 14 Demographic and 2 Open-ended questions).

Once a parent agreed to participate in the study, a home-visit was scheduled. During each visit the researcher followed a home-visit protocol (an information sheet and informed consent) [Appendices 3.1 and 3.2] based on sound family-centered guidelines. Through this protocol, the researcher promoted positive parent, child, and family functioning styles in order to enhance the family ability to become self-sustaining. The duration of a home-visit was approximately two and half hours, during which time the parents complete the family and child background and the informed consent forms, the MPOC, the

CSQ questionnaires and the single question on goal achievement. The MPOC was administered first so that items from this questionnaire, the CSQ-8, or the single question on goal achievement scale would not raise issues that could potentially bias parents' perceptions of family-centered care/ behaviors. That is, the three questionnaires: the MPOC, the CSQ -8 and the Single Question on Goal Achievement were administered using an interview format respectively. The investigator believed that this order would be best to reduce any potential bias in responding.

On the other hand, the 13 items were interspersed among the items of the MPOC in an attempt to decrease potential bias in responding (i.e., acquiescence bias or "Yea-saying" and "halo-effect") the respondents to shift their thinking when responding to items that ask about attitudes toward different components of care as noted by (Aday, 1996; Streiner& Norman, 1989).

This was also done so that each parent received the information in the same manner and items that might be unclear could be explained in the same way to each parent. Parents were asked to answer questions on the MPOC, the CSQ-8 and the single question on goal achievement in reference to their experiences over the past 6 months to 2 years or longer so that they were rating their experiences based on established relationship with their children's current rehabilitation workers as well as the center's program. In addition, defining a time frame for response ratings is an accepted mechanism used in survey research to reduce recall bias as noted by Aday (1996). All of these forms were collected by the investigator and kept confidential.

Pilot-Testing Study

Prior to data collection, after the language of the English versions were translated in to an Amharic by language professionals and modified for the purpose of this study, the pilot-testing study was conducted with similar population at the Ethiopian Evangelical Church of Mekane Yesus-Centre for

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Mentally Challenged Children (EECMY- CMCC), in Addis Ababa. The pilot-testing study enables the researcher to ascertain face validity of the instrument prior to administering it to all participants. In so doing, some of the overlapping {e.g., number 1&32;12&22;19,28&43; 31&33; 37&40} items were modified uniquely and some vague/ambiguous {e.g., number 13,29,31} items were modified in accordance with our societal/Ethiopian values and cultural context The collection of data for the main study shortly followed and was conducted in two phases: the first phase included letter of permissions/personalized forms [information sheet and an informed consent forms (Appendices 3.1 and 3.2 respectively]; the second phase was administration of the four types of questionnaires [Appendices 4, 5, 6, and 7] respectively, as it mentioned earlier.

Pre-test

The MPOC and CSQ measures are the established instruments, although they are new ones. Pre-tests have been conducted with similar populations by the developers of the tools at several Children's Treatment Centres. In the case of the present study, the pre-test was not feasible for the same reason mentioned at the beginning of this section.

Data Collection : The Measure of Processes of Care (MPOC) Questionnaire, the Measure of Satisfaction/ Client Satisfaction Questionnaire (CSQ-8), a Single Question on Goal Achievement and a Child and Family Background Form were administered to 81 sample respondents out of the total Cheshire Services Ethiopia–CBR program caseload, excluding the follow-up program and the waiting list. The package contained the information sheet- a letter explaining the purpose of the research and consent forms (Appendices 3.1 and 3.2), the four forms (Appendices: 4, 5, 6 and 7). The MPOC, CSQ-8 and Question on Goal Achievement are the constructed, self-administered questionnaires. The participants were asked to analyze each close-ended question and respond to a statement regarding their experiences at the Cheshire Services Ethiopia _ CBR/Treatment Centre's program. The completed questionnaires were numbered, the responses were coded, and the data were keyed in the SPSS Computer program (Norusis, 1990) for descriptive analysis.

Data Analysis

Three hierarchical multiple regression analysis (MRAs) were generated, one for each of the corresponding 5 MPOC scales ("Enabling and Partnership", "Respectful and Supportive Care", "Coordinated and Comprehensive Care for the Child and Family", "Providing General Information" and "Providing Specific Information about the Child") and the CSQ-8 and the Single Goal Achievement Question scales. For each analysis, the independent variables were entered into the regression equations in the following order: MPOC, between... CSQ-8, and Question on Goal Achievement.

The alpha level of significance testing was set at 0.10 to decrease the potential of *Type II error*. There is a high probability of a type II error in exploratory studies, such as this survey study, that examine scores on rating scale for attitudes and perceptions. To test the other hypotheses and to help explain the findings of the regression analyses, relationships among the independent variables and between the independent variables and the dependent variable were analyzed using the Pearson Product-Moment Correlation Coefficient. That is, Pearson Product-Moment Correlation Coefficients were calculated to look at the relationships among the scores obtained on the 5 MPOC scales, the CSQ and question on goal achievement.

The SPSS program (Norusis, 1990) was used to organize, manage, and analyze the data collected. Data were presented and analyzed using 65 columns for each of the items on the three types of questionnaires, excluding the family and child background form and 79 rows for the study population. Five additional columns were created for the MPOC consisted of 5 scales: Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care for the Child and the Family and Respectful and Supportive Care. Each scale was summed and then averaged to provide a scale score.

Mean scores, ranges and standard deviations were calculated for each of the five scales of the MPOC. For the CSQ-8, a total mean score and standard deviation were obtained. A single score was obtained for question on goal achievement. The mean value for the entire sample was calculated for the single question on goal achievement. *Thematic analysis* was conducted on the comments that were made by the parents on the MPOC and CSQ-8. It is to mean that comments were clustered into similar topic areas and then grouped into themes

Several items were inverted and recorded after the data was entered to establish item consistency within scales. Data for these analyses were gathered from returned MPOC, CSQ-8 and the single question on goal achievement questionnaires (Appendices: 5, 6, and 7) and the demographic information (Appendix 4) administered together with these questionnaires.

3.5 Ethical Review Procedures

Informed Consent

A cover letter [information sheet and consent forms (Appendices 3.1 and 3.2) was included in the package contains questionnaires, explaining the purpose of the research, and what the researcher intends to do with the responses. A statement was included; informing the respondents that participation is completely voluntary and anonymous. Parents were advised that failure to participate in no way would affect the child's involvement with the CBR center's programs.

Confidentiality/ Anonymity

Records from this study would be kept confidential. No names or other identifying information was requested on the questionnaires /forms. All data would be stored in a secure location. Any report published about this study would not identify the child or his/her family by name. The staff (social workers, teams and other caregivers) of the CBR did not have access to the original responses, in order to preserve anonymity.

Risks and Benefits to the Participants

Some parents expressed frustration to the researcher for receiving the questionnaires due to stress and lack of time to complete it. The participants had an opportunity to provide feedback on a program that they are involved with. Any feedback will help to shape future services to a more desirable direction, from a consumer's point of view.

Similarly, the agency (service provider) cooperating with this research project gained valuable information on how the services that it provides are perceived by the families receiving them.

Process of Dissemination of Research Results

The participants were informed in the cover letter of the package that a summary of the survey and the results will be given to the Cheshire Services Ethiopia–CBR Centre which is mailed to all clients. A copy of the completed research will be placed in the Cheshire Services Ethiopia -CBR Centre's library. The results will be shared with the Cheshire Chief Executive Officer and a report will be available for the Board of Directors and the Family Advisory Committee of the centre. The findings will be discussed at a Clinical (Social Workers) Services Meeting (attended by the CSE- CBR staff). The findings will also be shared with the Research Unit of Cheshire Services Ethiopia- CBR Centre.

CHAPTER FOUR

4. Results

4.1 Child and Family Background

Child and family background information was collected with a demographic form that was administered to each family with the MPOC and the CSQ forms of the survey. The data were coded and univariate analyses were conducted to describe the data.

Table 1

Characteristics of the Child with Special Needs

Age in years

Mean	Minimum	Maximum	SD
4.16	1.75	13.75	2.28

Age Distribution	**n**	%
0-23 months (less than 2 years)	13	16.46
24-47 months. (2& 3 year-olds)	26	32.91
48-71 months. (4&5 year-olds)	26	32.91
72-95 months. (6 &7 year-olds)	10	12.66
96 + months (8 year-olds & up)	4	5.06
	79	**100.00**
Gender		
Male	48	60.76
Female	31	39.24
	79	**100.00**
Primary Diagnosis		
Mentally Challenged	25	31.64
Motor Developmental Delays	36	45.57
Multiple Disability	6	7.60
Physical Disability	4	5.06
Visual Impairment	2	2.53
Hearing Impairment	6	7.60
	79	**100.00**
Other Special Needs		
Yes	28	35.44
No	51	64.56
	79	**100.00**

Table 1, summarizes age, gender, primary diagnosis, and the frequency of other special needs in addition to the primary medical diagnosis, in children on the Cheshire CBR program. The age ranged from twenty one months to thirteen years and nine months (SD=2.28). The average age of the child was four years and two months (4 years and 2 months). However, a closer scrutiny reveals that the majority (65.82%) of the children were between the ages of 24 months and 71 months (two to five years). There were more boys (60.76%) than girls (39.24%) represented in this sample. A number of categories of primary diagnoses were identified. The largest category was motor disorders/motor developmental delays (45.57%) These were conditions specified in the child and family background form; the next most frequently mentioned primary diagnoses were mentally challenged/mental retardation (31.64%), followed by multiple disability, and hearing impairment with equal percentage (7.60%). In addition to the primary diagnosis, other special needs were reported in 28 (35.44%) of the cases. In many cases, a child has a specific diagnosis, such as cerebral palsy which is the reason for the initial referral to the Centre. However, frequently, other special needs emerge, such as brain tumour, autism, orthopaedic problems or challenges with communication.

The families' involvement with the CBR is summarized on Table 2. The frequency of interaction ranged from weekly to monthly visits. The greatest number of respondents (83.54%) had weekly contact with the Center's CBR staff/social workers. The second and last largest group consists of those with monthly contact (16.46%).

The majority (50.63%) of the respondents had been involved with centre/CBR for two or more years. The second largest group (22.79%) reported an involvement between one year and two years.

The families received a number of services at the time of survey. Physiotherapy (65.82%), occupational therapy (64.56%), seating/mobility (60.76%), and social work/ family service coordination (55.70%) were most frequently reported, followed by program assistance/aide (40.51%). The average number of services received at one time was 2.80, ranging from none (0) to seven (7) with SD=1.99.

Table 2

Involvement with the CBR

Frequency of Visits	**n**	**%**
Weekly	66	83.54
Monthly	13	16.46
4 times a year	0	0.00
2 times a year	0	0.00
Once a year	0	0.00
less than once a year	0	0.00
	79	**100.00**
Length of Involvement		
less than 6 months	7	8.86
6 months to one year	14	17.72
one year to 2 years	18	22.79
2 years or more	40	50.63
	79	**100.00**
Services Received		
Occupational therapy	51	64.56
Physiotherapy	52	65.82
Social work	44	55.70
Augmentative Communication	9	11.39
Seating/Mobility	48	60.76
psychological consultation	4	5.06
Program Assistant	32	40.51
parent Group	18	22.78
Other	8	10.13

Number of Services Received at the time of Survey

Mean	Minimum	Maximum	SD
2.80	0.00	7.00	1.99

The majority of the respondents (74.69%) identified themselves as the main care /service coordinator of the services that their child receives (Table 3). The spouse (husband/wife) was identified (20.25%) of the time as the care coordinator. Other care coordinators were followed by (5.06%) of the time.

Table 3

Coordinator of Services

	n	**%**
Self	59	74.69
Centre Family Service Coordinator	0	0.00
Community advocate	0	0.00
Nobody	0	0.00
Spouse	16	20.25
Other Centre Staff	0	0.00
Other	4	5.06
	79	**100.00**

Amharic was identified as the language spoken by most at home in 40 (50.63%) cases, Afan Oromo 23 (29.12%), Tigrigna 7 (8.86%) and another language in 9 (11.39%) cases.

The number of siblings of the child with special needs ranged from none to nine (Mean= 1.13, SD= 1.20).

Of the total responses (n=79), 61 (77.22%) were from two- parent families and 18(22.78%) were from single- parent families.

As shown in Table 4, most of the responses were completed by both natural mother and father (74.68%). The table shows the total number of responses per category as well as percentage of total responses. The second largest number of responses was completed by natural mothers (16.45%). In four cases a natural father filled out the questionnaire (5.06%). Other respondents included foster mother, adoptive mother, and foster mother and foster father jointly.

Table 4

Respondents' Relationship with Child

	n	**%**
Natural mother	13	16.45
Natural mother and Father	59	74.68
Natural father	4	5.06
Foster mother	1	1.27
Adoptive mother	1	1.27
Foster mother and Father	1	1.27
	79	**100.00**

The educational level obtained by mothers in the families who responded to the survey is summarized in Table 5. The majority (61.33%) had grades one to eight educational level, the second largest group (20.00%) being those who had grades nine to twelve educational level. Eleven (14.67%) respondents mothers did not have any formal education and the questionnaire was completed with the help of other family members those who have formal education, through translation (reading) to them.

Table 5

Mothers' Education: Highest Level Completed

	n	**%**
No formal education	11	14.67
Grade 1-8	46	61.33
Grade 9-12	15	20.00
High School	0	0.00
College/Commercial school	3	4.00
University degree	0	0.00
Above University degree	0	0.00
	79	**100.00**

As summarized in Table 6, 50.77% of the fathers in the families who completed the questionnaires had grades one to eight. The second largest group was comprised of fathers who had completed grades nine to twelve (29.23%).

Table 6

Fathers' Education : Highest Level Completed

	n	**%**
No formal education	5	7.69
Grade 1-8	33	50.77
Grade 9-12	19	29.23
High School	0	0.00
Colleges/Commercial school	6	9.23
University Degree	2	3.08
Above University degree	0	0.00
	65	**100.00**

The respondents' educational level is summarized separately in Table 7. The majority of respondents have grades one to eight level of education (58.23%), followed by grades nine to twelve level of education (24.05%) and no formal education (11.39%).

Table 7

Respondents' Education: Highest Level Completed

	n	%
No formal education	9	11.39
Grade 1-8	46	58.23
Grade 9-12	19	24.05
High School	0	0.00
College /Commercial school	4	5.06
University Degree	1	1.27
Above University degree	0	0.00
	79	**100.00**

In terms of family income, the majority (92.41%) of the respondents were not employed outside the home. The rest (7.59%) reported as being employed at the time of the survey.

Of the respondents' spouses, most (88.81%) were not employed, (84.81%) were not working at the time of the survey, (18.99%) were marked as not applicable (single parent household)..

4.2 Scale Scores

4.2.1 The Measure of Processes of Care (MPOC)

Following the techniques that the MPOC developers (King, Rosenbaum & King, 1995) used, the scores on the five scales of MPOC questionnaire were calculated by averaging the valid scores of the items on each scale. The results are listed in Table 8.

Table 8

The 5 MPOC Scale Scores

Scale	**Mean**	**SD**	**Min**	**Max**	**Range**	**n**	**Within one SD**
Enablement and partnership	6.04	0.92	3.44	7.00	3.56	75	5.12-6.96
Providing General Information	5.03	1.56	1.00	7.00	6.00	65	3.47-6.59
Providing Specific information about the Child	5.97	0.97	3.00	7.00	4.00	71	5.00-6.94
Coordinated and comprehensive Care	6.02	0.87	3.24	7.00	3.76	75	5.15-6.89
Respectful and Supportive Care	6.28	0.69	3.89	7.00	3.11	77	5.59-6.97

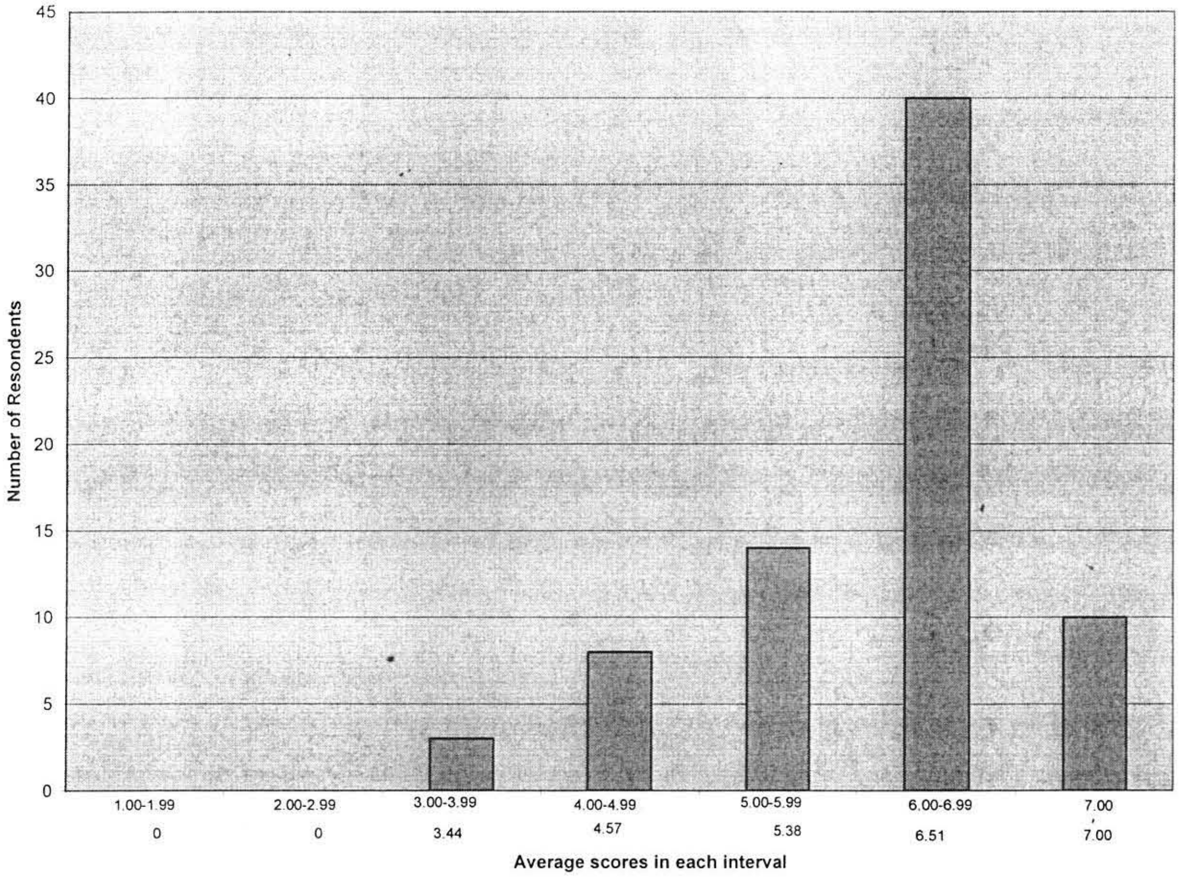
A score of four (4) on the MPOC indicates that services are provided in a family-centered manner "sometimes", as related to a specific scale score. Mean scores greater than four (4) signify "more than sometimes", with a mean scale score of seven (7) indicating that the respondents felt that services were provided in a family- centered manner "to a great extent" (Law, Brown, Barnes, King, Rosenbaum & King, 1997). Similarly, anything below the score four (4), can be interpreted as "less than sometimes". A mean score of one (1) indicates that services are "never" provided in a manner consistent with the family-centered principles.

The mean, the standard deviation and the range of scores were calculated to describe the variability in responses. In addition, the data were examined in terms of the range of values for each scale score within one standard deviation. This was done to look at the amount of variation in the majority of the responses (1 SD= 68% of scores) in each scale score, and to compare the range of responses between the five scale scores. A bar chart was created for each of the 5 MPOC scales (see figures 1-5, p.65-69) from (Table 10, Appendix- 9) which was created for this purpose. For the visual presentation of the scale scores, the values for each score were collapsed as follows: all the values from 1.00 to 1.99 in one category/interval, 2.00 to 2.99 in the next category/ interval up to 7.00 with similar increments.

Enabling and Partnership

The mean scale score for the Enabling and Partnership scale was 6.04 ranging from 3.44 to 7.00 (SD= 0.92). The values within one standard deviation ranged between, 5.12 to 6.96. The majority (40) of the scores on this scale were clustered between 6.00 and 6.99 (Figure 1).

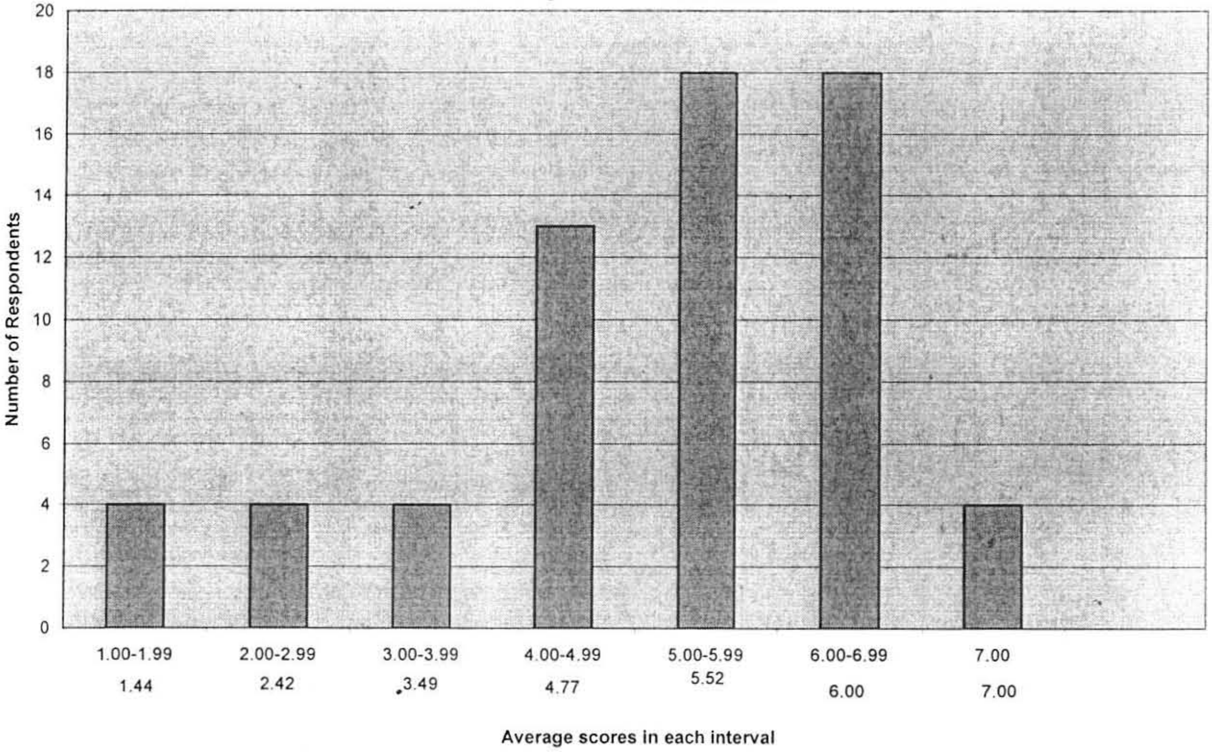
Figure 1
Enabling and Partnership



Providing General Information

The providing General Information mean scale score was 5.03, with a range from 1.00 to 7.00 (SD= 1.56). The scores ranged from 3.47 to 6.59 within one standard deviation from the mean score. This scale score had the widest range of values but also the largest number of missing values (14), n= 65 (Figure 2).

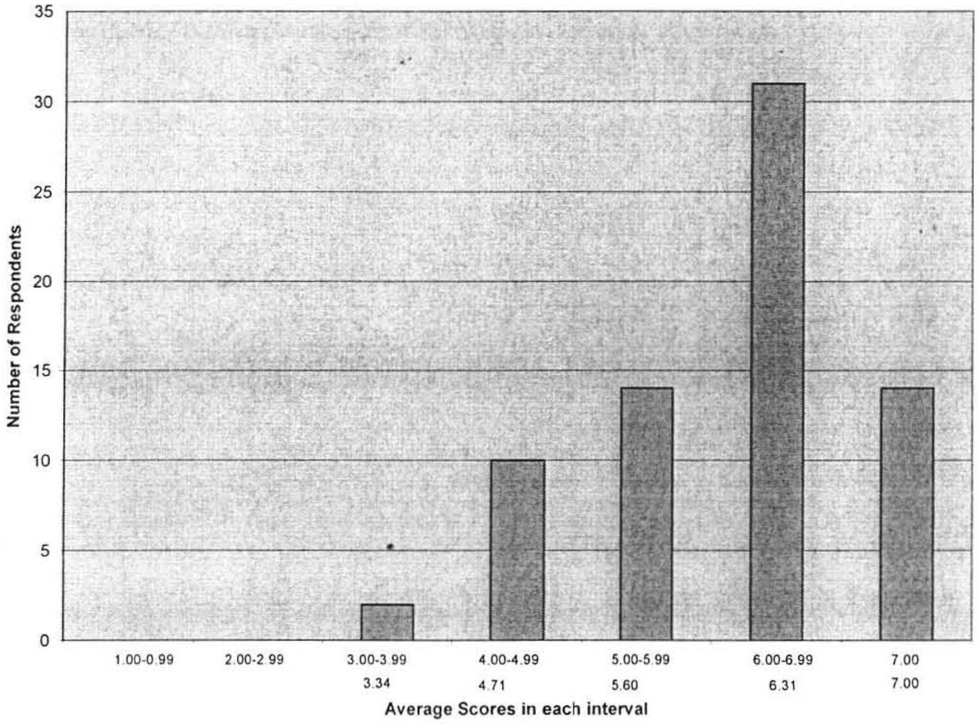
Figure 2
Providing General Information



Providing Specific Information on the Child

The values on the Providing Specific Information about the Child scale ranged from 3.00 to 7.00 (SD= 0.97), with a mean scale score of 5.97. The range of values within one standard deviation is from 5.00 to 6.94. Thirty one (31) scores are clustered between 6.00 and 6.99, with an even distribution of scores, 14 in each, in the 5.00 to 5.99 and 7.00 categories/intervals (Figure 3).

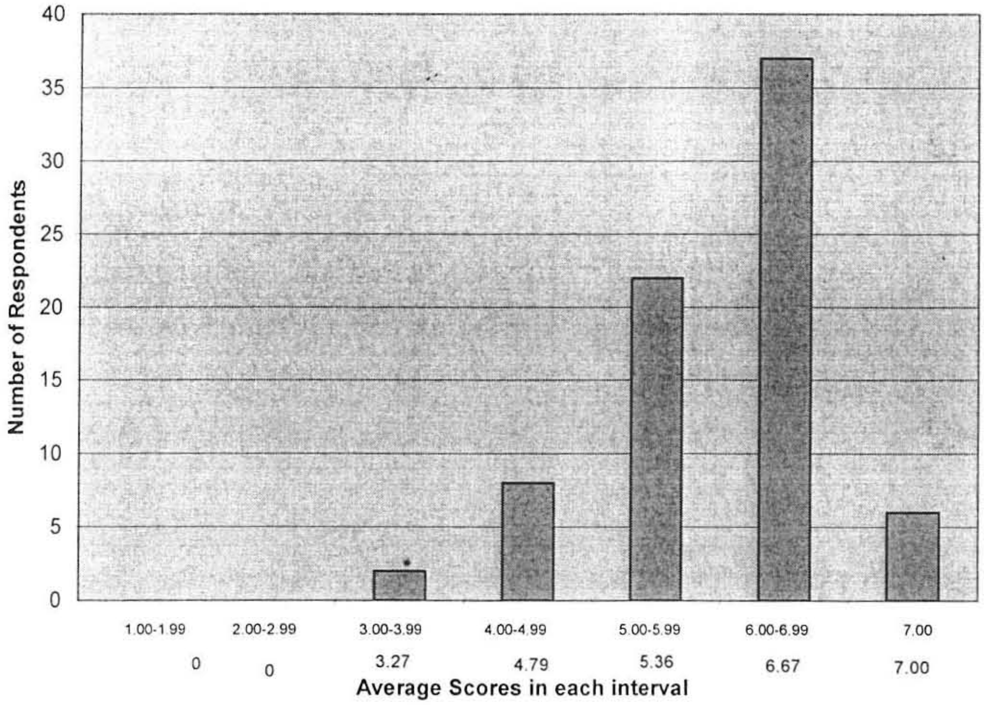
Figure 3
Providing Specific Information About the Child



Coordinated and Comprehensive Care

The Coordinated and Comprehensive Care scale has a range of 3.24 to 7.00 (SD= 0.87), with a mean scale score of 6.02. The scores within one standard deviation range from 5.15 to 6.89. The narrow range is evident in figure 4, with the largest cluster of scores (37) in the 6.00 to 6.99 category/interval.

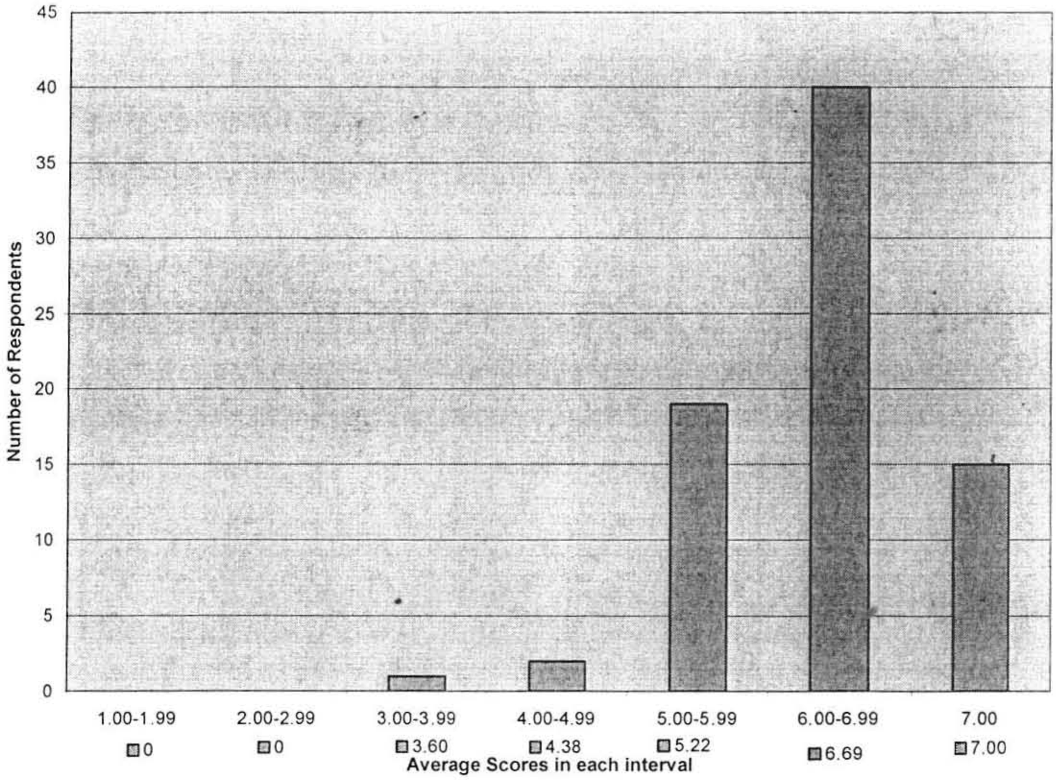
Figure 4
Providing Coordinated and Comprehewnsive Care for the Child and Family



Respectful and Supportive Care

The Respectful and Supportive Care Scale has a range of 3.89 to 7.00 (SD= 0.69), with a mean scale score of 6.28. The scores ranged from 5.59 to 6.97 within one standard deviation. Forty one (41) scores are found in the 6.00 to 6.99 category/interval, 18 scores fall in the 5.00 to 5.99 category/interval and 15 scores in the 7.00 category/interval (Figure 5).

Figure 5
Respectful and Supportive Care



The greatest amount of variability was detected on Providing General Information (Table 8, p. 61), with a range of 6.00 and values ranging between 1.00 and 7.00. While the scores within one standard deviation ranged between 3.47 and 6.59, a full range of scores were recorded (Figure 2). The Respectful and Supportive Care Scale has the least amount of variability with a range of 3.11, and values ranging between 3.89 and 7.00. The clustering of values in the higher end of the scale on all the five MPOC scales is evident in the visual presentation of the scales (Figures1-5).

The Respectful and Supportive Care scale has the largest number of valid responses (n=77), followed by the Coordinated and Comprehensive Care scale and Enabling and Partnership scale (both have n= 75). The Providing General Information scale has the largest number of missing values (14), with n=65 (Table 8).

4.2.2 The Measure of Satisfaction/Client Satisfaction Questionnaire

A mean score of 3.52 (SD=0.44) was obtained on the CSQ indicating high parental satisfaction with the program. Means scores ranged from 2.13 to 4.00 on the 4- point scale indicating that most parents were generally satisfied with the program. It is also interesting to note that even though the parents rated Providing General and Specific Information lower on the MPOC, they were still very satisfied with the care they had received.

Focus groups were conducted with parents to determine content validity using consensus methodology. Concurrent validity was determined by 2 correlation analyses as noted by (Larsen et al,. 1979): (1) the association between MPOC scores and scores from the Client Satisfaction Questionnaire, an- 8 item, satisfaction scale with a summated score (Pearson r= 0.46 to r = 0.77 across the 5 MPOC scales [n = 79]), and (2) the association between MPOC scores and the single item/question on goal achievement measure (Pearson r = 0.37 to r = 0.59 across the 5 MPOC scales [n= 79] as indicated below.

Correlation between MPOC and CSQ

The mean scores obtained on each of the five scales of the MPOC were correlated with the mean score obtained on the CSQ. The correlation coefficients ranged from 0.46 to 0.77 (Table 9) and were all statistically significant. The highest correlation coefficient was between satisfaction and the MPOC scale, Providing Specific Information. The lowest correlation coefficient was between satisfaction and the MPOC scale, Providing General Information. The results indicate that the MPOC scales correlate positively with the CSQ. That is, parental perceptions of care received during attending the CBR program are positively related to parental satisfaction with the CBR program.

4.2.3 Question on Goal Achievement

This question had a mean value of 5.12 (SD=0.97). A value of 5 indicates that parents, on average, perceived "quite a few" of their goals as being met during the program. This question had a wide range of scores from 3 indicating that "few" goals were met to 7 referring to "all" goals being met.

Correlation between MPOC and Question on Goal Achievement

When the mean scores obtained on the five scales of the MPOC were correlated with the mean score obtained on the single goal achievement question (Table 9), correlation coefficients ranged from 0.37 to 0.59. Only the General Information sub-scale of the MPOC failed to correlate with the single goal achievement question at a statistically significant level. Overall, there seems to be a positive relationship between parental perceptions of care and parental perceptions of goal achievement with the CBR program.

Table 9: Correlation Analysis between Mean Scores of the five Scales of the MPOC, the Mean Score of the CSQ, and the Mean Score of the Single Goal Achievement Question

	Enabling and partnership	**Providing General Information**	**Providing Specific Information**	**Coordinated and comprehensive care**	**The respectful and supportive care**	**The CSQ**	**The single Question on Goal Achievement**
Enablement and partnership	...	0.71***	0.77***	0.91***	0.86***	0.71***	0.59**
Providing General Information		...	0.61**	0.71***	0.51**	0.46*	0.37
Providing Specific Information			...	0.75***	0.57**	0.77***	0.51*
Coordinated and Comprehensive Care				...	0.85***	0.65***	0.55**
Respectful and Supportive care					...	0.64**	0.55**
The CSQ						...	0.78***
The Single Question on achievement Goal							...

Note: *** $\rho < 0.001$, ** $\rho < 0.01$, * $\rho < 0.05$

4.3 Comments by Parents

Majority of the respondent parents included comments about their perspectives of the care they received and 52% of parents made comments in a space provided at the end of the questionnaires. Even though, several themes emerged as a result of a review of these comments, using thematic analysis the themes emerged (the comments) could be divided in the following three categories:

(1) favorable comments about the Centre/CBR in general, the qualities of the staff(social workers), and specific services; (2) comments reflecting displeasure with the Centre /CBR on a personal level or with staff issues, and more general comments; and (3) general comments about the level of services, the questionnaires, and other service providers associated with the Centre/CBR.

1. Favorable Comments

These comments generally applaud the existence of the Centre/CBR, indicating that the Centre/CBR should be proud of what it offers to the community. A majority of parents were generally pleased with their interaction with the CBR staff (social workers), and found them to be helpful, knowledgeable, positive, and good communicators; they felt comfortable attending appointments and overall the comments reflect positive experiences with the CBR and the staff. Nearly half 49.37% of the parents in this study, also indicated that the staff (social workers) used family- centered care (behaviors) a majority of the time when providing early intervention services to their children. Several comments express satisfaction with specific services. Physiotherapy, occupational therapy, social work/family service coordination, program assistance, and care coordination are specifically mentioned. Special attention given by the CBR staff or social workers to parents/families during an especially stressful time was mentioned by several parents.

2. Comments Reflecting Displeasure with Aspects of Care

A second theme was that parents wished the CBR program could be longer. Thirty-two percent (32%) of the parents reported that they wanted more time to train, learn and practice on the various care-prevention, remediation and intervention/rehabilitation strategies. They commented that they were just beginning to train, learn and understand and then the program ended without further and they expressed their fear that this condition might be a risk for their children with disability.

On a personal level, comments from parents reflect feelings of being left out of decision-making, not being appreciated as someone who has valid comments about the care of the child, and feelings of inferiority in the presence of professionals, specifically supportive staff such as health care professionals who had involved directly or indirectly with their child care. Other comments address issues of staff competence, such as perceived lack of knowledge of a specific condition or failure to provide pertinent information to a parent. Other comments reflect some issues in the quality of the working relationship between a parent and a specific professional.

Other comments deal with the services provided by the CBR and health care centre in general. Twenty-eight percent (28%) of the parents commented on the assessment, intervention and treatment waiting lists and high caseload numbers, which affect timely service provision and treatment follow-up and availability of the professionals/CBR workers.

3. General Comments

The majority of cases, 47 (59.49%) in this survey study were commented as they encountered marital problems. As they were expressed, this is considered to be due to the additional demands of caring for a child with a handicap, though several other related factors may be involved. Spouses may disagree about the child's care or treatment and have insufficient time to resolve their conflicts. Several studies have also investigated the prevalence of negative effects on the marital relationship resulting from parenting a child with disabilities. For example, Max (1985) in Sharon and Roy (1992) noted that many parents of children with disabilities are reported to experience marital difficulties.

In addition, some of the respondent parents also reported that as the social life of their families tends to be restricted; as their families have to meet additional expenses (as a result their income reduced /deteriorated from time to time); as they do not received the benefits to which they are entitled. These issues also have been stressed by several professionals as follows: The social life such as family activities, leisure activities of many families with members who have disabilities tends to be restricted (Lonsdale, 1978 cited in Sharon & Roy, 1992). Families with children who have disabilities have to meet additional expenses (Lonsdale, 1978 and Murphy, 1982 cited in Sharon and Roy 1991).

These are most often for medical care, clothing and transport. The family's income may be reduced since one parent (more specifically, mothers) is prevented from going out to work because of the daily care requirements of the child with disability. Most countries have various financial benefits available to assist such families. However, this survey study showed that many parents in our country do not receive the benefits to which they are entitled as stressed by Hornby (1987) in Sharon and Roy (1992). Professionals must therefore, convey to parents by every means possible information about the benefits and services for which they are eligible.

Some responses contained specific comments about the questionnaires. Comments included reference to the fact that the instructions were clear and that the questions covered all areas of care. Some parents had not a more difficult time filling out the questionnaires as many areas applied to their situation, especially in cases where they did feel that their child had special needs.

In three cases parents felt that it was important to comment on the collaborative activities of the Cheshire Services Ethiopia-CBR, Health Care Centres including Black Lion, other children care centers and other agencies or individuals, including the society of Addis Ababa (community members), the family centre and the family physician.

CHAPTER FIVE

5. Discussion, Summary and Conclusions

5.1 Discussion

In general, the results confirm that the respondents' perceptions of the services are congruent with the service philosophy of the Cheshire Services Ethiopia (Cheshire Home)-CBR for children with disabilities. The agency bases its service philosophy on family-centered intervention principles and a care coordination model. The families who responded to the survey indicate that the services are being provided in a family centered manner. However, it is not possible to simply conclude that the center's Family-Centered Intervention/Care coordination model was the leading factor to which the high scale scores can be attributed. Factors challenging and supporting the findings are discussed below.

5.1.1 Response Rate

It is known from the literature that parents of children with disabilities, more specifically, those with long-term health care needs are typically difficult to engage as participants to research (Marchenko & Smith, 1992; Nelson, Ruch, Jackson, Bloom, & Part, 1992). With that in mind, the response rate warrants some discussion.

All survey packages/questionnaires were returned immediately, within 2 hours time interval, after administration and the response rate was 100%.

In evaluating other studies done on the topic of children with disabilities or chronic illness, researchers have favored designs and methodologies that allow small sample sizes, possibly participants. In their study, Marchenko and Smith

(1992) interviewed 32 mothers of children with both a developmental disabilities and chronic illness to study and formulate a family-centered intervention and care coordination model. Nelson et al. (1992) enrolled families of 42 children with developmental disabilities and chronic illness to study and formulate a family -centered intervention and care coordination model. Nelson et al. (1992) were able to engage ten families of adolescents with physical disabilities to study the family-dynamics and needs of the physically disabled and non-disabled offspring.

In developing the MPOC questionnaire, King et al. (1995) were able to engage forty parents from two children's treatment centres for the pretest. King, Rosenbaum and King (1995) also sampled parents from thirteen treatment centre for the pilot-test of MPOC. The response rate for the convenience sample was excellent, at 74.8% (n= 653). The response rate was also quite good at 62.3% for a field-testing sample examining some aspects of reliability and validity. These MPOC data were collected using an interview format/method.

It is important to evaluate the possible bias introduced to the results due to response selectivity. People who have good literacy skills are more likely to respond to written surveys. The MPOC questionnaire is rated at grade 8 reading level (King, Rosenbaum & King, 1995) whereas the CSQ-8 questionnaire is rated at grade 7 reading level (Larsen et al., 1979). The majority of the parents who responded to the survey in the present study have an educational level less than grade nine (69.62%). The largest category (58.23%) of the respondents have grades one to eight /elementary school level of education, followed some high school /grades nine to twelve educational level (24.05%) and have no schooling /have no formal education (11.39%) (Table 7).

The returns did not include two incomplete questionnaires, suggesting that the instrument was acceptable to the respondents in its length and clarity.

It is anticipated that the level of interest that people have on the topic of the survey will influence the response rate (Fowler, 1993; Weisberg & Bowen, 1977). It is possible that the 2 families, who chose not to respond, do not see the Cheshire Services Ethiopia-CBR for children with disabilities- as a very integral part of their life. It is also possible that they may not find the services that they receive from the CBR particularly helpful or a necessary part of their lives. On the other hand, it is also possible that if people have no concerns regarding the services, they do not see a need to respond.

5.1.2 Demographic Data

The Child and Family Background Form provides comprehensive information on the characteristics of the child, the family structure, educational level of the family, level of coordination/decision-making/control over the services they and their children received, the frequency and length of involvement with the CSE-CBR, and the type of services received from the CSE-CBR Centre by the respondents and their child.

The age range of the children was greater than initially anticipated (1 year and 9 months to 13 years and 9 months). Typically, children over 6 years of age are served through the Community Care Access Centre Sponsored School-Health Support Services in their school setting. Some older clients may be served by ~~the~~ some professionals other than the staff (social workers) from the Cheshire CBR Centre, usually through an individual agreement between the parents and the professionals in their health care and schooling. This in itself signals a certain amount of flexibility within the program and sensitivity to individual client needs. The data from families with the older children were included in the research because it was felt that they met the criteria for selection for the survey by receiving services from the CBR on the home-based program. However, most of the children were between 24 months and 5 years and 11

2 years

months, which is well within the age range of children who typically receive home-based services from the CBR program. The mean age (Mean=4.16 years) was elevated due to the older children (Table 1).

More than half (60.76%) of the children were males. Jackson, Finkler and Robinson (1992) similarly note the over-representation of male infants in some research projects involving infants with disabilities, suggesting increased developmental vulnerability of boys. It is beyond the scope of this study to explore gender distribution in relation to the results.

The primary diagnoses identified by the parents reflect the growing diversity of the clientele of the Cheshire Services Ethiopia-CBR projects/program. In the past, a typical client may have been a child with a primarily physical disability. Today, a wide range of needs are being served, including children with multiple disabilities, pervasive developmental disorders, and undiagnosed conditions.

About 35% of the respondents identified other special needs for their children, in addition to the primary diagnosis. This constitutes a certain stress factor for the family, with increased treatment and service coordination needs (Bernier, 1990; Peckham, 1991).

More than three-fourth (83.54%) of the parents who responded to the four types of questionnaires have frequent contact (weekly) with the CBR staff (social workers) (Table 2). A small number of families (n=13 or 16.46%) noted that they were visited by the CBR staff (social workers) monthly. Since the CBR social workers had been to their home for home-based services (rehabilitation), within the past year, their responses were also valuable and included. The Cheshire CBR program's least frequent visit schedule is an annual recall assessment even though it was not presented in this table, as commented by some parents. However, occasionally due to scheduling difficulties, more than twelve months will elapse between visits.

There seems to be a core group of parents who were visited by the CBR staff (social workers) on a weekly basis. The second largest groups of respondents have monthly contact with the staff. The frequency of visits tends to be linked to severity of disability and the number of services received. Children who have multiple disabilities or relatively severe disabilities receive a greater number of services, and at a greater frequency (less than once a week) than children with milder disabilities. Proper coordination of services becomes important with the greater number of contacts at the home-based intervention and in the community.

Just over half of the respondents (50.63%) have been involved with the CBR (home-based intervention) for two or more years-more specifically, four years of involvement on the average. Over 70% have an involvement of one year or more. Seven (8.86%) parents reported an involvement of less than six months. Since the intake protocol is quite intensive, with a pre-assessment visit from the Family Service Coordinator, an assessment and the establishment of a care plan within six weeks of referral, responses from parents who had recently become involved with the CBR provide valid information on the process.

In general, parents who have more frequent contact with the CBR were represented in much greater numbers than those parents who have less contact with the CBR. However, there may be some proportion of non-respondents who also have frequent contact with the CBR, and may have very different responses from the ones who chose to respond.

The core therapy services provided by the CBR staff were rated as those most frequently received by the children. In that sense, the respondents were families who received the typical services offered by the CBR program. The most often mentioned services include physiotherapy, occupational therapy, seating/mobility, social work/family service coordination, and program assistance/aide in descending order.

A considerable range of services being received, by the families, (0-7, Table 2). On average, a child received three different interventions at one time. Children who did not receive any services at the time of the survey were possibly on a service break, or received services less frequently than some of the regular clients. Some children were visited by CBR staff [team coordinators) once, twice, or four times a year for a recall assessment but they do not require interventions in between the visits.

It was interesting to note that the majority (74.69%) of the parents considered themselves as the care coordinator. The service/care coordinated by the spouse was listed as the second largest group (20.25%) (Table 3). The fact that the families reported a number of different care coordinators suggests that the system allows parents to engage a service coordinator who is suitable to their particular needs and with whom the parents are comfortable.

Little variability was detected in language spoken at home. Most people were Amharic speaking (50.63%). About 29.12% listed Afan Oromo, 8.86% Tigrigna and 11.39% another as the language spoken at home. The size of the family varied from *a small nuclear family* (the child and one-or two-parents) to *a large family* with many siblings. Family size influences the availability of resources, such as finances and time, and the parents' ability to manage the resources (Bernier, 1990).

The majority of the respondents reported that both parents (two-parent family) were not employed at the time of the survey.

Based on the data, the characteristics of the respondents could be summarized as follows: the family would have one or more children. The child with special needs would be approximately 4 years old and would receive 3 different interventions from the Cheshire CBR program. The family would have been involved with the CBR for at least 6 months. The parents, more specifically, the mothers would be the primary coordinator of the services and resources. She could be expected to have at least a basic education, and work outside the home full or part-time.

Even though the response rate was very high (100%), it is not possible to conclude that the responses are representative of the survey population. However, there are a number of characteristics common to the population and the respondents that support the validity of the responses. For example, the majority of the children fall between the ages of two years and five years and eleven months. This is, the typical age of children involved with the Cheshire CBR. Also, the primary diagnoses of the children seen in the Cheshire CBR centre are compatible with the survey data. Of the total caseload, nearly half of the children are referred due to motor developmental delays/ motor disorders. A number of these children later receive a diagnosis of cerebral palsy and/or spina bifida (hydrocephalus). These categories are congruent with the responses obtained from the respondents (Table 1).

It is also noteworthy that the data summarizing the families' involvement with the CBR reflect the core services offered, namely, various therapy services (physiotherapy, occupational therapy, and seating/mobility) and social work/family services coordination. Of the total caseload, three-fourth are seen on an active basis (once a week), one-fourth on a consult basis (once a month or less than once a month depending on the situation of a case) and the others are seen only for check-ups (once, twice or four times a year), though the last one was not present in Table2 (Personal Communication, Health Information Services, Cheshire Services Ethiopia-CBR for Children with Disabilities, March 2007). The results indicate that five times more responses were received from families whose children are seen on an active basis than from those of a consult basis.

Finally, the respondents' residence is comparable to that of the population. Most families reside in Addis Ababa.

The non-respondents whose literacy level is lower/higher than those who responded are an issue of concern. As discussed above, even though an interview format/method tends to generate responses from highly educated individuals, this seems to be not the case in this research, as the responses rate was highly satisfactory (100%).

5.1.3 Family-Centered Care/Intervention Practices-Scale Score Results

5.1.3.1 The Measure of Processes of Care (MPOC)

In general, the outcome of the survey was very encouraging and positive for the Cheshire Services Ethiopia-CBR program for Children with Disabilities. On the perceptions of care measure, the CBR program was rated very highly on three scales. These were: Providing Respectful and Supportive Care which includes treating each client as an individual rather than as a case and providing enough time to talk so that clients do not feel rushed; Partnership and Enablement which includes explaining reasons for treatments, explaining treatment choices fully, and enabling clients to choose when to receive information, the type of information they would prefer and which treatment they want; and Providing Coordinated and Comprehensive Care which refers to having a continuous relationship conducive to the expression and resolution of needs, and valuing continuity in services and the individuals providing these services.

Providing Specific Information about the Child and Providing General Information were given lower ratings by the parents indicating that parents felt that the program provided information "sometimes" (King, Rosenbaum & King, 1995). For the scale, Providing General Information, the range of scores was from 1.00 to 7.00, indicating that some parents ranked the items very low. The items in the Providing General Information scale consider providing parents with information, both spontaneously and in response to questions, providing advice on how to get information, and providing information about services available in the community. For the scale, Providing Specific Information, the range of scores was from 3.00 to 7.00, also indicating that some parents ranked the items very low. The items in the scale specifically relate to the provision of verbal and written information on the child's assessment and treatment sessions. The results on these two scales are surprising in that the program provides information specific to the child by encouraging all parents to observe assessment and treatment sessions, and the provision of written handouts and reports. General information is also provided in the weekly parent group and through written handouts. However, some parents evidently felt that not enough information was provided. The mean scores on all the five scales of the MPOC were higher than five (5). As is mentioned above, three scales (Enabling and Partnership, Coordinated and Comprehensive Care and Respectful and Supportive Care) were rated higher than six (6) (Table 8, p. 61). All scale scores had minimum values below the score 4, indicating that some parents perceived the family-centered behaviors happening less than "sometimes".

The majority of scores fell within a fairly narrow range. All were above 4, which can be interpreted to mean that services are being provided in a manner consistent with the family centered values and principles (King, Rosenbaum & King, 1995). Parent statements seem to suggest that in general, they have opportunities to participate in the planning and implementation of the care plan. They feel like partners in their child's care, they have opportunities to make-decisions about treatment, and professional practitioners trust them as experts on their child (MPOC, Enabling and Partnership Scale). There seems to be a sense of collaboration between parent/family and professional /CBR practitioner and respect for the strengths of the family.

According to the data, the Cheshire CBR provides coordinated services. Parents' responses to questions such as "to what extent do people who work with your child plan together so that they are all working in the same direction?", indicated that they felt it happened more than "sometimes". The majority of the responses indicate that the services are provided in a holistic manner. The child is treated within the context of his/her family and environment.

The mean scale score of Respectful and Supportive Care is very high (6.28) with the majority of the scores falling well above the score of 4.00 (Table 8). These responses suggest an environment that fosters parent competence and *non*-judgmental attitudes.

The widest range of responses was obtained in items concerned with parents' general information needs (Providing General Information scale). This scale refers to such items as how to contact other parents or information on resources and services within and beyond the Cheshire CBR centre. The mean scale score of 5.03 is a little surprising if one compares its range of responses (1.00 – 7.00 = 6.00) to the range on the Coordinated and Comprehensive Care scale (3.76), which was rather narrow with a mean scale score of 6.02. One might think that in order for services to be well coordinated and provided in a comprehensive manner, people would also feel that they have all the possible information that is pertinent to their situation. One may postulate that parents find the services related to the needs of their child well coordinated. However, general information relevant to the entire family may not be as readily available. The range of responses in the Providing Specific Information about the Child was narrower (4.00) than the general information scale, and the mean score was relatively high (5.97). This point is certainly reflected in the literature on family centeredness and continues to be one of the challenges faced by service providers (Arango, 1990; Cardoso, 1991; Diehl, Moffitt& Wade, 1991; Letourneau & Elliot, 1996; Summers et al., 1990; Winton & Bailey, 1997).

5.1.3.2 The Measure of Satisfaction/Client Satisfaction Questionnaire

As hypothesized, perceptions of the program as family-centered were significantly positively correlated with satisfaction scores. The Cheshire CBR program received high ratings by the parents on satisfaction. This positive relationship is in keeping with the theoretical literature and previous research. Caro and Derevensky (1991) found a similar positive relationship for a home-based intervention for families who had children with moderate or severe disabilities. Jackson, Bradham & Barwall (1978) and Styba et al. (1992) also found a positive relationship between parental satisfaction and parents being involved in all aspects of their child's care. Dunst et al. (1988) reported that if health care providers used the behaviors that are consistent with family-centered care, families would be empowered and positive outcomes would result from the care that they received including satisfaction with care. Branspach (1986) also found that when parents perceived control over their child's program, they felt more satisfied with the program.

Other factors may be involved in the relationship between the family-centeredness of a program and satisfaction. It may be important that parents have finally found a program that will listen and address their concerns. Many of these parents have been seeking help for an extensive period of time, being told that nothing is wrong or that their children will outgrow their difficulties. Another factor may be the parents' perceptions that their children have improved in attending the program. Parental satisfaction could be linked to child's development of skills as suggested by Kopec-Schrader et al. (1993) and Plapp and Rey (1989). A study that compares child-centered to family-centered *care* is needed, to examine these additional factors. Also incorporating qualitative methodologies such as interviews rather than rating scales to measure satisfaction would provide more information on the high satisfaction ratings received. Satisfaction questionnaires must be interpreted with caution due to the high levels of reported satisfaction caused by factors such as the halo-effect (Tuckman, 1994) and *social* desirability (Lebow, 1983). The Cheshire CBR program/Centre has collected satisfaction information for the past few years and report that their ratings are always high. A factor that may be linked to satisfaction is that perhaps the parents are grateful for any services that they receive. Looking more closely at satisfactions might be beneficial.

5.1.3.3 Question on Goal Achievement

As hypothesized, parental perceptions of care were also positively correlated with parental perceptions of goal achievement. In looking at the results obtained on the single question on goal achievement all parents felt that "quite a few" of their goals had been met. The results illustrate that there is a moderate relationship between goal achievement and enablement and partnership, providing specific information, providing coordinated and comprehensive care and providing respect and supportive care.

Enablement and partnership, and respect and supportive care are linked to empowerment which is a key concept in family-centered care. Dunst, Trivette & Deal. (1994) list two characteristics of the health care provider that help to promote empowerment in the client or the family. The first is the belief that people are competent or have the capacity to be competent. This characteristic is congruent with the quality of providing the client with respect and support. If you feel that someone is competent then you will most likely treat them with respect. The second characteristic is enablement, which refers to creating opportunities for competence to be learned or displayed. This is consistent with the findings here that the two qualities of care most associated with goal achievement in this study were providing respect and support, and enablement and partnership. Since these are two significant factors that lead to empowerment then it makes sense for them to be linked to goal achievement. The family that is empowered will be able to insure that their goals are met.

McBride et al's. (1993) principles of family-centered care also highlight the concepts of respect, support and partnership.

The positive relationships between goal achievement, partnership, and providing support are in keeping with the theoretical and research literature. Adubato, Adams & Budd (1981) and Schriebman, O'Neil & Koegel (1983) both conducted studies which demonstrated that partnerships formed between therapists and families supported them in successfully working towards achieving their goals. Minke and Scott (1995) reported that models that stress enablement of families are based on the philosophy that family goals take priority and must be respected. In this study, more or less the Cheshire CBR parents set the goals, prioritized them and then ranked them to measure achievement. Bass and Leavitt (1963) and Latham and Locke (1979) reported that goals are more likely to be successfully achieved when a person sets his/her own goals. Further studies are required to look more closely at this relationship to determine if other factors may be contributing to this relationship.

In order to define the needs of families, and for service providers to respond to those needs, input from families is required. Arango (1990), herself a parent of a child with complex-health care needs, emphasizes that this should not be done on a piecemeal basis. Rather it should be done by designing service models that have built in processes that support families. This can be accomplished by involving parents in agency policy-making; in evaluation of services through family-advisory councils; and in having parent representation on the board of directors. One of the continuing dilemmas for parents is stress and time demands. The complex needs of a child with disabilities often rob parents of time and energy to participate in agency functions.

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If these indicators are related to the current research, the items on the Coordinated and Comprehensive Care scale represent similar concepts. Parents were asked to rate to what extent the following happens: TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD. . .

1. ... suggests therapy plans that fit with your family's needs and life style?
5. ... take time to establish rapport with you or your child when changes occur in your services?
10. .... Provide ideas to help you work with the health care "system"?
13. .... Look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?
21. ... Make sure that at least one team member is someone who works with you and your family over a long -period of time?
34. ... plan together so that they are all working in the same direction?
44. ... make themselves available to you as a resource (e.g., emotional support, advocacy, information)? (MPOC, 1995)

The Coordinated and Comprehensive Care scale consists of seventeen such items. The overall mean scale score of this scale is 6.02 of a maximum of 7.00 with the majority of scores (within one standard deviation) falling within the range between 5.15 and 6.89. The high average score indicates respondents' perceptions that the indicated behaviors do take place within the context of the service provision principles.

In evaluating her research, Berkowitz, Halfon and Klee (1992) discuss strategies for successful case management (care coordination). Their findings suggest that the relationship aspects of case management (care coordination) are especially important. To achieve successful outcomes the case manger (care coordinator) needs to work with clients, show empathy for the client's situation, and work with the client's [priorities, as well as to promote client to client support. These principles are compatible with the relationship-related helpgiving attitudes that Dunst et al. (1993) promote in their enabling and empowering model. This model seeks to enhance family strengths and competencies and independent resource management. The family centered principles outlined by Shelton, Jepson and Johnson (1989) and others promote similar approaches.

The findings of this research are therefore compatible with literature on family-centered care/intervention models, which support the notion that the model is satisfactory to parents dealing with health care systems (Kaufman, 1992; Marchenko & Smith, 1992). It may be possible that the model is especially suitable for situations where parents have frequent contact with the service providers. The interactions may foster collaboration and opportunities for the exchange of ideas. Parents also have an opportunity to learn skills related to the treatment needs of their child, which enhances their competence as parents (Cormany, 1993; Moore, 1992). Professional practitioners get to know the families well and will be able to plan treatments that are suitable for the family's life style and involve the resources and supports available.

5.1.5 Comments by Parents

The results of the thematic analysis of the comments that parents independently added to the end of the questionnaires, quality some of the responses to individual items. For instance, some of the parents' comments may help to understand the lower ratings on the two scales of the MPOC-Providing General Information and Providing Specific Information about the Child. Many parents felt that their child's handicapping/health conditions had improved in the process of the CBR program which was received on home-based intervention and parent's whished the program could be longer so that they could have more time to learn and practice the various rehabilitation/

intervention strategies. The results on the two scales of MPOC suggest that the parents may not have received enough general and specific information because of the short-term nature of the program, and the fact that the majority of the program was only home-based intervention rather than the combination (home-based and centre-based). Shortage of qualified professionals in the area of the CBR practitioners that is, qualified social workers, care coordinators, case managers, etc, could also be mentioned as a contributing factor. Therefore, even though the CBR staff may perceive that they provide a great deal of information because of these three reasons (and probably because of other reasons which were not identified in this survey) the parents are asking for more information or for information to be delivered in another format. The comments that the parents made regarding the above issues-having the combined form of intervention settings and a longer program have been also reported by some studies conducted previously. Mahoney, O'Sullivan and Dennebaum (1990) found a strong relationship between mothers' perceptions of the family-centeredness of a program and the effectiveness of intervention services received. They also found that programs with both home-based and centre-based components tended to have a greater family-centered orientation. Yoshikawa (1994) reported that successful programs for children with disability (behavior problems) must be at least 2 years in length, and involve both home-based family support and centre-based educational day-care and preschool.

Assael (1985) in William & Michael (1988) also noted the following points about home-centre intervention programs. Perhaps the most commonly used intervention model is the one that offers both centre-based activities and home-visitation. Few centre programs take children for more than a few hours a day, for up to 5 days a week; but for young handicapped children intervention must be more then a few hours a day. Thus, many programs combine the intensive help of a variety of professionals in a centre with the continuous attention and sensitive care of parents at home. This effort to establish intervention that carries over from centre to home clearly offers many of the advantages of the two types of programs and negates some of their disadvantages.

The parents' perceptions of the centre (CBR) services are qualified with comments about the helpfulness and the friendliness of the staff. More specifically, these comments describe the qualities of staff (social workers), including such descriptive as helpful, friendly, supportive, encouraging and caring. Many parents commented on their support needs and how the CBR staff is able to meet these needs. The comments certainly reflect some of the aspects of care that family -centered service philosophy fosters.

The respondents who were not pleased with the services or service providers address similar relationship issues. Some parents felt that they were not supported and unable to become a part of the "team".

In general, there is a good variety of comments. Some express satisfaction with the services, some displeasure, reflecting the range of responses on the various scales.

It is evident that from the Cheshire Services Ethiopia- CBR's point of view, there is room for improvement. An ultimate goal for any service provider would be that no parent needs to express dissatisfaction with their relationship with service providers or their ability to access the services and participate in the care process. Other issues, such as waiting lists, are beyond the staff's control. However, the agency can continue to develop services, addressing the waiting list and other service issues in a manner compatible with the family-centered principles.

5.2 Summary

Overall, the results of the survey were encouraging. The parents of children with disabilities (long-term health care needs) are typically difficult to survey. Lack of time for self and normal daily-activities is a major issue for families of children with special needs (Slater & Wikler, 1986). These issues possibly affect to some extent the response rate of the survey although it was not the case for this particular survey study. Personal interview format/method was chosen to administer the survey package in hopes to promote a confidential and anonymous forum for responses as families selected for the survey were receiving services from the Cheshire CBR Centre.

All of the survey packages/questionnaires administered to the respondents were fully completed, speaking for the appropriateness of the instruments for the research-in terms of relevance, clarity and length. Most respondents had an education less than grade 8 literacy levels, but easily complete all the questionnaires without any difficulty. Language was not an issue as most respondents were Amharic speaking and the English versions of the questionnaires were translated into Amharic language and modified for the purposes of this survey study.

The responses were representative of parents who interact with the staff of the Cheshire CBR on a frequent basis. Mothers of children with disabilities still seem to carry the main responsibility of care/service coordination. The children receiving services were identified with a wide range of diagnoses, reflecting the current trend in service provision in children's treatment centre or in other service provision settings.

The high scale scores on each of the MPOC scale in this study: Enabling and partnership, providing General Information, providing Specific Information about the Child, Coordinated and Comprehensive Care for the Child and Family, and Respectful and Supportive Care), the CSQ and question on goal achievement indicated that services were in general perceived by respondent parents to be provided in a family-centered manner in the Cheshire Services Ethiopia-CBR centre. The impact of service/care coordination on the parents' perceptions on the services is still unclear. However, service/ care management (coordination) principles appear compatible with those of family-centered care/ service principles, and may help to facilitate the implementation of family-centered care/services.

Further research is needed to explore the demographic characteristics of the respondents and any influence that those factors might have on the responses. Also, further research is required in learning more about the role of the service/ care coordinator in enhancing the family-centered care/services. The child-level is not presented in this model which is a serious concern. To further complicate the picture child-dimensions need to be added

In today's climate of financial constraint and restructuring in every sector, especially in the field of health care, this research helps to underscore the importance of the holistic care for the child and the family. Children with special needs (long-time health care needs) have a hard time fitting into the service delivery system. Long-term care is dominated by issues dealing with the growing population of the elderly, adults with disabilities and mental health services. The education system is coping with funding cuts and changes in teachers' contracts and class sizes. The issues addressing the needs of children with disabilities are not seen as priority for the decision- makers. Child welfare falls in the realm of mandated services, such as protective services, leaving issues regarding children with disabilities to be dealt with by the Ministry of Health. Even though the making services work for people (the Constitution of the Federal Democratic Republic of Ethiopia (FDRE), December 1991 and the Developmental Social Welfare Policy (1996) on Health Care, Education and Social Services) document is beginning to bridge the gap between different services systems, a great deal of work is required to facilitate avenues for the different ministries to talk to each other.

Consumers of services are expected to manage/coordinate their own resources to an increasing degree. This is done to promote a collaborative approach, but also to limit the time and resources of professionals. If service/care coordinators can help to empower families, create positive self-sufficiency, teach assertive and advocacy behaviors, and import independent decision-making skills as expected according to the family-centered care /intervention model, families will be in a better position to negotiate their way through the various systems created by separate ministries for health care, education and child welfare (Cormany, 1993; Fiene & Taylor, 1991; Hartman & Laird, 1983).

5.3 Conclusions

Even thought the response rate was very high, the findings of this survey study need to be treated with caution. When comparing the demographic characteristics of the families who responded to the survey with those of the entire population, one can present an argument that certain similarities exist. These similarities can be viewed as supporting the validity of the responses, even though generalizations to larger populations are not possible.

From the scale scores it is possible to conclude that respondents perceive the Cheshire Services Ethiopia- CBR (Treatment Centre) services to be provided in a family–centered manner. The composition of the families and their service needs varied .This supports the families that at least according to the respondents' perceptions, the CBR Centre, indeed operate within a family-centered philosophy, able to respond to the unique needs of individual families. The Centre uses a family–centered care/intervention model to implement family-centered services. In the discussion section, indicators of care/service coordination effectiveness were discussed and how these indicators are consistent with the items in the Coordinated and Comprehensive Care scale. It is not possible to conclude from this exploratory study that the implementation of the family-centered care/intervention model has a direct relationship with high scores on the MPOC, the CSQ, and Question on Goal Achievement. However, one may postulate that family-centered service provision and care coordination are compatible and that the care/intervention model appears to be facilitative of family-centered practices. Family-centered care/intervention model can be seen as one way of implementing family-centered services. To this end, from the preceding discussion, the following conclusions are drawn:

1. Parental perceptions of care, specifically, the extent to which a program is perceived to be family-centered, are positively correlated with parental satisfaction in the CBR programs.
2. Parental perceptions of care are positively correlated with parental perceptions of goal achievement in the CBR program. The qualities most highly related are enablement and partnership, and providing respect and supportive care.

5.4 Implications

5.4.1 Implications of the Study for Family-Centered Intervention

As indicated in the literature, family-centeredness is a comprehensive service philosophy which is implemented on all levels of services, from direct services to policy-formulation at the agency (Korteland & Cornwell, 1991; Mahoney, O'Sullivan & Dennebaum, 1990; Shelton, Jepposn & Johnson, 1989). Whether care/services coordination is an effective way of implementing the model has been one of the major focuses of this research. The findings indicate that in general, respondents perceive the services to be provided in a family-centered manner. The majority identified themselves as the care coordinator for their child. This is of course, the ultimate goal of family-centered intervention care management and coordination (Brown, Thurman & Pearl, 1993; Cormany, 1993; Fiene & Taylor, 1991; Kaufman, 1992). Research also suggests that the success of early intervention services relies on a positive supportive relationship between members of the early intervention team and caregivers (Phys Ther, 1997; Kalmanson & Seligman, 1992; Washington & Schwartz, 1996; Shonkoff & Hauser-Cram, i987; Able-Boone, 1996). However, it is not known, to what extent parents were influenced and encouraged to assume this role by the family service coordinators (social workers), team and other caregivers.

In this study, positive relationships were found between the family-centeredness of the program and satisfaction with the program. A statistically significant positive relationship was also found between the two MPOC scales: providing support and respect, and enablement and partnership, and goal achievement. These findings suggest that there is a positive association between the CBR program staff adopting the characteristics of a family-centered model and enhanced parental satisfaction. The findings also suggest that it is two particular characteristics of family-centered care that the CBR program staff should consider adopting that is associated with goal achievement. These include providing the families with support and respect, and providing the families with the opportunities for enablement and partnership to occur. The parents who participated in this study indicated that the program provided information, both general and specific, "sometimes". This indicated that service provider agencies may wish to find a variety of ways to address these areas of family functioning in a family-sensitive manner.

The parents also identified three issues that are important to them and their families. First, they identified the need for not only more home-based intervention to help them to generalize the strategies that they learned but also they need in the center-based component of the program (that is, the combined form of intervention: both home-based and center-based programs). Second, directed toward administrative components of care (e.g., mothers identified the need for a longer program-they wanted more therapy services for their children and more consistent appointment times). Finally, parents identified the need for good follow-up programs. These are three issues that the CBR Centre as well as teams and caregivers need to consider in order to ensure that the needs of families are met.

Parental input is essential in understanding aspects of caregiving that they value and that will empower them in meeting their child and family's needs. To provide effective care/services to families who have children with disabilities (long-term health care needs) it is essential to provide them with respect and support throughout the program. It is also essential to believe that they have the skills and the abilities to acquire the knowledge they require to help their families meet their needs and priorities. These approaches would allow for analysis of family strengths and needs, using the family-centered care/service model as a means of implementing family-centered intervention.

The themes identified by some respondent parents in response to open-ended questions summarized as follows: Formal support systems such as early intervention or social service programs are too rigid to meet the individual needs of some families. Regarding this issues, Viscardis (1998) also suggested that some agencies and institution may not have clear guidelines or strong commitments toward implementing family-centered care (intervention) .These comments suggest a need to incorporate a measure of program policy or agency practice in to program evaluation and clinical research.

Measurement of family characteristics, such as informal family support systems, might increase the exploratory power of the model. Informal family support systems include extended family and neighborhood networks that are reported to have a protective influence on parenting stress, which is also a predictor of parents' perceptions (Gallagher, Beckman & Cross, 1983; Dunst, Trivette, Dyson & Fewell, 1989). Informal family support systems may mediate the influence of children's handicapping conditions (limitations) on parenting stress, and in turn, on parents' perceptions of therapists' family-centered care/behaviors.

As a point of interest, the Neurodevelopment Clinical Research Unit (1995) provides the scale score values for the children's treatment centre that participated in the development of the MPOC questionnaire. All thirteen centres rated between 5.00 and 5.70 on the Coordinated and Comprehensive Care scale. In the present study, the Cheshire Services Ethiopia-CBR Centre's score in this scale is 6.02, which is somewhat higher than that of any other children's

6.28 with (SD= 0.69_1.56) for a sample of 79 parents (94.94% were mothers). King, Rosenbaum and King (1995), reported mean scores on the 5 MPOC scales for a sample of 653 parents (78% were mothers) that ranged from 4.13 to 5.79 with (SD= 1.11_ 1.60).Most children's treatment centres in this study operate on the family-centered principles. In the researches done in our country's context (Ethiopia's literature), this researcher is not aware of any other children's treatment centre /CBR operate on family-centered intervention, where each team (social worker) has on family –centered care/services coordination model. This is the case for the Cheshire Services Ethiopia-CBR Centre's. Other centers could be viewed as 'control groups'. However, there are several confounding variables, such as different staff, programs, child and family circumstances and backgrounds, which prevent one from concluding that the high scale scores in the present study can be attributed solely to the family-centered intervention/care coordination model.

A more comprehensive discussion on the roles and functions of the CBR staff (t would be a topic for another research. The staff (social worker), as a case manager (service coordinator) may encourage and empower families to assume a major role in coordinating their own services. This is consistent with the generalist social work practice (Kirst-Ashman & Hull, 1993).

On the basis of this exploratory study, it is not possible to conclude that the implementation of the family-centered care model has a direct relationship with the high scale scores on the MPOC, the CSQ and question on goal achievement. However, the model certainly does not seem to hinder the provision of family-centered care/intervention services. From a consumer satisfaction point of view, there appears to be little need to look for another model. Whatsoever the case may be, further research may also examine other measure of processes of care for service providers (MPOC-SP), measure of satisfaction, measure of goal achievement tools or informal measures [e.g., structured conversation and more open-ended questions] in order to determine if there are more appropriate ways to assess these dimensions.

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On the basis of this exploratory study, it is not possible to conclude that the implementation of the family-centered care model has a direct relationship with the high scale scores on the MPOC, the CSQ and question on goal achievement. However, the model certainly does not seem to hinder the provision of family-centered care/intervention services. From a consumer satisfaction point of view, there appears to be little need to look for another model. Whatsoever the case may be, further research may also examine other measure of processes of care for service providers (MPOC-SP), measure of satisfaction, measure of goal achievement tools or informal measures [e.g., structured conversation and more open-ended questions] in order to determine if there are more appropriate ways to assess these dimensions.

5.4.2 Implications of the Study for Further Research

In order to expand from this exploratory research, further questions on the basis of the already collected data can be asked. The scale scores calculated for each respondent can be compared to parents' level of education. Parents with higher level of education may rate the items differently from parents with less formal education. The impact of employment on parents' responses can be investigated. One might postulate that parents who are employed outside of the home may have a more difficult time attending appointments and less time to interact with the staff than parents who are available during the day. On the other hand, families where both parents work may possibly have more resources, e.g., child care and finances, which might affect the families' perceptions of the services, and how much support they need from the CBR Centre.

On the basis of the demographic data it would be interesting to find out what significance, if any, gender of the child with disabilities has on the parents' responses. Similar evaluation could be done with family composition, e.g., single-versus two-parent families and number of siblings.

For the CBR Centre's purposes, an item by item analysis on all of the scales would be helpful in determining what specific questions parents tended to rate low. The CBR Centre can then take action in improving these specific service areas.

It would be beneficial to conduct an analysis of the internal consistency of the scales within this survey, especially, in the light of the very high response rate and low educational level. An item analysis could be done to evaluate the discrimination index (power) of each question. If parents rated individual items within a scale rather consistently, the results will further support the reliability and construct validity of the MPOC and the CSQ questionnaires, as well as to add in the validity of the responses in this survey.

In order to learn more about the various aspects of service/care coordination, it may be of interest to look for any possible relationships between parents' education and whom they identified as care coordinator. Intuitively one might think that parents with a higher level of education may choose to coordinate their own services more often than parents with less formal education. The number of services received by families at one time may have an influence on who acts as a services/care coordinator. One may postulate that when the number of services increases, people more often choose a professional, such as the Centre (CBR) family service coordinator, to take on the role of a care manager or coordinator. In future research, various methods of measuring the effectiveness of care management (coordination) should be looked at.

To further explore the aspects of family-centered care/intervention, one can compare responses of different groups of parents, depending on whom they identified as the care manager (coordinator) for their family. One can argue that under ideal conditions, it should not matter whom families choose to coordinate their services. The family–centered care/services model should be able to accommodate the families' needs.

From this research, it is evident that mothers of children with disabilities continue to be the major contact between the child and the Treatment Centre (CBR) staff. Women still seem to carry the major responsibility as caregivers and service coordinators in the families. Further research in the roles and attitudes of parents and professionals might aid efforts to involve fathers and other caregivers to participate in the processes of care in greater numbers. The use of these approaches along with a family problem-solving strategy could be used with individual families and studied within a single-case (subject) research design.

The researcher recommended changes in design and predictor and outcome variables to further investigate the research model. The distributions of scores on parent respondents' perceptions of family-centered care/behaviors (MPOC) was narrow (i.e. had minimal variance) and was negatively skewed (i.e. most scores were high). Minimal variance in the distribution of this data reduced the explanatory power of the model. The predictor variables should be revised to incorporate multidimensional characteristics of children, families, and therapists. Child characteristics such ass temperament, personality resiliency, motivation, and cognitive ability should examined for inclusion in the model, as these behaviors may be predictors of parents' satisfaction with care as noted by (king, Rosenbaum, Goffin & King, 1999).

Outcomes should include direct observation of rehabilitation practitioners, family-centered care behaviors during intervention as well as measures of intervention practitioners, satisfaction with early intervention roles and parents' satisfaction with intervention (therapy services).

The guide to physical therapist practice (Phys Ther, 1997) identifies professional roles of the therapist including education and consultation at the policy making level for local, state and federal agencies. Intervention practitioners working in family-centered care are in a unique position to educate policy-makers to ensure that services are structured to meet the needs of children and their families. The researcher believe that it is important for intervention practitioners to provide input to health and education policy-makers and administrators on how changes in service delivery policy affect the ability to provide family-centered care in early intervention (O'Neil, Farel, & Palisano,1999).

For example, rehabilitation practitioners can collaborate with local health departments to identify needs for children with disabilities and to facilitate access to appropriate services. The researcher contend that the inclusion of intervention practitioners (therapists) on local interagency coordinating councils the local governing councils for family-centered care (early intervention) programs, is needed to provide input on the role of therapy services and to promote a coordinated tear approach to service delivery.

In general, further research is needed (required) in in this very important area of family-centered care /intervention models. Professionals deal with more complex cases in the rehabilitation/ health care setting, such as an increasing number of extremely premature babies and drug affected infants. Especially in the case, there is a growing need to coordinate between health care and social services. Some mothers may lack the skills and confidence to take charge of the resources themselves and skilled care coordinators are needed.

To sum up, further research is required to clarify parental perceptions of care that are associated with parental satisfaction and parental perceptions of goal achievement. Replication and refinement of the present study would strengthen the results obtained. Recommendations for refinement include:

1. Increasing the size of the sample (i.e., a large and more heterogeneous and representative sample of parents) would increase the variance of the outcome variables and add to the validity of the results. Also, incorporating respondents from other programs would aid in the generalization of the results.
2. Collecting more comprehensive demographic characteristics on the sample would allow statistical analyses to see if there is a relationship between certain demographic characteristics and qualities of family-centered care. Examples of characteristics that may be important include socioeconomic status, and support systems (formal and informal family support systems) that presently exist.

3. It would be interesting to include the perceptions of the family-centeredness of the program staff and then to compare the family and program staff's perceptions of the program and goal achievement.

4. Qualitative methods can be used to gather more in-depth and more comprehensive information from the parents. For example, more individual interviews, structured conversation (focus-groups discussion) and/or more open-ended questions could be used to gather more comprehensive feed back from the parents.

5. The use of a comparison group based on another theoretical model-would permit the evaluation of the independence of the family-centered model by controlling for factors such as parent perceptions of their child's performance or the availability of a team willing to address their concerns.

6. Longitudinal research is needed to examine changes in parents' perceptions of intervention workers' family-centered behaviors over time and to identify relationship between parents' per captions and children's health out comes.

7. The predictor variables should be revised to incorporate multidimensional characteristics of children, families, and intervention workers. More specifically, the child-level is not presented in this model which is a serious concern. To further complicate the picture child-dimensions need to be added. That is, in research about the family-centered care/intervention model, both the family-and child-level need to be discussed. In this study no measures adequately used at child-level and this expansion of the model is called for.

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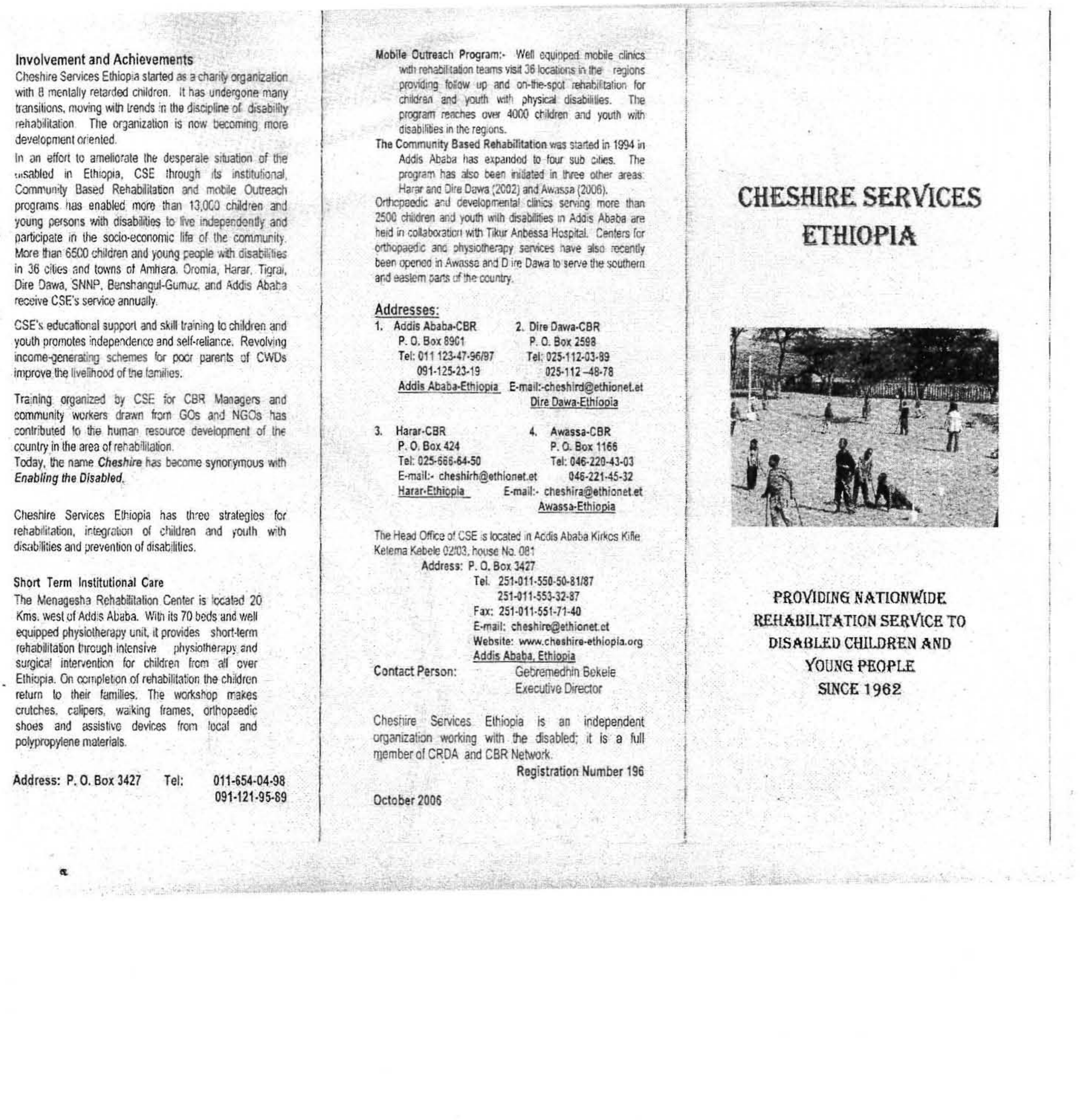
APPENDICES

Appendix -1 The Cheshire Services Ethiopia-CBR Program



Involvement and Achievements

Cheshire Services Ethiopia started as a charity organization with 8 mentally retarded children. It has undergone many transitions, moving with trends in the discipline of disability rehabilitation. The organization is now becoming more development oriented.

In an effort to ameliorate the desperate situation of the disabled in Ethiopia, CSE through its institutional, Community Based Rehabilitation and mobile Outreach programs has enabled more than 13,000 children and young persons with disabilities to live independently and participate in the socio-economic life of the community. More than 6500 children and young people with disabilities in 36 cities and towns of Amhara, Oromia, Harar, Tigrai, Dire Dawa, SNNP, Benshangul-Gumuz, and Addis Ababa receive CSE's service annually.

CSE's educational support and skill training to children and youth promotes independence and self-reliance. Revolving income-generating schemes for poor parents of CWDs improve the livelihood of the families.

Training organized by CSE for CBR Managers and community workers drawn from GOs and NGOs has contributed to the human resource development of the country in the area of rehabilitation.

Today, the name ***Cheshire*** has become synonymous with ***Enabling the Disabled.***

Cheshire Services Ethiopia has three strategies for rehabilitation, integration of children and youth with disabilities and prevention of disabilities.

Short Term Institutional Care

The Menagesha Rehabilitation Center is located 20 Kms. west of Addis Ababa. With its 70 beds and well equipped physiotherapy unit, it provides short-term rehabilitation through intensive physiotherapy and surgical intervention for children from all over Ethiopia. On completion of rehabilitation the children return to their families. The workshop makes crutches, calipers, walking frames, orthopaedic shoes and assistive devices from local and polypropylene materials.

Address: P. O. Box 3427 Tel: 011-654-04-98
091-121-95-89

Mobile Outreach Program:- Well equipped mobile clinics with rehabilitation teams visit 36 locations in the regions providing follow up and on-the-spot rehabilitation for children and youth with physical disabilities. The program reaches over 4000 children and youth with disabilities in the regions.

The Community Based Rehabilitation was started in 1994 in Addis Ababa has expanded to four sub cities. The program has also been initiated in three other areas: Harar and Dire Dawa (2002) and Awassa (2006).

Orthopaedic and developmental clinics serving more than 2500 children and youth with disabilities in Addis Ababa are held in collaboration with Tikur Anbessa Hospital. Centers for orthopaedic and physiotherapy services have also recently been opened in Awassa and Dire Dawa to serve the southern and eastern parts of the country.

Addresses:

1. **Addis Ababa-CBR**
   P. O. Box 8901
   Tel: 011 123-47-96/97
   091-125-23-19
   Addis Ababa-Ethiopia
2. **Dire Dawa-CBR**
   P. O. Box 2598
   Tel: 025-112-03-89
   025-112 –48-78
   E-mail:-cheshird@ethionet.et
   Dire Dawa-Ethiopia
3. **Harar-CBR**
   P. O. Box 424
   Tel: 025-666-64-50
   E-mail:- cheshirh@ethionet.et
   Harar-Ethiopia
4. **Awassa-CBR**
   P. O. Box 1166
   Tel: 046-220-43-03
   046-221-45-32
   E-mail:- cheshira@ethionet.et
   Awassa-Ethiopia

The Head Office of CSE is located in Addis Ababa Kirkos Kifle Ketema Kebele 02/03, house No. 081

Address: P. O. Box 3427
Tel. 251-011-550-50-81/87
251-011-553-32-87
Fax: 251-011-551-71-40
E-mail: cheshire@ethionet.et
Website: www.cheshire-ethiopia.org
Addis Ababa, Ethiopia

Contact Person: Gebremedhin Bekele
Executive Director

Cheshire Services Ethiopia is an independent organization working with the disabled; it is a full member of CRDA and CBR Network.

Registration Number 196

October 2006

CHESHIRE SERVICES ETHIOPIA

PROVIDING NATIONWIDE REHABILITATION SERVICE TO DISABLED CHILDREN AND YOUNG PEOPLE SINCE 1962

Cheshire Services Ethiopia

General

Cheshire Services Ethiopia (CSE) is one of the Cheshire Homes and Services around the world. It is affiliated with Leonard Cheshire International (LCI) based in London, sharing the belief of enabling the disabled to achieve their full potential as integrated members of society.

The organization was first established as the Cheshire Home by Group Captain Leonard Cheshire, Princess Seble and Commander Eskinder Desta, the grand children of Emperor Haileselassie in 1962. The Rehabilitation Centre was opened at Menagesha in 1967.

CSE is an independent, indigenous, non-profit making, non-self-serving non governmental organization (NGO) working for the welfare and benefit of children and young people with disabilities (PWDs) in Ethiopia.

Decision-making Body

The General Assembly of CSE is the highest decision-making body. It meets every year to assess plans against achievements as well as giving general policy guidelines. The Board of Management, elected from the General Assembly, is headed by a chairman and is responsible for overseeing and following up program implementation. The Board of Management appoints an Executive Director who is responsible for the overall management of the organization.

Legal Status

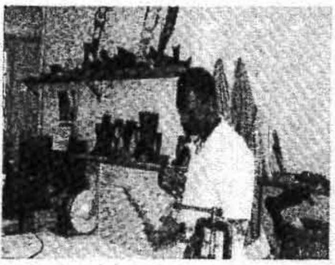
CSE registered as an indigenous NGO with the former Ministry of Interior in 1965 and 1967, and again in 1998 with the Association Registration Department of the Ministry of Justice. It has a general agreement with the Disaster Prevention and Preparedness Agency (DPPA), and a tripartite project agreement with the Ministry of Labour and Social Affairs (MoLSA) and DPPA to provide need-based nationwide service to PWDs.

Vision

CSE wishes to see a world in which disability is prevented and PWDs can participate equally and as fully as possible in the life of their society.

Mission

Bring about attitudinal change in society and PWDs by taking affirmative actions for inclusive opportunity in Ethiopia through provision of rehabilitation services and economic empowerment.



Objectives

CSE has the following objectives; to:

- Ensure that people with disabilities are able to maximize their physical and mental abilities.
- Enable PWDs to become independent and active contributors to the community and society at large.
- Enhance access to physiotherapy and rehabilitation services for people with disabilities.
- Empower youth with disabilities to obtain better employment opportunity.
- Promote gender equality and social integration of persons with disabilities.
- Enable communities to promote and protect the rights of people with disabilities through changes within the community.
- Contribute towards poverty reduction and social inclusion of persons with disabilities.
- Help maintain full functioning of physical health among members of the community.

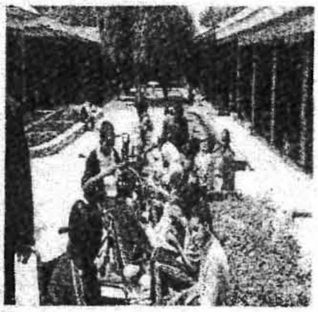
Strategies

CSE has designed the following strategies to achieve its objectives:

- Institutional-based rehabilitation
- Community Based Rehabilitation
- Mobile Outreach Coverage,
- Collaboration and exchange of information and experience
- Partnership and Networking
- Community participation at all levels

Major Activities

- Admission of CWDs for physical rehabilitation
- Production and provision of walking-aids
- Provision of Outreach service in the regions
- Provide access to referral services
- Provide home based rehabilitation services
- Promote early identification of impairment
- Counseling
- Awareness raising
- Advocacy
- Promote basic rights, self esteem
- Inclusion and integration
- Sponsor skill training
- Provide educational support
- Organize saving and credit schemes
- Facilitating training in rehabilitation



Appendix-2

Premises, Principles, and Elements of Family-Centred Service

Premises (basic assumptions)		
● Parents know their children best and want the best for their children.	● Families are different and unique.	● Optimal child functioning occurs within a supportive family and community context: The child is affected by the stress and coping of other family members.
Guiding Principles ("should" statements)		
● Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child. ● Parents should have ultimate responsibility for the care of their children.	● Each family and family member should be treated with respect (as individuals).	● The needs of all family members should be considered. ● The involvement of all family members should be supported and encouraged.
Elements (key service provider behaviors)		
Service Provider Behaviors	**Service Provider Behaviors**	**Service Provider Behaviors**
● to encourage parent decision-making * to encourage parent decision-making in partnership with other team members (to utilize family empowerment strategies) ● to assist in identifying strengths * to assist families in identifying their strengths and building their own resources ● to provide information * to inform, answer and advise parents (to encourage informed choices) ● to assist in identifying needs * to work in partnership with parents and children and help them identify and prioritize their needs from their own perspective ● to collaborate with parents * to collaborate with parents at all levels (care of the individual child; program development, implementation and evaluation; policy formation) ● to provide accessible services * to provide systems that will not overwhelm families with paperwork and bureaucratic red tape ● to share information about the child * to share complete information about their child's care on an ongoing basis	● to respect families * to respect the values, wishes, and priorities of families ● to support families * to accept and support decisions made by families ● to listen ● to provide individualized service * to provide flexible and individualized services (and to respond to the changing needs of the family) ● to accept diversity * to be knowledgeable about and accept diversity among families (racial, ethnic, cultural and socioeconomic) ● to believe and trust parents ● to communicate clearly * to communicate in a language understandable by parents	● to consider psychosocial needs of all members * to consider and be sensitive to the psychosocial needs of all family members ● to encourage participation of all members * to provide an environment that encourages the participation of all family members ● to respect coping styles * to respect the family's own style of coping without judging what is right and what is wrong ● to encourage use of community supports * to encourage family to family support and the use of natural community supports and resources ● to build on strengths * to recognize and build on family and child strengths

Appendix 3.1

Information Sheet

Dear Parent/ Guardian

The Cheshire Services Ethiopia- (Cheshire Home) was established in 1962 by Ethiopian and foreign philanthropists to care for children with mental retardation at Menagesha 30 kilometers away from Addis Ababa - have adopted a Family-Centered Care orientation in providing services to children with disabilities and their families. A number of Ethiopian literature indicated that currently, the Cheshire Services Ethiopia provides CBR/intervention for young children with disabilities (mentally challenged / mental retardation, multiple disability, physical disability, visual impairment, hearing impairment and motor developmental delays/motor disorders) and their families based on this principle and values by expanding its dimension in eight towns including Addis Ababa. Relatively little is known whether families actually think that the services that they receive are provided in a manner that is sensitive to family needs. Thus, this survey study aimed at finding out the dimension of family-centered care/intervention for children with disabilities: parental/familial perceptions of care.

The major aim of this research study is to find out whether the Cheshire CBR/Children's Treatment Centre/Program is guided by the key assumptions of the family-centered care/ intervention. Thus, indicating/identifying the level/dimension of parental/familial perceptions of care, client/parental satisfaction with the services given, and parental perceptions of the goal achievement would be the focus of the study.

This package contains a questionnaires that aim to measure parents' / families' perceptions of the services received from the Cheshire CBR Centre / projects.

The title of the survey: Dimension of Family-Centered care/ Intervention for Children with Disabilities: Parental/Familial Perceptions of Care (Cheshire Services Ethiopia -CBR projects, Addis Ababa).The research is a partial requirements for the fulfillment of a master of *Special Needs Education* (Psychology) at Addis Ababa University, and is done in cooperation with the Cheshire Services Ethiopia-CBR Centre.

About half an hour of your time is required to fill out the attached family and child background form; responses from either parent are welcomed. Please, accept my apologies for taking up your precious time. Hopefully you will see this as an opportunity to express your views on the services that you used/received during the interventions.

All information obtained from you will be kept confidential and the collected data will be presented only in general terms when the results are compiled. Please, do not record your name on the family and child background form or the return questionnaires to *preserve anonymity*. Participation is completely voluntary and does not affect your involvement with the CBR Center /program in any way. I am asking you for your permission to look at/to complete four types of questionnaires: (1) the Measure of Processes of Care (MPOC) Questionnaire. This questionnaire consists of 56 items with an 8-point response scale that measure how you feel about the care you received from the CBR program; (2) the Measure of Satisfaction/Client Satisfaction Questionnaire (CSQ-8). It consists of 8-items with a 4-point response scale; (3) the Goal Measure/ Question on Goal Achievement. It consists of only a single-item using a 7- point rating scale; and (4) the child and family background form.

The Cheshire Services Ethiopia-CBR/ Children's Treatment Centre will receive a summary report of the results of this research by the fall of 2007. This information will be useful in evaluating family- centered care / services and for future planning. Please, be advised that the data will be securely stored in the department of psychology, Addis Ababa University at least for a five years period.

Thank you very much for taking the time to provide your invaluable response.

Yours truly
24/11/2006
Adugna Asfaw
MSNE

This project has been reviewed and approved by the Ethics Committee of Addis Ababa University

Approved by ________________
Signature __________________
Date ______________________

Appendix 3.2

Consent Form

Research Title: **DIMENSION OF FAMILY-CENTERED CARE/INTERVENTION FOR CHILDREN WITH PHYSICAL DISABILITIES: PARENTAL PERCEPTIONS OF CARE** (Cheshire Services Ethiopia–CBR projects, Addis Ababa)

Investigator: Adugna Asfaw (MSNE)
Advisor: Dr. S.N. Dubey (Ph.D), Psychology, Addis Ababa University.
Purpose:

1. To find out how parents/families feel about the care or service they received from the Cheshire CBR centre/program.
2. To look at how satisfied parents are with the care or service they received from the Cheshire CBR program.
3. To look at whether parents / families felt that their goals were met with the Cheshire CBR program.

Procedures

During the last quarter week of the program you will be asked to complete a questionnaire that measures how you felt about the processes of care/ service you received from the Cheshire CBR program/projects. I will also be looking at your completed goal and satisfaction measures that are standard part of the CBR program/projects. Finally, you will be requested to complete child and family background form/questionnaire, which provides comprehensive information on the *characteristics of the child,* and *the family structure* and *the type of services* reviewed from the CBR program.

Risks/Benefits

The results of this study will help us to provide better care for future children and their families. There will be no direct benefits for participants. There are no known risks involved in participating.

Confidentiality

Records from this study will be kept confidential. No names or other identifying information will be released. All data will be stored in a secure location at least for a five years period. Any report published about this study will not identify your child or yourself by name.

Voluntarily I agree to participate. I may refuse to answer any question. I am free to withdraw my consent and stop my participation at any time. If I decide not to participate or I withdraw from the study, this will not affect present or future care for my self or my family.

I have read the information sheet and consent form and this project has been discussed with me. All of my questions about this study have been answered to my satisfaction. I understand my involvement in this study. I have been given a copy of this consent form.

If I have any further questions I can contact Adugna Asfaw at 0911 06 02 02 or 0911 79 12 09. If I have concerns about how this research is being done, I can contact Addis Ababa University, Department of Psychology at251-111 22 59 49.

Signature of participant(s)_______________ Signature of witness_________

Date 24/11/2006 Date 24/11/2006

The person signing this form appears to understand what is involved in the study and voluntarily agrees to participate.

This project has been reviewed and approved by the Ethics Committee of Addis Ababa University

Investigator: Adugna Asfaw
Signature _____________
Date 24/11/2006

Approved by_________________
Signature____________________
Date________________________

Appendix 4

MEASURING PROCESSES OF CARE (MPOC) STUDY CHILD AND FAMILY BACKGROUND FORM

Please complete the following background questions about your child receiving services at the cheshire CBR and about your family. This information will be used only to describe the group of families participating in the survey. Your individual responses will not be identified in any way.

1. How old is your child with special needs?_____ Years and ____months.
2. Is the child a ☐ Male ☐ Female?
3. What is your child's primary diagnosis, health or other special needs? Check (X) one only.

☐ Acquired Brain Injury	☐ Cerebral Palsy
☐ Communication Disorder	☐ Developmental Delay
☐ Seizure Disorder	☐ Hearing Impairment
☐ Learning Problems	☐ Muscle Disorder
☐ Spina Bifida/ Hydrocephalus	☐ Visual Impairment
☐ Prematurity	☐ Other, please specify:____

4. Does your child have any other special needs?

☐ Yes ☐ No If yes, please specify:________

5. How often do you have contact with the centre (CBR)?

☐ weekly	☐ monthly	☐ 4 times a year
☐ two times a year	☐ yearly	☐ less than once a year

6. How long have you received services from the centre (CBR)?

☐ less than 6 months	☐ 6 months to a year
☐ 1 year but less than two years	☐ 2 years or more

7. What type of service does your child and family currently receive ? Check **(X)** all that apply.

☐ Occupational Therapy	☐ Phsio Therapy
☐ Speech-Language Therapy	☐ Social Work (Family Service Coordinator)
☐ Augmentative Communication	☐ Seating/ Mobility
☐ Pediatric Clinic	☐ Psychological Consultaton
☐ Orthopaedic Clinic	☐ Program Aide
☐ Daycare	☐ Parent Group

☐ Other, please specify: ________________________________

8. Who do you consider as the main coordinator of services for your family regarding the special needs of your child? Check (X) one.

☐ self ☐ spouse ☐ other family member ☐ friend
☐ center (CBR) family service coordinator ☐ other center(CBR) staff
☐ community professional/advocate ☐ Other, please specify:________
☐ nobody

9. What language is spo ken most often at home?
☐ English ☐ Amharic ☐ Afaan Oromoo ☐ Tigrigna ☐ Other

10. How many siblings does your child with special needs have?
Sisters [indicate age(s]: _________Brothers[indicate age(s)]:_________

11. Please, indicate if you are a ☐ two-parent or a ☐ Single-parent family?

12. What is the highest level of education completed by each parent? Answer only for yourself if you are a single parent. Check (x) one level for each parent.

	MOTHER	**FATHER**
a. No schooling	☐	☐
b. Elementary school (grades 1-8)	☐	☐
c. Some high school (grades 9-12)	☐	☐
d. Completed high school	☐	☐
e. college graduate/comerce school	☐	☐
f. University graduate/degree	☐	☐
g. Above university graduate/degree	☐	☐

13. Are you currently employed? ☐ Yes ☐ No
If a two-parent family, is your spouse
currently employed? ☐ Yes ☐ No

14. Where do you live?
☐ ity of Addis Ababa ☐nearby city of Addis Ababa☐ other Administive Region

Confidential when completed

Appendix 4

የአካል ጉዳተኛ ሕፃንና ቤተሰቡ የህይወት ታሪክ ቅጽ

በአካል ጉዳተኛ ሕጻን የአያያዝ ሂደት መለኪያ (MPOC) ሰርቬይ ጥናት፤ የሕፃንና ቤተሰቡ የህይወት ታሪክ ቅጽ

የሚከተሉት ጥያቄዎች ልጅዎና ቤተሰብዎ **ቸሻየር ማዕከል** ታገኙ የነበረውን ልዩ ልዩ እርዳታዎችን/ አገልግሎቶችን በሚመለከት መረጃ ለማሰባሰብ ይረዳን ዘንድ የተዘጋጀ ቅጽ ስለሆነ እባክዎትን **የ(X)** በተዘጋጀው ሳጥን ውስጥ በማስቀመጥ በጥንቃቄ እንድትሞሉልን እንጠይቃለን፡፡

ይህ መረጃ/ እንፎርሜሽን የሚያገለግለው በሰርሼይ ጥናቱ ላይ የሚሳተፉትን የቤተሰቦች ቡድን ለመግለጽ ያህል ብቻ መሆኑ ሊታወቅ ይገባል፡፡ በዚህ ጥናት በማናቸውም መልኩ የግሌሰብ ምላሾች/ አስተያየቶች ይፋ አይወጡም፡፡

1. ልዩ ፍላጎት ያለው (ላት) የአካል ጉዳተኛው (ዋ) ልጅዎ እድሜ ምን ያህል ነው?
_______ ዓመት ከ _______ ወር (ራት)
2. የልጅዎ ጾታ? ☐ ወንድ ☐ ሴት
3. በመጀመሪያው የህክመና ምርመራ አማካይነት የተገኘው የልጅዎ የአካልና የአእምሮ ችግር/ ጉዳት፤ ጤንነት ወይም ሌሎች ለየት ያሉ ፍላጎቶች? ለአንዱ ብቻ (X) ያረጋግጡ

☐ በአደጋ ምክንያት የሚመጣ የአእምሮ ጉዳት/ ችግር (Aquired Brain Injury)
☐ የእንቅስቃሴ/ ንቅናቄና የሰውነት አቋም መዛባት (Cerebral Palsy)
☐ የመግባቢያ ቋንቋ/ሥርዐት መዛባት (Communication Disorder)
☐ በዕድገት መደኋላ የመቅረት/የመዘግየት (Developmental Delay)
☐ የሚጥል በሽታ (Seizure Disorder)
☐ የመስማት ችግር (Hearing Impairment)
☐ የመማር ችግሮች (Learning Problems)
☐ የጡንቻ መዛባት (Muscle Disorder)
☐ የጀርባ አጥንት ክፍተት ችግር/ ስፓይና ባይፍዳ (Spina Bifida/Hydrocephalus)
☐ የማየት ችግር (Visual Impairment)
☐ በዕድገት ያለመጎልመስ (Prematurity)
☐ እባክዎትን ከዚህ ውጪ ሌላ ካለ ይግለፁ:________________________________
____

4 ልጅዎ ለየት ያለ ሌላ ፍላጎቶች አሉት (ሏት)?
☐ አዎ ☐ አይደለም
መልስዎ አዎ ከሆነ እባክዎትን ምን እደሆነ በአጭሩ ይግለፁ________________________

5. ከማዕከሉ ጋር ለእርዳታ/ ለአገልግሎት ይገናኙ የነበረው በምን ያህል ጊዜ ነው?
☐ በየሳምንቱ ☐ በየወሩ ☐ በዓመት 4 ጊዜ
☐ በዓመት 2 ጊዜ ☐ በየዓመቱ ☐ በዓመት ከ 1 ጊዜ ያነሰ

6. ከማዕከሉ እርዳታዎችን/አገልግሎቶችን ያገኙ የነበረው ለምን ያህል ጊዜ ነው?
☐ ከ 6 ወራት ላነሰ ጊዜ ☐ ከ6 ወራት እስከ ዓመት
☐ ከ1 ዓመት በላይ ነገር ግን ከ 2 ዓመት ላነሰ ☐2 ዓመት ወይም በላይ

7. በአሁኑ ወቅት ለእርስዎና ለቤተሰብዎ በመደረግ ላይ የሚገኘው የአገልግሎት/የእርዳታ ዓይነት ምንድነው? የሚመለከትዎትን ሁሉ (X) የረጋግጡ

☐ የመልሶ ግንባታ ቴራፒ (Occupational Therapy)
☐ የአካል ጉዳተኛ እንክብካቤ/ የአካል ብቃት ቴራፒ (Physio-Therapy)
☐ የንግግርና ቋንቋ ቴራፒ (Speech-Language Therapy)
☐ የማህበራዊ ሥራ /የቤተሰብ አገልግሎት አስተባባሪ (Social Work)
☐ አማራጭ የመግባበያ ዘዴዎች (Augmentative Communication)
☐ የፔዲያትሪክ ክሊኒክ/ሕክምና ክትትል (Pediatric Clinic)
☐ የአቀማመጥወይም የአካል እንቅስቃሴ/ንቅናቄ (Seating/Mobility)
☐ የሳይኮሎጂ አማካሪ/ የማማከር አገልግሎት (Psychological Consultation)
☐ የአጥንቶች ፣ የጡንቻዎችና የመጋጠሚያዎች ክሊኒክ/ ህክምና ክትትል (Orthopedic Clinic)
☐ የፕሮግራም ጉዳይ አማካሪ/ረዳት (Program Aide)
☐ የወላጅ ቡድን (Parent Group)
☐ የዕለት ተንከባካቢ (Day-Care)
☐ እባክዎትን ከዚህ ውጪ ሌላ ያልተጠቀሰ ካለ ይግለፁ________________________
____

8. ልዩ ፍላጎት ያለውን/ላትን/ የአካል ጉዳተኛው/ዋ/ ልጅዎን በተመለከተ፤ ለቤተሰብዎ ይደረግለት ስለነበረው ዕርዳታ/አገልግሎት በዋና አስተባባሪነት ትልቅ ሥፍራ የምስጡት ለማን ነው? ለአንዱ ብቻ /X/ ያረጋግጡ

☐ የማዕከሉ ስታፍ
☐ የትዳር ጓዴኛዬ (ባሌ/ሚስቴ)
☐ ሌላ የቤተሰቤ አባል
☐ ጓዴኛዬ
☐ የማዕከሉ የቤተሰብ ጉዳይ የእርዳታ/አገልግሎት አስተባባሪ
☐ የሌላ ማዕከል ስታፍ
☐ የኮሚዩኒቲው/ የማኅበረሰቡ የሕፃናት መብት ተሟጋች ባለሙያ
☐ እባክዎትን ከዚህ ሌላ ካለ ይግለፁ:-____
☐ ማንም

9. በቤትዎ ውስጥ ለመነጋገሪያ/ለመግባቢያ መሳሪያነት የሚዘወትር ቋንቋ ምንድነው?
☐ እንግሊዘኛ ☐ አማርኛ ☐ ኦሮምኛ ☐ ትግርኛ ☐ ሌላ

10. ልዩ ፍላጎት ካለው/ላት/ ከአካል ጉዳተኛው(ዋ) ልጅዎ ጋር አብሮ የተወለዱ የልጆች ብዛት ስንት ናቸው?
☐ እህት (ቶች) [ዕድሜዋን(ዎቹን) ያመልክቱ] ____________________________
☐ ወንድም (ሞች) [ዕድሜውን (ዎቹን) ያመልክቱ]__________________________

11. እባክዎትን አንዱን ብቻ ያመልክቱ፤ባለ ______________________________________?
☐ ሁለት- ወላጅ ቤተሰብ (እናትና አባት አብሮ)
☐ አንድ- ወላጅ ቤተሰብ (እናት ወይም አባት ብቻ)

12. እያንዳንዱ (ዷ) ወላጅ ያጠናቀቁት ከፍተኛው/ትልቁ የትምህርት ደረጃ ምንድነው? ባለ አንድ-ወላጅ ቤተሰብ ከሆንም ለራስዎ ብቻ ይመልሱ፤ ለአንድ(ዷ) ወላጅ አንድ የትምህርት ደረጃ ብቻ (X) ያረጋግጡ

	እናት	አባት
ሀ. ምንም የትምህርት ደረጃ	☐	☐
ለ. የመጀመሪያ/ አንደኛ ደረጃ ዕውቀት (ከ1ኛ-8ኛ ክፍሎች)	☐	☐
ሐ. ጥቂት የከፍተኛ 2ኛ ደረጃ ዕውቀት (ከ9ኛ-12ኛ ክፍሎች)	☐	☐
መ. የከፍተኛ 2ኛ ደረጃ ትምህርትን ያጠናቀቁ	☐	☐
ሠ. የኮሚዩኒቲ ኮሌጅ/የንግድ ስራ ት/ቤት /የኮሌጅ ትምህርት ያጠናቀቁ	☐	☐
ረ. የዩኒቨርሲቲ ዲግሪ/የዮኒቨርሲቲ ትምህርት ያጠናቀቁ	☐	☐
ሰ. ከዮኒቨርሲቲ ዲግር በላይ	☐	☐

13. በአሁኑ ወቅት ደመወዝ እየተከፈልዎት ነውን? ☐ አዎ ☐ አይደለም
ባለሁለት-ወላጅ ቤተሰብ ከሆንም የትዳር ጓደኛዎ በአሁኑ ወቅት ደመወዝ እየተከፈለው/ላት/ ነውን?
☐ አዎ ☐ አይደለም

14. የምኖሩት የት ነው?
☐ በአዲስ አበባ ከተማ
☐ በአዲስ አበባ ከተማ ዙሪያ
☐ ከአዲሰ አበባ ከተማ ውጪ ባሉት ክፍለ ሀገራት/ክልላዊ መስተዳጻሮች

መረጃው ሲጠናቀቅ ሚስጢራዊነቱ የተጠበቀ ነው!!
እናመሰግናለን!!

Appendix-5

PROCESSES OF CARE QUESTIONNAIRE

We would like to understand and measure the experiences of parents who have a child with a disability. In particular we wish to know about your perceptions of the care you have been receiving over the past year from your child's **Treatment (Rehabilitation) Centre.**

The questions in this section are based on what parents, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn't happen) to you at your treatment centre. You are asked to answer each question on a scale from 7 (To a Great Extent) to 1 (Never).

The care that you and your child receive from the Centre may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. PEOPLE: refers to those individuals who work directly with you or your child. These may include psychologists, therapists, social workers, doctors, teachers, etc.
2. CENTRE: refers to all staff from the centre, whether involved directly with your child or not. In addition to health care people they may include support staff such as office staff, housekeepers, administrative personnel, etc.

The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

Indicate how much each event or situation happens to you.

TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES...	To a Great Extent			Sometimes			Never	Not Applicable
... provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (To a Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.

We would like you to think about your experiences over the past year at your child's Centre. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate <u>how much</u> the event or situation happens to you by circling one number (from 1 to 7) that you feel best fits your experience. When answering these questions, we would like you to think about the Centre from which you first found out about this study.

For easy reference, we have written the name of that Centre on this line: Cheshire CBR Children's Treatment Centre

PEOPLE refers to those individuals who work <u>directly</u> with you or your child. These may include teachers, psychologists, therapists, social workers, doctors, etc.

IN THE PAST YEAR

Indicate <u>how much</u> this event or situation happens to you.

TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Great Extent			Sometimes			Never	Not Applicable
1. ... suggest therapy plans that fit with your family's needs and lifestyle?	7	6	5	4	3	2	1	0
2. ... fully explain treatment choices to you?	7	6	5	4	3	2	1	0
3. ... offer you positive feedback or encouragement (e.g., in carrying out a home program)?	7	6	5	4	3	2	1	0
4. ... explain things to your child in a way that your child understands?	7	6	5	4	3	2	1	0
5. ... take the time to establish rapport with you or your child when changes occur in your services?	7	6	5	4	3	2	1	0
6. ... discuss with you everyone's expectations for your child, so that all agree on what is best?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

Indicate how much this event or situation happens to you.

TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...		To a Great Extent			Sometimes			Never	Not Applicable
7.	... make sure that your child's skills are known to all persons working with your child, so the skills are carried across services and service providers?	7	6	5	4	3	2	1	0
8.	... tell you about options for treatment or services for your child (e.g., equipment, school, therapy)?	7	6	5	4	3	2	1	0
9.	... accept you and your family in a nonjudgemental way?	7	6	5	4	3	2	1	0
10.	... provide ideas to help you work with the health care "system"?	7	6	5	4	3	2	1	0
11.	... recognize the demands of caring for a child with special needs?	7	6	5	4	3	2	1	0
12.	... trust you as the "expert" on your child?	7	6	5	4	3	2	1	0
13.	... look at the needs of your "whole" child (e.g., at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0
14.	... show sensitivity to your family's feelings about having a child with special needs (e.g., your worries about your child's health or function)?	7	6	5	4	3	2	1	0
15.	... anticipate your concerns by offering information even before you ask?	7	6	5	4	3	2	1	0
16.	... make sure you have a chance during visits to the centre to say what is important to you?	7	6	5	4	3	2	1	0
17.	... let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

Indicate how much this event or situation happens to you.

	TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Great Extent			Sometimes			Never	Not Applicable
18.	... remember personal details about your child or family when speaking with you?	7	6	5	4	3	2	1	0
19.	... tell you about the reasons for treatment or equipment?	7	6	5	4	3	2	1	0
20.	... follow up at the next appointment on any concerns you discussed at the previous one?	7	6	5	4	3	2	1	0
21.	... make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0
22.	... provide opportunities for you to make decisions about treatment?	7	6	5	4	3	2	1	0
23.	... answer your questions completely?	7	6	5	4	3	2	1	0
24.	... explain what they are doing when you are watching your child in therapy?	7	6	5	4	3	2	1	0
25.	... recognize that your family has the final say when making decisions about your child's treatment?	7	6	5	4	3	2	1	0
26.	... tell you about the results from assessments?	7	6	5	4	3	2	1	0
27.	... provide you with written information about what your child is doing in therapy?	7	6	5	4	3	2	1	0
28.	... consult with you when discussing equipment or services?	7	6	5	4	3	2	1	0
29.	... provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

Indicate how much this event or situation happens to you.

	TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Great Extent			Sometimes			Never	Not Applicable
30.	... tell you details about your child's services, such as the reasons for them, the type of therapies and the length of time?	7	6	5	4	3	2	1	0
31.	... treat you as an individual rather than as a "typical" parent of a child with a disability?	7	6	5	4	3	2	1	0
32.	... develop both short-term and long-term goals for your child?	7	6	5	4	3	2	1	0
33.	... treat you as an equal rather than just as the parent of a patient (e.g., by not referring to as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
34.	... plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0
35.	... make sure you have opportunities to explain what you think are important treatment goals?	7	6	5	4	3	2	1	0
36.	... make you feel like a partner in your child's care?	7	6	5	4	3	2	1	0
37.	... make sure you are informed ahead of time about any changes in your child's care (e.g., therapists, programs, equipment)?	7	6	5	4	3	2	1	0
38.	... help you to feel competent as a parent?	7	6	5	4	3	2	1	0
39.	... provide you with written information about your child's progress?	7	6	5	4	3	2	1	0
40.	... seem aware of your child's changing needs as he/she grows?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

Indicate how much this event or situation happens to you.

TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...	To a Great Extent			Sometimes			Never	Not Applicable
41. ... provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0
42. ... treat you and your family as people rather than as a "case" (e.g., by not referring to you by diagnosis, such as "the spastic diplegic")?	7	6	5	4	3	2	1	0
43. ... listen to what you have to say about your child's needs for equipment, services, etc.?	7	6	5	4	3	2	1	0
44. ... make themselves available to you as a resource (e.g., emotional support, advocacy, information)?	7	6	5	4	3	2	1	0
45. ... give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0

CENTRE refers to all staff from the centre, whether involved directly with your child or not. In addition to health care professionals, these people may include support staff such as office staff, housekeepers; administrative personnel; etc.

IN THE PAST YEAR

Indicate how much the event or situation happens to you.

TO WHAT EXTENT DOES THE CENTRE WHERE YOU RECEIVE SERVICES...	To a Great Extent			Sometimes			Never	Not Applicable
46. ... have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0
47. ... have support staff that are polite and courteous to you and your family?	7	6	5	4	3	2	1	0

IN THE PAST YEAR

Indicate <u>how much</u> the event or situation happens to you.

TO WHAT EXTENT DOES THE CENTRE WHERE YOU RECEIVE SERVICES...

		To a Great Extent			Sometimes			Never	Not Applicable
48.	... give you information about the types of services offered at the Centre or in your community?	7	6	5	4	3	2	1	0
49.	... promote family-to-family gatherings for social, informational or shared experiences?	7	6	5	4	3	2	1	0
50.	... provide opportunities for special guests to speak to parents on topics of interest?	7	6	5	4	3	2	1	0
51.	... provide support to help cope with the impact of childhood disability (e.g., by advocating on your behalf or informing you of assistance programs)?	7	6	5	4	3	2	1	0
52.	... notify you about the reasons for upcoming case conferences, meetings, etc. about your child?	7	6	5	4	3	2	1	0
53.	... have information available about your child's disability (e.g., its causes, how it progresses, future outlook)?	7	6	5	4	3	2	1	0
54.	... provide advice on how to get information or to contact other parents (e.g., Centre's parent resource library)?	7	6	5	4	3	2	1	0
55.	... provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0
56.	... have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)?	7	6	5	4	3	2	1	0

Please continue to the next page...

What is your relationship to your child with special needs?

☐ Natural Mother
☐ Stepmother
☐ Adoptive Mother
☐ Foster Mother

☐ Natural Father
☐ Stepfather
☐ Adoptive Father
☐ Foster Father

☐ Other Guardian, please specify:____________________

On what date did you complete this questionnaire? ________________
day/month/year

ANY COMMENTS:

____

____

____

____

PLEASE CHECK THAT <u>BOTH</u> SIDES OF ALL PAGES ARE COMPLETED

CONFIDENTIAL WHEN COMPLETED

THANK YOU!

Appendix 5

ልዩ ፍላጎት ያላቸውን/የአካል ጉዳተኛ ሕፃናትን አያያዝ ሂደት የሚመለከት መጠይቅ (Processes of Care Questionnaire)

በዚህ መጠይቅ የአካል ጉዳተኛ ልጆች ወላጆች ያኋቸውን የአየያዝ ሂደት ልምድ(ተሞክሮ) ለማወቅና ለማጥናት እንሻለን። በተለይም ለማወቅ የምንፈልገው ጉዳይ ላለፋት ዓመታት በቸሻየር የአካል ጉዳተኛ ሕፃናት ማቋቋሚያ ማዕከል (Cheshire Children’s Treatment/ Rehabilitation Centre) ሲደረግላችሁ ስለነበረው አያያዝ /እርዳታ የሚሰማችሁን ስሜት እንድትገልፁልን ነው።

የዚህ ክፍል መጠይቅ የሚሞረኮዘው እርስዎን የመሳሰሉ ወላጆች ማዕከሉ በየጊዜው ለአካል ጉዳተኛ ልጆቻችሁ ስለሚያደርግላችሁ አያየዝ/እርዳታ የሚሰጡን አስተያየት ላይ ነው። የዝርዝር መጠይቁም ዐቢይ ዓላማ ማዕከሉ ለልጆቻችሁ የሚያደርገው የአያያዝ ሂደት ሁኔታ ምን ያህል አጥጋቢ/አርኪ እንደሆነ ወይም እንዳልሆነ ለማወቅ ስለሆነ ከልምድዎ/ ተሞክሮዎ በመነሳት የሚጠየቁትን ባለ 7-ነጥቦች ስኬል መጠይቅ ከ7 (ከሚፈለገው በላይ/ ከበቂ በላይ) እስከ 1 (ፍፁም) ምላሽዎትን ቀጥሎ ከተሰጠው ሠንጠረዥ ውስጥ መርጠው በመክበብ እንዲሰጡ እንጠይቃለን።

እርስዎና ልጅዎ ከማዕከሉ የምታገኟቸው አገልግሎት/ እርዳታ ከብዙ ግለሰቦች/የማዕከሉ ሠራተኞች ጋር እንድትገናኙ ያስገድዳችኋል። በዚህ መጠይቅ/ቅጽ ላይ የተሰጡት የጥያቄዎች ዝርዝር የምትገናኟችሁን ግሌሰቦች/ባለሙያዎችና ማዕከል ቀጥሎ በተመለከተው መሠረት በሁለት ዋና ዋና ምድቦች በመክፈል አቅርቧል።

1. ሰዎች/ PEOPLE፡ በዚህ ጥናት/መጠይቅ መሠረት ሰዎች የሚለው ቃል ከእርስዎና ከልጅዎ ጋር በቀጥታ የሚገናኙ ግሌሰቦችን/ ባለሙያዎችን ያመለክታል። ይህም ዘርፍ ሳይኮሎጂስቶችን፣ ቴራፒስቶችን፣ የማህበራዊ ዘርፍ ሰራተኞችን፣ ዶክተሮችን/ሐኪሞችን፣ መምህራንን፣ወ.ዘ.ተን... ያጠቃልላል።
2. ማዕከል/CENTRE፡ በዚህ ጥናት/መጠይቅ መሠረት ማዕከል የሚለው ቃል ከልጅዎጋር በቀጥታ መልኩ ይገናኙም አይገናኙ የማዕከሉ ሠራተኞችን/ የስታፍ አባላትን በሙሉ ያጠቃልላል። ይህም ዘርፍ በጤና አጠባበቅ ሥራ ከተሠማሩ ግሌሰቦች/ባለሙያዎች በተጨማሪ የሚያጠቃልላቸው የማዕከሉ አጋዥ ሠራተኞችን (Support Staff)፣ የቢሮ ሠራተኞችን (Office Staff) ፣ የቤት ጠባቂችን (House Keepers)፣ የአስተዳደር ሠራተኞችን (Administrative Personnel)፣ ወ.ዘ.ተ.ን... ነው።

ይህን ክስተት/ሁኔታ በምን ያህል ደረጃ/መጠን
እንደሚቀበሉ አንዱን መርጠው በመክበብ ያመልክቱ

	ላለፉት ዓመታት ከእርስዎ ልጅ ጋር ይሰሩ የነበሩ ሰዎች/ባለሙያዎች በምን ያህል ደረጃ/መጠን ...	ከሚፈለገው በላይ /ከበቂ በላይ			አልፎ አልፎ			ፍፁም	መጠይቁ አይመለከተኝም
1	...ከቤተሰብዎ ፍላጎትና የሕይወት አቅጣጫ /የአኗኗር ዘይቤ/ ጋር የተመጣጠነ የቴራፒ ዕቅድ አውጥተው በተግባር ተርጉመዋል?	7	6	5	4	3	2	1	0
2	...የልጅዎን የጤንነት አጠባበቅ፣ አያያዝ / የእንክብካቤ ዘዴዎችን በተመለከተ አማራጮችን ያለመታከት /ያለምንም እንከን ገለፃ አድርገውልዎታል?	7	6	5	4	3	2	1	0
3	...ገንቢ ወይም አበረታች ምላሽ ይሰጦዎታል (ለምሳሌ:- የቤት ውስጥ የልጅዎ የጤንነት አጠባበቅና አያያዝ ፕሮግራም በማውጣት አኳያ)?	7	6	5	4	3	2	1	0
4	...ልጅዎን በሚገባው(ባት) መልኩ ነገሮችን ያስረዱታል (ዷታል)?	7	6	5	4	3	2	1	0
5	...ለእርስዎና ለልጅዎ በሚደረገው የአያያዝ/ የአገልግሎት ሂደት አንዳች ለውጥ ሲከሰት፤ ጊዜ ወስደው አስፈላጊውን ሪፖርት ያደርጉልዎታል?	7	6	5	4	3	2	1	0
6	...ልጅዎን በተመለከተ ሁሉም በሚጠብቁት ውጤት/ ስኬት ላይ በመመካከር ተመራጭነት ባለው ሀሳብ ላይ ይስማማሉ?	7	6	5	4	3	2	1	0
7	.... ልጅዎ ያለው ክህሎት በዘርፉ በሚሰሩ ሰዎች ሁሉ ዘንድ እዲታወቅ ስለመደረጉ እርግጠኛ ነዎት? በመሆኑም ይኸው ክህሎት በሚደረግለት (ላት) የአያያዝ/ የአገልግሎት ሂደትና አገልግሎት ሰጪዎች በኩል ይንጸባረቃል?	7	6	5	4	3	2	1	0
8	.... ለልጅዎ ስለሚደረገው እንክብካቤ/አያያዝ/ አገልግሎት ለእርስዎ በማስተዋወቅ ይተባበራሉ (ለምሳሌ፤ ስለተለያዩ ቁሳቁሶች፤ ት/ ቤት፤ ቴራፒ አገልግሎት)?	7	6	5	4	3	2	1	0
9	.... ያለ አንዳች አድልዎ እርስዎንና ቤተሰብዎን ያቅፋሉ/ ያስተናግዳሉ?	7	6	5	4	3	2	1	0
10	.... በጤና አጠባበቅ/ አያያዝ ስርዓት እርስዎን ለመርዳት በሚደረገው ሥራ ገንቢ ሀሳብ በማፍለቅ/ በማቅረብ ይተባበራሉ?	7	6	5	4	3	2	1	0
11	....ልዩ ዝንባሌ/ ፍላጎት ያላቸውን ሕፃናት ኮትኩቶ በማሳደግ አኳያ የሚያሳዩት ተነሳሽነት?	7	6	5	4	3	2	1	0
12	....በልጅዎ ጉዳይ “ኤክስፐርት” እንደሆኑ በመረዳት አፍቅሮት/ አክብሮት ይቸርዎታል/ ይሰጥዎታል?	7	6	5	4	3	2	1	0
13	.... ከአካላዊ ፍላጎት ይልቅ/ በመለስ የልጅዎን አጠቃላይ ፍላጎት/ ዝንባሌ ለይተው ያውቃሉን (ለምሳሌ፤ በአእምሮ፤በኢሞሽናል፤ በማህበራዊ ፍላጎት ደረጃ)?	7	6	5	4	3	2	1	0
14	.... ልዩ ፍላጎት ባለው(ላት) ልጅዎ የተነሳ የቤተሰብዎ ስሜት እንዳይጎዳ ተገቢውን ጥንቃቄ ያደርጋሉ (ለምሳሌ፤ ስለልጅዎ ጤንነት ወይም ሁለንተናዊ ክንዋኔ ጭንቀት / ስስት)?	7	6	5	4	3	2	1	0
15	...ከመጠየቅዎ በፊት እንኳ ቢሆን ልጅዎን በተመለከተ ሊመጣ ስለሚችለው አዳዲስ ክስተቶች ኃላፊነት እንዳለብዎት መረጃ/ ኢንፎርሜሽን ይሰጥዎታል?	7	6	5	4	3	2	1	0
16	...በጉብኝት ወቅት ይጠቅመኛል ብለው ስለሚገምቱት ጉዳይ ለማዕከሉ ሀሳብ/አስተያየት የማቅረብ እድል እንድያገኙ በእርግጠኛነት የማበረታታት ብቃት አላቸው?	7	6	5	4	3	2	1	0
17	...እንፎርሜሽን በምስጡበት ወቅትና የምፈልጉትን ዓይነት እንፎርሜሽን ስጠይቁ የመምረጥ መብት ይሰጥዎታል?	7	6	5	4	3	2	1	0
18	...ከእርሥዎ ጋር ስለልጅዎና ቤተሰብዎ ምክክር በምታደርጉበት ወቅት ስለግል ማንነታቸው/ የሕይወት ታሪካቸው ያስተውሳሉ?	7	6	5	4	3	2	1	0
19	...ስለልጅዎ አያያዝ/እንክብካቤ ወይም የቁሳቁሶች አጠቃቀም ምክንያት ያስረድዎታል?	7	6	5	4	3	2	1	0
20	...ቀደም ሲል ተመካከረው ስለነበረው፤ ልጅዎን የሚመለከት ማናቸውም ጉዳይ በሚቀጥሉት የቀጠሮ ወቅት ክትትል ያደርጋሉ?	7	6	5	4	3	2	1	0
21	ቢያንስ አንድ የማዕከሉ የቡድን አባል/ ሠራተኛ ረዘም ላለ ጊዜ ከእርስዎና ከቤተሰብዎ ጋር የሚሠራ/የምትሠራ ስለመሆኑ እርግጠኛ ናቸው?	7	6	5	4	3	2	1	0
22	...ስለልጅዎ ጤናማ አያያዝ/ እንክብካቤ ጉዳይ የመወሰን/ የመምራት ሚና እንዲጫወቱ ዕድል ይሰጥዎታል?	7	6	5	4	3	2	1	0
23	...የምጠይቁትን ጥያቄ ሙሉ በሙሉ ይመልሱልዎታል?	7	6	5	4	3	2	1	0
24	...ልጅዎን በቴራፒ ሥራ ሂደት ወቅት በሚመለከቱበት አጋጣሚ ስለሂደቱ ያስረድዎታል?	7	6	5	4	3	2	1	0

25	...የልጅዎን ጤናማ አያያዝን በሚመለከት የቤተሰብዎ አባላት የሚያቀርቡትን ገንቢ ሀሳብ ያለምንም ገደብ ያዳምጧቸዋል/ ይቀበሏቸዋል?	7	6	5	4	3	2	1	0
26	...ከግምገማ የሚገኘውን ውጤት በወቅቱ ያሳውቅዎታል?	7	6	5	4	3	2	1	0
27	...ልጅዎን በቴራፒ ሥራ ሂደት መሥራት ያለበትን እንፎርሜሽን አሰባስበው በጽሑፍ መልክ ይሰጥዎታል?	7	6	5	4	3	2	1	0
28	...ስለቁሳቁሶች አጠቃቀምና አገልግሎት አሰጣጥ ጉዳይ ከእርስዎ ጋር ተቀራርበው/ተገናኝተው ይወያያሉ?	7	6	5	4	3	2	1	0
29	...እንፎርሜሽን ብቻ ከመስጠት ይልቅ ልጅዎን በአግባቡ ኰትኩቶና ቀርፆ የማውጣቱን ሥራ ያመቻቻሉ?	7	6	5	4	3	2	1	0
30	...ለልጅዎ ስለሚደረገው አገልግሎት/ዕርዳታ፤ ለምን እንደሚረዱ፤ የቴራፒ አገልግሎት ዓይነቶች እና የጊዜውን ርዝማኔ የመሳሰሉትን በጥልቀት ይገልፁልዎታል?	7	6	5	4	3	2	1	0
31	...እርስዎን “ከዓይነተኛው” የአካል ጉዳተኛ ልጅ ወላጅ ይልቅ እንደማንኛውም ግሌሰብ ያስተናግድዎታል?	7	6	5	4	3	2	1	0
32	...ለልጅዎ የአጭርና የሩቅ/የረጅም ዕቅድ በማውጣት ሥራ ላይ ያውላሉ?	7	6	5	4	3	2	1	0
33	...የአካል ጉዳተኛ ልጅ እንዳለው ወላጅ ሳይሆን ከማንኛውም ግሌሰብ እኩል ያስተናግድዎታል?	7	6	5	4	3	2	1	0
34	...በጋራ የመምራት መርህ ላይ በመመርኰዝ ከእርስዎ ጋር በወል ያቅዳሉ?	7	6	5	4	3	2	1	0
35	...እርስዎ የሚያመነጩት ወይም የምያቀርቡት ሀሳብ ለጤናማ የልጅ አያያዝ ስኬት በጣም ጠቃሚ መሆኑን በማመን የመግለፅ ዕድሉ እንዲያገኙ ስለማበረታታቸው እርግጠኛነት?	7	6	5	4	3	2	1	0
36	...በልጅዎ ጤናማ አያያዝ/እንክብካቤ ጉዳይ እንደየጋራ ጥቅም/ችግር ተካፋይ ያዩዎታል?	7	6	5	4	3	2	1	0
37	...የልጅዎን ጤናማ አያያዝ በሚመለከት ማንኛውም ለውጥ ሲከሰት አስቀድሞ/ ወዲያውኑ የማሳወቁ ልምድ ላይ እርግጠኛ ስለመሆን (ለምሳሌ፣ የቴራፒስቶች፤ የፕሮግራሞች፤ የቁሳቁሶች ለውጥ) ?	7	6	5	4	3	2	1	0
38	... እንደወላጅ የብቁነት /Competent/፣ በራስ የመተማመን ስሜት እንድያድርብዎት ይረድዎታል?	7	6	5	4	3	2	1	0
39	...ልጅዎ በየጊዜው የሚያሳየውን/ የሚታሳየውን መሻሻል/ለውጥ በጽሁፍ የተደገፈ መረጃ/እንፎርሜሽን ይሰጥዎታል?	7	6	5	4	3	2	1	0
40	...ልጅዎ ባደገ (ች) ቁጥር ለአዳዲስ ክስተቶች/ ነገሮች/ለለውጥ የሚያደርገውን / የሚታደርገውን ዝንባሌ/ፍላጎት የመረዳት ጥረት?	7	6	5	4	3	2	1	0
41	...ግንኙነታችሁ/ቅርርባችሁ የበለጠ ይጎልበት ዘንድ በሚያነጋግርዎት ወቅት በቂ ጊዜ በመውሰድ ነውን?	7	6	5	4	3	2	1	0
42	...እርስዎንና ቤተሰብዎን የሚያስተናግዷችሁ እንደማናቸውም ጉዳይ/ክስተት/ ሁኔታ ሳይሆን እንደሰብዓዊው ሰው(ሕጋዊው ሰዎች)ነውን?	7	6	5	4	3	2	1	0
43	...ልጅዎ ለተለያዩ ቁሱሳቁሶች፤ አገልግሎቶች፤ ወ.ዘ.ተ. ያለውን (ያላትን) ባህርይ/ ፍላጎት በተመለከተ የምያቀርቡትን ሀሳብ በቀና መንፈስ ይቀበላሉ?	7	6	5	4	3	2	1	0
44	... ለእርስዎ ራሳቸውን፣ እንደድጋፍ/ አገልግሎት ሰጪ አባል/ አካል ምንጭ (ችግሮች ማቃለያ) አድርገው ያዩታል (ለምሳሌ፣ የእሞሽናል ድጋፍ፣ የመብት ተከራካሪ፣ የመረጃ /እንፎርሜሽን ሰጪ)?	7	6	5	4	3	2	1	0
45	... ስለልጅዎ ከሰው ወደ ሰው ተከታታይ/ ተመሳሳይ የሆነ አያያዝ /ይዞታ/ ባህሪይ መረጃ /እንፎርሜሽን ይሰጥዎታልን?	7	6	5	4	3	2	1	0

ይህን ክስተት/ሁኔታ በምን ያህል ደረጃ/መጠን
እንደሚቀበሉ አንዱን መርጠው በመክበብ ያመልክቱ

	ላለፉት ዓመታት፤ እርዳታ/አገልግሎት ያድርግልዎት የነበረው ማዕከል በምን ያህል ደረጃ /መጠን፡- ...	ከሚፈለገው በላይ /ከበቂ በላይ			አልፎ አልፎ			ፍፁም	መጠይቁ አይመለከተኝም
46	... በተለያዩ ቅጾች/ መልኮች፣ መረጃ/እንፎርሜሽን፣ እንደቡክሌት፣ ክት፣ የመሳሰሉትን ቁሳቁሶች አቅርቦልዎታል?	7	6	5	4	3	2	1	0
47	... ድጋፍ ሰጪ የማዕከሉ የስታፍ አባላት/ ሰራተኞች እርስዎንና የቤተሰብዎን አባላት በአግባቡና ትህትና በተሞላበት መልኩ ያስተናግድዎታል?	7	6	5	4	3	2	1	0
48	... በማዕከሉ ወይም በኮሚዩኒቲ ደረጃ ስለሚደረገው የአገልግሎት/ የእርዳታ አይነቶች መረጃ/ እንፎርሜሽን ይሰጥዎታል?	7	6	5	4	3	2	1	0
49	... ለማህበራዊ፣ ለወቅታዊ መረጃ ልውውጥ/ እንፎርሜሽናዊ ወይም የልምድ ልውውጦች የቤተሰብ ለቤተሰብ ስብሰባዎችን በአግባቡ ያንቀሳቅሳሉ?	7	6	5	4	3	2	1	0
50	...በምፈልጉት አርዕስት ላይ ዝግጅት፣ አድርገው ለወላጆች ንግግር እንዲያደርጉ ለልዩ/ ለታዋቂ እንግዶች እድል ይሰጧቸዋል?	7	6	5	4	3	2	1	0
51	...የተለየ የልጅነት ፍላጎት ያላቸው/ የአካል ጉዳተኛ ልጆች ወላጆች ራሳቸውን ከክስተቱ/ ሁኔታው ጋር እንዲያስማሙ ያግዟቸዋል/ ይረዷቸዋል?	7	6	5	4	3	2	1	0
52	...ልጅዎን በሚመለከት ከመደበኛው የጊዜ ሰሌዳ ውጪ የሚደረጉትን አስቸኳይ ኮንፈረንሶች፣ ስብሰባዎች፣ ወ.ዘ.ተ ምክንያት ያሳውቅዎታል?	7	6	5	4	3	2	1	0
53	...ስለአካል ጉዳተኛው(ዋ) ልጅዎ በቂ መረጃ/ እንፎርሜሽን አላቸውን (ለምሳሌ፤ ስለጉዳቱ መንስኤና መጠን ፤ ሊሻሻል ስለሚችልበት መንገድ፤ ስለወደፊት አያያዝ/ አመለካከት)?	7	6	5	4	3	2	1	0
54	...ወቅታዊ የሆነ መረጃ/ እንፎርሜሽን እንዴት ሊያገኙ እንደሚችሉ ወይም ከሌሎች ወላጆች ጋር እንዴት ሊገናኙ እንደሚችሉ ምክርና መረጃ ይሰጥዎታል?	7	6	5	4	3	2	1	0
55	...የቤተሰብዎ አባላት ወቅታዊ መረጃ/ እንፎርሜሽን እንዲያገኙ እድል ይሰጧቸዋል?	7	6	5	4	3	2	1	0
56	...ሊኖር ይችላል ተብሎ ስለሚገመተው ልዩ ልዩ የአካል ጉዳተኛ ሕፃናት ጤናማ አያያዝ ሥልት አጠቃላይ መረጃ/እንፎርሜሽን አላቸውን (ለምሳሌ፡- የፋይናንስ ዋጋ ወይም እገዛ/እርዳታ፣ ስለጄኔቲክ የምክር አገልግሎትና አመራር፣ ስለሰዓትና ቀጠሮ ክቡርነት፣ ስለፆታዊ ስሜት፣ አመለካከት/አቀባበልና፣ ግንኙነት/ክነዋኔ)?	7	6	5	4	3	2	1	0

Appendix 6

Part II: Client Satisfaction Questionare (CSQ-8)

The questions in this section are based on what parents, like yourself have told us about the way care is sometimes offered. Here, we used the CSQ-8 to assess the overal level of satisfaction with the treatment received. It consists of 8 items that can be scored on a response scale from 1 (representing low satisfaction) to (high satisfaction) with the program.We sould like you to indicate your answers by circling.

CSQ-8 Nº.	**Items of the CSQ-8**	**Low Satisfaction**			**High Satisfaction**
CSQ 1	How would you rate the quality of service received?	1	2	3	4
CSQ2	Did you get the kind of service you wanted?	1	2	3	4
CSQ3	To what extent has this program met your needs?	1	2	3	4
CSQ4	If a friend were in need of similar help, would you recommend this program to him/her?	1	2	3	4
CSQ5	How satisfied are you with the amount of help you have received?	1	2	3	4
CSQ6	Have services you received helped you to deal more effectively with your problems?	1	2	3	4
CSQ7	In an overall, general sense, how satisfied are you with the service you have received?	1	2	3	4
CSQ8	If you were to seek help again, would you come back to the program?	1	2	3	4

Appendix 6

ክፍል ሁለት

የዚህ ክፍል መጠይቅ የሚመረኮዘው እርስዎን የመሳሰሉ ወላጆች ማዕከሉ በየጊዜው ለአካል ጉዳተኛ ልጆቻቸው ስለሚያደርግላቸው አያያዝ/ ዕርዳታ የሚሰጡን አስተያየት ላይ ነው:: የዝርዝር መጠይቁም ዐቢይ ዓላማ ማዕከሉ ለልጆቻችሁ የሚያደርገው አያያዝ ሁኔታ ምን ያህል አጥጋቢ/አርኪ እንደሆነ ወይም እንዳልሆነ ለማወቅ ስለሆነ መልስዎን ቀጥሎ ከተሰጠው ሰንጠረዥ ውስጥ መርጠው በመክበብ ያመልክቱ::

ተ.ቁ. (CSQ-8 №)	የተገልጋይ/ደንበኛ የእርካታ ደረጃ መለኪያ ዝርዝር መጠይቅ	ዝቅተኛ እርካታ			ከፍተኛ እርካታ
CSQ1	ማዕከሉ አድርጉልዎት ስለነበረው የእንክብካቤ/የአገልግሎት ጥራት እንዴት መዘኑት/ አዩት?	1	2	3	4
CSQ2	ከማዕከሉ የሚፈልጉትን ዓይነት አገልግሎት /ዕርዳታ አግኝተው ነበርን?	1	2	3	4
CSQ3	የማዕከሉ ኘሮግራም ፍላጐትዎን ያሟላልዎት ይመስልዎታል?	1	2	3	4
CSQ4	እንደእርስዎ በተመሳሳይ መልኩ በማዕከሉ ኘሮግራም ለመታቀፍ(ለመረዳት የሚፈልግ(የምትፈልግ) ጓደኛ ቢኖርዎት ይህ ኘሮግራም ይረደዋል(ታል) ብለው ይገምታሉ?	1	2	3	4
CSQ5	ከማዕከሉ ባገኙት አገልግሎት/ዕርዳታ ፍላጐትዎ ተሟልቷአልን?	1	2	3	4
CSQ6	ከማዕከሉ አግኝተው የነበረው አገልግሎት /ዕርዳታ ችግርዎን በውጤታማ መልኩ ለመፍታት አስችሎዎት ነበር?	1	2	3	4
CSQ7	በሁለንተናዊ መልኩ፣ በአጠቃላይ ሁናቴ፣ ከማዕከሉ በሚያገኙት አገልግሎት ዕርዳታ ሊረኩ ችለዋልን?	1	2	3	4
CSQ8	እንደገና እገዛ/ዕርዳታ ቢያሻዎት ወደ ማዕከሉ ተመልሰው ለመምጣት ይፈልጋሉን?	1	2	3	4

እባክዎትን ከተጠቀሰው ውጪ ሌላ አስተያየት ካለዎት ይግለጹ ………………………………………

……………………………………………………………………………………………

……………………………………………………………………………………………

Appendix 7

Part III. Question on Goal Achievement

One item using a 7- point rating scale will used to determine parental perceptions of goal achievement. It is: "Did the Cheshire CBR/ Children's treatment program/ centre) meet your goals?" The response scale scores consists of 1-none, 2- very few, 3-few, 4-some, 5-quite a few, 6-most, and 7- all.

Appendix 7

ክፍል ሶስት

ቀጥሎ የወላጆች የግብ ስኬት አቀባበል መረጃ መሰብሰቢያ ቅጽ ሆኖ የሚያገለግል ባለ 7 - ነጥብ ምላሽ ስኬል ያለው አንድ ጥያቄ ተዘጋጅቷል፡፡ ይኸውም **በቸሻየር የልዮ ፍላጎት ሕፃናት ማዕከል (Cheshiere)** በእርዳታ/ አገልግሎት አሰጣጡ ዓላማዎትን አሳክቶልዎታልን/ ከግብ አድርሶልዎታልን? የምላሽ ስኬሉም አመዘጋገብ፡- 1 -ምንም፣ 2 በጣም ጥቂት፣ 3-ጥቂት፣ 4-በከፊል ፣ 5-በተሻለ ሁኔታ ፣ 6-ከሞላ ጎደል፣ 7-ያለምንም እንከን (ሙሉ በሙሉ) የሚለው ነው፡፡ አንዱን ብቻ መርጠው በመክበብ ምላሽዎን ይስጡ፡፡

ልዩ ፍላጎት ካለው(ላት) ልጅ ጋር ያለዎት ዝምድና ምንድነው?

☐ የተፈጥሮ ወላጅ/ እናት
☐ የእንጀራ እናት
☐ የጉድፈቻ /ማደጎ ልጅ እናት
☐ አሳዳጊ እናት

☐ የተፈጥሮ ወላጅ/ አባት
☐ የእንጀራ አባት
☐ የጉድፈቻ/ማደጎ ልጅ አባት
☐ አሳዳጊ አባት

እባክዎትን ሞግዚት /ሌላ ጠባቂ ከሆኑ ይግለፁ ____________________
ይህን መጠይቅ ሞልተው የጨረሱበት ቀን፡- ____________________

እስካሁን ከተጠቀሰው ውጪ የተለየ አስተያየት ካልዎት ይግለጹ ____________________
____
____
____
____

እባክዎትን በሁሉም ገጾች ላይ ያሉትን መጠይቆች በአግባቡ ሞልተው ማጠናቀቅዎን ያረጋግጡ፡፡

መጠይቁ ተሞልቶ ሲያልቅ ምስጢራዊነቱ የተጠበቀ ነው
እናመሰግናለን!!

Appendix -8

Table 10: The Average Scores Obtained from each Respondent on the 5 MPOC Scales

No	Tee 5 MPOC scales	Number of respondents	Interval of the average scores	Average scores	sum of the average scores
1	Enabling and Partnership	0	1.00-1.99	0	0
		0	2.00-2.99	0	0
		3	3.00-3.99	3.44	10.32
		8	4.00-4.99	4.57	36.56
		14	5.00-5.00	5.38	75.32
		40	6.00-6.99	6.51	260.40
		10	7.00	7.00	70
		n=75		Mean=6.04	Mean=6.04
2	Providing General Information	4	1.00-1.99	1.44	5.76
		4	2.00-2.99	2.42	9.68
		4	3.00-3.99	3.49	13.96
		13	4.00-4.99	4.77	62.01
		18	5.00-5.00	5.52	99.36
		18	6.00-6.99	6.00	108.00
		4	7.00	7.00	28.00
		n=65		Mean=5.03	Mean = 5.03
3	Providing Specific Information about the Child	0	1.00-1.99	0	0
		0	2.00-2.99	0	0
		2	3.00-3.99	3.34	4.68
		10	4.00-4.99	4.71	47.10
		14	5.00-5.00	5.60	78.40
		31	6.00-6.99	6.31	195.61
		14	7.00	7.00	98.00
		n=71		Mean = 5.97	Mean = 5.97
4	Providing Coordinated and Comprehensive Care for the Child and Family	0	1.00-1.99	0	0
		0	2.00-2.99	0	0
		2	3.00-3.99	3.27	6.54
		8	4.00-4.99	4.79	38.32
		22	5.00-5.00	5.36	117.59
		37	6.00-6.99	6.67	246.29
		6	7.00	7.00	42.00
		n=75		Mean = 6.02	Mean-6.02
5	Providing Respectful and Supportive Care	0	1.00-1.99	0	0
		0	2.00-2.99	0	0
		1	3.00-3.99	3.60	3.60
		2	4.00-4.99	4.38	8.76
		19	5.00-5.00	5.22	99.18
		4015	6.00-6.99	6.69	267.60
		15	7.00	7.00	105.00
		n=77		Mean=6.28	Mean=6.28

Appendix 9

3. What is your child's primary diagnosis, health or
Other special need? Check (X) one only.
Other, please specify:
Brain Tumour
Autism/ PDD
Craniofacial disorder
Torticollis
One leg shorter than the other
Birth defect affecting big motor skills
Sphenodal encephecele
Cleft Lip and Palate
Hypoplastic left heart
Feeding Problems
Downs Syndrome
Rett Syndrome
Autism
Cerebral Palsy
Cleft Palate
Torticollis
Upper *and* lower limb abnormalities
Tuberous Sclerosis
Motor movements
Cleft palate
Fine motor
Hypotonia
Brachial Plexus injury
Stroke, left side