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LAKEHEAD UNIVERSITY

A FAMILY CENTRED CASE MANAGEMENT APPROACH IN LONG-TERM HEALTH

CARE FOR CHILDREN: PARENTS' PERCEPTIONS OF CARE

A THESIS SUBMITTED TO

THE FACULTY OF ARTS AND SCIENCE IN CANDIDACY FOR THE DEGREE OF

MASTER OF SOCIAL WORK

DEPARTMENT OF SOCIAL WORK

BY

TUIJA PUIRAS ©

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CHAPTER ONE

INTRODUCTION

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INTRODUCTION

One of the more 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 and families in ways that are respectful and supportive (Ahmann, 1994; Letourneau & Elliott, 1996; Wharf, 1992). In children's rehabilitation services it is hard to find a treatment centre in Ontario that would not have revisited its mission statement and revised its programs and policies to reflect more family centred practice principles in accordance with this shift (Law et al., 1997).

The George Jeffrey Children's Treatment Centre in Thunder Bay responded to this shift in approach by implementing a family centred case management model in 1987 (Appendix A). In this model, clinicians work in interdisciplinary teams in partnerships with families and clients. The social worker, called a Family Service Coordinator, assumes responsibility for ensuring that the services for the child and the family are provided in a coordinated and comprehensive manner throughout their involvement with the Centre programs.

The coordinator assesses the psychosocial aspects of the child and the family functioning by informal interviews and standardized measures; links the family with needed supports; provides resources and counselling; monitors the care plan; and ensures that family centred principles are adhered to. All staff are sensitized to the family centred case management model, and are expected to provide services according to family centred principles.

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My own interest in family centred services was sparked when years ago, as a front line clinician, I facilitated a group entitled "Parents as Partners with Professionals". It became apparent from these parents that their active participation in the health care of their child was extremely important. It was also evident from comments from the parents that, at times, their feedback was not accepted and appreciated by professionals. The parent interaction emphasized the profound effect that professionals have on families, the self esteem of a parent, and on the overall outcome of the health care plan. Because of the significance of the relationship between the health care provider and the parent, I became interested in exploring systematic ways of involving the parents of children with disabilities and ensuring their active participation as team players where their input, rights, and concerns are respected. This exploration stimulated interest in family centred practices and case management.

The literature on family centred service provision indicates that there may be a number of barriers to the implementation of family centred 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, & 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.

The purpose of this exploratory study is to determine from the

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parents involved with the George Jeffrey Children's Treatment Centre Infant and Preschool Program, how well the Family Centred Case Management model facilitates the provision of family centred services, as perceived by parents of children with long term health care needs.

TITLE OF RESEARCH THESIS

A Family Centred Case Management Approach in Long-Term Health Care for Children: Parents' Perceptions of Care.

RESEARCH QUESTION

"Do parents of children who have long term health care needs, perceive the practices of George Jeffrey Children's Treatment Centre as reflecting the family centred case management philosophy and principles?"

DEFINITION OF TERMS

Family Centred **Philosophy:**	Recognizes that the family is central in a child's life and should be central in the child's plan of care. Family centred care embraces diversity in family structures, cultural backgrounds, choices, strengths, and needs. The philosophy of family centred care calls for partnerships between parents and Professionals that support parents in

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their central caring role (Ahmann, 1994).

Case Management: A procedure to plan, seek, and monitor services from different social agencies and staff on behalf of a client (Barker, 1995).

Family: A primary group whose members assume certain obligations for each other and generally share 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).

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

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

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CHAPTER TWO

CONCEPTUAL FRAMEWORK

(a) Family Centred Care

(b) Case Management

(c) Family Centred Case Management

(d) Summary

FAMILY CENTRED CARE

Over the years, there has been a growing recognition by health care professionals and service providers that in order to provide quality children's health care, the families of children need to be involved in the development of care plans in a respectful and meaningful manner (Ahmann, 1994; Johnson, 1990; Letourneau & Elliott, 1996).

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 centred practitioner is the enhancement of the quality of life and the adaptive balance between human beings and their ecological environments (Shelton, Jeppson, & Johnson, 1989). The key elements of family centred care, as identified by these authors 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

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- 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-Centred 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.

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

King, Rosenbaum, Law, King and Evans (1996) 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[1].

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-centred 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 et al., 1982; Fiene & Taylor, 1991; Mahoney et al., 1990).

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[1]For more detail see Appendix B, reprinted with permission of the authors.

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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 pooling of resources, information and labour to meet shared objectives. It means working with groups and/or individuals who bring insight and experience to the table (Barter, 1996; Delaney & Weening, 1995). This is in line with the shifting paradigm from what Schriver (1995) refers to as binary or competing and oppositional terms, such as "we-they", to cooperative and inclusive terms, such as "us".

According to Tjosvold'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 centred 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

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centred practice (Barter, 1996; Shelton et al., 1989).

The goal of family centred 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 et al., 1988). The service 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 centred 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., 1996). The very definition of family changes over time with changes in family structures in society. Family

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centred care embraces diversity in family composition, cultural backgrounds, choices, strengths and needs (Ahmann, 1994; Johnson, 1990; Hartman, 1992; Letourneau & Elliott, 1996; Shelton et al., 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 Eurocentricity.

The feminist view parallels the family centred 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 patienthood",

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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 goal 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 centred 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 centred 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,

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

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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 et al. (1989) state that family centred 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 neighbours, 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 centred 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, 1986; 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, 1986; Slater & Wikler, 1986). Marital difficulties and issues with sibling adjustment are common, as 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).

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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 centred principles regards human problems, needs, and conflicts as adaptive tasks providing the client with opportunities for growth, mastery, and competence development (Pecora et al., 1992).

The family's ability to assist a child who has 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 et al., 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., 1996; Knoll, 1992, Winton & Bailey, 1997).

CASE MANAGEMENT

Case management is viewed as a means to provide services to clients with complex needs requiring long term care (Applebaum & Austin, 1990; Roberts-DeGennaro, 1987; Rothman, 1991). It is seen as a way to mitigate the chaos created by fragmented systems

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(Moore, 1992). Case management intervention takes place on a number of levels from the individual client level to the realm of legislation and policy making.

The day-to-day case management intervention happens on two levels: the client and the service system (Vourlekis & Greene, 1992). The range of services may be determined by such factors as the target population, the type of agency, caseload size and the nature of the service delivery system. Greene (1992) equates case management with generic social work practice, as one of its core technologies. Case management is defined as a process of service coordination, with built in accountability to ensure the client's right to service. The process is not linear but cyclical, as new needs arise and people move in and out of the system at different times (Rothman, 1991).

Case management is generally defined by its functions (Applebaum & Austin, 1990; Long, Katz, & Pokorni, 1989; Moore, 1992; Netting, 1992; Roberts-DeGennaro, 1987; Rothman, 1991; Vourlekis & Greene, 1992), which can be summarized as follows:

1. entry (intake/prescreening),

2. assessment,

3. goal setting/care plan drafting/service planning,

4. care plan implementation/counselling/resources/linkages (formal & informal),

5. monitoring, reassessment,

6. review/evaluation/discharge.

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The functions are progressive and overlapping, combining aspects of all three methods of social work practice, namely casework, group work and community organization (Roberts-DeGennaro, 1987). Case management deals with the needs of an individual client and the client systems, including family and community resources. In addition, it concerns itself with the community structures, programs and resource allocation policies that affect the client's situation.

Case management models have their origins in the care planning task (Austin, 1990; Vourlekis & Greene, 1992), which are client specific. The case manager focuses on the system within which the individual functions. The systems theory, the person-in-situation configuration, is seen as the conceptual foundation of case management practice (Applebaum & Austin, 1990; Bernier, 1990; Pecora et al., 1992; Roberts-DeGennaro, 1987; Vourlekis & Greene, 1992). Greene (1992) identifies three goals for case management intervention: 1. continuum of care, 2. coordination and linking of service delivery systems, and 3. maximizing and enhancing client independence. These goals are incorporated in the case management functions which also reflect the values that case management is based on. To facilitate collaboration between the client and worker, an environment that promotes mutual trust and client self determination needs to exist (Applebaum & Austin, 1990). Belief in client competence and power sharing in the decision making process is fundamental to case management (Pecora et al., 1992; Roberts-DeGennaro, 1987). In assuming that the client and people in his/her

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environment possess certain strengths and successful coping strategies, the case manager can enhance these skills by providing information, techniques or resources which will empower the client to take control of their situation (Fiene & Taylor, 1991; Schriver, 1996).

When dealing with children's health care needs, the family becomes the unit of attention. Pecora et al. (1992) note that:

> focus on the family does not mean that the child's needs and interests are of secondary importance. It means that, in most cases, the child can best be helped through regarding the family as the central unit of service or focus of attention, whenever and as much as possible. Human beings can best be understood and helped within their significant environment, and the family is the most intimate environment of all (p. 46).

Ideally, the goal of case management is client empowerment by teaching needed skills and strategies so that clients and families develop the self-efficacy that enables them to be in control of their own services (Fiene & Taylor, 1991; Kaufman, 1992; Netting, 1992). This is an approach consistent with generalist social work's emphasis on the rights of a client (Kirst-Ashman & Hull, 1993).

FAMILY CENTRED CASE MANAGEMENT

Indeed, one element mutual to the family centred philosophy and the case management process is the promotion of client

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empowerment (Cormany, 1993; Fiene & Taylor, 1991; Jackson et al., 1992; Kaufman, 1992; Marchenko & Smith, 1992). It can be facilitated by provision of information (Moore, 1992), parent-to-parent support and skill building sessions (Marchenko & Smith, 1992), by increasing individual opportunities, choices and responsibilities (Cormany, 1993), and specifically by forming a collaborative partnership with the family (Barter, 1996; Pecora et al., 1992; Schriver, 1995).

Service coordination remains one of the top issues with parents who have children with long term health care needs (Cormany, 1993; Peckham, 1991). The role of a service coordinator (case manager) is based on assumptions that it is to be proactive, family centred rather than system centred, and that families are empowered and enabled through promoting family competencies to obtain services and resources. Active efforts are made by the service coordinator to avoid creating dependence or learned helplessness in families by teaching, encouraging and reinforcing advocacy and independent decision making skills. Families prefer "participatory democracy as opposed to representative democracy" (Cormany, 1993, p. 13). Coordination of activities and collaboration occurs on the case manager to family, as well as agency to agency level.

Jackson et al. (1992) describe a care coordination process based on assumptions that are congruent with what Dunst et al. (1988) define as a client empowerment approach. The coordination process is based on the family systems approach, the services are

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individualized, and the care coordination is expected to support families in order to maximize their capacity to access services independently.

Empowerment based practice is established on the recognition of family strengths and that the client and social worker collaborate as peers to solve problems (Solomon, 1985). Gutierrez (1994) identifies major issues and themes which characterize the process of empowerment: increasing self-efficacy, developing a critical consciousness, developing skills and involvement with similar others. Case management lends itself to this model as it seeks to provide clients with skills to make informed decisions about services offered, provides linkages to service providers and promotes parent-to-parent support (Applebaum & Austin, 1990; Fiene & Taylor, 1991; Marchenko & Smith, 1992; Rothman, 1991).

Lord and Farlow (1990) identified the following characteristics of services that contribute to personal empowerment: they are personalized, interactive, and are aimed at reducing dependency. The focus is not only on the psychological or illness related needs of the person, but rather on the "person-in-the-environment". In contrast to traditional human service practices where interventions are typically provided following the onset of some problem or difficulty (Slater & Wikler, 1986), family centred programs are oriented toward preventing families' and children's problems. Dunst et al. (1988) argue that the use of promotion and enhancement models increases the likelihood that people will become more capable and competent in managing the long

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term health care needs of their loved ones, as a result of intervention efforts.

SUMMARY

Family centred practice principles represent a fundamental shift in the way long term health care services are provided to children and their families. The shift has occurred from an expert driven service system to a collaborative partnership between service providers and the consumers (Winton & Bailey, 1997).

The following key assumptions guide the family centred services:

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. (King et al., 1996).

The family centred principles view parents of children with disabilities from a strengths perspective, as competent partners in designing service plans. The holistic approach acknowledges the importance of formal and informal support systems. Acceptance of diversity in terms of family composition, knowledge, skills, cultural and ethnic background and coping methods, is incorporated in the family centred values (Schriver, 1996; Shelton et al.,

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1989).

Case management's value base, including the tasks and functions that define case management, are compatible with the family centred principles (Fiene & Taylor, 1991). Based on the Ecological Systems Theory (Germain & Gitterman, 1980), the goal of case management is to provide parents with linkages, resources and the building of skills to become self sufficient in managing the resources and services that the family needs (Rothman, 1991). Case management is one way of implementing family centred practice principles.

The key element in implementing the family centred principles through the family centred case management approach is the collaborative partnership between the parents and the service providers. The end result is an enabling and empowering service model which is personalized, interactive and focuses on consumer needs from a holistic point of view (Dunst et al., 1988).

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CHAPTER THREE

LITERATURE REVIEW

(a) Descriptions of Models

(b) Implementation of Family Centred Practice Models

(c) Barriers to Family Centred Practice

(d) Research in Family Centred Case Management

(e) Summary

DESCRIPTION OF MODELS

A number of features are common to programs that operate within the family centred 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 centred 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 centred programs promote the identification of a service coordinator. The role can be taken up by a professional or a parent or other care giver (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 centred programs are based on individualized outcomes (Boone, Moore, & Coulter, 1995; Brown et al., 1991; Brown et al., 1993; Cormany, 1993; Dunst, Trivette, Gordon & Starnes, 1993; Fiene & Taylor, 1991; Jackson et al., 1992; Kaufman, 1992; Korteland & Cornwell, 1991; Mahoney et al., 1990; Rosenbaum, 1996).

IMPLEMENTATION OF FAMILY CENTRED PRACTICE MODELS

The publication of the key elements of the family centred care by the Association for the Care of Children's Health (Shelton et al., 1987) 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 centred care is more difficult to put into practice. Even though health care professionals generally support and respect the philosophy of family centred care, many experience conflict in their helping styles, based on the medical model, and the expectations for practice according to the family centred principles. Specifically the support needs of families are not consistently recognized as interventions tend to focus primarily on the child (Dunst & Trivette, 1987; Korteland & Cornwell, 1991; Shelton et al., 1989).

Boone et al. (1995) assessed family centred practices in infant and toddler programs. They reviewed Individual Family Service Plans (IFSPs) to determine quality indicators reflecting family centred practices. Both parents' and professionals' perceptions of family centred practices were assessed. They found that the IFSPs were primarily child centred, focusing on facilitating the child's development. The majority of written outcome statements addressed child centred 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 expectations for ideal services. According

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to this study, parents and professionals in rural areas perceived greater family centred practices in current service delivery than in urban areas.

Diehl et al. (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 et al. (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 et al. (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 Wikler (1986) propose that professionally provided services tend to substitute families rather than support them.

Arango (1990) notes that family centredness 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 how easily the service fits into all aspects of a child's and the family's life. To promote a

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true parent-professional partnership, Arango 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 centred point of view.

BARRIERS TO FAMILY CENTRED PRACTICE

Often parents and professionals are operating within limited models, which prevents them from living up to the family centred philosophy (Brown et al., 1991; Boone et al., 1995; Jacono, Hicks, Antonioni, O'Brien & Rasi, 1990; Letourneau & Elliott, 1996; Mahoney et al., 1990). Parents may be unaware of their unique and important role in the early intervention process (Boone et al., 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 centred care is the reluctance of care providers to see parents as competent. Summers et al. (1990) conducted a qualitative study that

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focused on the Individualized Family Service Plan 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 nonjudgemental. 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 and Bailey (1997) agree that the family centred 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.

RESEARCH IN FAMILY CENTRED CASE MANAGEMENT

Many articles addressing case management are descriptive in nature (e.g., Cormany, 1993; Fiene & Taylor, 1991; Rothman, 1991). Netting (1992) provides a word of caution to the fact that case managers 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

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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.

Marchenko and Smith (1992) found that a family centred case management project was limited by the general supports provided by the community. The case managers also encountered "system problems". Due to fragmented service systems, for instance the need to apply to several funding resources, the case manager's functions were limited by time spent on attaining funding and arranging services, which detracted from the amount of time and energy the case manager and families could have focused on other concerns.

Family centred 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). Case management, however, strives for cost effectiveness (Cormany, 1993; Fiene & Taylor, 1991; Rothman, 1991), creating a potential conflict between family centred care and effective case management.

Cnaan (1994) evaluated the effectiveness of case management, and notes that it had no significant effect on the development of larger and more diverse social networks for clients in mental health setting. Marchenko and Smith (1992) note that with the case management approach, access to services increased and the mothers' life satisfaction was increased. High service needs continued in other areas. Berkowitch, Halfon and Klee (1992) evaluated the effectiveness of the case management approach provided in pediatric

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outpatient programs. The authors chose four indicators of case management effectiveness, namely comprehensiveness, continuity, duration and coordination of care. They found that case management was effective in improving comprehensiveness and continuity of care among participating families. To improve case management effectiveness, one person was identified across programs and among service providers as a case manager. Rothman (1991) notes that little research has been done in terms of the overall usefulness of case management to the client.

Some studies (Brown et al., 1991; Dunst et al., 1993; Fiene & Taylor, 1991; Jackson et al., 1992; Kaufman, 1992; Marchenko & Smith, 1992; Smith et al., 1994) look specifically at the family centred case management model. All articles reflect findings in the United States, some dealing with Neonatal Intensive Care settings and some with Home and Community Care programs or pilot projects.

In Canada, Rosenbaum (1996) describes the Measure of Processes of Care (MPOC) questionnaire that his research group specifically developed to evaluate parents' perceptions of family centred services in pediatric rehabilitation settings. King, Rosenbaum and King (1995) conducted a number of surveys at various children's rehabilitation settings across Ontario 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 centredness. Letourneau and Elliott (1996) studied professionals' perceptions of family centred service practices at a Western

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Canadian children's hospital. No Canadian articles were found that addressed specifically a family centred case management approach at an outpatient facility, such as a children's treatment centre.

Jackson et al. (1992) evaluated a pilot project and found that a family centred case management 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 centred case management 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 coping. Smith et al. (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 definition of case management 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.

Three articles describe models of family centred case management programs(Brown et al., 1991; Fiene & Taylor, 1991; Kaufman, 1992) but do not involve an evaluative component.

Dunst et al. (1993) investigated the extent to which different relationship-related help-giving attitudes and behaviours vary among case managers. The findings demonstrate that there is a link

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between case manager practices consistent with family support principles, and the practices presumed to being family centred. In brief, better family outcomes are related to case manager helping styles that are consistent with the intent of family support principles.

SUMMARY

In reviewing the literature on family centred services, the health care plan centers around the Individual Family Service Plan (IFSP). This is a mandated early intervention process in the United States. According to the reviews, the Individual Family Service Plans do not generally meet the needs of the entire family. They tend to be narrow in focus, concentrating on child centred needs or discharge planning (e.g., Boone et al., 1995). Parents are not comprehensively involved in the decision making process, and many programs fail to provide emotional support, or fit in the family's life style (Arango, 1990).

Both parents and professionals may operate from limited models, which serve as barriers to implementing family centred practice principles (Jacono et al., 1990). Service providers often fail to see parents as competent partners in designing services (Summers et al., 1990). Professionals may need to reconsider traditional interaction techniques and terminology (Mogedal, 1994; Powell, 1996).

Even though the case management approach has generally been well accepted by parents, more research is required to compare case

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management to other approaches (Berkowitz et al., 1992). Some researchers warn that certain control issues are affiliated with case management due to the role of the case manager as a gate keeper to resources (Marchenko & Smith, 1992; Netting, 1992).

Dunst et al. (1993) support the family centred case management as a model most consistent with the enabling and empowering principles. The model is reported as highly satisfactory to parents, it can be effectively implemented and it is readily accepted by parents (Smith et al., 1994). However, a Canadian component in the literature of family centred case management is missing.

CHAPTER FOUR

METHODOLOGY

(a) Design

(b) Study Population

(c) Instruments

(d) Procedure

(e) Ethical Review Procedures

DESIGN

As indicated in the literature review, even when a 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 centred case management model, it was necessary to find out whether the parents involved with the George Jeffrey Children's Treatment Centre Infant and Preschool Program actually felt that they were receiving services that were congruent with the family centred case management 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 Infant and Preschool Program before the parents become involved with the services of the program. For that reason, a pretest was not feasible. The research was conducted as a one-shot case study, or post-test only one-group design (Leavitt, 1991).

A cross-sectional mail survey was chosen as a method of data collection.

STUDY POPULATION

The total caseload of the George Jeffrey Children's Treatment Centre Infant and Preschool Program, excluding the waiting list, was surveyed. The Centre's catchment area includes the city of

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Thunder Bay, rural areas surrounding the city, and the district of Thunder Bay. The majority of the families reside within the city of Thunder Bay and the rural townships. District families are able to choose services at the Centre during their trips to the city, or through the Integrated Services for Northern Children program in their own communities on a consultation basis.

All children in the Infant and Preschool Program have acquired or congenital neurological disorders, motor developmental delays, communication challenges in speech and/or language development, or they are at risk for delays due to premature or traumatic birth. The children may receive one or several services, such as physiotherapy, occupational therapy, speech language pathology and social work. They may also attend medical or orthopaedic clinics. The frequency of intervention may vary (once a week, twice a month, once a month, every 2,3,4,6 months, once a year) and a number of modalities are used (individual or group therapy, mediated therapy, consultation).

The survey was limited to families receiving services from the Infant and Preschool teams. 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 setting.

Two hundred and sixty nine (269) children were identified as eligible to participate in the survey. Out of these, five (5) were siblings of children already selected for the survey. Each family was mailed only one questionnaire. Two hundred and sixty four

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(N=264) families were mailed the survey package. The distribution of the initial mailing was as follows: 232 packages were sent to the city of Thunder Bay residents, 20 to rural residents and 12 to families living in the district. Twelve (12) of the packages were returned due to the respondent having moved without leaving a forwarding address, reducing the number to 252. Forty three (43) responses were returned from the first mailing. Another thirty five (35) were returned after the first reminder (second mailing). Three (3) more responses were received after the second reminder (third mailing). After the last reminder, four (4) people telephoned stating that they did not wish to participate in the survey due to minimal involvement with the Centre.

Eighty one (81) responses were returned out of the 252 mailed for the response rate of 32.1 percent. Two of the returns were discarded due to insufficient data. The data analysis is based on 79 (N=79) completed questionnaires.

INSTRUMENTS

The Measure of Processes of Care (MPOC) questionnaire was used (Appendix E). Permission to use the tool was obtained from its developers, the Neurodevelopmental Clinical Research Unit (NCRU) of McMaster University and Chedoke-McMaster Hospitals. The Chief Executive Officer of the George Jeffrey Children's Treatment Centre authorized in writing the use of their Infant and Preschool caseload as the survey population (Appendix C). The Board of Directors and the Family Advisory Committee of the agency were

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informed verbally by the Chief Executive Officer of the research and the mailing of questionnaires.

The MPOC is a 56-item self-administered questionnaire which was developed to measure parents' perceptions of the care they and their children receive from rehabilitation treatment centres. The authors of the questionnaire state that the measure is viewed as "tapping the important features of family-centredness" (King et al., 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 a rehabilitation centre. Statements are rated by the respondent on a scale ranging from 1 (never) to 7 (to a great extent).

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 et al., 1995). A brief overview of these studies follows:

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Reliability.

The internal consistency of MPOC-56 scales was assessed by Cronbach's Coefficient Alpha. All values, except for the third scale in the smaller sample (N=29) (Providing Specific Information about the Child = .63), were above the minimally accepted criterion of .80.

The stability of the scales over time was assessed with data collected in a test-retest reliability study. Parents answered MPOC the same way after an interval of 3 to 4 weeks. The Intraclass Correlation Coefficient was used as a reliability coefficient, ranging from .78 to .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 centres 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 et al., 1995, p. 42).

Construct Validity: Evidence is presented by the research group that MPOC's five scales are distinct and represent meaningful aspects of care. The data to support these findings were derived

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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 on MPOC scale scores would be associated with lower levels of stress on all scales. The results of this 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, Attkisson, Hargreaves, & Nguyen, 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 et al., 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 type (urban, small urban, rural), family type (single, two parent), gross family income, mothers' education, fathers' education (Spearman Rank r), and child's gender (eta coefficient). These findings provide evidence for discriminant validity.

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The developers of the instrument predicted a negative relationship between a child's age and some of the scale scores. Enabling and Partnership (-.13) and Coordinated and Comprehensive Care (-.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 et al., 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, which makes it suitable for the purposes of this reseach. 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 centres. The questionnaire was

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developed with extensive input from parents. The five scales are based on the aspects of care that parents viewed as important (King et al., 1995). Although new, the MPOC is an established instrument to measure the extent of family centredness of service providers.

The intent of case management 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 et al. (1992) proposed four indicators of case management 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 behaviours 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 et al., 1995, p. 25). This scale especially can be seen as one measuring elements of case management. Case management is based on the systems theory framework, and in the case of children with long-term health care needs, planning takes place within the context of the family (Bernier, 1990; Pecora et al., 1992). Ensuring continuum of care and coordination and linking of service delivery systems are primary functions in case management (Greene, 1992; Rothman, 1991).

Demographic questionnaire.

In order to describe the participants, a demographic questionnaire was constructed and added to the MPOC questionnaire

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(Appendix D). The descriptive variables were chosen for the demographic questionnaire from similar questionnaires used in the pilot studies. Some questions were chosen on the basis of the literature review. For instance, parents' perception of services may be influenced by the number of services being received. Also, individuals with higher level of education tend to respond to mail surveys more often than individuals who have less formal education. The researcher was also interested in finding out who the respondent (care giver) saw as the main case manager or care coordinator for the child's health care needs. This question was of interest to the researcher in order to explore the case manager component of the service model. The agency family service coordinators (social workers) were assigned the case manager role when the family centred case management 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 and the demographic questionnaire were reviewed by the Family Advisory Committee of the George Jeffrey Children's Treatment Centre. 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.

PROCEDURE

A mailing list was generated by the Health Information

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Services of the George Jeffrey Children's Treatment Centre after obtaining permission from the Chief Executive Officer to carry out the research.

Pretest.

The MPOC is an established instrument, although a new one, and pretests have been conducted with similar populations at other children's treatment centres in Ontario.

Data Collection.

The Measure of Processes of Care (MPOC) questionnaire and a Child and Family Background form were mailed to the total Infant and Preschool Program caseload, excluding the waiting list. The package contained a letter explaining the purpose of the research (Appendix F), the two forms (Appendix D and E), two self-addressed envelopes, a response card (Appendix I), and instructions for completion of the two forms and the mailing of the questionnaire and the response card (Appendix J). Two separate addresses, the Centre address and the researcher's home address, were provided as return addresses of the questionnaire and the response card.

The MPOC is a structured, self-administered questionnaire. The participants were asked to read each closed question and respond to a statement regarding parents' experiences at the treatment centre, by circling an appropriate number on a scale of 1 (Never) to 7 (To a Great Extent).

After completing the questionnaire, parents were asked to

return it in the self-addressed, stamped envelope, as well as to mail in the response card. Another stamped envelope was provided for the card.

The mailing list was monitored by the response cards for the second mailing. The first reminder letter (Appendix G) was sent out to all potential respondents approximately two weeks after the initial packages were mailed out.

A second reminder letter (Appendix H) was sent approximately a month after the first reminder. Both letters contained phone numbers where the researcher could be contacted in case people had questions about the forms or the procedure. After the second reminder, the Centre Family Service Coordinators working in the Infant and Preschool Program were also asked to verbally remind people and encourage them to complete the questionnaire.

As the response cards and the questionnaires were received at different addresses, it was not possible to match the completed questionnaires with client names, thus anonymity was maintained. Only the researcher had access to the questionnaires, in order to guard confidentiality of the Centre clients.

The completed questionnaires were numbered, the responses were coded, and the data were keyed in the SPSS program (Norusis, 1990) for a descriptive analysis. Programming information on how to calculate the scale scores was obtained from the Neurodevelopmental Clinical Research Unit in Hamilton.

ETHICAL REVIEW PROCEDURES

Informed Consent.

A cover letter (Appendix F) was included in the mail out 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 Centre's programs.

Confidentiality/ anonymity.

A mailing list was generated by the Health Information Services at the Children's Treatment Centre. No identifying information was requested on the questionnaire or the return envelope. A response card was filled separately in order to avoid connecting a client or a family members's name with a completed questionnaire. A mailing list was generated from the response cards, making it possible for the researcher to mail a reminder letter to non-respondents only (second and third mailing).

The clinical staff of the Centre did not have access to the original responses, in order to preserve anonymity.

Deception.

No deception was involved in this survey.

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Risks and benefits to the participants.

Some parents expressed frustration to the clinical staff for receiving the questionnaire 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 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 that a summary of the survey and the results will be included in the Centre newsletter which is mailed to all clients. A copy of the completed research will be placed in the Treatment Centre library.

The results will be shared with the 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 Services Meeting (attended by clinical staff). The findings will also be shared with the Neurodevelopmental Clinical Research Unit.

CHAPTER FIVE

RESULTS

(a) Child and Family Background

(b) Scale Scores

(c) Comments by Parents

(d) Summary

CHILD AND FAMILY BACKGROUND

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

Table 1
Characteristics of the Child with Special Needs
(N= 79)

Age in Years

Mean	Minimum	Maximum	SD
4.16	.41	13.75	2.28

Age Distribution

	n	%
0-23 mos. (less than 2 yrs)	13	16.5
24-47 mos.(2 & 3 year-olds)	26	32.9
48-71 mos.(4 & 5 year-olds)	26	32.9
72-95 mos.(6 & 7 year-olds)	10	12.7
96+ mos. (8 years and up)	4	5.1

Gender	n	%
male	48	60.8
female	31	39.2

Primary Diagnosis	n	%
Prematurity	17	21.0
Developmental Delay	13	16.5
Cerebral Palsy	12	15.2
Muscle Disorder	5	6.3
Communication Disorder	3	3.8
Brain Injury	2	2.5
Learning Problems	2	2.5
Spina Bifida	2	2.5
Seizure Disorder	1	1.3
Other	22	27.8

Other Special Needs		
Yes	28	35.4
No	51	64.6

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Table 1 (P. 50) summarizes age, gender, primary diagnosis, and the frequency of other special needs in addition to the primary diagnosis, in children on the Infant and Preschool program. The age ranged from five months to thirteen years and nine months ($\underline{SD}$ = 2.28). The average age of the child was four years and two months (4 yrs 2 mo). However, a closer scrutiny reveals that the majority (65.8%) of the children were between the ages of 24 months and 71 months (two to five years). There were more boys (60.8%) than girls (39.3%) represented in this sample. A number of categories of primary diagnoses were identified. The largest category was Other[2] (27.8%). These were conditions not specified in the Child and Family Background form, including brain tumour, autism, etc. The next most frequently mentioned primary diagnoses were Prematurity (21.0%), Developmental Delay (16.5%) and Cerebral Palsy (15.2%). In addition to the primary diagnosis, other special needs were reported in 35.4% 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 orthopaedic problems or challenges with communication.

The families' involvement with the Centre is summarized on Table 2 (p. 53). The frequency of interaction ranged from weekly visits to less than once a year. The greatest number of respondents (44.3%) had weekly contact with the Centre. The second largest group consists of those with monthly contact (15.2%), with a fairly

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[2]See Appendix K for specific diagnoses.

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even distribution of contacts that varied from four (4) times a year to once a year. A smaller percentage (6.3%) of respondents had contact less than once a year with the Centre staff.

The majority (50.6%) of the respondents had been involved with the Centre for two or more years. The second largest group (24.1%) reported an involvement between one and two years.

The families received a number of services at the time of the survey. Occupational therapy (65.8%), speech language pathology (60.8%) and physiotherapy (50.6%) were most frequently reported, followed by social work (21.5%) and orthopaedic clinic (19.0%).

The average number of services received at one time was 2.8, ranging from none (0) to seven (7), $\underline{SD}$ = 1.99.

Table 2
Involvement with the Centre

Frequency of visits	n	%
weekly	35	44.3
monthly	12	15.2
4 times a year	8	10.1
2 times a year	10	12.7
once a year	9	11.4
less than once a year	5	6.3
	79	100.0

Length of involvement		
less than 6 months	7	8.9
6 months to one year	13	16.6
one year to 2 years	19	24.1
2 years or more	40	50.6
	79	100.0

Services received		
Occupational therapy	52	65.8
Speech Language Pathology	48	60.8
Physiotherapy	40	50.6
Social Work	17	21.5
Orthopaedic Clinic	15	19.0
Augmentative Communication	9	11.4
Daycare	9	11.4
Pediatric Clinic	9	11.4
Seating/Mobility	8	10.1
Psychology Clinic	2	2.5
Program Assistant	2	2.5
Parent Group	2	2.5
Other	8	10.1

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 (69.6%) identified themselves as the main care coordinator (case manager) of the services that their child receives (Table 3, p. 54). The Centre Family Service Coordinator (Social Worker) was identified 21.5% of the time. Other

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case managers included spouse, other Centre staff, community advocate, other or nobody.

Table 3
Coordinator of Services

	n	%
Self	55	69.6
Centre Family Service Coordinator	17	21.5
Community Advocate	2	2.5
Nobody	2	2.5
Spouse	1	1.3
Other Centre Staff	1	1.3
Other	1	1.3
	79	100.0

English was identified as the language spoken most at home in 76 (96.2%) cases, French in 2 (2.5%), and another language in one (1.3%) case.

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

Of the total responses (N=79), 65 (82.3%) were from two parent families and 14 (17.7%) were from single parent families.

As shown in Table 4 (p. 55), most of the responses were completed by natural mothers (75.9%). The table shows the total number of responses per category as well as percentage of total responses. The second largest number of responses were completed by both natural mother and father (11.4%). In five cases a natural

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father filled out the questionnaire (6.3%). Other respondents included foster mother, adoptive mother, and foster mother and foster father jointly.

Table 4
Respondent's Relationship with Child

	n	%
Natural mother	60	75.9
Natural mother & father	9	11.4
Natural father	5	6.3
Foster mother	3	3.8
Adoptive mother	1	1.3
Foster mother & father	1	1.3
	79	100.0

The educational level obtained by mothers in the families who responded to the survey is summarized in Table 5. The majority (46.8%) had a college or trade school education, the second largest group (25.3%) being those who had completed high school. One respondent did not have any formal education and the questionnaire was completed over the phone.

Table 5
Mothers' Education
Highest level completed

	n	%
No formal education	1	1.3
Grade 1-8	0	0.0
Grade 9-11	7	8.9
High School	20	25.3
College or Trade	37	46.8
University	14	17.7
	79	100.0

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As summarized in Table 6, 38.0% of the fathers in the families who completed the questionnaire had a college degree or a trade school diploma. Two of the second largest groups were comprised of fathers who had completed grades nine to eleven (16.5%), and those who had a university degree (16.5%).

Table 6
Fathers' Education

Highest level completed

	n	%
Grade 1-8	1	1.3
Grade 9-11	13	16.5
High School	12	15.1
College or Trade	30	38.0
University	13	16.5
n/a	10	12.6
	79	100.0

The respondents' educational level is summarized separately in Table 7 (p.57). The majority of respondents have a college level of education (43.84%), followed by high school education (28.09%) and a university degree (19.10%).

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Table 7
Respondents' Education

Highest level completed	n	%
No formal educ.	1	1.1
Grade 1-8	0	0.0
Grade 9-11	7	7.9
High School	25	28.1
College or Trade	39	43.8
University	17	19.1
	89	100.0

n = 89 as in some cases both parents reported as respondents.

In terms of family income, the majority (63.3%) of the respondents were employed outside of the home. The rest (36.7%) reported not being employed at the time of the survey.

Of the respondents' spouses, most (68.4%) were employed, 13.9% were not working at the time of the survey, 17.7% were marked as not applicable (single parent household).

The majority (77.2%) of responses were received from the city of Thunder Bay, then (21.5%) from rural Thunder Bay, and one response was received from the Thunder Bay District.

SCALE SCORES

The scale scores on the MPOC questionnaire (Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care, and Respectful and Supportive Care), were calculated by averaging the valid scores of the items on a scale. The results are listed in

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Table 8.

Scale	Mean	SD	Min	Max	Range	n	within one SD
Enabling & Partnership	6.04	.92	3.44	7.00	3.56	75	5.12-6.96
Providing General Information	5.03	1.56	1.00	7.00	6.0	65	3.47-6.59
Providing Specific Information about the Child	5.97	.97	3.00	7.00	4.0	71	5.0-6.94
Coordinated and Comprehensive Care	6.02	.87	3.24	7.00	3.76	75	5.15-6.89
Respectful and Supportive Care	6.28	.69	3.89	7.00	3.11	77	5.59-6.97

A score of four (4) indicates that services are provided in a family centred 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 centred manner "to a great extent" (Law et al., 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 centred 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

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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 scale (see Appendix L, Figures 1-5). 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, 2.00 to 2.99 in the next category, 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 =.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).

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).

Providing Specific Information on the Child.

The values on the Providing Specific Information about the Child scale range from 3.00 to 7.00 (SD =.97), with a mean scale

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score of 5.97. The range of values within one standard deviation is from 5.0 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 (Figure 3).

Coordinated and Comprehensive Care.

The Coordinated and Comprehensive Care scale has a range of 3.24 to 7.00 (SD =.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.

Respectful and Supportive Care.

The Respectful and Supportive Care scale has a range of 3.89 to 7.00 (SD =.69) with a mean scale score of 6.28. The scores range from 5.59 to 6.97 within one standard deviation. Forty one (41) scores are found in the 6.00 to 6.99 category, 18 scores fall in the 5.00 to 5.99 category and 15 scores in the 7.00 category (Figure 5).

The greatest amount of variability was detected on Providing General Information (Table 8, p.58), with a range of 6.0, and values ranging between 1.00 and 7.00. While the scores within one standard deviation range 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

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values ranging between 3.89 and 7.00. The clustering of values in the higher end of the scale on all five MPOC scales is evident in the visual presentation of the scales (Figures 1-5).

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, p. 58).

COMMENTS BY PARENTS

Several parents included comments in a space reserved for them in the end of the questionnaire. The comments could be divided in the following categories: 1. favourable comments about the Centre in general, the qualities of the staff, and specific services; 2. comments reflecting displeasure with the Centre on a personal level or with staff issues, and more general comments; and 3. general comments about the level of services, the questionnaire, and other service providers associated with the Centre.

1. Favourable comments.

These comments generally applaud the existence of the Centre, indicating that the Centre should be proud of what it offers to the community. Parents were generally pleased with their interaction with the centre staff, they felt comfortable attending appointments and overall the comments reflect positive experiences with the Centre and the staff. Several comments express satisfaction with

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specific services. Physiotherapy, occupational therapy, speech language pathology, care coordination and day care are specifically mentioned. Other comments describe the qualities of staff, including such descriptives as helpful, friendly, supportive, encouraging and caring. Special attention given by staff to a parent during an especially stressful time was mentioned by one parent.

2.Comments reflecting displeasure with aspects of care.

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. 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 Centre in general. A number of parents comment on the assessment and treatment waiting lists and high caseload numbers, which affect treatment follow-up and availability of the professionals.

3.General comments.

Some parents commented that they did not see the Centre as a primary source of care due to minimal involvement. These parents

did not see their children as disabled or having "special needs".

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

In three cases parents felt that it was important to comment on the collaborative activities of the Centre and other agencies or individuals, including the Easter Seal Society, Lakehead Regional Family Centre and the family physician.

SUMMARY

Descriptive statistical analyses were conducted to summarize the data. Frequency distribution tables were created to describe and examine the demographic characteristics of the participants. The mean, range and standard deviation for each scale score (Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care and Respectful and Supportive Care) were calculated to examine the values of each scale score and the variability of responses within each scale score. The scale score values are indicative of how care was perceived by parents. Qualitative data were summarized.

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CHAPTER SIX

DISCUSSION

(a) Response Rate

(b) Demographic Data

(c) Family Centred Practices-
Scale Score Results

(d) Case Management Practices-
Scale Score Results

(e) Comments by Parents

(f) Implications for Family Centred
Case Management

(g) Further Research

(h) Summary

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In general, the results confirm that the respondents' perceptions of the services are congruent with the service philosophy of the George Jeffrey Children's Treatment Centre. The agency bases its service philosophy on family centred principles and a case management model. The families who responded to the survey indicate that the services are being provided in a family centred manner. However, it is not possible to simply conclude that the Centre's Family Centred Case Management model was the leading factor to which the high scale scores can be attributed. Factors challenging and supporting the findings are discussed below.

RESPONSE RATE

It is known from the literature that parents of children 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.

Even though many surveys were returned promptly after the initial mailing, and the reminder letter generated another good response, the overall response rate was somewhat low, at 32.1%. The third mailing, with verbal reminders from the Centre family service coordinators, yielded minimal response.

Mail surveys in general tend to generate lower response rates than interviews or phone surveys (Singleton, Straits, Straits, 1993; Fowler, 1993). Fowler notes that a response rate of 75% or

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more would be desirable, and a rate of 5-20% is unacceptable, with most surveys falling somewhere in between. Singleton et al. (1993) note that rates of 50% or lower are fairly common for mail surveys, even though it is possible to obtain rates of 60 to 75%.

In evaluating other studies done on the topic of children with disabilities or chronic illness, researchers have favoured designs and methodologies that allow small sample sizes, possibly anticipating the difficulty of engaging a large number of participants. In their study, Marchenko and Smith (1992) interviewed 32 mothers of children with both a developmental disability and a chronic health condition. Jackson et al. (1992) enrolled families of 42 children with developmental disabilities and chronic illness to study and formulate a family centred 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. Bennett, Deluga and Allen (1996) interviewed twelve parents of children with disabilities in their research of formal and informal supports.

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 et al. (1995) also sampled parents from thirteen treatment centres 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

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MPOC data were collected via mailed surveys.

In the case of this survey, follow-up phone calls after the third mailing might have been one way of increasing the response rate. However, since confidentiality and maintaining anonymity of respondents was the reason for choosing a mail survey, phone calls would not have been appropriate in this case.

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 et al., 1995). The majority of the parents who responded to the survey have an educational level of grade nine or higher. The largest category (43.8%) of the respondents have a college level education, followed by high school diploma (28.1%) and a university degree (19.1%) (Table 7, p. 57).

The returns did not include many 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 families who chose not to respond, do not see the George Jeffrey Children's Treatment Centre as a very integral part of their life. It is also possible that they may not find the services that they receive from the Centre particularly helpful or a necessary part of their lives. On the other hand, it is also possible that if people

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have no concerns regarding the services, they do not see a need to respond.

DEMOGRAPHIC DATA

The Child and Family Background form provides comprehensive information on the characteristics of the child, the family structure and the type of services received by the respondents from the Infant and Preschool Program at the George Jeffrey Children's Treatment Centre.

The age range of the children was greater than initially anticipated (5 months to 13 years 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. The Centre also has a School Age program for clients who do not fit the criteria of the School Health Support Services program. Some older clients may be served by the staff at the Infant and Preschool Program, usually through an individual agreement between the parents and the Centre Program. 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 Centre based program. However, most of the children were between 24 months and 5 years 11 months, which is well within the age range of children who typically receive services at the Infant and Preschool Program. The mean age (Mean =

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4.16) was elevated due to the older children (Table 1, p. 50).

More than half (60.8%) of the children were males. Jackson et al. (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 George Jeffrey Children's Treatment Center. 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).

Nearly half of the parents who responded to the MPOC questionnaire have frequent contact with the Centre (Table 2, p. 53). A small number of families (N=5) noted that they visit the Centre less than once a year. Since they had been to the Centre within the past year, their responses were included. The Infant and Preschool Program's least frequent visit schedule is an annual recall assessment. However, occasionally due to scheduling

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difficulties, more than twelve months will elapse between visits.

There seems to be a core group of parents who visit the Centre on a weekly basis. The second largest group of respondents have monthly contact with the staff. The frequency of visits tend 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 than children with milder disabilities. Proper coordination of services becomes important with the greater number of contacts at the Centre and in the community.

Just over half of the respondents (50.6%) have been involved with the Centre for two or more years. Over 70% have an involvement of one year or more. Seven parents reported an involvement of less than six months. Since the intake protocol is quite intensive, with a preassessment 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 Centre provide valid information on the process.

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

The core therapy services provided by the Centre staff were rated as those most frequently received by the children. In that

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sense, the respondents were families who received the typical services offered by the Infant and Preschool Program. The most often mentioned services include occupational therapy, physiotherapy, speech language pathology, social work and orthopaedic clinic.

A considerable range of services were being received by the families (0-7, Table 2, p. 53). 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 visit the Centre once or twice a year for a recall assessment but they do not require interventions in between the visits.

It was interesting to note that the majority (69.6%) of the parents considered themselves as the care coordinator (case manager). The Centre Family Service Coordinator was listed as the second largest group (Table 3, p. 54). The fact that the families reported a number of different case 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 English speaking. About 2.5% listed French as the language spoken at home. This information is consistent with the Lakehead Social Planning Council Human Service Needs Data Base (1996). In Thunder Bay, 91% of the population is English speaking,

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with about 1% French. There is a considerably larger French and native population in the district. The responses from the Thunder Bay District were extremely limited (one response out of twelve). It is impossible to speculate what the reasons for not responding may have been.

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 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 two children. The child with special needs would be approximately 4 years old and would receive 3 different interventions from the Centre Infant and Preschool Program. The family would have been involved with the Centre for at least 2 years. The mother would be the primary coordinator of the services and resources. She could be expected to have at least a high school education, and work outside the home full or part-time. The English speaking family would live within the immediate radius of the City of Thunder Bay.

Due to the low response rate, 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 age of two years and five years eleven months. This is the typical age of children involved with the Centre. Also, the primary diagnoses of the children seen at the Centre are compatible with the survey data. Of the total caseload, one quarter of the children are referred due to prematurity. A number of these children later receive a diagnosis of cerebral palsy and/or developmental delay. These categories are congruent with the responses (Table 1, p. 50).

It is also noteworthy that the data summarizing the families' involvement with the Centre reflect the core services offered, namely various therapy services and social work. Of the total caseload, one third are seen on an active basis (once a week to once a month), one third on a consult basis (less than once a month but more than twice a year) and one third are seen only for check-ups (once or twice a year) (Personal communication, Health Information Services, George Jeffrey Children's Treatment Centre, Winter 1998). The results indicate that more responses were received from families whose children are seen on an active basis.

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

The non-respondents whose literacy level is lower than those who responded is an issue of concern. As discussed above, mail surveys tend to generate responses from highly educated individuals. This seems to be the case in this research.

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FAMILY CENTRED PRACTICES - SCALE SCORE RESULTS

In general, the outcome of the survey was very encouraging and positive for the George Jeffrey Children's Treatment Centre Infant and Preschool Program. The mean scores on all scales were higher than five (5). Three scales (Enabling and Partnership, Coordinated and Comprehensive Care and Respectful and Supportive Care) were rated higher than six (6) (Table 8, p. 58). All scale scores had minimum values below the score 4, indicating that some parents perceived the family centred behaviours 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 centred values and principles (King et al., 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 professionals trust them as experts on their child (MPOC- Enabling and Partnership Scale). There seems to be a sense of collaboration between parent and professional and respect for the strengths of the family.

According to the data, the Centre provides coordinated services. Parents' responses to questions such as "to what extent do people who work with your child plan together so they are all working in the same direction?", indicated that they felt it happened more than "sometimes". The majority of the responses

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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 (Table 8, p. 58). These responses suggest an environment that fosters parent competence and nonjudgemental 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 treatment centre. The mean scale score of 5.03 is a little surprising if one compares its range of responses (6.0) 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 (4.0) than the general information scale, and the mean score was relatively high (5.9). This point is certainly reflected in the literature on family centredness and continues to be one of the challenges faced by

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service providers (Arango, 1990; Cardoso, 1991; Diehl et al., 1991; Letourneau & Elliott, 1996; Summers et al., 1990; Winton & Bailey, 1997).

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.

On the other hand, agencies, in this case the George Jeffrey Children's Treatment Centre, will need to reflect on how well it promotes parent participation and educates staff and parents about the family centred principles.

CASE MANAGEMENT PRACTICES - SCALE SCORE RESULTS

From the literature it is known that service coordination is an important aspect of the care for parents of children with disabilities (Jackson et al.,1992; Marchenko & Smith, 1992; Smith et al., 1994). Proper coordination can promote parent satisfaction with services and successful outcomes (Berkowitz et al., 1992;

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Cormany, 1993; Peckham, 1991). Berkowitz et al. (1992) identify four indicators of case management effectiveness:

1. Comprehensiveness

2. Continuity

3. Duration

4. Coordination of Care.

Comprehensiveness of care means medical, developmental, psychological and social aspects of care. Services are provided both at the facility and through linkages and collaborative efforts with community resources. Advocacy is used when barriers to services are identified. Continuity of care consists of two factors: at least one member of the team remains the same over a period of time, and parents remain committed to the treatment program. Duration is an indicator of length of participation in the program. Berkowitz et al. (1992) measured coordination of care by the successful linkages with services within the program and the community.

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. ...suggest therapy plans that fit with your family's
       needs

     and life style?

5. ...take time to establish rapport with you or your child

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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 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 7.0, 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' perception that the indicated behaviours do take place within the context of the service provision.

In evaluating her research, Berkowitz et al. (1992) discuss strategies for successful case management. Their findings suggest that the relationship aspects of case management are especially important. To achieve successful outcomes, the case manager needs

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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 help-giving 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 centred principles outlined by Shelton et al. (1989) and others promote similar approaches.

The findings of this research are therefore compatible with literature on family centred case management 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). Professionals 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.

COMMENTS BY PARENTS

The comments that parents independently added to the end of the questionnaire qualify some of the responses to individual items. There is a good variety of comments. Some express

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satisfaction with the services, some displeasure, reflecting the range of responses on the various scales.

The parents' perceptions of the Centre services are qualified with comments about the helpfulness and the friendliness of the staff. Many parents commented on their support needs and how the staff at the Centre is able to meet these needs. The comments certainly reflect some of the aspects of care that family centred 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".

It is evident that from the George Jeffrey'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 centred principles.

IMPLICATIONS FOR FAMILY CENTRED CASE MANAGEMENT

As indicated in the literature, family centredness is a comprehensive service philosophy which is implemented on all levels of services, from direct services to policy formulation at the

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agency (Korteland & Cornwell, 1991; Mahoney et al., 1990; Shelton et al., 1989). Whether case management is an effective way of implementing the model has been the focus of this research. The findings indicate that in general, respondents perceive the services to be provided in a family centred manner. The majority identified themselves as the care coordinator for their child. This is of course, the ultimate goal of family centred case management (Brown et al., 1993; Cormany, 1993; Fiene & Taylor, 1991; Kaufman, 1992). However, it is not known, to what extent parents were influenced and encouraged to assume this role by the family service coordinators (social workers).

As a point of interest, the Neurodevelopmental Clinical Research Unit (1995) provides the scale score values for the children's treatment centres that participated in the development of the MPOC questionnaire. All thirteen centres rated between 5.0 and 5.7 on the Coordinated and Comprehensive Care scale. The George Jeffrey Children's Treatment Centre's score is 6.02, which is somewhat higher than that of any other children's treatment centre. Most children's treatment centres operate from the family centred principles. At the time of the MPOC research, this researcher is not aware of any other treatment centre where each team has one family service coordinator. This is the case at the George Jeffrey's. Other centres therefore do not use a case management model. The other centres could be viewed as 'control groups'. However, there are several confounding variables, such as different staff, programs and family circumstances and backgrounds, which

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prevent one from concluding that the high scale scores can be attributed solely to the case management model. The low response rate is also a limiting factor.

A more comprehensive discussion on the roles and functions of the social worker would be a topic for another research. The social worker, as a case manager, 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 centred case management model has a direct relationship with the high scale scores on the MPOC survey. However, the model certainly does not seem to hinder the provision of family centred services. From a consumer satisfaction point of view, there appears to be little need to look for another model.

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

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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 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 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 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 low response rate. An item analysis could be done to evaluate the discriminative 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 questionnaire, as well as to add in the validity of the responses in this survey.

In order to learn more about the various aspects of case management, it may be of interest to look for any possible relationships between parents' education and whom they identified as case manager. Intuitively one might think that parents with a

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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 case manager. One may postulate that when the number of services increases, people more often choose a professional, such as the Centre family service coordinator, to take on the role of a case manager. In future research, various methods of measuring the effectiveness of case management should be looked at.

To further explore aspects of family centred case management, one can compare responses of different groups of parents, depending on whom they identified as the case manager for their family. One can argue that under ideal conditions, it should not matter whom families choose to coordinate their services. The family centred services 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 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.

In general, further research is required in family centred case management models. Professionals deal with more complex cases in the health care setting, such as an increasing number of

extremely premature babies and drug affected infants. Especially in the latter 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 case managers are needed.

SUMMARY

The parents of children with 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 affected the response rate of this survey. The mail survey method was chosen in hopes to promote a confidential and anonymous forum for responses as families chosen for the survey were receiving services from the Centre.

The majority of the questionnaires 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 above grade 8 literacy level, which is required to easily complete the MPOC questionnaire (King et al., 1995). Language was not an issue as most respondents were English speaking.

The responses were representative of parents who interact with the staff of the Centre on a frequent basis. Mothers of children with disabilities still seem to carry the main responsibility of care coordination. The children receiving services were identified

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with a wide range of diagnoses, reflecting the current trend in service provision in children's treatment centres.

The high scale scores on each scale (Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care for Child and Family, Respectful and Supportive Care) indicated that services were in general perceived by respondents to be provided in a family centred manner at the George Jeffrey Children's Treatment Centre. The impact of case management on the parents' perceptions on the services is still unclear. However, case management principles appear compatible with those of family centred service principles, and may help to facilitate the implementation of family centred 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 case manager in enhancing the family centred services.

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 long-term 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

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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 (Ministry of Community and Social Services, 1997) document is beginning to bridge the gap between different service 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 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 case managers can help to empower families, create positive self-sufficiency, teach assertive and advocacy behaviours, and impart independent decision making skills as expected according to the family centred case management 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).

CHAPTER SEVEN

CONCLUSIONS

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With the low response rate, the findings of this survey need to be treated with caution. When comparing the demographic characteristics of the families who responded to the survey with those of the entire Infant and Preschool 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 George Jeffrey Children's Treatment Centre services to be provided in a family centred manner. The composition of the families and their service needs varied. This supports the findings that, at least according to the respondents' perceptions, the Centre indeed operates within a family centred philosophy, being able to respond to the unique needs of individual families.

The Centre uses a family centred case management model to implement family centred services. In the discussion section, indicators of case management 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 centred case management model has a direct relationship with the high scores on the MPOC survey. However, one may postulate that family centred service provision and case management are compatible and that the case management model appears to be facilitative of family centred practices. Family centred case management can be

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seen as one way of implementing family centred services.

APPENDIX A

Family Centred Services

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Family Centred Service

Family Centred Service recognizes that the family is the
constant in the child's life. For this reason, family centred care is
built on *partnerships* between families and professionals.
Families differ in the strategies they adopt to realize their
dreams for their children and themselves. The amount of support the family will
need from the service delivery system also differs. There is no single approach
that is right for all families. Family centred professionals acknowledge and
respect each family's uniqueness and seek their input into service delivery.

Family Supports

We offer support groups and training courses with families:
- Reducing Stress in Mothers of Children with Special Needs;
- Craft & Chat for Girls;
- Hanen Program (an early language parent program);
- Life Skills Group:
- Caring for the Care Giver,
- Income Tax Information Night;
- Parent Support Group.

If you are interested in any of the above, or have any questions or suggestions
for a session, please call one of our Family Service Coordinators.

Additional Family Resources

We invite you to make use of . . .
- our library—we have resource books and videos available in our
  Augmentative Communication Program, Day Care Resource Room,
  Infant & Preschool Program, and medical library;
- our toy lending library;
- equipment loans;
- our pool;

- our newsletter "Family Connections"—it is distributed to families and clients three times a year. We invite comments and contributions; and
- our bulletin boards—articles of interest and additional community resources are posted in our main hallway. Please have a look when you are in.

We have a Family Advisory Committee . . .

Our Family Advisory Committee acts as an advisory body on matters relating to our programs and services. The majority of members on the committee are parents. The Family Advisory Committee:
- participates in the development of family centred services;
- receives and reviews reports and proposals relating to client service delivery providing their perspective and recommendations for consideration; and
- advocates on behalf of families and clients to ensure that, to the best of our ability, our services are meeting needs.

Parent / Client
Complaints / Appeal Review Process

George Jeffrey Children's Treatment Centre provides families, clients and parents with a process to resolve issues. If you have a concern, please contact us at (807) 623-4381 and the Receptionist will assist you in this process.

For further information, please contact:

one of our Family Service Coordinators
George Jeffrey Children's Treatment Centre
(807) 623-4381

June 1995

APPENDIX B

Premises, Principles, and Elements of Family Centred Service

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** o **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 C

Letters of Permission

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Neurodevelopmental Clinical Research Unit

McMaster University, Faculty of Health Sciences
OT/PT Building, T-16, Room 126
1280 Main Street West, Hamilton, Ontario L8S 4K1
Telephone: (905) 525-9140 Ext 27850, Fax: (905) 529-8870
email: ncru@fhs.mcmaster.ca

October 30, 1996

Tuija Puiras
Program Manager for Clinical Services
George Jeffrey Children's Treatment Centre
507 N. Lillie Street
Thunder Bay, Ontario
P7C 4Y8

Dear Tuija,

As per your request, this letter grants approval for you to use two pieces of material generated by the NCRU.

Specifically, you have our permission to use the Measure of Processes of Care (MPOC) questionnaire to collect data for your thesis. We also grant our approval for you to include in the text of your thesis the family-centred service framework developed by the NCRU entitled "Premises, Principles and Elements of Family-Centred Service" by Gillian King, Peter Rosenbaum, Mary Law, Susanne King and Jan Evans. It is copyrighted to these authors in 1996. You should probably state somewhere on this framework "Reprinted with permission of the authors" or something to that effect.

We are pleased that these materials will be useful in your work.
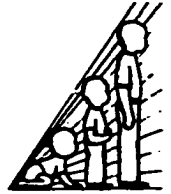
Sincerely,

Susanne King, M.Sc.
NCRU Research Coordinator and Co-Investigator in the MPOC Research Group

sk|c:\mpoc\xsect\tuijperm.ltr

GEORGE JEFFREY CHILDREN'S TREATMENT CENTRE

Providing paediatric rehabilitative and habilitative services with children
and adults with disabilities

Celebrating our 35th Anniversary in 1996
Patron: Mr. Tom Hainey

November 15, 1996

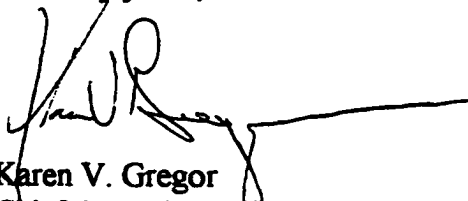Ethics Committee
Lakehead University
Thunder Bay, Ontario

Colleagues:

I have reviewed the research submission for completion of a Master's of Social
Work by TUIJA PUIRAS, Measure of Process of Care Survey, to be
completed by the spring of 1997.

I am formally approving this research at the Centre and give Ms. Puiras
permission to conduct her study.

Please contact me should you have any questions.

Sincerely yours,

Karen V. Gregor
Chief Executive Officer

507 N. Lillie St.
Thunder Bay On
P7C 4Y8
Telephone:
(807) 623-4381
Fax:
(807) 623-6626

Charity Reg No
0221622-20-20

Supported by . . .

The United Way
Thunder Bay Wins
Kiwanis Club of
 Thunder Bay Inc.

19 December 1996

Ms. Tuijas Puiras
Department of Social Work
Lakehead University
THUNDER BAY, ONTARIO
P7B 5E1

Dear Ms. Puiras:

Based on the recommendation of the Ethics Advisory Committee, I am pleased to grant ethical approval to your research project entitled: A FAMILY CENTRED CASE MANAGEMENT APPROACH IN LONG-TERM HEALTH CARE FOR CHILDREN: FAMILIES' PERCEPTION OF CARE.

Best wishes for a successful research project.

Sincerely,

ROBERT G. ROSEHART
President

/lw
cc: Dr. Ken Barter, Supervisor

APPENDIX D

Child and Family Background Form

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

Please complete the following background questions about your child receiving services at the George Jeffrey Children's Treatment Center 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 need? Check (X) one only.

☐ Acquired Brain Injury   ☐ Cerebral Palsy   ☐ Communication Disorder   ☐ Development Delay

☐ Seizure Disorder   ☐ Hearing Impairment   ☐ Learning Problems   ☐ Muscle Disorder

☐ Spina Bifida/Hydro cephalus   ☐ 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 Center?

☐ 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 center?

☐ 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   ☐ Physio Therapy   ☐ Speech language Therapy   ☐ Social Work (Family Service Coordinator)

☐ Augmentative Comunic.   ☐ Seating/ Mobility   ☐ Pediatric Clinic

☐ Psychological Consult.   ☐ Orthopaedic Clinic   ☐ Program Aide   ☐ Parent Group

☐ Daycare   ☐ Other, please specify: _____.

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

☐ Self   ☐ Spouse   ☐ Other family member   ☐ Friend

☐ Center Family Service Coordinator   ☐ Other Center staff   ☐ Community professional/ advocate   ☐ other please specify: _____

☐ nobody

9. What language is spoken most often at home?

☐ English   ☐ French   ☐ Ojibwa/Cree   ☐ Other

10. How many siblings does your child with special needs have? Sisters(indicate age(s)):_____   Brothers(age):_____.

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 9-11)	☐	☐
d. completed highschool	☐	☐
e. community college/ trade school	☐	☐
f. university 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?

☐ City of Thunder Bay   ☐ rural Thunder Bay   ☐ Thunder Bay district

CONFIDENTIAL WHEN COMPLETED

Measure of Processes of Care

(MPOC)

Questionnaire

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 how much 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: *George Jeffrey Children's Treatment Centre*

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

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
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

TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...

Indicate how much this event or situation happens to you.

Item		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

TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...

Indicate how much this event or situation happens to you.

	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

What is your relationship to your child with special needs?

☐ Natural Mother   ☐ Natural Father
☐ Stepmother   ☐ Stepfather
☐ Adoptive Mother   ☐ Adoptive Father
☐ Foster Mother   ☐ Foster Father

☐ Other Guardian, please specify: _____

On what date did you complete this questionnaire?   _____

day/month/year

ANY COMMENTS:

_____

_____

_____

_____

PLEASE CHECK THAT BOTH SIDES OF ALL PAGES ARE COMPLETED

CONFIDENTIAL WHEN COMPLETED

THANK YOU!!

APPENDIX F

Letter 1

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Dear Parent,

Most Children's Treatment Centres in Ontario have adopted a family centered focus in providing services to children and their families. 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.

This package contains a questionnaire that aims to measure parents' perceptions of the services received at the George Jeffrey Children's Treatment Centre.

The title of the survey is A Family Centered Case Management Approach in Long-Term Health Care for Children: Families' Perceptions of Care. The research is a partial requirement for a Master of Social Work degree at Lakehead University, and is done in co-operation with the George Jeffrey Children's Treatment Centre. This survey is conducted separately from my role as the Program Manager of Clinical Services at the Centre.

About half an hour of your time is required to fill out the attached 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 use.

All information 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 form or the return envelope to preserve anonymity. A seperate response card has been provided to be sent to another address, in order to monitor our mailing list. Participation is completely voluntary and does not affect your involvement with the centre programs in any way.

The results will be summarized in the Centre Newsletter and a copy of the full report will be available through the Centre library by the fall of 1997. In addition, the George Jeffrey Children's Treatment Centre will receive a summary report of the results of the research. This information will be useful in evaluating services, and for future planning. Please be advised that the data will be securely stored in the department of Social Work for a seven year period.

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

Please contact myself at 767-4313, or 625-6799, or Ken Barter D.S.W., the thesis supervisor, at Lakehead University at 343-8110 if there are any questions.

Yours truly

Tuija Puiras
MSW candidate

APPENDIX G

Letter 2

97

January 27, 1997

Dear Parent:

About two weeks ago you were mailed a Processes of Care questionnaire. The purpose of the survey is to find out what parents think about the way services are provided at the George Jeffrey Children's Treatment Center.

If you have already filled out your questionnaire, please accept this letter as a Thank You for your prompt response.

If you have not had a chance to respond, yet, please take a minute to review the form that was sent to you. You will find that it should take no more than half an hour to fill in your answers. Your views are important, and therefore it would be appreciated if you could take the time to send in your response.

Please be assured that all responses will remain confidential.

Upon completing the questionnaire, please mail it in the self addressed envelope. Do not write your name or address on the envelope or the form. However, the "response card" should be sent separately. This will help us to monitor the responses in general without matching the questionnaires with any names.

Thank you very much for your assistance in collecting this data.

Feel free to call me at 625-6799 or 767-4313 or Ken Barter, D.S.W., Chair of the thesis committee, at 343-8110, regarding any questions or comments, or if you need any help with completing the questionnaire.

Tuija Puiras
MSW candidate

ACHIEVEMENT THROUGH EFFORT

APPENDIX H

Letter 3

98

55 Oliver Road, Thunder Bay, Ontario, Canada P7B 5E1

Dear Parent   March 19, 1997

About six weeks ago, a Measure of Processes of Care questionnaire
was sent to your address.

Even though the response rate from parents has been satisfactory,
a few more responses would be greatly appreciated.

Please take a moment to review the survey package. Should you
have any questions or require any clarification, feel free to
call myself at 625-6799 or 767-4313. If you have not received the
original package, or have misplaced it, let me know, and a new
package will be sent.

Thank you so much for all your time and effort. Your input will
provide invaluable assistance to children and families receiving
similar services at Children's Treatment Centres.

Sincerely

Tuija Puiras
MSW candidate

APPENDIX I

Response Card

99

Dear Tuija,

Please be advised that _____

_____

has completed the MPOC survey.

----

send to:

        Tuija Puiras

        R.R.#1 Kaministiquia

        Ontario

        POT 1X0

APPENDIX J

Instructions

100

INSTRUCTIONS

1. PLEASE FILL IN YOUR ANSWERS (RESPONSES FROM EITHER PARENT ARE ACCEPTED, IF A TWO PARENT FAMILY). MAKE SURE YOU COMPLETE BOTH THE MPOC FORM AND THE BACKGROUND FORM.

2. MAIL THE COMPLETED FORMS IN THE SELF ADDRESSED ENVELOPE. THE FORMS ARE TREATED AS CONFIDENTIAL WHEN COMPLETED.

3. COMPLETE THE RESPONSE CARD AND MAIL SEPARATELY FROM THE QUESTIONNAIRE.

THANK YOU FOR YOUR CONTRIBUTION!

IF YOU HAVE TROUBLE ANSWERING ANY SECTIONS OR FOR OTHER QUESTIONS OR COMMENTS, FEEL FREE TO CALL MYSELF AT 767-4313 OR 625-6799, OR KEN BARTER AT 343-8110.

IT IS ALSO POSSIBLE TO PROVIDE YOUR ANSWERS BY PHONE, IF YOU SO PREFER. JUST CALL ANY OF THE ABOVE NUMBERS.

APPENDIX K

Other Diagnosis

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
Cleft Palate
Torticollis
Upper & lower limb abnormalities
Tuberous Sclerosis
Motor movements
Cleft palate
Fine motor
Hypotonia
Brachial Plexus injury
Stroke, left side

Appendix L

Figures 1-5

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Figure 1.

Enabling & Partnership
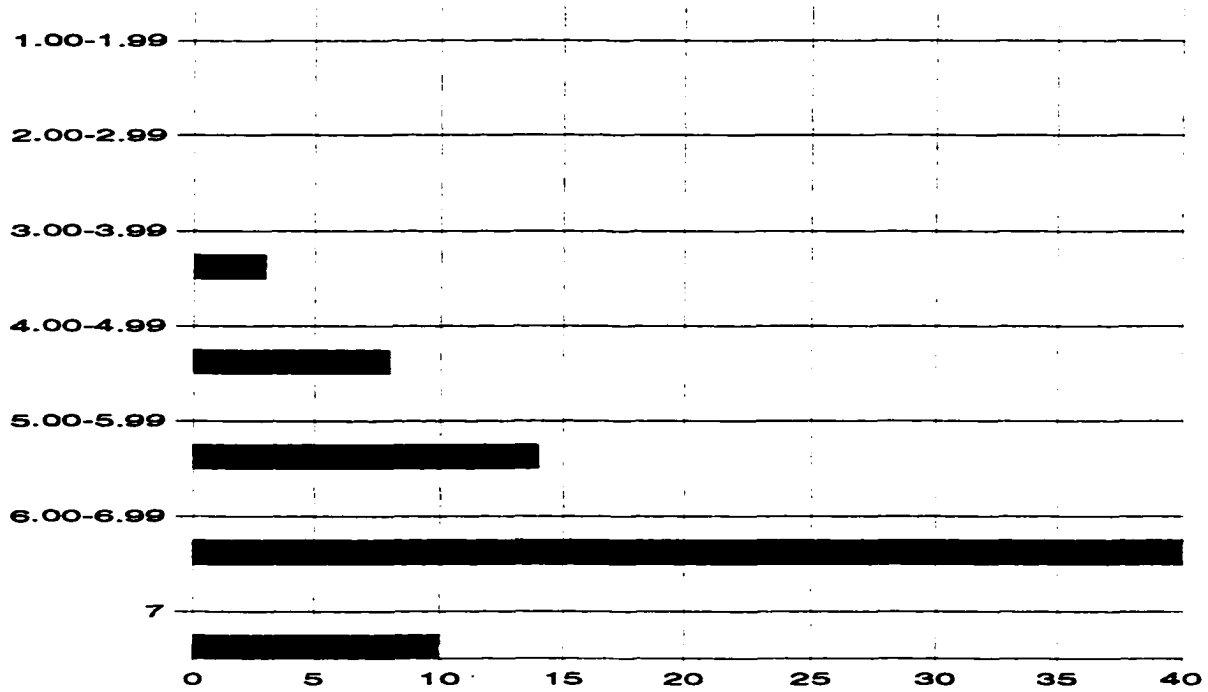
Figure 2.

Providing General Information
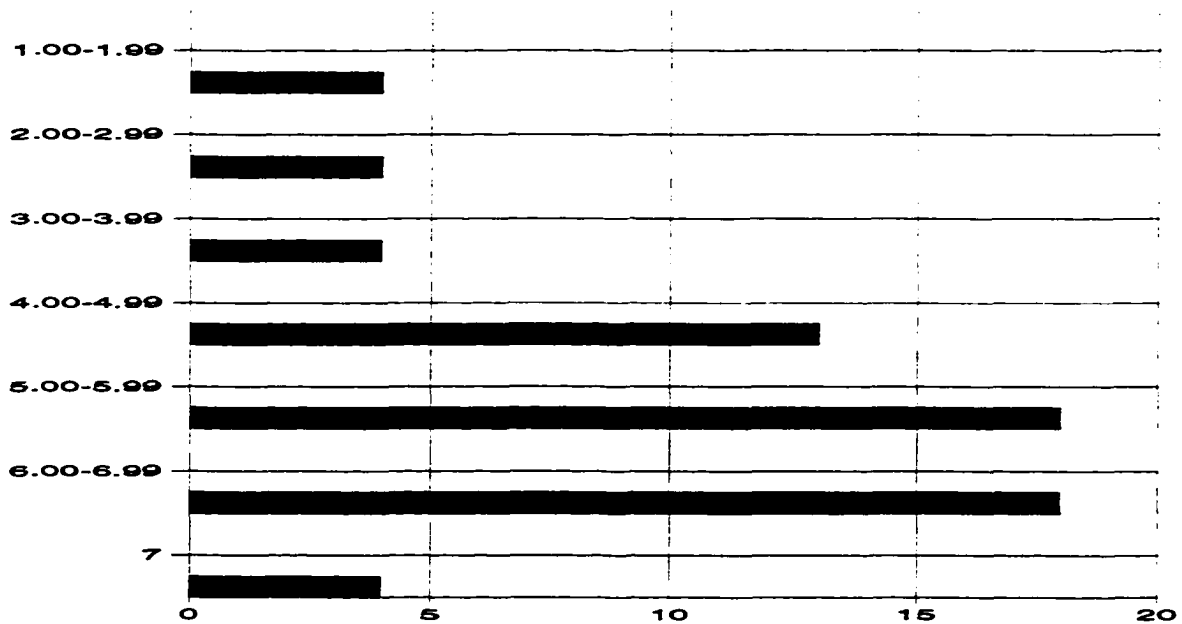
Figure 3.

Specific Information on the Child
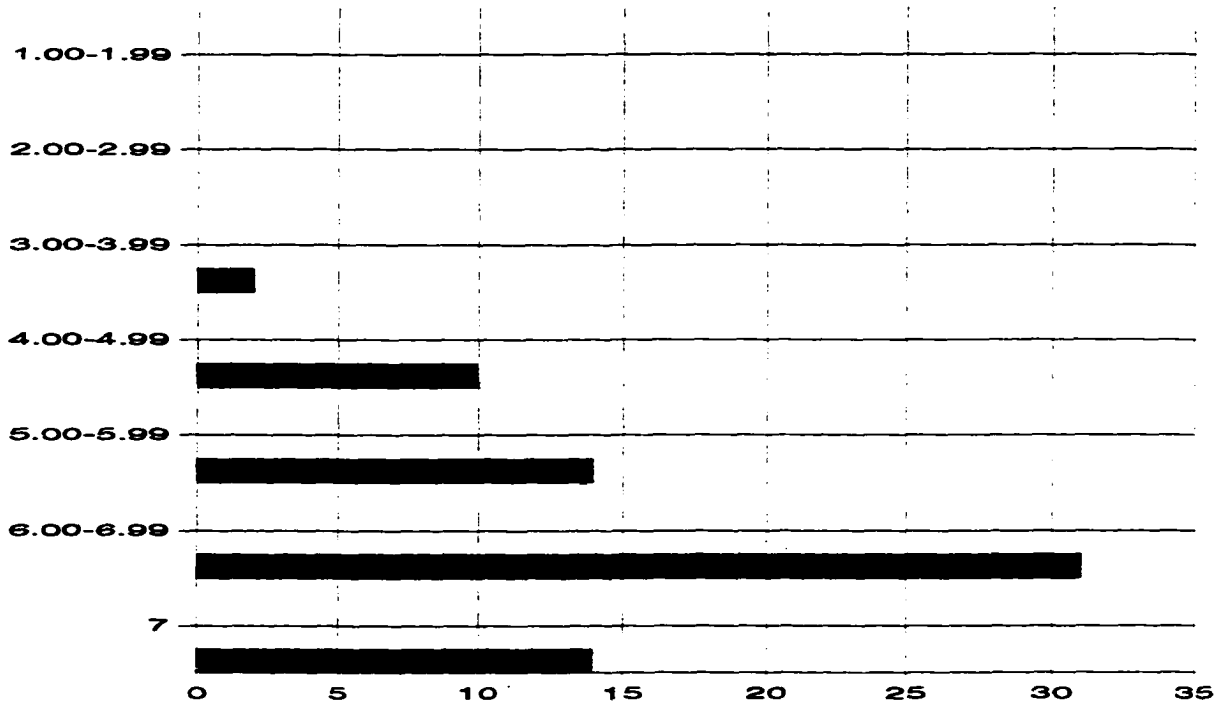
Figure 4.

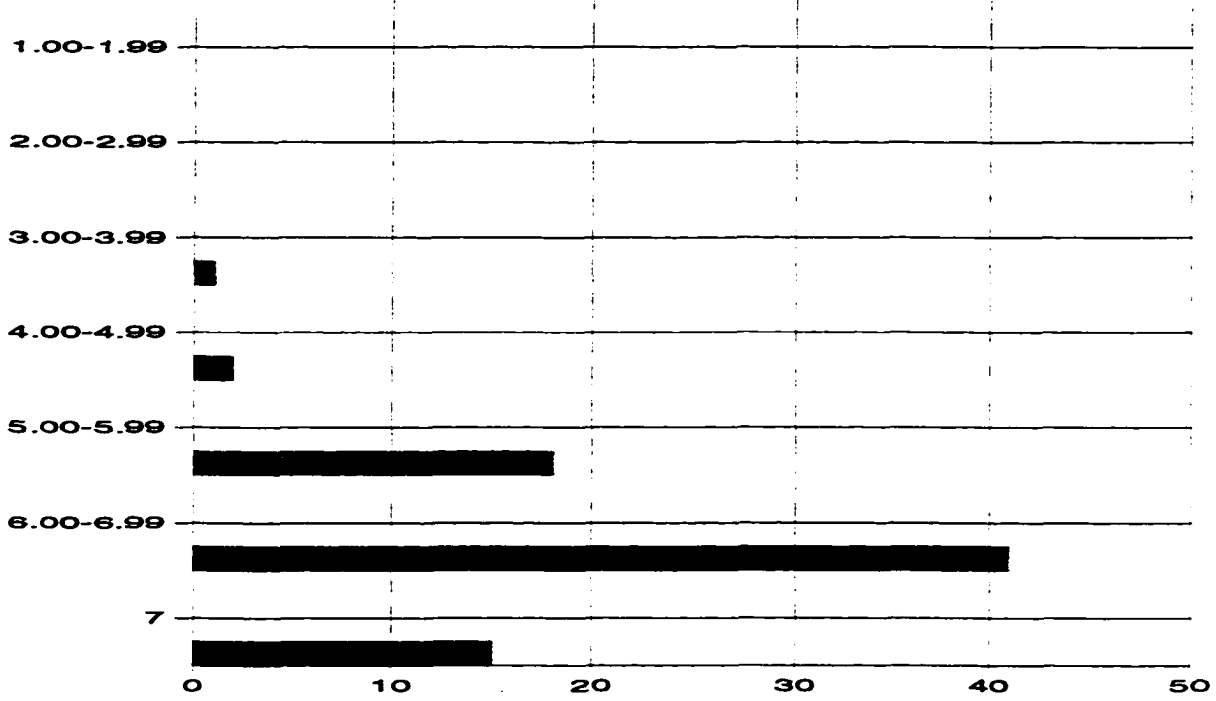## Coordinated and Comprehensive Care
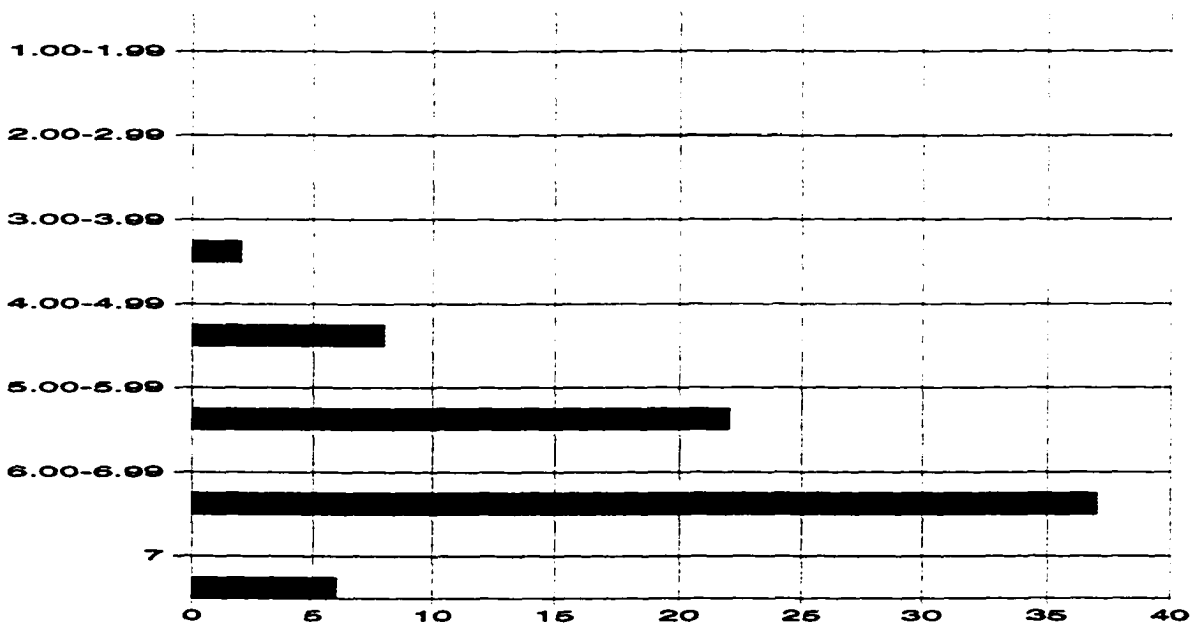
Figure 5.

Respectful and Supportive Care

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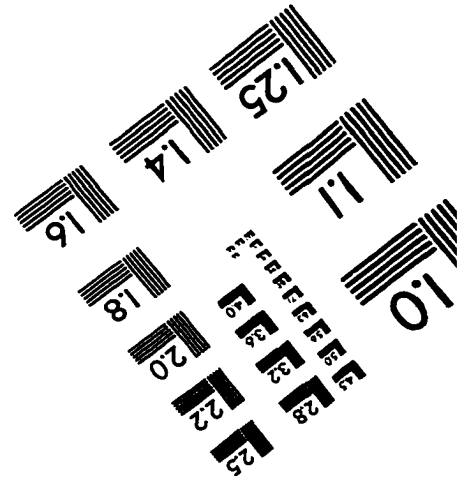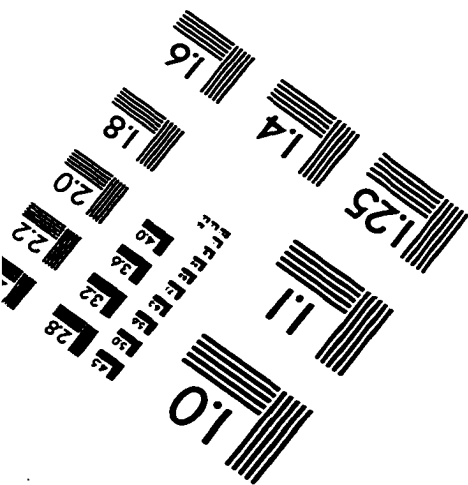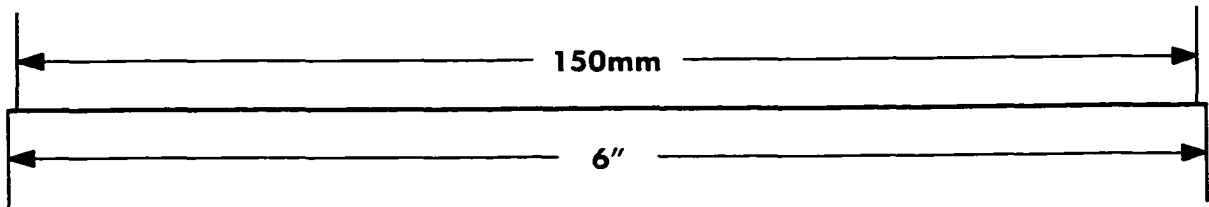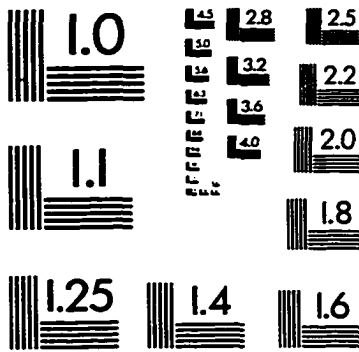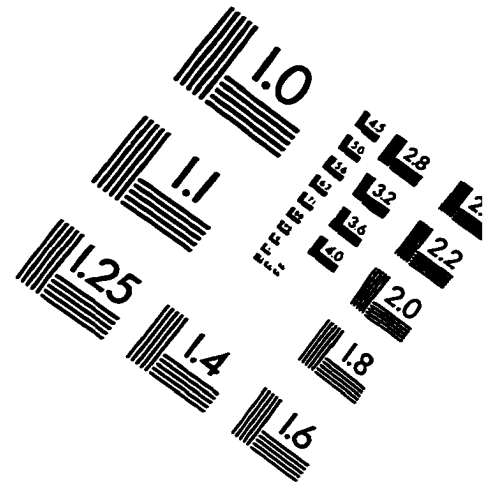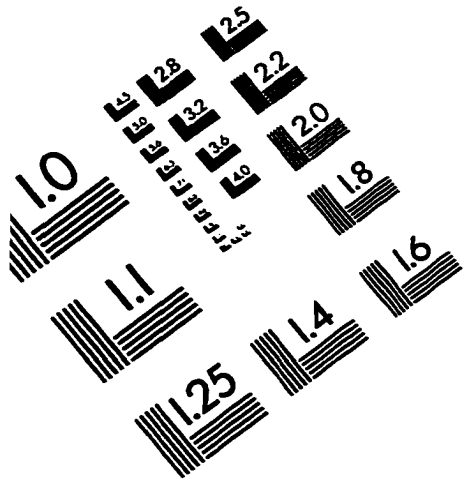
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