PARENT EDUCATION IN FAMILY-CENTERED PRACTICE WITH FAMILIES OF CHILDREN WITH SPECIAL NEEDS:

A PARTNERSHIP TOWARDS FAMILY EMPOWERMENT

By:

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MASTER OF SOCIAL WORK

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BY

DONATILDE ("DONA") MARY CABRAL CAMARA

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

of

Master of Social Work

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"The Journey is the Destination"

- Author Unknown

ABSTRACT

Parent education in the area of family-centered practice with families of children with special needs was the focus of my practicum. Identified as a pilot project under the Family Strengths in Childhood Disability Project, a project assessing the implementation of family-centered practice in Manitoba, this practicum provided me with an opportunity to develop advanced skills in utilizing a family-centered approach to practice. An orientation guide for parents was developed, a curriculum and training manual were designed, and two parent education groups were co-facilitated with a parent of an adult child with special needs.

Seven families currently involved in the FSCD project participated in the parent education groups; four families attended the full day session and two families attended the two evening sessions. Parents rated the group experience positively and indicated that the intervention met their need for information, increased their awareness and knowledge, and significantly reduced confusion and uncertainty. Added findings revealed that the education groups reduced parents' fear and isolation and provided opportunities for parents to interact with other parents. There is compelling evidence to suggest that parent education, in the context of this practicum, is a key intervention that promotes interagency collaboration, community partnerships, and, most importantly, parental empowerment.

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CHAPTER ONE:

INTRODUCTION

Parents who have children recently diagnosed with special needs often feel powerless in satisfying the daily care needs of their child as well as their family (Hulme, 1999; Seligman & Darling, 1997). Faced with uncertainty, some parents encounter overwhelming challenges when they are required to deal with numerous service providers, obtain medical supplies, and access community supports (Paterson & Garwick, 1994; Seligman & Darling). Feelings of powerlessness have been linked to a lack of information, knowledge, and skills around procuring the supports and services necessary to meet the unique circumstances of these families (Darling & Baxter, 1996; Hulme, 1999; Seligman & Darling, 1997).

In Canada, between one and three per cent of the population consists of families who have children with varying special needs (The Roeher Institute, 1996). Approximately 3,500 families of children with special needs in Manitoba are currently in receipt of family support services. Every month, approximately forty new families enter the social services system (E. Chornoboy, personal communication, April 5, 2002).

Several authors have discovered that parents of children recently diagnosed with a disability express the need to gain information on how to promote the development of their child, how to access support in dealing with the demands of parenting, and how to identify and mobilize community resources (Baxter, 1986; Darling & Baxter, 1996; Gowen, Christy, & Sparling, 1983; Hornby, 1994; Greene, 1999; Mahoney & Filer, 1996; Summers, Dell'Oliver, Turnbull, Benson, Campbell,

& Siegel-Causey, 1990). Heflinger and Bickman (1997) suggest that intervention that provides the opportunity for parents to develop knowledge and skills, and encourages active participation in decision making, is the key to facilitating family empowerment.

The concept of empowerment implies a process whereby individuals gain control over their own lives by influencing their interpersonal and social environment (Singh & Curtis, 1995). In the context of human service delivery, family empowerment has been conceptually defined as a process by which families access knowledge, skills, and resources that enable them to gain positive control of their lives as well as improve the quality of their life-styles (Singh & Curtis, 1995).

Empowerment practices involve not only educating parents, but also providing them with opportunities to help develop the necessary skills and competencies that will help them define for themselves what is best for their family, and allow them to become active consumers of mobilizing support services. When parents become involved, they begin to feel empowered because they are doing something to help their child and family (Darling & Baxter, 1996). Minke and Scott (1993) state that greater attention needs to be given to parental control of goal-setting. Judge (1997) found that parents who experienced highly effective help-giving practices that actively involved them in making decisions and choices indicated greater degrees of perceived control.

Boone, Moore, and Coutler (1995) and Judge (1997) state that ideal practices include parent education that provides information and support to family members.

Seligman (1993) states that although there is very little empirical research on the

effectiveness of parent education groups specifically, the available literature indicates that these groups focus on providing information and serve to inform families about their rights and benefits, and where and how to obtain needed services.

The parent education model assumes that family members can cope adaptively when they are provided with accurate and relevant information (Seligman & Darling, 1997), and that providing information is one of the most effective ways of providing parental support. Professionals empower parents by sharing information with them, and by embracing them as equal partners in the decision-making process (Thompson, Lobb, Elling, Herman, Jurkiewicz, et al., 1997)

Family-centered practice is an approach to working with families of children with special needs that is based on a set of principles, values, and beliefs that not only identifies the role of the family as the central unit of attention (McGonigel, Kaufmann, & Johnson, 1991), but aims to promote optimal family decision-making skills (Bailey, 1987), capabilities, and competencies (Dunst et al., 1991). The ultimate objective of family-centered practice is to strengthen family functioning (Dunst et al., 1991).

The involvement of the family in decision making is one of the key aspects of family-centered practice (Judge, 1997). Literature on the principles of family-centered practice suggests that service provision must involve parents as equal collaborators who hold parental authority, are viewed as experts on their own situations, and are in the position of making final decisions in matters concerning their family (Dunst et al., 1988, 1994).

Although family-centered practice has gained popularity over the last twenty years, no empirical studies have examined parent education in the area of family-centered practice and its effect on family empowerment. With the adoption of family-centered practice in Manitoba and the importance of parent education, it seems reasonable to explore the development of parent education, specifically as it relates to providing parents with an opportunity to learn about the principles of family-centered practice, the role of the worker, the role and rights of parents, the process of developing Individualized Family Support Plans (IFSPs), and community-based supports and services.

GOALS OF THE PRACTICUM

This practicum was carried out as a pilot project within the Family Strengths in Childhood Disability Project. My overall practicum objective was to advance my practice skills in providing parent education in the area of family-centered practice to parents who have children with special needs. Four learning objectives were identified and formed the basis to guide my practicum:

- to advance my skills in utilizing a family-centered approach to practice with families who have children with special needs;
- 2. to develop skills in facilitating parent education groups;
- to develop skills in creating an orientation guide for parents and a training manual for practitioners; and
- 4. to understand, from the parents' perspective, how parent education can be a useful intervention.

In order to accomplish these learning objectives, my practicum was carried out in three intervention phases. These intervention phases are referred to as the developmental phase, the implementation phase, and the evaluation phase. Each intervention phase will be discussed in the analysis of the practicum and will be the basis for further discussion.

COMMITTEE MEMBERS

Committee members are those researchers who currently run the Family

Strengths in Childhood Disability Project. Dr. Diane Hiebert-Murphy is my primary
faculty advisor. Dr. Hiebert-Murphy is an Associate Professor in the Faculty of

Social Work, Associate Director of the Psychological Service Centre at the University
of Manitoba, and co-investigator for the Family Strengths in Childhood Disability

(FSCD) Project. Dr. Barry Trute is the faculty representative for my practicum. Dr.

Trute is a Professor in the Faculty of Social Work at the University of Manitoba as
well as in the School of Social Work at McGill University and is the principal
investigator for the FSCD Project. Ms. Kathy Levine is my external committee
member. Ms. Levine is employed as a social worker with the Child Guidance Clinic
in Winnipeg and is the research coordinator for the FSCD project.

SUPERVISION

Supervision was made available to me as needed. Supervision was required in order to monitor the progress that I was making in terms of reaching my learning objectives and my overall practicum objective. Communication with committee

members was made through direct meetings, telephone contact, and/or through the use of e-mail. As deemed necessary, this communication was with either my practicum advisor, my practicum supervisor, and to some extent with all committee members.

MY VALUES

Family-centered practice is an approach to working with families that I not only believe in but have practiced as a social worker for several years. My personal and professional goals with respect to assessment and intervention are predicated on remaining true to my values as a practitioner. I believe that every person possesses personal strength and has the internal resources to cope with life's difficulties. I believe that achieving personal empowerment comes, to a large extent, by validating and promoting people's capabilities and competencies. I believe in working collaboratively with people, not *for* people. These values set the tone for my practice and establish a foundation of partnership with the families with whom I work.

RELEVANCE TO SOCIAL WORK

As a social worker who has worked for over six years with many families who have children with special needs, I have learned that most parents require some level of support in order to maintain the integrity of the family unit. Supports may be formal (respite, behavioural support, in-home support), informal (network of friends, family, neighbours, and community), or a combination of the two, depending on the family's ability to cope with life stressors, the nature of their child's special needs,

and the resources available to meet their individual needs. Each family circumstance is unique, yet I have learned that upon their child receiving a diagnosis, most parents look for assistance in the area of obtaining information, acquiring new skills, and seeking support.

It is my opinion that parents should be provided with a comprehensive orientation and description of the services that are available to them, as well as the steps that are involved in accessing those resources. Having a reference that they can draw upon will enable parents to be better equipped to access the kinds of supports that reflect their individual needs. Providing parents with the tools to help them obtain the resources that they identify as necessary punctuates the overriding objective of family-centered practice—to strengthen family functioning. This philosophy reflects the belief that parent education, as an empowerment practice, enables parents to access supports and services that will not only be family-defined but, more importantly, family-governed.

This practicum represents an extension of the professional and ethical standards of social work practice with respect to working with families—self-determination, empowering families, focusing on family strengths and competencies, and providing parents with a powerful source of knowledge that will assist them in defining and governing the supports they require. In an era of large caseloads, budget restraints, and limited resources, parent education is an exciting and practical prospect. Implementing the principles of family-centered practice in an educative capacity and on a larger scale will not only serve to define and clarify the relationship between families and helping professionals, but it will serve to re-affirm the

humanitarian and egalitarian principles of social work practice. Social work, therefore, is a logical discipline for providing parent education in the area of family-centered practice with families of children with special needs.

CHAPTER TWO:

LITERATURE REVIEW

FAMILY-CENTERED PRACTICE

The Emergence of Family-Centered Practice with Families of Children with Special Needs

Family-centered practice emerged as a direct departure from the traditional child-focussed, deficit-based approaches that prevailed in the field of childhood disability prior to 1970 (McWilliam, 1992). During the last thirty years, several historical, social, and political influences marked this paradigm shift.

Prior to 1960, few early intervention services for families of children with special needs existed, as institutionalized care was the dominant ideology. The development and implementation of early intervention programs in Canada coincided with changes in the perceptions about people with disabilities as well as the strong rise of parent advocacy groups (McWilliam, 1992; The Roeher Institute, 1996). The most significant movement can be traced to the self-help and grassroots efforts that emerged in the late 1960s (Dunst, Johnson, Trivette, & Humbly, 1991). These major influences forced the Federal government to address parents' desires to have their children live in their own communities (Johnson, Gallagher, LaMontagne, Gallagher, Huntinger, et al., 1994). In response to this public pressure, Federal-Provincial cost-sharing arrangements, introduced in 1966 under the Canada Assistance Plan (CAP), made it possible for parents and professionals to influence the creation of institutional alternatives (The Roeher Institute, 1996). Political and social movements in the

1970s, as well as an increase in public funds, resulted in a rapid growth of many community-based services for families of children with special needs (Briar-Lawson, 1998; Johnson et al., 1994). By the mid-1980s, every Canadian province and territory had community-based early intervention services (The Roeher Institute, 1996).

Although community-based early intervention services emerged as an alternative to institutionalized care, services were based on a traditional medical model. Professional interventions, therefore, were child-focused, pathologically oriented, and deficit-based. During the mid-seventies, however, the growing recognition and need to identify the family as a constant and critical component of a child's life (Seligman & Darling, 1997) as well as the family's interdependent relationship with larger social systems (Bronfenbrenner, 1979), propelled a paradigm shift away from child-focused intervention strategies to a more family-focused, home-based model of early intervention services (Briar-Lawson, 1998; Wayman, Lynch, & Hanson, 1990).

The rise of family empowerment-based services directly resulted in the creation of mandated family-centered services in the United States in 1986. The passage of the Preschool and Early Intervention Act (P.L. 94-457), as an amendment to the Education for All Handicapped Children Act of 1975 (P.L. 94-142), clearly establishes the role of the family as paramount and directs intervention practices, specifically the development of Individualized Family Support Plans, in a manner that reflects the principles of family-centered practice (McGonigel, Kaufmann, & Johnson, 1991). Since the passage of this law, literature on family-centered practice has flourished (Bailey, Simeonsson, Winton, Huntington, Comfort, et al., 1986;

Dunst, Trivette, & Deal, 1988 & 1994). This philosophy, which also has its historical roots in the paediatric nursing field (Newton, 2000), continues to influence the growing adoption of a family-centered approach to practice in Canada. In Manitoba, family-centered practice with families of children with special needs has been embraced with significant efforts being made to facilitate a shift to family-centered practice in the field.

Family-Centered Practice

There appears to be some debate over what constitutes family-centered practice (Dunst et al., 1991; McGonigel, Kaufmann & Johnson, 1991). In response, Dunst et al. (1991) created a framework for classifying and understanding existing philosophical orientations of various programs for children and their families. These orientations include professionally-centered, family-allied, family-focussed, and family-centered services. In professionally-centered services, professionals are viewed as the experts of delivering early intervention services. Within this orientation, parents are typically viewed as people who require help from the professionals who know what is best. In family-allied services, families are enlisted to help the professionals implement interventions. In this orientation, families are viewed as minimally capable of making positive changes without the assistance of professional expertise. In family-focussed services, families and professionals work together to define how to make the family function best. Families are viewed positively but also as being in need of professionals' help and guidance. Familycentered practice is an approach that is based on a set of principles, values, and beliefs that identifies the role of the family as the central unit of attention (McGonigel et al., 1991). Families' needs and concerns drive all aspects of services.

Professionals work together to promote optimal family decision-making skills

(Bailey, 1987; McCallion & Toseland, 1993), capabilities, and competencies (Dunst et al., 1991). The ultimate objective of family-centered practice is to strengthen family functioning (Dunst et al., 1991). Essentially, when services are truly family-centered, parents receive the support and information they require to be able to make the necessary decisions about their child and family (King, Rosenbaum, & King, 1997).

Principles

The term "family-centered" refers to a combination of beliefs that define a particular way of working with families in a manner that reflects family driven (Bailey, 1987) and competency enhancing (Dunst et al., 1991) practices. Many authors who have written about family-centered practice (Ahmann, 1994; Bailey, 1989; Bailey, Palsha, & Simeonsson, 1991; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson et al., 1998; Baird & Peterson, 1997; Bennett, Lingerfelt, & Nelson, 1990; Bond, Phillips, & Rollins, 1994; Bradley, Parette, & VanBiervliet, 1995; Dunst et al., 1988 & 1994; Farel, Shackelford, & Hurth, 1997; Harman & Laird, 1983; Hodges, 2000; King et al., 1997; McWilliam, 1992; Notari & Drinkwater, 1991; Seligman & Darling, 1997) make reference to core principles that guide this approach. Hodges (2000) identifies the following core principles in family-centered practice: (a) partnership and collaboration, (b) strengths-based, (c) empowerment-based, (d) family-friendly, and (e) cultural responsiveness.

(a) Partnership and Collaboration

Partnership and collaboration involve developing mutual relationships that reflect family and professional partnerships and shared responsibilities (Bennett et al., 1990; Dunst et al., 1988; Seligman & Darling, 1997; Zipper, Weil, & Rounds, 1993). Dinnebeil, Hale, and Rule (1996) assert that relationships between parents and professionals form the basis for all services provided to children with special needs and their families. Parents are viewed as full partners in the helping process, with all the rights, privileges, and responsibilities inherent in knowing their own situation best, thus shifting the focus of service provision away from families (Sokoly & Dokecki, 1992).

Bailey (1987) states that collaborative goal-setting resolves the likelihood of parent-professional conflicts and recognizes the value and importance of parents' perspectives. He continues by stating that active participation in goal setting helps parents learn to set goals and priorities for themselves. The service provider, therefore, is obligated to reach out to the family members, involve them, solicit their opinion, and respect their wishes (Williams, 1995). A reciprocal relationship based on loyalty, trust, honesty, and full disclosure (Zipper et al., 1993) is created by focussing on family priorities and by engaging in an open process of assessing, listening, and negotiating with families (Bailey, 1987).

(b) Strengths-based

A strengths-based approach recognizes and builds on family strengths and competencies (Dunst et al., 1988, 1994; Hartman & Laird, 1983; Hodges, 2000; Saleebey, 1997; Seligman & Darling, 1997; Walton, Sandau-Beckler, & Mannes,

2001). The strengths approach moves away from the deficit model of finding and fixing problems and towards helping families develop skills, competencies, and resources that can be translated into strengths (Rappaport, 1981; Roberts, Rule, & Innocenti, 1998).

Family strengths are characteristics that family members identify as contributing to the growth and development of the child and the family (McGonigel et al., 1991). Dunst et al. (1988) suggest that there are 12 major, non-mutually exclusive qualities of a strong family. These include: (a) a belief in and sense of commitment toward promoting the well-being and growth of individual family members as well as that of the family unit; (b) appreciation for the small and large things that individual family members do well, and encouragement to do better; (c) concentrated effort to spend time and do things together, no matter how formal or informal the activity or event; (d) a sense of purpose that permeates the reasons and basis for "going on" in both bad and good times; (e) a sense of congruence among family members regarding the value and importance of assigning time and energy to what the family considers its goals, needs, projects, and functions; (f) the ability to communicate with one another in a way that emphasizes positive interactions among family members; (g) a clear set of family rules, values, and beliefs that establishes expectations about acceptable and desired behaviour; (h) a varied repertoire of coping strategies that encourage positive functioning in dealing with both normative and non-normative life events; (i) the ability to engage in problem-solving activities designed to evaluate options for meeting needs and procuring resources; (j) the ability to be positive and see the positive in almost all aspects of their lives, including the

ability to see crises and problems as an opportunity to learn and grow; (k) *flexibility* and *adaptability* in the roles necessary to procure resources to meet needs; and (l) a *balance* between the use of internal and external family resources for coping and adapting to life events and planning for the future.

(c) Empowerment-based

Family-centered practice is based on the model of family empowerment.

Rappaport (1987) suggests that empowerment is a process by which people gain a sense of mastery of their own affairs. Heflinger and Bickman (1997) define empowerment as a process through which people become more able to influence the people and organizations that affect their lives and the lives of those they care about.

Dunst et al. (1988) identify three beliefs central to empowerment: (a) people are already competent or they posses the capacity to become competent, (b) failure to exercise competence is not associated with individual deficits but rather the barriers that exist within social systems, and (c) empowerment comes from a belief that individuals are able to change in a manner that redefines their position in the decision-making process. These authors suggest that empowerment practices involve taking a proactive stance with families and enabling or creating opportunities for families to develop competencies by encouraging personal and social change, promoting self-efficacy, and developing and strengthening competencies and skills that essentially promote positive family functioning. Ackerson and Harrison (2000) assert that the concept of empowerment is multi-dimensional as it encompasses a

personal process of self-determination as well as a socio-political construct of largescale competence building.

(d) Family Friendly

Family-centered practice is based on a proactive approach which views all families in a positive regard and focuses on family strengths and capabilities in a manner that supports and strengthens family functioning (Dunst et al., 1988). The focus of intervention is on promoting the development of skills and competencies by positive communication and addressing family needs with sensitivity, reassurance, and normalization (Bennett, Nelson, & Lingerfelt, 1992).

A family-friendly approach maintains the belief that children with special needs can and deserve to grow up with their families, that services should be provided in-home and in the family's community, and that, as families' needs change over time, services should be provided in a manner that is adaptive, flexible, and responsive (Kinney, Haapala, & Booth, 1991). According to Wayman et al. (1990), the family's home is the ideal setting to gather information about family needs and priorities, to plan interventions with families, and to provide families with information and education about services that would best reflect the family's needs. Judge (1997) found that greater parental involvement was reported by parents who participated in home-based programs, indicating that support and encouragement for families to be actively involved in making decisions and choices may be dictated by how and where services are delivered.

The concept of an "array of services" is used in family-centered services because a family's needs may be varied and complex (Dunst et al., 1994). The

supports and services provided to the family should be designed to fit each family's needs because every family is unique and requires services and supports that reflect their individual circumstances. Furthermore, supports and services must be not only family-friendly but also community-friendly if they are to be effective and long-lasting (Dunst et al., 1994). Community-friendly supports are those community-based services that are responsive to and designed to meet the unique needs of families of children with special needs. These supports and services foster and enhance a sense of community that reflect strong, interdependent ties among people (Dunst et al., 1988). According to Dunst et al. (1994), strong communities, in turn, "increase the availability of needed supports and resources, and enrich the community environment for families and their members" (p. 37).

(e) Cultural Responsiveness

Cultural responsiveness is a core value that underscores respecting ethnic and cultural diversity, being sensitive to and aware of cultural differences, respecting and honouring family cultural beliefs, traditions, socioeconomic status and styles, and valuing and seeking to strengthen ethnic resources and community supports (Beckman, 1991; Bennett, Zhang, & Hojnar, 1998; Degangi, Wietlisbach, Poisson, Stein, & Royeen, 1994; Gallagher & Desimone, 1995; Johnson et al., 1994). Wayman et al. (1990) state that culturally sensitive interventions can only occur when each family is viewed and treated as a unit that is influenced by culture but not defined by it. Family-centered practice involves creating a relationship that is supportive of families and demonstrates an understanding of the family's values,

beliefs, and practices, and creating opportunities for increased respect, trust, and understanding (Hanson, Lynch, & Wayman, 1990).

Theoretical Foundations of Family-Centered Practice

Family-centered practice is grounded in two theoretical perspectives. These are family systems theory and ecological theory (Dunst et al., 1988 & 1994; Hartman & Laird, 1983; Hodges, 2000; Rosenbaum, King, Law, King & Evans, 1998; Seligman & Darling, 1997).

Family Systems Theory

Rosenbaum et al. (1998) state that the systems approach recognizes that the family is the constant in a child's life. Furthermore, the family system is interactive, interdependent, and influenced by the actions of individual members, and that all members are therefore affected by one another (Hartman & Laird, 1983; Minuchin, 1974; Seligman & Darling, 1997). In essence, family systems theory suggests that a child with special needs cannot be viewed in isolation and as separate from the family unit. Consequently, a child with special needs, embedded within the context of the family, has an effect on each of the other family members and this has a direct impact on the family unit (Lynch & Morley, 1995).

The dynamics of family structure, family interaction, family functioning, and family life cycle exist within the context of family systems theory (Seligman & Darling, 1997) and are relevant to understanding families with children with special needs (Turnbull, Patterson, Behr, Murphy, Marquis et al., 1993; Turnbull & Turnbull, 1990).

Family Structure

Family structure represents those characteristics that make a family unique.

These include membership characteristics, cultural style, and ideological style (Bailey & Simeonsson, 1988; Bailey & Winton, 1990; Seligman & Darling, 1997).

Among families in general, Seligman and Darling (1997) state that membership characteristics such as the number of parents residing in the home, the influence of extrafamilial members, the socio-economic status of the parents, and the psychological disorders of family members impact family functioning. Familial characteristics such as two-parent families, high socio-economic status, parental education, and older parents are associated with strong family units (Sloman & Konstantareas, 1990; Trute, 1990; Whitehead, Deiner, & Toccafondi, 1990). Thus, family demographics should be considered in the initial stage of assessing family strengths and needs (Bradley et al., 1995; Whitehead et al., 1990).

Patterson and Garwick (1994) state that when a family member has a chronic condition such as a developmental disability, boundary ambiguity may be present. This is evident in the physical limitations that a child with special needs may have that prevent him or her from contributing as other members are able to, and/or the presence of service providers in the home who may add to the ambiguity within the family structure.

Adapting to a child's special needs is, to some extent, determined by the degree of role assignment in a family. Turnbull and Turnbull (1990) state that parents of children with special needs are often dealing with having to assume additional roles such as service developers, teachers, advocates, and decision makers. Mothers

are often primary caregivers assuming the additional demands of caring for the child, while fathers are assigned secondary responsibilities. In addition, most families of children with special needs are likely to be traditionally structured because of the extra care-giving demands (Trute, 1995). Malone, McKinsey, Thyer, and Straka (2000) assert that siblings may need to be assigned additional roles in order to compensate for what the parents are unable to do or what the child with special needs is unable to do.

Since the family's cultural background and identification, values, and beliefs tend to remain more constant, the fundamental structure of a family is significantly shaped by its cultural background (Bennett et al., 1998; Wayman et al., 1990). The cultural style of a family may be influenced by religious, ethnic, and racial beliefs and socioeconomic status (DeGangi et al., 1994; Lynch & Morley, 1995). Cultural beliefs may influence a family's response to service systems (Seligman & Darling, 1997).

Ideology is based on a family's beliefs, values, coping behaviours, and cultural beliefs (Seligman & Darling, 1997). A family's ideology may influence the manner in which members come to terms with having a child with special needs (Sloman & Konstantareas, 1990) as well as how families confront their beliefs about what and who is in control of life events as they adapt to their child's special needs (Lynch & Morley, 1995). Seligman and Darling (1997) found that parents who tend to blame others for their child's special needs or those who feel a significant amount of guilt and shame in having a child with special needs will have more difficulty adapting to the disability.

Family Interactions

Family interactions refer to the dynamic interrelationships that exist between members of a family. Components of the interactional relationship (Turnbull, Summers, & Brotherson, 1986) include subsystems, cohesion, adaptability, and communication. Subsystems include the marital (partner-partner interactions), the parental (parent-child interactions), the sibling (child-child interactions), and the extrafamilial (child-grandparent, father-coworker interactions) (Minuchin, 1974). Each subsystem interacts according to rules that are governed by its cohesion, adaptability, and patterns of communication, which are dynamic in nature and change in response to different stages of the family's life cycle (Summers, Dell'Oliver, Turnbull, Benson, Santelli, et al., 1988). Hornby (1994) suggests that interventions that are aimed at improved family functioning between members can have an impact on other subsystems. Strategies, therefore, need to consider the potential impact of all subsystems in order to guard against the emergence of difficulties.

Cohesion refers to the closeness among family members and is conceptualized by enmeshment and disengagement (Seligman & Darling, 1997). Highly enmeshed families have weak boundaries between subsystems and tend to be overprotective of their child with special needs (Hornby, 1994). Highly disengaged families have rigid subsystem boundaries and exhibit a lack of care for and involvement with each other. A balance between enmeshment and disengagement characterizes a well functioning family (Hornby, 1994).

Adaptability refers to the family's ability to change in response to stress, changing circumstances, and needs (Seligman & Darling, 1997). Hornby (1994)

states that the more inflexible family members are, the more difficult it will be to adjust to their child's special needs. Rigid families do not change in response to stress whereas chaotic families are characterized by instability and inconsistent change (Seligman & Darling, 1997).

Communication refers to the ways in which families share information. Olsen (1999) states that family communication is a significant variable in family adaptation and functioning. When a family is adjusting to having a child with special needs, communication patterns of interaction may include positive or negative styles of conflict resolution and problem solving. Expressiveness, cohesion, and cooperation among family members have been linked to positive adjustment, whereas conflict is negatively associated with individual adjustment (Alston & McCowan, 1995). Within a systems approach, communication breakdown stems from problematic family interactions rather than difficulties with individual members (Seligman & Darling, 1997). It is suggested that professionals focus on changing patterns of interaction within the family, not on an individual's communication difficulties (Hornby, 1994).

Family Functioning

Family functioning is the consequence of family interaction and reflects the ability of the family to meet its own needs (Turnbull et al., 1986). These authors report that several functions exist. These include economic, domestic/health care, recreation, socialization, self-identity, affection, and educational/vocational (Turnbull & Turnbull, 1990). Families who have children with special needs may have depleted resources in carrying out these functions (Seligman & Darling, 1997).

Caring for a child with special needs may place excessive demands on the internal and external resources of the family. Demands placed on families with children with special needs may include financial strain (e.g., equipment, medical supplies, home modifications, transportation costs), difficulties with service providers, lack of community resources, loss of family privacy, and care giving demands (Patterson & Garwick, 1994; Seligman & Darling, 1997). Adapting to a child's special needs may require a modification of family functions, roles, and priorities, depending on the extent of the child's special needs (Lynch & Morley, 1995).

The Family Adjustment and Adaptation Response Model (FAAR) was developed to determine a family's attempt to maintain balanced functioning by using their capacities (resources and coping behaviours) to meet their demands (stressors and strains) (Patterson & Garwick, 1994; Seligman & Darling, 1997). The demands of raising a child with special needs requires adjustment and adaptation. This adjustment can come from the family's attempt to use existing resources to meet their needs. Patterson and Garwick (1994) state that adaptation to stressors can only occur once new resources and coping behaviours have been acquired, demands have been reduced, and the family has established a new meaning about their situation and a new perception about their world.

Individual family members can utilize both internal and external resources in order to cope with their situation. Coping refers to a family member's specific efforts to restore the balance between his/her demands and his/her resources (Patterson & Garwick, 1994). Internal resources include coping strategies that relate to one's perception of the situation. Positive coping occurs when families are able to mobilize

adaptive appraisals (Seligman & Darling, 1997) such as reframing (Turnbull, 1990). Turnbull (1990) states that family members who are able to engage in action-oriented coping are more likely to function more positively.

External resources include coping strategies which relate to one's ability to access social, emotional, spiritual, and formal supports. Accessing external resources has been found to have a significant impact on the family's ability to cope (Sloman & Konstantarea, 1990) and reduce family stress (Seligman & Darling, 1997). External resources can be divided into two support systems. These are informal and formal supports (Seligman & Darling, 1997).

A family's informal support system may include relatives, friends, neighbours, co-workers, and social groups (Olsen, 1999; Valentine, 1993). Families of children with special needs can often feel isolated (Seligman & Darling, 1997) and receive decreased levels of support because some individuals in their support network may not be able to help them (Olsen & Marshall, 1999). Valentine (1993) asserts that some parents experience relief when they discover other parents who have children with special needs.

Formal supports may include social service and health care centers, early intervention programs, day cares, the school system, and transportation services (Herman & Thompson, 1995; Valentine, 1993) and have been found to be crucial for families who have limited informal support networks (Seligman & Darling, 1997).

Family Life Cycle

Family life cycle refers to the developmental stages that a family unit experiences in the course of its life span (Seligman & Darling, 1997). These stages include the following: couple, childbearing, school age, adolescence, launching, post-parental, and aging. For a family with a child with special needs, additional stress factors may influence family functioning in each of these stages (Patterson & Garwick, 1994). These stress factors relate to making emotional adjustments to a child's diagnosis, arranging appropriate services and education that best meet the child's needs, and adjusting to the, sometimes stressful, transitional planning issues for services to adults with special needs (Lynch & Morley, 1994).

Malone et al. (1997) state that the involvement of new systems at each life stage may be stressful for some families as they attempt to redefine their roles, responsibilities, and relationships with these systems. Some children with special needs will be slow to develop in some areas and therefore have life cycles that differ from typical children (Hornby, 1994). Life cycle variables affect family functions and resources, which in turn affect family interaction patterns.

Many parents experience some degree of grief in their attempt to adjust to having a child with special needs (Bailey, McWilliam, Winton, & Simeonsson, 1991), mourning the loss of what they thought their child would be (Lynch & Morely, 1994). These feelings of grief may surface as the family enters into a new life cycle stage (Malone et al, 1997; Turnbull & Turnbull, 1990). This is evident in some families who enter the post-parental stage of their life with their adult child who is not able to live independently.

In spite of the fact that some families' experiences of chronic stress and sorrow is evident, many parents report that as a result of having a child with special needs, they recognize the unique strengths in their child and family (Wikler, Wasow, & Hatfield, 1983). Strengthening of the family system, increased tolerance of diversity, opportunities for personal growth and fulfillment, and a greater appreciation for the accomplishments of the family member with special needs, are some of the numerous positive benefits associated with having a child with special needs (Dunst et al., 1994; Seligman & Darling, 1997).

Mahoney, O'Sullivan, and Robinson (1992) state that although parents of children with special needs are likely to experience additional stressful events, these stresses do not result in family dysfunction. These authors found that parents of children with special needs do not display greater signs of depression or psychological symptoms other than stress, and have family and marital relationships that are comparable to those families of children who do not have special needs. Some research suggests that the adjustment of the family is not typically related to specific characteristics of the child with special needs and that families who have children with special needs appear to be no different than any other family (Trute, 1990). Mahoney et al. (1992) found that the majority of families of children with special needs have positively adjusted to their child's special needs, are satisfied in their marital relationship, utilize support networks, rely upon moral-religious beliefs, and have emotionally well-adjusted children.

Professionals, therefore, need to utilize their knowledge of family systems theory in planning interventions with the families with whom they work (Hornby,

1994). The consequence of not using a family systems approach to working with families results in support services that will not reflect the needs of the entire family (Seligman & Darling, 1997; Hornby, 1994).

Ecological Theory

Ecological theory posits that families do not operate as a unit in isolation. Rather, families are embedded in larger social systems (Bronfenbrenner, 1979), and families of children with special needs (Hornby, 1994) are no different. This perspective "moves the focus from the individual to the family, subsystems within the family, and the family's interaction with the community" (Kaplan & Girard, 1994, p. 4). An ecological perspective on families who have children with special needs asserts that when professionals are working with families, it is essential to approach assessment and intervention strategies from a holistic view of the family, which includes the microsystem, the mesosystem, the exosystem, and the macrosystem. The activities, roles, and interpersonal relationships between family members represent the microsystem. How well the family functions depends on variables associated with each member (Hornby, 1994). Features of the child's special needs such as the type, severity, and when s/he was diagnosed as well as features of each family member will have an influence. The family's microsystem is influenced by the mesosystem in which it is embedded. The mesosystem is comprised of a range of settings in which the family participates, such as the extended family, health care professionals, friends/neighbours, work, and local community. The exosystem represents those settings in which the family participates such as the media, welfare, healthcare, and education. For example, the way that children with special needs are

portrayed in the media, the quality and types of health, education, and social welfare services available to parents, the availability of various voluntary societies and support groups, and the availability of recreational facilities in local communities will have a significant influence on the family (Hornby, 1994). Finally, the values, or held beliefs, that exist in society represent the macrosystem. The macrosystem includes the economic, political, religious, ethnic, and socioeconomic ideologies that influence a family's ability to cope with raising a child with special needs.

Hodges (2000) states that ecological theory works to incorporate all the systems with which the family interacts in order to best serve the family's needs. This perspective suggests the following: problems or difficulties with families of children with special needs are deficits in the environment and reflect dysfunction between systems, rather than dysfunction within individuals; family difficulties are viewed as outcomes of the transactions and interactions of various systems; and change in one part of any system that interacts with the family system will have an impact on all other systems (Hartman & Laird, 1983; Kaplan & Girard, 1994; Seligman & Darling, 1997).

Grounded on both the family systems and ecological theory, family-centered practice, therefore, reflects a dynamic, fluid, and ever-evolving interactional relationship between all systems, thereby focussing attention away from the child with special needs and individual family deficits, to a total systems approach of viewing, supporting, and strengthening family functioning. The principles of family-centered practice define the quality of the working relationship that must exist between the social worker and the family by clearly establishing the role of the social

worker, the role of parents, and the importance of developing a partnership in the planning process for individual families.

The Implementation of a Family-Centered Model The Role of the Social Worker

A family-centered approach to service coordination is based on family-support principles that enable families to help themselves (Dunst & Trivette, 1989). Family support principles are predicated on the assumption that families possess the ability to set goals, make decisions, assess their needs, and determine what is best for themselves (Bennett et al., 1992). Essentially, family-centered service coordination is based on a belief that services must be provided in a manner that is respectful of the rights of parents, focuses on family strengths and competencies, maintains the integrity of the family unit, focuses on quality of life for children, and reflects a community partnership that is respectful of the family's unique needs. The service coordinator, therefore, is the link between the family and service delivery (Bennett et al., 1992).

Although service coordinators are commonly referred to as case managers, it is my opinion that this term negatively implies that families are cases to be managed and assumes that the social worker's role is that of a "manager". This is not a term that I wish to adopt. Consistent with the language of family-centered practice, the term "service coordinator" clearly identifies the role of the social worker as someone who is responsible for facilitating the coordination of services with families.

Gallagher and Desimone (1995) suggest that if professionals are viewed as

consultants instead of experts, family participation is likely to increase. Viewing the professional as a consultant reflects the view of the worker as a partner with family members who identify resources, rather than an expert who provides services (Dinnebeil, Hale, & Rule, 1996).

The interactions between families and professionals prior to goal planning are of critical importance in establishing a positive, trusting, and collaborative relationship with families (Bailey, Winton, Rouse, & Turnbull, 1990). Dunst and Trivette (1989) state that help-giving is most effective if professionals; (a) assume a positive and proactive stance toward families; (b) emphasize the families' responsibility for solving problems and meeting needs; (c) assume that all families have the capacity to understand, learn, and manage events in their lives; (d) build upon family strengths rather than correct deficits; (e) proactively work with families in an anticipatory fashion rather than wait for things to go wrong before intervening; and (f) promote acquisition of competencies that permit families to become better able to negotiate their developmental course. These authors further suggest that enabling and empowering professionals: (a) place major emphasis upon helping families identify and prioritize the needs from their own and not a professional's point of view; (b) encourage active family participation as part of mobilizing resources to meet needs; (c) use partnerships and parent-professional collaboration as the foundation for creating opportunities for families to become more capable and competent; (d) provide families with the necessary information to make informed decisions about their needs and courses of action to meet needs; and (e) accept and support decisions made by families.

Malone et al. (2000) state that the service coordinator must demonstrate knowledge related to child development, issues facing families who have children with special needs, and community resources that are available to meet the needs of families (Malone et al., 2000; Summers et al., 1990). In cooperation with families, service coordinators:

- assess child and family strengths and needs;
- assist in developing Individualized Family Support Plans;
- link families with needed services and supports;
- listen to family members and support them in achieving their goals;
- monitor outcomes; and
- advocate on behalf of families (Bennett et al, 1992; Dunst et al., 1988 & 1994)

Service coordinators can promote a family-centered atmosphere (Bennett et al., 1992) by viewing families as competent, helping families develop skills, establishing a partnership with families, empowering families to become active decision makers, and building on family strengths with sensitivity and respect (Summers et al., 1990).

Dunst et al. (1988) identified twelve help-giving principles: (a) be positive toward the family; (b) offer help rather than wait for it to be requested; (c) allow the family to make the decisions; (d) give help that is culturally familiar and does not imply incompetence on the part of the family; (e) give help that matches the family's perceived need for help; (f) make sure the cost (financial and psychological) of receiving help does not exceed the benefit to the family; (g) accept but do not expect

some form of repayment that might be informational or emotional, and less often material; (h) try to arrange for immediate success in the family meeting its stated needs; (i) promote the use of the family's natural, informal support networks, rather than supplementing those with formal, professional networks; (j) convey a sense of partnership in meeting the need; (k) help the family acquire skills to meet future needs independently; and (l) promote the family's ability to see improvement and to feel responsible for producing the change.

Service coordinators can help parents decide for themselves to what extent they would like to actively participate in the planning, implementation and the monitoring of services and supports. Relinquishing decision-making to family members as well as facilitating parental decision-making skills in order to enable parents to participate at a level that suits their needs is the ultimate goal of the service coordinator (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993).

The Role of the Parents

The involvement of the family in decision making is one of the key aspects of family-centered practice (Judge, 1997). Literature on the principles of family-centered practice suggests that service provision must involve parents as equal collaborators who hold parental authority, are viewed as experts on their own situations, and are in the position of making final decisions in matters concerning their family (Dunst et al., 1988 & 1994; Farel et al., 1997; Shelton, Jeppson, & Johnson, 1987; Williams, 1995; Zipper et al., 1993). McWilliam (1992) states that families' roles place more emphasis on decision-making, providing information, and

using their own resources in the intervention process. In terms of decision-making, a family-centered approach to practice emphasizes the importance of giving families choices in how assessment, intervention planning, and interventions are conducted. More specifically, parents should be given the choice about what assessment process will be used (e.g., questionnaires, focused interviews, standardized testing, and/or informal observation), what interventions plans will be implemented, and what the nature of those interventions will be. In terms of providing information, this relates to family members providing information that is important to the family, information about their child in the context of the family, and the functioning and resources of the family unit. With respect to the use of available resources, the family is responsible for deciding how much it wants to use its own resources. These include personal characteristics of the adults, physical resources, informal support, and formal support networks (McWilliam, 1992).

Hodges (2000) states that practitioners must support and encourage parents to be able to exercise these rights and allow for parents to be active participants in the planning process. Minke and Scott (1993) state that greater attention needs to be given to parental control of goal-setting and that parents who fill out summary forms of child and family strengths, needs, and goals have been found to be more active in the goal-setting process. These authors recommend that parents be given the option regarding how active they would like to be in this process. Judge (1997) found that parents who experienced highly effective help-giving practices that actively involved them in making decisions and choices indicated greater degrees of perceived control. However, the literature also suggests that the extent to which parents are involved in

the planning, implementing, and monitoring process varies with each family and that variation must be honoured and respected (Joanning et al., 1994; McCurdy & Daro, 2001; Minke & Scott, 1993; Zipper et al., 1993).

Individualized Family Support Plans

The implementation of family-centered practice is guided by the development of what is commonly referred to as an Individualized Family Service Plan (Bailey et al., 1986; Dunst et al, 1988; Seligman & Darling, 1997). Bailey et al. (1986) provided a "goodness of fit" or functional approach for planning, implementing, and evaluating support services. This approach is predicated on matching the unique characteristics of the child with special needs and his/her family as they interact with the coping demands of their day to day life. Dunst et al. (1988) developed a model based on helping families identify their own needs, aspirations, strengths, capability, supports, and resources. A modification of the word "service" to the word "support" reflects a broader range of resources that families access (Bennett et al., 1990), and is a term that I have adopted.

Individualized Family Support Plans (IFSPs) are working documents that reflect a family-centered approach to not only identifying the individualized needs of families who have children with special needs, but include an action plan that contains information on obtaining the supports and services that are necessary to strengthen the family unit (Fewell, 1991; Moroz & Allen-Meares, 1991). This document is often referred to as the blueprint for identifying family strengths, competencies, and sources of support, and it includes an evaluative component to

achieving family-defined goals (Boone, Moore, & Coulter, 1995; Seligman & Darling, 1997).

The IFSP is guided by four values that "enable, empower, support, and strengthen family functioning" (Deal, Dunst, & Trivette, 1994, p. 67). The overall purpose of the IFSP is to develop and implement a program for not only the child with special needs, but for the entire family (Joanning, Demmitt, Brotherson, & Whiddon, 1994). In addition, it outlines the child's and family's strengths, needs, and the goals, it identifies supports and services required to achieve those goals and is developed within the context of a multidisciplinary team-based approach (Joanning et al., 1994). The IFSP process includes three phases that overlap in an on-going process: (a) establishing rapport and assessment; (b) development of the IFSP; and (c) implementation of the IFSP (Joanning et al., 1994).

Procedures for identifying family strengths and needs are numerous and varied. These can include the use of standardized and validated family assessment tools (Krauss, 1988; Salisbury, 1989; Walker & Crocker, 1988), structured checklists to identify family needs (Deal et al., 1989; Dunst et al., 1988), and semi-structured interviews (Bailey, 1988). Summers et al. (1990) discovered that parents were more receptive to the use of informal information-gathering processes, primarily in the initial stages of the assessment process. However, Sexton, Snyder, Rheams, Barron-Sharp, and Perez (1991) found that current best practices indicate that identifying family needs and strengths should involve the use of multi-methods, depending on the preferences of parents.

Slentz and Bricker (1992) assert that family assessment and intervention should be family-guided, rather than family-focused. Since the family guides the content of the assessment and intervention, service provision becomes individualized according to the family's membership, priorities, values, culture, and activities. These authors advise that the intent of collecting family information needs to be conducted in a manner that enhances the development of the child in the context of the family and that only information that facilitates meeting the family's objectives should be obtained.

The IFSP reflects the following principles: (a) the development of the IFSP is done within the context of collaboration and partnerships between the family and human service practitioners (McGonigel & Garland, 1988); (b) any and all information included in the IFSP is done so with the explicit permission and authorization of the family (Dunst & Paget, 1991); (c) the development and the revision of the IFSP should be responsive to the broad-based needs of families, although no human services practitioner or program should be expected to offer support to meet all family needs (Dunst et al., 1988); and (d) both the development and implementation of the IFSP should emphasize promotion of the competence of the family and interdependence with members of the family's community (Dunst et al., 1988).

The IFSP includes eight elements that lead to the development and implementation of the IFSP. These are: (a) family concerns, (b) family needs, (c) outcome statement, (d) resources and support, (e) courses of action, (f) family

strengths, (g) partnership, and (h) evaluation (Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne, et al., 1984; Rappaport, 1981, 1987).

Dunst et al. (1988) developed a format for writing IFSPs. They divided the IFSP into two parts. Part one includes the following information: (a) the name of the human services practitioner, (b) a statement of the child's strengths and current levels of functioning, (c) a statement of the family's strengths and interfamilial resources, and (d) a cumulative record of the specific services, programs, community agencies, and other community supports and programs accessed by the family.

Part two, referred to as the "working" document, includes: (a) a list of family identified needs, aspirations, and desires in order of priority; (b) a series of statements regarding the sources of support and resources that will be mobilized to meet the family's needs; (c) a series of statements regarding the actions that will be taken to mobilize resources; and (d) procedures for evaluating the extent to which needs are met (Dunst et al., 1988, p. 67).

Barriers to Adopting a Family-Centered Approach

A review of the literature suggests that one of the most significant barriers to adopting a family-centered approach to practice has been linked to a reluctance to shift one's philosophical orientation from a child-focused approach to a family-centered approach (Boone et al., 1995).

Minke and Scott (1995) found that many professionals have not developed the attitudes and beliefs that can facilitate parental control. Some of the prevailing beliefs have to do with staff members not expecting parents to posses or be capable of

developing the skills and competencies needed to carry out a family-centered model. The reluctance on the part of the professional to shift the function of his/her relationship can have a negative impact on the amount of parental control that can be exercised. Dunst and Trivette (1989) assert that if professionals view their role as being solely responsible for implementing the IFSP, then the likelihood of families becoming the passive recipients rather than active consumers of services will increase. In addition, if professionals, rather than families, determine what children and their parents need and what services they can have, parental involvement will inevitably decrease. Professionals often have difficulty adopting this perspective, being uneasy about families having too much decision-making power, and some consider that relinquishing control decreases the value of professional knowledge and expertise. Degangi et al. (1994) discovered that poor communication between parents and professionals as well as the limited resources for providing services were additional barriers.

Barriers to Effective Implementation of the IFSPs

The literature suggests that one of the most fundamental barriers to effective implementation of the IFSP is lack of training (Beckman & Bristol, 1991; Farel et al., 1997; Gallagher & Desimone, 1995). Gallagher and Desimone (1995) found that the lack of staff and parent training to develop meaningful IFSPs is linked to a lack of parental involvement, missing data, poorly written goals and objectives, and unclear links between assessments, goals, programs, evaluation, and monitoring. A direct consequence to a lack of training is related to the professional's perception of the

usefulness of IFSPs. Farel et al. (1997) found that when service providers did not perceive the IFSPs as useful, the potential benefits for families decreased. Minke and Scott (1995) found that staff tended to have concerns about whether all parents possess the skills to effectively participate in the IFSP process.

Boone et al. (1995) discovered that IFSPs continue to be primarily child-centered, focussing on facilitating the child's development as opposed to family-centered. Gallagher and Desimone (1995) state that in order for IFSPs to reflect family-centered values, both professionals and parents should receive training, which may occur in the form of an orientation for parents and a workshop for professionals.

PARENTAL INVOLVEMENT AND PARENT EDUCATION

Traditional approaches to involving parents in early intervention were limited to clinically oriented educational and therapeutic service models (Mahoney & Filer, 1996). These models focused on providing parents with instructional and therapeutically oriented activities that would address their children's learning and developmental needs. Parent education, therefore, focused primarily on providing parents with specific knowledge and skills related to improving the parent-child relationship in the context of the child's developmental needs (Mahoney, Kaiser, Girolametto, MacDonald, Robinson, et al., 1999). These skills included "teaching parents strategies to assist children in attaining developmental skills, helping parents manage children's behaviour in the course of daily routines, and enhancing parents'

skills in engaging their children in play and social interaction" (Mahoney et al., 1999, p. 131).

More contemporary family-centered approaches to family involvement shift the emphasis from child-focused activities to enhancing and supporting the family (McBride et al., 1993). Mahoney and Filer (1996) assert that parent and family involvement is critical to the success of early intervention and that a family-needs-driven model provides parents greater opportunities to negotiate the services they require for their family. Moxley, Raider, and Cohen (1989) state that family involvement specifies the role of family members in formulating, planning, and evaluating services to children with special needs. Sheerer and Sheerer (1977) identify several reasons for promoting the involvement of the family: (a) since family members are consumers of services, they should have input into which services are provided and how they should be provided; (b) family members are the best people to advocate for the programs that are needed; and (c) family members can and should identify service goals and objectives.

Baxter (1986) reported that parents indicated that the most important type of help they received from professionals, over sympathy and emotional support, was information. Parents express the need to gain information on how to not only promote the development of their child, but how to access support in dealing with the demands of parenting, identifying community resources, mobilizing those resources, and planning for their child's future (Darling & Baxter, 1996; Gowen, Christy, & Sparling, 1983; Hornby, 1994; Greene, 1999; Mahoney & Filer, 1996; Summers et al., 1990). Heflinger and Bickman (1997) suggest that intervention that provides

knowledge and skills, and encourages active participation in decision making is the key to facilitating parental empowerment.

Campbell, Strickland, and La Forme (1992) found that parents who attended informational workshops on developing IFSPs felt more confident and were more likely to write their own IFSPs and were more active in the goal-setting process (Minke & Scott, 1993). Gallagher and Desimone (1995) and McWilliam, Ferguson, Harbin, Porter, Munn, and Vandiviere (1998) propose that in order for IFSPs to reflect family-centered values, both professionals and parents should receive training, which may occur in the form of an orientation for parents and a workshop for professionals.

Boone et al. (1995) and Judge (1997) state that ideal practice must address the need to provide information and support to family members, emphasizing the importance of parent education, parent networking, and encouraging parents to seek advice and support from other parents. Concurrently, the results of this study support the notion that continued staff development in the area of implementing IFSPs is critical, emphasizing the need to address key training areas in the use of parent-friendly (lay) language, functional outcomes, community and informal supports, and addressing all family concerns.

Parent education, as a key component of early intervention, has been significantly de-emphasized during the last fifteen years (Mahoney et al., 1999). Several authors argue that parent education, as traditionally defined, does not reflect the principles of family-centered practice (Winton & Sloop, 1999). Rather, some of the criticisms against parent education include the burden that home programming

has on parents and the disruption it can cause on family life; the view that parent education is professionally driven; the implicit deficiency and blaming of parents; and potential cultural bias.

Most authors agree, however, that parent education can be a philosophy that is compatible with the principles of family-centered practice as long as the concept is re-defined (Dinnebeil, 1999; Dunst, 1999; Mahoney et al., 1999; McCollum, 1999; & Turnbull & Blue-Banning, 1999) to extend beyond the child's developmental needs. Kelly and Barnard (1999) assert that a renewed and reformed focus of parent education should include a relationship-focused component, where parentprofessional and parent-child relationships are fostered and enhanced. Winton, Sloop, and Rodriguez (1999) add that parent education should only be reinstated if it adopts a new definition, emphasizing the pivotal role that parents play in educating professionals about the needs of their child and family. Dinnebeil (1999) suggests that parent education be defined in the context of addressing the specific and unique learning outcomes of parents. Turnbull and Blue-Banning (1999) postulate that parent education must reflect an ecological approach to skill development and building knowledge, emphasizing the importance of enhancing the child's and family's quality of life, in all areas of life, not just with the child's developmental progress. They refer to this redefinition as partnership education, which shifts the focus away from child development issues to concentrating on gaining the skills and knowledge of the services and supports that foster the needs of the family.

Kaiser, Mahoney, Girolametto, MacDonald, Robinson, et al. (1999) assert that a comprehensive working definition of parent education must reflect a family-

centered approach to facilitating parent-child interactions and strengthening families. Components of this renewed paradigm emphasize a relationship-focused approach to strengthening, enhancing, and supporting relationships as well as fostering partnerships between parents and professionals.

PARENT EDUCATION GROUPS

Group Work with Parents

Group work with parents of children with special needs varies depending on the presenting issues. A review of the literature suggests that traditional parent counselling groups have been generally designed to serve either educative, therapeutic, or both educative and therapeutic functions (Hornby, 1994; Hornby & Murray, 1983; Seligman, 1993). Three basic models of group work exist. These include the group therapy model, the support group model, and the parent education model (Friedlander & Watkins, 1985). Traditional group therapy models, prevalent in the 1950s and early 1960s, focused on two assumptions: (a) that parents' emotional reactions are manifestations of pathologic personality processes, and (b) that adaptive difficulties would result unless treatment focusing on uncovering hidden concerns was provided. Contemporary views, however, hold that family members are relatively healthy and are attempting to adjust to living with a child with special needs (Friedlander & Watkins, 1985; Seligman, 1993; Seligman & Darling, 1997). The focus is now on family strengths and the restoration of adaptive capacities. With its roots in the self-help movement, the support group model emerged as a way of providing mutual aid to parents. The parent education model is based on the premise

that problems emerge from deficiencies in skills and information. Seligman and Darling (1997) state that education groups are primarily focused on providing families with information about their child's special needs as well as training in effective coping and parenting skills.

A review of the literature suggests that group work with parents of children with special needs predominantly focuses on a combination of reflective counselling and behavioural training (Hornby, 1994), which fall under group therapy and the parent education model. In reflective counselling groups, the focus is on the parents' emotional needs. The goal of this approach is to help parents express and attempt to resolve their feelings and concerns around their child's special needs and thereby attempt to improve their adaptation to their circumstances (Hornby, 1994). In behavioural group training, the focus is on changing the children's behaviour. Parents are taught behaviour modification techniques in order to improve their children's behaviour and learning difficulties (Hornby, 1994).

Although rigorous research in the area of parent education groups is largely absent, some preliminary findings indicate that this approach has been linked to a decrease in isolation, an increase in coping skills, and a reduction of stress (Seligman, 1993). On post-group questionnaires, Hornby and Murray (1983) found that parents of children with special needs reported that they experienced more confidence in their ability to parent their children, felt more knowledgeable about themselves, and other resources, and appreciated the sharing and identification with other parents.

Heflinger and Bickman (1997) studied the effects of conducting parent education groups in the area of caregiver empowerment. Parents of children with

mental health issues were asked to participate in a parent training program aimed at enhancing caregiver empowerment in three areas. The first area focused on knowledge building. This area addressed critical issues such as providing information about the nature of the mental health system and other available community resources, understanding and participating in the assessment and intervention process, assessing the child's and family's needs, and reviewing the rights of parents when dealing with the mental health system. The second area focused on skill development. This included training in communication, goal setting, the relationship between parents and professionals, and finding community resources. The final area addressed mental health services efficacy. This involved teaching parents about how the mental health services system functions, encouraging active participation in decision making, and promoting collaborative relationships between families, caregivers, and professionals. The results of this study support the effectiveness of using parent education groups to enhance caregiver empowerment. These authors state that increased knowledge and mental health services efficacy led to increased parental involvement, parent-professional partnership, and enhanced child and family outcomes.

Seligman (1993) states that although there is very little empirical research on the effectiveness of parent education groups specifically, the available findings suggest that these groups offer strength and support to their participants. Seligman and Darling (1997) state that parent education groups focus on providing information and serve to inform families about their rights and benefits, and where and how to obtain needed services. The parent education model assumes that family members can

cope adaptively when they are provided with accurate and relevant information (Seligman & Darling, 1997) and is one of the most effective ways of providing parental support (Seligman, 1993). This model, therefore, is based on the ideology that difficulties emerge in coping with the demands of raising a child with special needs as a result of lack of information, skills, and resources.

Effective group work, whether it is educationally or therapeutically based, not only requires knowledge in the area of working with families of children with special needs, but also knowledge in group process (Seligman & Darling, 1997).

Group Process

Corey and Corey (1987) emphasize the importance of group process, or group stage development and the interactions that characterize each stage. Although several authors have different ideas about the number and types of stages, most of these models propose that groups pass through three stages of development—beginning, middle, and ending (Toseland & Rivas, 2000). Toseland and Rivas (2001) suggest that stages of group development may be affected by the type of group, the needs of the members, the goals of the group, the setting, and the orientation of the leader.

Toseland and Rivas (2000) state that the primary purpose of educational groups is to help members learn new information and skills. They include opportunities for group discussion to foster learning. When leading educational groups, workers concentrate on both the individual learner and the group as a whole as vehicles for learning, reinforcement, and discussion. Radin (1974) points out the fact that group leaders take on the educational role with the "socioeducation" group. He asserts that this implies a different orientation in the way the group leader views his/her role and

states the following: "there is more equality and the worker teaches, but also learns from members. This egalitarian relationship is the heart of the worker-member relationship in socioeducational groups" (p. 29).

Corey and Corey (1987) highlight several characteristics that make up each stage of group development. The beginning stage is characterized by getting acquainted, clarifying the purpose of the group, establishing group cohesion, establishing group norms and developing trust. It is during this stage that group participants get acquainted and learn how the group functions, what is expected of them, and what they will learn.

The middle stage of group development is a time where groups are focused on accomplishing the objectives, goals, and tasks developed earlier in the life of the group (Corey & Corey, 1987; Seligman, 1993; Shulman, 1984; Toseland & Rivas, 2001). Corey and Corey (1987) state that the middle stage (or working stage) is characterized by the members' willingness to explore personally meaningful experiences. This is a time when members are open to practicing new skills, listening to new ideas, and providing feedback to one another.

Termination and consolidation characterize the ending stage (Toseland & Rivas, 2001). This is the stage where the group is coming to a close, the objectives of the group members are achieved, and the members are preparing for termination. For members, the ending stage of group development is an opportunity to express what the group experience means to them (Corey & Corey, 1987). It is during this stage that members are given an opportunity to talk about what they have learned about the information and skills acquired, about themselves, and about other members.

Consolidating learning also includes an exploration of how they can incorporate what they have learned in their every day life. More importantly for some members, they may want to talk about the impact that the end of group may have had on them.

Unlike multiple session groups, the beginning, middle and ending phases of group stage development must be encompassed in a single session group design.

Although this limits the development of group cohesion, Shulman (1984) suggests that it is possible to structure single session groups so that information may be presented in a manner that still allows members to participate and interact and enables participants' experiences to be more meaningful.

Strategies to enhance participants' learning stems from early work on adult learning and the principles that guide this type of approach. Knowles' (1984) theory of adult learning is based on the following five assumptions: (a) adults are autonomous and self-directed; (b) adults have accumulated a foundation of life experiences and knowledge; (c) adults are goal-oriented; (d) adults are relevancy—oriented; and (e) adults are practical. Given these assumptions, Brookfield (1995) identified three types of learning that work well with adults. These are (a) self-directed learning; (b) critical reflection; and (c) experiential learning.

Galbraith (1991) states that adult learning is a transactional process that reflects challenging, sharing, and reflective activities. Brookfield (1986) adds that the nature of the teaching-learning transaction occurs within the context of mutual respect, negotiation, and collaboration.

Bennett et al. (1990) summarize some of the training strategies that reflect adult learning. These authors suggest the use of concrete study materials (both

written and visual), discussion, demonstration, and small group activities, such as role-plays and brainstorming, are important components of adult learning methods.

Although the types of adult learning strategies that are utilized depends on the format of the educational group, many of the techniques reflect the principles found in competency-enhancing and capacity-building skills used in one-on-one professional/parent interactions.

CONCLUSION

A review of the literature on family-centered practice, parental involvement and education, and parent education groups provided me with a firm theoretical and empirical base from which I was able to integrate the knowledge I acquired to implement parent education, in the area of family-centered practice, as an empowerment intervention. The principles of family-centered practice, the role of the social worker, the rights of parents, and the development of the IFSP formed the basis for the training curriculum and the information I obtained was translated in parentfriendly language. A review of the literature on parental involvement and education provided me with an ability to design a training program that provided parents with information about family-centered practice, an orientation to supports and services, and an opportunity to understand how service delivery systems operate. Finally, knowledge in facilitating parent education groups allowed me to design group activities that promoted parental participation and enhanced learning, observe group dynamics, and facilitate group process. This firm knowledge base provided me with the tools to carry out my practicum.

CHAPTER THREE:

THE INTERVENTION

As a component of the Family Strengths in Childhood Disability Project, my practicum involved developing an orientation guide for parents, developing a curriculum and training manual to conduct parent education groups in the area of family-centered practice, and facilitating two parent education groups.

The practicum process was carried out in three intervention phases. Since each phase represents a particular aspect of my learning, I have referred to these phases as the developmental phase, the implementation phase, and the evaluation phase. What was done in each phase is described and a summary of my findings is provided. All three intervention phases form the basis of my analysis and subsequent discussion.

(1) THE DEVELOPMENTAL PHASE

The developmental phase of my practicum consisted of the time that was needed to develop the parents' orientation guide as well as the training material. I will begin with highlighting key points in the development of the orientation guide and follow with the development of the training material.

THE ORIENTATION GUIDE

SUMMARY

As a social worker employed in the area of providing coordinating services to families who have children with special needs, one of the most frequently asked questions parents have asked me is, "How does it all work?". Confused about how to access the supports and services that may exist, parents asked for a guide that would help them understand service delivery. In a community of the lower mainland of British Columbia, I developed an orientation guide for families who had entered the provincial Community Living Services Department for Children with Special Needs. This guide included information on all the program-based services that the Ministry provided. Included in this description, I developed a generic format that contained a description of the services, eligibility criteria, referral process, and community contact. As well, a list of frequently asked questions was included to provide parents with a basic foundation of knowledge and to help parents understand that they are not alone in their questions.

The parents' guide for this practicum was developed based on the orientation package that I had developed in British Columbia. As a prototype, the same format was used to link supports and services in the Winnipeg region. Again, this format consisted of a description of the service, the eligibility criteria, the referral process, and the community contacts. In addition, there was a more detailed section on answers to some of the more frequently asked questions made by parents.

On a personal note, although I was a resident of Manitoba, I was a practicing social worker in British Columbia and was not aware of many of the resources that

exist and I was not familiar with how the social service system, the education system, and the health system operate. Aware of this steep learning curve, I consulted with staff from various organizations to get an overview of how services operated in the city of Winnipeg.

The development of this orientation guide occurred during several stages. I began my process with an orientation to the Child Development Clinic. This proved to be very helpful because for the most part families begin their involvement with the Child Development Clinic. I then interviewed a representative of Children's Special Services, Winnipeg Region. This person gave me some clarifying information with regards to what services are offered by Children's Special Services and discussed the usefulness of this orientation guide. It was at this time that a modification to the guide's overall format was made.

During my discussion with this representative, she indicated that an orientation guide that provides information to families already eligible for family support services through Children's Special Services exists. She suggested that a guide that reflects a more general approach to providing information to all families was needed and that there should be more emphasis on reaching families who do not strictly meet the eligibility criteria of government-run services. It was at this point that the format of the orientation guide was modified to better accommodate all families of children with special needs. A family-needs approach became the framework for creating this guide.

A family-needs approach represented a departure from most orientation guides which are usually program-specific (orientation guides developed by agencies)

or disability-specific (orientation guides developed for children eligible for services based on their diagnosis). With this new framework, I consulted with staff from the Association for Community Living and was given an orientation to programs and services provided by this organization. I met with a policy representative from the Department of Family Services and Housing and was provided with an orientation to the organizational structures of programs and services in the area of children with special needs. Finally, I met with staff from the Society for Manitobans with Disabilities. This opportunity afforded me a clearer sense of how the Society for Manitobans with Disabilities co-exists with Children's Special Services.

The first draft of this orientation guide was distributed to members of the Project Advisory Committee: a member from the Association for Community Living-Winnipeg, a member from the Child Development Clinic, two members from Children's Special Services, two members from the Society for Manitobans with Disabilities, and my practicum committee members. Each draft copy was edited and some suggestions, corrections, and revisions were made. A further revision was made in order to ensure that the guide reflected a general approach to accessing services.

The overall language of the guide was modified to reflect a grade eight level of reading. My 13 year old niece was asked to highlight every word she did not understand. There were twelve words that were either replaced, or used with an attached glossary that defined the word. This will be further discussed in the next section. The final draft was edited by an English teacher before it was distributed to each member for final feedback. Revisions were made accordingly.

The orientation guide, "A Family-Centered Orientation to Supports and Services for Children with Special Needs and their Families" (see Appendix A), is divided into two major sections. The first section begins with answering frequently asked questions made by parents. These include: how is eligibility determined?; who may be involved in my family's life?; what is the role of my worker?; what will my worker need to know about my child and family?; what are my rights as a parent?; how are my family's support needs assessed?; what is an individualized family support plan?; is there a waitlist for services? and; if I'm not happy with a decision that has been made regarding the services my family requires, where can I turn for assistance?. These answers provide families with basic information about how services are accessed, who may become involved in the family's life, and how services should be provided.

The second section is a roadmap to address families' needs. Using a family-needs perspective, these needs include: child assessment and development; early intervention; supplies, equipment, and home modifications; child care/preschool and school support; relief/respite; behavioural support; in-home/homemaker support; special health care support; personal/family support; recreation, leisure, and summer support; and transitional planning to adult services.

Two parents' stories, "Welcome to Holland", by Emily Perl Kingsley, and "Celebrating Holland", by Cathy Anthony, were included with permission from the authors. These two stories reflect the journey that they traveled in caring for a child with special needs. The essence of both stories is that having a child with special

needs requires a different understanding, new learning, and some challenges, but it is a life that can be celebrated and enriching.

FINDINGS

1. My Own Shift In Thinking

One of the most striking realizations in developing this guide was recognizing my own need to fully embrace a family-centered approach to practice. Although I believe I have adopted the principles of family-centered practice in my own work with families, I realized that I was still operating from a program-based perspective with respect to developing the guide. In other words, I wanted to develop an orientation guide for parents already in the system and offer an orientation for those families. Only when I realized that that approach was narrow, I began to reflect on what family-centered practice teaches practitioners about *where* to begin with families. This reflection allowed me to make the connection with what social work practice teaches us in terms of beginning where the client is. It was at that moment that I realized that this guide could be developed in a manner that truly reflected a family-centered orientation to supports and services—an approach that would be family-needs based.

A family-needs perspective cuts across all sectors of disability-related services and program-specific guides. Disability-related services (such as services for children with Autism) or program-specific guides (such as the orientation material distributed by government-run services) contain information specific to the population served. A family-needs perspective marks a shift towards a family-driven

model and is not restricted to programs or the child's diagnosis. Rather, it includes child-specific developmental needs (e.g., the need for speech therapy) as well as family life stages (e.g., transitional planning to pre-school, school, and adult services). Operating from a family-needs perspective provides a context for developing a document that can be used throughout the family's life. As families pass through life stages, their needs change. As there are needs common to most families, this guide become a life resource that can be accessed as changes occur for any family.

2. System Collaboration

System collaboration is an important theme that emerged. In developing this guide, I collaborated with several systems in order to make this document reflect a total systems approach to meeting a family's identified needs. Representatives from social services, health, and education joined with me and embraced the philosophy of a family-centered approach to the development of the guide. When I explained the purpose of the orientation manual, individuals within these systems responded favourably and offered feedback, suggestions, and corrections to the information included about their services, the process involved in obtaining those services, and other information about their organizations.

Each person understood the family-needs driven model and agreed to edit the guide in a manner that was consistent with the approach I took. The feedback was positive and suggestions made were more around the content of the information provided, grammar, language, and spelling. A respectful approach to helping me

develop a guide from a family-centered perspective was taken by everyone who was involved.

3. Community Partnerships

The theme of community partnerships was evident in my endeavour to produce a document that was useful, helpful, and acted as a resource to families. All organizations listed in this orientation guide were contacted and, out of common courtesy, permission to include them as a community contact was obtained. In contacting each organization, I asked whom I could talk to in order to obtain permission to include their resource as a community contact.

There was a spectrum of support with respect to the responses I received. Most organizations, at the level of the receptionist, gave immediate approval. Some directed me to the organization's Executive Director and once I spoke with the Executive Director, immediate approval was obtained. Only one organization did not provide immediate approval. I was not sure of the position of the person that I spoke to in relation to the organization, but I was asked to provide some written material so that it could be approved by the Board of Directors. Once this was provided to them, a faxed copy was sent to me that contained the material that they wanted me to include. Overall, the community partnerships that developed were very positive and organizations were very responsive to being included.

4. Organizational Responses

Another striking theme was the overwhelming responses I received from organizations about this guide. As a component of my practicum, the orientation guide was designed specifically for the families who participated in the parent education groups. This guide was distributed only to them as part of their education. However, during the course of my community consultation and contacts, there was a growing interest in accessing this guide from several organizations. Apparently, there were some attempts in the past to develop a resource guide but nothing had yet been developed. These organizations indicated that there exists a need in the city of Winnipeg for such a resource, and that this guide would fill that gap and would be very useful to distribute to families.

In addition, there seemed to be a positive response to the format of this guide. Apparently, there are no manuals that provide an orientation to families of children with special needs. More specifically, there are no manuals that provide a family-centered orientation to supports and services and no guide has ever used family-needs as a basis on which to help families navigate their way through the various service systems.

I have been asked by several organizations if copies of the guide could be made available for distribution. These copies would then be made available to new families entering the system, families already in the system, and families currently connected to community-based organizations.

5. The Use of Language

During the development of the guide the issue of language became a factor.

During the initial feedback from organizations, I was told that the manual would be very useful if it was written in simpler language for parents who may not have average literacy abilities. In response to this request, I asked my 13-year-old niece, who had a grade eight level of education, to highlight every word in the document she did not understand. As well, I asked her to highlight the sentences that she thought were complicated.

There were no sentences that she found difficult to understand, but she did highlight twelve words. These words were: eligibility, referral, endeavours, interfamilial, intervention, subsidy, assessment, facilitate, intermittent, leisure, impaired, and manifested. As a response, the word endeavour was replaced with effort, interfamilial was replaced with family members, and the word facilitate was removed. The words impaired and manifested were removed not because of the words but because it was part of the eligibility criteria for adult services, and I decided to remove that piece entirely. The words eligibility, referral, intervention, subsidy, and assessment remained in the body of the guide. I decided that because these were terms that parents would hear time and time again, they needed to become familiar with their definitions. To address the concern about those words, a glossary was included in the back of the guide.

The use of language has significant implications to practice. If information is to be accessible to families, then it must be written in a manner that is understood by

a range of parents with varied educational levels. This has certainly made me aware of the fact that the use of language can serve to empower or to marginalize the reader.

THE TRAINING MATERIAL

SUMMARY

The training material that I compiled came from various sources. These included information on parent education groups, principles of adult learning, family-centered practice, and group process/group stage development. I also included pregroup planning issues that I used as a guide for my preparation in developing the training groups. I used content from my literature review and included it as part of the points to cover for the presentations.

I decided on the following modules or issues to be included: what family-centered practice is; what the role of the social worker is, what the role of parents is and their rights as active consumers of support services; and the development of an Individualized Family Support Plan. The content for these modules came from the literature review I had completed previously. A draft outline was developed that included the purpose of the module, the time required, the material needed, and the procedure. This outline was given to my practicum advisor for approval. Once approval was obtained, I included key points to cover and used this material to develop transparencies (see Appendix B).

The final training manual was actually developed after the parent education groups partly because there was no time to do it before-hand and partly to incorporate changes that were made during the process. The manual contains essential

background information that I found to be very important when I co-facilitated my groups. The manual includes information on education groups, principles of adult learning, and information on group process/group stage development. The training manual also includes information that is required in order to conduct the group, an agenda that reflects the content required to meet the learning objectives of this type of group, and directions on how to facilitate the sessions (please refer to Appendix C).

FINDINGS

As a parent education training manual in the area of family-centered practice does not exist, the manual I developed reflects my own approach and contains essential elements that I needed to rely on in order to help the groups run effectively. These elements included having a solid understanding of family-centered practice, pre-group planning issues, and key strategies to facilitate groups.

Facilitating the groups and reflecting on my learning allowed me to develop the training manual in a manner that truly reflected my learning process. I began my learning with studying the literature on family-centered practice and compiling key material. I then researched material on group work and decided that there were key elements to follow ranging from pre-group planning issues, to effective facilitation skills. Receiving feedback from my advisor was a critical piece to my learning. She was able to provide me with feedback that confirmed that I was prepared to facilitate the groups. After I facilitated the groups, I was able to use my experience to create the training manual. To conclude, there is no other manual that contains all of the elements that I've included and, based on my preparation and experience in

facilitating the groups, I believe that this manual reflects a comprehensive approach to running this type of parent education group.

(2) THE IMPLEMENTATION PHASE

The implementation phase of my practicum included conducting two parent education groups. Before I was ready to conduct the group, it was necessary to make several arrangements in order to ensure that I was prepared. I used the seven preplanning stages outlined by Kurland, Getzel, and Salmon (1986) as my guide in preparing for the groups. I will use the same components to analyze this section of the implementation phase. The pre-planning components include: (a) agency context, (b) need, (c) purpose, (d) structure, (e) composition, (f) content, and (g) pregroup contact.

PRE-PLANNING COMPONENTS

(a) Agency Context

The Family Strengths in Childhood Disability Project, a project assessing the implementation of family-centered practice in the province of Manitoba, has a joint research relationship with Children's Special Services and the Society for Manitobans with Disabilities. Parents were recruited from among those families participating in the FSCD project. They include families from both the Society for Manitobans with Disabilities (SMD) and Children's Special Services (CSS) who have been referred for services within the past 6-18 months.

The Association for Community Living (Winnipeg) (ACL), a community-based organization that provides a broad range of support services to families of children with special needs as well as adults with disabilities, offered their office as the site to hold these education groups. Given the role of family support and client advocacy in its mandate, this organization was an appropriate site for running these groups.

The building, where ACL was located, was centrally located in Winnipeg, had accessible parking, and the room was comfortably decorated with couches, tables, and pleasant lighting to welcome parents. I provided an ongoing supply of refreshments and snacks for the group.

(b) Need

It has been my experience, as a social worker in the field of working with families who have children with special needs, that one of the first things that parents require is information. When parents initially enter the service delivery system, they are often confused about how the system works and are not aware of what services exist and what supports are available. This makes it difficult to ask for help. Parents are often so overwhelmed about the numerous systems they must be involved with that they may not know where to turn. They often must rely on their worker to offer them information and this may not happen in a consistent way. Obtaining information from community-based organizations is rarely accomplished solely through individual contact between service coordinators and families.

Information about what services can be accessed, what the role of workers is, what the rights of parents are, and what the nature of the helping relationship between the families' workers should be, is essential. Given the fact that family-centered practice has been adopted by Children's Special Services (CSS) and the Society for Manitobans with Disabilities (SMD), parent education, as an empowerment practice, has been identified as the next step to advancing the movement.

(c) Purpose

The purpose of running these parent education groups was to help parents understand family-centered practice, the role of their SMD or CSS social worker, their role as parents and active consumers of support services, the process of developing Individualized Family Support Plans, and how to access supports and services. The overall objective was to empower parents by providing them with a supportive learning context. The secondary objective was to foster support and networking opportunities for the parents in the group.

(d) Structure

Two group formats were developed in order to accommodate the needs of parents. The first group consisted of a full, six-hour day workshop on a Saturday. The other group consisted of two successive two-hour evening sessions. Table 1 outlines the content and organization of the sessions.

Table 1
Group Format

Group Format	Content
Full Day 9:00 a.m. – 12:00 p.m. Evening 7:00 p.m. – 9:00 p.m.	Part One: What is family-centered practice, What is the role of the worker, What is the role and rights of parents, and What is an Individualized Family Support Plan
Full Day 12:30 p.m. – 3:00 p.m.	Part Two: Guest Speakers (parent, Children's Special Services, and the Association for Community Living), Orientation Guide, and Evaluations
Evening 7:00 p.m. – 9:00 p.m.	Guest Speakers (parent, Child Development Clinic (CSS), Association for Community Living, Day Care Office and the Department of Education), Orientation Guide, and Evaluations

(e) Composition

Recruitment

Thirty-one families already participating in the Family Strengths in Childhood Disability Project were randomly selected for this practicum. All of the selected families were sent a letter offering them an opportunity to attend these information groups (please refer to Appendix D). The letter indicated that participation was completely voluntary and that I would be contacting them in approximately one week to find out whether parents would be interested in attending.

Two of the 31 telephone numbers provided to me were temporarily disconnected. Out of 29 families I contacted, nine families agreed to participate. However, two families, who agreed to attend the evening sessions, did not attend. Out of the seven families, five families participated in the full day session and two families participated in the evening sessions. At the full-day session, both the mother and father from one family attended. The remaining families included three mothers and one father. At the evening sessions, both the mother and father of one family and the mother of the second family attended the first evening. At the second evening, only the two mothers attended (the father had to provide child care).

Out of the remaining twenty families, three families never returned any of the two telephone messages I left, and six families stated they would get back to me but never did. The remaining eleven families declined the offer due to various reasons. The reasons are shown in Table 2.

Table 2

The Reasons For Declining

Number of Families who Declined	Reason For Declining
1	Unable to commit to six hours
1	Already knows the system—learned the hard way
2	Working those days
6	Not a good time
1	Not interested at this time

Although 29 out of the 31 families were contacted, only seven families participated. When this number was first suggested as the number of families to contact, I thought that it was too high, especially when a limit of six families per group was established. Instead, given the results of my attempt to recruit families, it appeared that this was an appropriate number to begin with. Although a high number of families were interested in participating in this group, parents stated that the timing of the groups and the length of the session were not convenient for them. In addition, there were a high number of families who did not return my call, even after the second message was left. Given the results of my contacts, I have learned that it is reasonable to consider beginning with a sample size that is at least three times the size of the number of desired participants.

During my telephone contacts with parents, I learned that even though all families were sent letters of invitation, many parents did not remember having received the letter. Although the letter indicated that I would be contacting families in approximately one week, I was not able to contact families until almost three weeks after the letters were sent out. This was due to the fact that there were some administrative issues the FSCD project and CSS needed to clarify before families could be contacted. Although this may not be the reason why most parents did not remember having received the letter, it may be important to make sure that parents are contacted within a reasonable amount of time so that they are not surprised about the telephone call.

I learned that it is important to offer different group formats for parents.

When both the full-day and evening session were presented as options, five families

chose the full-day session and four families chose the evening sessions. Out of four families who agreed to participate in the evening sessions, only two families attended. Regardless of this fact, I did learn that in order to reach many families, it is important to offer a choice between full-day and evening events.

I also learned that in order to encourage both parents to attend the group, it is important to clarify whether child care can be made available. This was not stipulated in the letter that parents received and was only discussed with parents once I obtained clarification from the Project. Although child care was not a barrier for any of the parents who did not participate, child care options must be discussed at the onset since most families require time to arrange suitable care.

A client log was used to record information about each family that was contacted. I found this to be very helpful because it allowed me to keep track of when parents were contacted, what was discussed, and what was agreed.

Content

The content of these parent education groups was educational in that the presentation provided parents with information about family-centered practice, the role of their worker, their role as parents and as active consumers of support services, and the development of Individualized Family Support Plans. Guest speakers from Children's Special Services, Child Development Clinic, Association for Community Living, Day Care and the Department of Education presented information and responded to parents' questions. Finally, the orientation guide was distributed and a brief overview was provided to the parents.

(f) Pre-group Contact

I met with each family who agreed to participate in the groups. At this meeting, a more detailed description of the group was provided to them and each parent was asked to read and sign a consent form (please refer to Appendix E). Once the consent form was signed, a brief interview was conducted. In order for me to get a sense of where parents were in terms of their understanding, four questions were asked. These were:

- 1. Have you ever heard the term "family-centered"?
- 2. Do you know what some of your rights are as parents and consumers of services?
- 3. Have you ever heard the term "Individualized Family Support Plan"? and
- 4. Are there any issues/concerns you have that you would like addressed during the group?

All of the responses were recorded, including actual quotes. At the end of the interview a thank you letter was given to each parent with details explaining the dates, time, and location of the group. Included in this letter, parents were told that there would be snacks and refreshments, and lunch provided for the Saturday session. In addition, I informed them that a poster board would be hanging on the wall for family pictures and I suggested that participation was optional (Appendix F).

Although I would have preferred to ask more questions by administering a questionnaire, it was decided that since these families were already participating in the project that the researchers did not want to overwhelm the families with extensive interviewing. Given this direction, the few questions asked provided me with some

baseline information that I could draw upon to tailor the material to the parents. As well, in order for me to understand what parents learned, the baseline information was used to compare information obtained at the end of the session. For the purposes of this section, I have combined the responses from the parents attending both groups.

When parents were asked whether they knew the term "family-centered", two parents had heard the term but did not know what it meant, one parent had heard the term but was not sure what it meant, and the remaining six had not heard the term nor did they know what it meant.

When parents were asked whether they knew what their rights were as parents and consumers of services, one parent indicated she knew some of them, two found out about some of their rights but didn't really know them, one wanted to know more about rights, and five parents did not know they had rights.

When parents were asked whether they knew what an Individualized Family Support Plan was or any variation of that term, all nine parents replied, "no". All of them responded that they were not aware if a plan exists for their child and family.

When parents were asked whether they had any questions, concerns, or issues that they would like addressed, the following issues were raised.

(1) UNCERTAINTY ABOUT TRANSITIONAL PLANNING INTO THE SCHOOL SYSTEM

Four parents expressed concerns around transitional planning into the school system. These parents did not know to whom they should be talking or where to turn for assistance. None of these parents knew what the first step was in terms of what they should be doing.

Some of the concerns parents expressed had to do with the fear that upon entering school their son or daughter might not get the kinds of supports s/he was currently receiving. Some of the parents were under the impression that the services would continue upon school entry. They did not know that pre-school services ended upon school entry. They wanted to know who gets involved in the planning issues, when that should occur, and who would be responsible for making sure that their child's needs would be met.

(2) CONCERN AROUND HOW TO DEAL WITH OTHER PEOPLES' REACTION TO THEIR CHILD

One family expressed concerns around how to deal with other peoples' reaction to their child, even though their child looks typical. Both parents shared a story about being at church with their child who was being disruptive. Other church members were offering suggestions on how to discipline their child or offering to intervene. The intervention made their child's behaviour escalate. In addition, these parents expressed concerns around their distrust of caregivers because of an experience they had leaving their child with someone who assured them that they knew how to discipline the child. It turned out that they tried to discipline the child in a manner that made the situation worse. These parents expressed concern that people make judgments about their parenting style because their child appears to act typically.

(3) UNCERTAINTY ABOUT OTHER SERVICE OPTIONS AND HOW TO ACCESS THESE SERVICES

One parent wanted to know what other options exist for early intervention therapy for his son. This family had been on a waitlist for one and a half years and was recently told that they would have to wait another year. This parent was afraid that his three year old son would lose opportunities to benefit from therapy while he was young enough to learn. This parent wanted to know what other options exist, but he did not know who to turn to for assistance.

(4) UNCERTAINTY ABOUT HOW LONG SERVICES CAN BE MADE AVAILABLE

One parent was not sure about the services that she is currently receiving for her daughter. Her fear was that early intervention services would stop and she would not be able to access them again. She was not certain about the length of time she is able to access support from the organization that is currently involved with her. As well, she was not sure how long her child can remain eligible for family support services in general.

(5) LACK OF KNOWLEDGE ABOUT HOW THE SYSTEM WORKS

One mother expressed concerns about feeling very overwhelmed and confused about how services work. Claiming that all she wants is what's best for her son and to be the best mother she can be, she indicated that she just doesn't know what questions to ask. She was concerned that there may be something out there that might benefit her son but doesn't know how to go about searching or who to turn to

for support and assistance. This parent said, "I'm so in the dark, I don't even know what questions to ask...I don't know how it all works".

Another parent stated that she just doesn't know what services are available, stating that she did not receive any information about what might be available for her daughter and family. In addition, this parent stated that she knew she had a social worker but did not know what the social worker could do for her family. She felt very alone and wasn't sure who she could turn to for support or assistance. She said, "I don't know what services are available...nobody up front tells you things...I don't know what my social worker does...we find out about things when it's too late".

(6) CONCERNS ABOUT THE QUALITY OF SERVICES

One parent had specific concerns around the supports she is currently receiving through a community-based organization. She was having difficulty with a worker in terms of the worker's inappropriate conduct and the supervisor's defence of the worker. This parent felt powerless in her situation, fearing that she would lose services if she complained too much. Not having any support from the supervisor, this parent felt isolated in her concerns and had little energy to deal with advocating for her rights as a consumer. This parent said, "If you're having trouble with a worker and the supervisor, who can you turn to? Even the supervisor doesn't believe you when you try to complain about one of the workers."

FINDINGS

Pre-group interviews proved to be an essential component of the intervention process because it provided me with several learning opportunities. Firstly, I found it rewarding to meet the families individually prior to the group. Families had an opportunity to meet me and ask any questions they had. Secondly, one-to-one contact provided me with an ability to assess where each family was at in their knowledge and understanding. Each family was at a different point. Thirdly, obtaining information from all the families allowed me to tailor my presentation in a manner that reflected everyone's learning needs. Obtaining specific information in terms of parents' concerns/fears/issues also allowed me to prepare the guest speakers as to what needed to be addressed. This, in turn, helped speakers prepare their presentation in a manner that was useful and meaningful for the parents.

Although most of the questions asked required a "yes" or "no" answer, it provided me with a very quick assessment of each parent's knowledge. The last question, however, required each parent to think about concerns/issues that they wanted to have addressed during the group session. I found this exercise to be most rewarding because I was provided with important information about where parents were in terms of their concerns.

The pre-group interview was an invaluable part of this process, and I was able to incorporate many of the interpersonal communication skills I learned as a social worker. Active listening, paraphrasing, and summarizing were techniques I used to gain accurate information.

One of the challenges I encountered had to do with scheduling appointments. Some visits needed to be re-scheduled and one visit was cancelled upon my arrival due to a family emergency. Some parents were interrupted by their child or by the telephone, making it difficult for them to complete their sentences or stay on track. I encouraged parents to tend to their children and reminded them of what they were talking about to help them complete the interview. They were not rushed in their answers and time was spent listening to some of their concerns with their current circumstances.

Information obtained during the pre-group interviews established a baseline of data. In general, I knew that all the parents knew very little about what family-centered practice means, what the role of the worker is, and what their rights as parents are. Not one parent knew what an Individualized Family Support Plan was; none of these parents were aware that a plan should be developed. All the parents had issues/concerns related to wanting to access information and to gain knowledge. This information helped me facilitate the groups in a manner that was helpful to all the parents.

THE PARENT EDUCATION GROUPS

As I facilitated two groups, I will combine shared elements of both groups in the summary. Key differences specific to the evening sessions will be included in my findings. I will use Corey and Corey's (1987) description of beginning, middle, and ending stages of group development to organize this section.

THE BEGINNING STAGE

SUMMARY

The beginning stage started with me hanging a poster on the wall for family pictures, welcoming parents, and providing name tags for each member. The session began with a welcoming message from one of the project's members followed by a brief introduction of the parent/co-leader and myself. Prior to introductions from each of the parents, the session began with a personal reflection exercise—an exercise that allowed parents to reflect on what the term "family-centered" means to them. I asked that everyone take two minutes to write about what they thought the term meant. Once the two minutes were complete, I asked that everyone put their piece of paper away. If they so chose, I suggested that at the end of the session they could pull out their piece of paper and see if what they learned matched what they thought the term meant. The purpose of this exercise was to allow the parents to tune in to the whole area of family-centered thinking and engage in a personal reflection on their own thoughts. This exercise was done intentionally without sharing among parents to eliminate any anxiety among the members.

The beginning stage continued by having each person introduce him/herself, talk about his/her family, what interested him/her about coming to this group, and what brought him/her here. Specific issues raised by parents were written on flip chart paper and acknowledged as points that would be covered during the session. I also indicated that if the points were not discussed to any parent's satisfaction, then I would follow-up by obtaining either the information or finding a contact person who would be able to respond to the parent's request.

The objectives of the session were discussed by clarifying my role. I explained that I was not an expert on their families but was present as a social worker who has experience working with families of children with special needs. I explained that my role, for the purpose of the group, was to provide them with information that will help them understand more about supports and services and help them navigate their way through the various service systems (social services, health, and education). The length of the group was discussed including information on breaks, refreshments, and lunch. Basic housekeeping rules including the location of the bathroom, confidentiality, respect for people's shared opinions, allowing people to take turns speaking during discussion and to ask questions when needed, were also covered.

The goals of the education group were discussed. These included providing parents with information that will help them obtain the supports that meet their family's individual needs, assisting them in developing more skills that will help them define for themselves what is best for their family, and providing them with a set of "tools" that will equip them with the ability to access the kinds of supports that reflect their individual needs. An outline was presented that specified the topics to be covered (what family-centered practice means, what the role of the worker is, what the role of parents is, what the rights of parents are, what an Individualized Family Support Plan is, and an orientation to supports and services) and identified which presenter would take the lead on the various topics.

FINDINGS

The picture poster for family photos proved to be a critical activity. It became a conversation-starter amongst parents and was often referred to during the introductions. During breaks, parents would visit the poster board and spend time looking at each family, commenting on the size of the family, the appearances of the children, and particular qualities of the picture. I enjoy pictures, and I always ask the families that I work with for a picture of their child to put in their child's file. It helps to make their child real and personal to me. The pictures created a climate of warmth as it gave meaning to the experiences and stories shared by members. I wanted an opportunity to bring that reality to the group, so that everyone was reminded of why we were all together. It was a very powerful activity, and I felt very delighted that everyone in the full-day session participated. The families of the evening session, however, did not bring pictures, claiming they forgot to do so. The impact of having only one picture on the poster (from the co-leader) was evident. It was still used as a reference for the parents who were interested in getting to know the co-leader's son, but having only one picture on the poster made it stand alone. Both mothers commented, on several occasions, that they should have remembered to bring their pictures.

Before beginning to deliver content material to the group, I was interested in collectively creating a list of parents' learning objectives. This was the rationale for having each parent state what brought him or her to the groups. Parents indicated they came to the group to obtain information, skills, and support. One parent was not sure what s/he wanted out of the group (see Table 3).

Table 3
Parents' Learning Objectives

What interested you to come to this group? What brought you here today?

Parent	Responses
Parent	To get services
One	
Parent	To get as much information as possible
Two	possioic
Parent	To get some ideas about how to deal with others who don't
Three	understand
Parent	To interact with other parents for support
Four	paronio for support
Parent	My obligation to help my childto get any kind of information
Five	to help me
Parent	To understand my rights as a consumer
Six	y Gant Siz W Constitution
Parent	To get new information, some support in accessing services
Seven	support in accessing services
Parent	To make sense of how services work—who does what
Eight	wito does what
Parent	I'm not sure
Nine	

The opening exercise proved to be meaningful because it allowed each parent to express to the rest of the group what s/he would like to get out of attending this group. Some of the statements were as I had expected because they were discussed during the pre-group interviews. These statements had to do with the need to obtain information, to access services, and to understand how services work. Surprisingly, I did not know that some parents wanted an opportunity to hear other ideas from parents and to be able to interact with others for support.

I reviewed each statement with the group, acknowledging what would be covered, and clarified that there would not be many opportunities for parents to interact with one another for support but reminded everyone that there would be breaks during the day for parents to use as opportunities to get to know one another.

Having this list of statements allowed me to pay particular attention to my presentation and highlight the points raised by parents. It also allowed me to stay focused on making sure that the material that I covered was meaningful and relevant to the parents present.

THE MIDDLE STAGE

SUMMARY

The middle stage consisted of the actual information modules that would be shared with the families (please refer to the presentation transparencies in Appendix B). Module One included information on what family-centered practice is, including the history on how it evolved, its beliefs, and its five principles (partnership and collaboration, strengths-based, empowerment-based, family-friendly, and cultural

responsiveness). Module Two included information on the role of the worker.

Module Three and Four were presented by the parent co-facilitator. Module Three included information on the role of parents. Module Four began with an exercise where parents were asked to break up in pairs and participate in a brainstorming activity. They were asked to create their Bill of Rights. They were asked to create a list of statements that reflected the manner in which they should be treated by service providers. The points were then shared with the larger group, written on flip chart, and then supplemented with additional rights. Each group's Bill of Rights was typed and provided to the parents (see Appendix G). Module Five included information on developing an Individualized Family Support Plan. It contained information on what it is and the process of developing the plan (the assessment planning; their child's assessment; identifying the family's concerns, priorities, and resources; developing the IFSP, the components of the plan; carrying out the plan; and the review of the plan).

Part Two of the Group included presentations from the parent co-facilitator and community guest speakers. Community guest speakers included representatives from Children's Special Services, the Association for Community Living, the Day Care Office, and the Department of Education. I had provided the guest speakers, prior to the session, with the list of questions and concerns parents had shared with me during the pre-group interview. The presentations revolved around transitional planning into the school system, the role of the worker, and advocacy. The orientation guide was then distributed to families and I provided a brief description of its contents.

FINDINGS

During the middle stage, we engaged parents in activities that promoted discussions, allowed parents to ask questions, and provided a safe environment for some parents to share personal stories. For both the full-day and evening sessions, the presentations generated discussion around identifying who is involved with each family, gaining clarity of each worker's role (e.g., distinguishing between a worker who is the family's service coordinator and a worker who provides direct early intervention therapy). Some parents used this opportunity to express concerns around workers (e.g., workers not being responsive to the needs of the family, some workers using inappropriate language and passing judgments on parents). Some parents talked openly about the stress that they are under with a lack of services, not understanding how services operate, and not knowing what supports are available. There was also some sharing of specific techniques around child management, knowledge about resources, and tips on how to handle people who don't understand their children.

Parents who shared their concerns about the stress they were under were encouraged to express their thoughts. Others contributed to the discussion by describing their circumstances. I validated parents' experiences and feelings while keeping the discussions on track. Because I had allocated time periods for each module, I paid attention to the time and indicated to parents, by reframing, that although the discussions were important I was conscious of the time and needed to cover more information. Validation normalized parents' feelings, and I was

conscious that my voice remained calm at all times. This contributed to the overall relaxed and informal atmosphere of the group.

By the end of Part One, parents indicated that they had learned a great deal about what workers should be doing with their families, how services should be delivered, and how parents should be treated. In addition, some of the frustration, anger, and concern expressed by some of the parents had been dealt with and allowed parents to listen to the guest speakers in a more informed manner.

Group process during the middle stage fit with what the literature indicates about focusing on accomplishing the objectives, goals, and tasks established in the beginning of the session. Members were open to sharing their opinions, their stories, and their experiences. A comfortable atmosphere was evident with the depth of sharing that occurred, the laughter that some comments generated, and in some instances tears that personal disclosures evoked.

The panel discussion with the guest speakers generated questions and considerable interest. One parent who needed help in advocating for services was able to get connected with the parent advocate who was a presenter. Another parent who was told that his son would have to wait an additional year for speech therapy had the representative from Children's Special Services take down his telephone number for follow-up. Parents who were wanting information on transitional planning to the school system were able to receive step-by-step instructions on what to do, who needs to be involved, and when planning needs to occur.

As the session came to an end, it was evident that parents moved from a place of ignorance, fear, and confusion to knowledge, insight, and clarity. Parents were

speaking more comfortably, there were more questions asked, and in asking for feedback, parents expressed that they understood what I was teaching them. This transformation was very noticeable and exciting to witness.

These findings were common for both the full-day session as well as the evening session. However, there were some key differences that characterized the middle stage of group development in the evening session. As the second evening was considered part of the middle stage, I had an opportunity to use a check-in exercise to explore how the parents were doing with the information they received the previous night. One parent stated she felt drained but was not sure if it was because it was the end of a long day or if it was because of everything that was shared. She continued by saying that when she went home, she looked for an IFSP and one did not exist. She stated that she now knows this will be one of the first things she will be asking for when she speaks with her worker. All in all, she found the first session helpful. The second parent stated that at the end of the session, she felt very happy and excited about everything she learned. Then she felt anxious because she was not sure what to do next and how to tell her worker that she was not doing her job. I responded to both parents' statements by validating their experiences and clarifying the responsibilities of parents and workers. This dialogue demonstrated to the parents that their views and concerns had been addressed.

The parents' statements were interesting because I was able to benefit from hearing how the parents took some time to think about what they learned, integrate it into their own circumstances, and come back to share their thoughts, ideas, concerns,

and questions. The check-in proved to be a valuable piece in starting off the evening session.

THE ENDING STAGE

SUMMARY

The ending stage consisted of the wrap up, where the session came to a close. A round-robin check-out was conducted. Each parent was given an opportunity to talk about what s/he learned and what s/he will take away that s/he didn't know before. These points were written on flip chart for everyone to view. Next, parents' learning objectives listed on flip chart at the beginning were reviewed, and each point was commented on in terms of how it was covered during the group. Evaluation forms were distributed for each parent to complete and the family pictures were returned.

FINDINGS

The round-robin check-out was a helpful exercise because it provided me with an opportunity to understand what each parent had learned. This was a critical component because it demonstrated the changes that occurred amongst all the parents. Each person learned something new, and that was acknowledged at the end of the session.

In reviewing the original list of goals identified by the parents, I was able to provide a summary of what was discussed throughout the session. This exercise allowed me to link the parents' learning objectives with the statements that they made

about what they learned as a result of the presentations. This exercise helped me stay focused on my objectives as well as the objectives of the group members. It provided an opportunity to ensure that no issue had been left un-addressed. After I reviewed the goals, I asked the group for feedback in terms of whether everything had been covered. This exercise proved to be very useful because it was an appropriate way of bridging the beginning of the session with the end and wrapping up the group.

3. THE EVALUATION PHASE

SUMMARY

Since the parents who participated in the groups are currently involved in the Family Strengths in Childhood Disability Project, no post-session interviews were conducted within the scope of this practicum. Instead, the evaluation phase consisted of comparing the pre-session information I obtained from each parent with the information obtained during the post-session wrap-up discussion (see Table 4). A final evaluative piece consisted of distributing evaluation forms for parents to complete. Each parent was asked to provide feedback on the following areas: what we did well, what we could do better, what should be kept in, what should be left out, and how the presentation was rated overall (poor, fair, satisfactory, good, or excellent).

Table 4

Pre-Session and Post-Group Comparison

Parent	Pre-Session	Post-Session	Theme
Parent One	To get services	I now know that services should be based on needs	Knowledge
Parent Two	To get some ideas about how to deal with others who don't understand	It was like there were broken pieces and it's all come together. It started off as a skeleton, now it's come together.	Awareness and understanding
Parent Three	I feel like I'm in the dark, I don't even know what questions to askMy obligation to help my childto get any kind of information to help me	I now feel like I'm on the right path. I feel a sense of calm. Thank you	Awareness, knowledge, and confidence
Parent Four	To interact with other parents for support	I enjoyed listening to what everyone else had to share – there's a lot to think about	Connection with others
Parent Five	To get as much information as possible	I enjoyed listening to others, I learned that I'm not alone	Knowledge and connection with others
Parent Six	To understand my rights as a consumer	I can talk to someone about the problems I'm having and get some help	Knowledge and skills
Parent Seven	To make sense of how services work—who does what	I learned to not be afraid to ask, to be a little more assertive	Confidence
Parent Eight	To get new information, some support in accessing services	I learned I do not have to be afraid to address the process or issues that come up	Confidence

FINDINGS

PRE-SESSION AND POST-GROUP COMPARISON

Based on the data collected during the pre-session interview and the post-group statements made by the parents, there seems to be compelling evidence to suggest that parents learned something from the education groups. The comparison between the pre-session interviews and the post-group discussions highlighted some of the changes that occurred amongst the parents. This information provided me with valuable insight in terms of how the intervention affected each parent.

The pre-session and the post-group statements were combined for each parent and several themes emerged as a result of comparing the two statements. Some of these include increased knowledge, awareness, and understanding. Other findings include the connection parents made with others in terms of sharing similar experiences and discussing similar issues. Yet other findings include the increased level of confidence expressed by some parents. These parents talked about not feeling afraid to participate in the process with respect to the planning issues, or dealing with professionals in terms of their role and responsibilities. To honour the parents' experiences, the following is a list of actual statements made followed by an analysis.

(1) "I now know that services should be based on needs"

This parent came to the session not knowing the process involved in accessing supports or services. This parent expressed the fear that if she "rocks the boat", she will get nothing. She came away from this session knowing that the services she requires are based on her needs as a family, not on what is available. She learned that

services should be responsive to her family's needs. She also became aware, however, that access to services is based on her child meeting the eligibility criteria, as well as availability of resources. This parent appreciated the honesty and reality of the current climate of services. Her response demonstrates increased knowledge and awareness.

(2) "It was like there were broken pieces and it's all come together. It started off as a skeleton, now it's come together".

This parent made sense of what was a very confusing and overwhelming system for her. Now she knows who to turn to when she needs assistance and how the various systems work. She stated that awareness and "coming together" of the pieces made her feel more secure and certain about her future responses to issues that might arise for her child and family. She added that she felt more confident and had more knowledge about what she needs from service providers, who she is as a parent and consumer, and how services should be delivered.

(3) "I now feel like I'm on the right path. I feel a sense of calm. Thank you".

This was the parent who said, "I feel like I'm completely in the dark. I don't even know what questions to ask. All I know is that I want to be the best mom I can be". She stated that things were now making more sense to her. She added that there was a direction and it feels okay now that she knows. This statement demonstrates a move from confusion and uncertainty to clarity and purpose. This parent now has the information that she needs to be able to understand the system and to be able to access the supports she requires for her family.

(4) "I enjoyed listening to what everyone else had to share – there's a lot to think about."

This parent appreciated the sense of connection she felt with other parents. She valued listening to others' stories, shared some of her own stories, and gained a deeper appreciation for being able to interact with other parents who are facing similar issues. She also mentioned that there was a lot to think about in terms of what had been taught and what she had learned during this session. She stated that she appreciated the guide and was certain that she would find it useful when she has the time to read it. This demonstrates the importance of networking with others so as not to feel alone.

(5) "I enjoyed listening to others, I learned that I'm not alone...I enjoyed connecting with other parents who have similar issues as me"

This parent expressed her appreciation for having the opportunity to interact with other parents, to listen to their stories, to share her own stories, and to realize that in the company of other families, she is not alone in her concerns, her questions, her dreams, and her hopes. This experience was validating for her in that it allowed her to feel safe in sharing with others.

(6) "I can talk to someone about the problems I'm having and get some help."

This parent was able to get some specific support and suggestions regarding a situation with which she was currently dealing. As well, community links to help her with the troubles she faced with the staff and supervisor of an organization was provided to her that day, when she took down some telephone numbers and actually

had a chance to speak with a parent advocate who was more than happy to assist her with her current difficulties.

(7) "I learned I do not have to be afraid to address the process or issues that come up"

This parent expressed feeling the confidence to get on with her life and the life of her family knowing that she is more aware and more knowledgeable. The knowledge that she obtained took away the overwhelming fear and concern she had about her daughter's and family's future with respect to accessing services. This demonstrates the transformation from fear and uncertainty to power and confidence.

(8) "I learned to not be afraid to ask, to be a little more assertive"

This parent also expressed a sense of personal empowerment by feeling less afraid and being more assertive as a parent and consumer of support services. She stated that now she knows how things work and has a guide to help her along the way. This too demonstrates the change from not being clear about how the system operates or the process of accessing services to being able to feel confident enough to ask questions and be clear about the decision-making power she assumes as a parent.

EVALUATION FORMS

The information on the evaluation forms proved to be very useful. It was encouraging to receive positive feedback; it validated my efforts. It was also encouraging to be told that I presented the information clearly, and that the material was well organized and planned. The feedback I received confirmed that I expressed myself clearly and I demonstrated effective group facilitation skills. The feedback I received was personally and professionally empowering for me.

The evaluations also provided me with insight in terms of what specifically was valuable and what was less useful for parents. This was beneficial because it allowed me to gain some understanding about how the format may be changed or modified in order to improve future parent education groups. Of particular interest to me was the comment that if evening groups are going to be offered again, the sessions should be spread one week apart so that the information learned could be integrated. This was useful information to know and should be a consideration for the future. All the evaluation categories and the parents' responses are presented in Table 5.

Table 5

Evaluations

What we did well:

Presentations, information
Inspire hope
Organized process; that it was presented in order; guest speakers, encouraging feedback
Everything
I enjoyed (parent's) talk. Was heart-warming and to the heart
Family-centered programs, services, guest speakers
Explaining the services, the family-centered plan in a very clear way
Addressing the emotional aspect of relating to all of the systems

What we could do better:

Parent One	Nothing
Parent Two	Stick to the information on the overhead
	when presenting (parent)
Parent Three	Blank
Parent Four	A parent directory
Parent Five	Allow more time for questions and
D	answers. Maybe add an extra ½ hour or so
Parent Six	Blank
Parent Seven	Allowing more interaction with the
	speakers, more specifics about certain
	education topics
Parent Eight	If you choose to do evening groups again,
	please space them one week apart

Keep it in:

Everything Lunch and refreshments
Blank
Everything
I think everything was most interesting
All of the content; guest speakers Blank
All of the information and speakers

Leave it out:

Parent One	Nothing
Parent Two	Nothing
Parent Three	Blank
Parent Four	Nothing
Parent Five	Blank
Parent Six	None
Parent Seven	Blank
Parent Eight	Nothing

Overall rating:

Parent One	Excellent
Parent Two	Excellent
Parent Three	
	Excellent - thank you Dona. I will treasure
Parent Four	and use my manual to its fullest
Parent Five	Excellent
	Good
Parent Six	Good
Parent Seven	Blank
Parent Eight	Excellent – thanks for the opportunity

CHAPTER FOUR:

DISCUSSION

Several themes emerged from the analysis of the practicum: promoting family involvement; awareness and increased knowledge, a shift in thinking, parental beliefs and rights, and a decrease in fear and isolation; promoting community partnerships, and interagency collaboration. These themes will be discussed at greater length in this chapter. Particular attention will be made in comparing these findings with what exists in the literature. This discussion will provide a context for addressing recommendations, which will be addressed later in this section. Since the parent sample is small and as my analysis is contained within the parameters of a practicum, this discussion is only limited to the parents who participated in this practicum and cannot be generalized to any other parent or parent education group.

PARENT EDUCATION AS THE KEY TO PROMOTING FAMILY INVOLVEMENT

Seven families of children with special needs were taught that family-centered practice is an approach based on a set of principles, values, and beliefs that clearly identify the role of their family unit as the critical foundation of their child's life (McGonigel et al., 1991). They learned this is a belief that asserts that the best way to meet the needs of their child with special needs is within the context and the consideration of the entire family, emphasizing the centrality of family involvement and full participation (Bailey, 1987; Dunst et al., 1991; Rosenbaum et al., 1998). These parents were exposed to an approach that marks a dramatic shift in thinking—from child-centered approach to a total systems approach that focuses on family

strengths, empowerment, and partnership (Bailey, 1987; Dunst et al., 1991; McCallion & Toseland, 1993).

The parent education group was based on a family-centered model and, as Mahoney and Filer (1996) suggested, this intervention provided parents with information that will help them be better prepared to access the services they require for their family. This intervention encourages and promotes family involvement by specifying the role of family members in all levels of accessing supports and services. This is consistent with what Moxley et al. (1989) state with regards to the role of family members in family-centered practice.

The parent education groups provided parents with an opportunity to understand the full spectrum of family involvement. According to their feedback, they understand they have the choice with respect to how involved they would like to be. This is encouraged and supported by Moxley et al. (1989) who state that family involvement can occur at multiple levels of the system, ranging from where the individual family is, and extending to general society or even to policy levels. These authors report that levels of family involvement include family-focused, program-focused, community-focused, and policy-focused.

Several parents stated that they are now in a better position to become more actively involved in the planning issues related to their child and family. The literature substantiates the finding that parents who are given information become more actively involved in working collaboratively with professionals in developing plans, advocating on behalf of their child, evaluating the care provided, and educating service providers about their child and family's needs (Dunst et al., 1988 & 1994;

Farel et al., 1997; Judge, 1997; Moxley et al., 1989; Shelton, Jeppson, & Johnson, 1987; Williams, 1995; Zipper et al., 1993).

Several families talked about how they now feel more confident to deal with some of the issues related to the programs that their son or daughter may be involved with and that they are no longer afraid to deal with the process. Moxley et al. (1989) refer to this level of involvement as program-focused and may include parent participation in advisory activities, agencies, and/or governance.

Community-focused involvement is the third level of involvement. At this level, Moxley et al. (1989) state that family members may work to promote community understanding of special needs, to encourage generic community agencies to make their services accessible, and to monitor and evaluate the accessibility and appropriateness of generic service.

In the final level of family involvement, policy-focused, family members seek to influence social policy in the field of disabilities. Legislators and other government officials may give more legitimacy to family members' identification of the needs of children with special needs than they do to professionals. Although the parents did not report an interest in getting involved in either the community-focused or policy-focused level of empowerment, it is worth identifying these levels as a possible future undertaking. For example, several parents discussed how frustrating it is to be told that they must wait for services for their child. In response, parents were told that the lack of resources stems from a lack of government funding. When asked what parents could do to affect change, I encouraged them to speak with their MLA or get involved in lobbying groups run by parents and organizations. Thus, parents

know their involvement can extend beyond their family and the programs they are currently receiving.

Based on parents' statements, parent education seems most effective for promoting family-focused and program-focused involvement. Although community and policy-focused involvement were not identified by any of the parents, it does not mean that those parents who have increased confidence, knowledge, and awareness cannot, in the future, affect change in their community or government. In fact, it would seem reasonable to suggest that parents who have a better understanding of service delivery could move towards making the community in which they live more responsive to their needs and/or encourage policy changes to reflect the growing demands of the services they may require.

A MOVE TOWARDS PERSONAL EMPOWERMENT

There is no question, based on the outcome of the parent education groups, that the parents were provided with an opportunity to learn more information, develop knowledge, and gain skills in areas they virtually knew very little or nothing about. The shift from feeling overwhelmed, confused, and uncertain to being able to say, "I feel like there is a direction" was evident with all of the parents. Having said this, the transformation that was witnessed begs the question of whether there is compelling evidence to substantiate what the literature says about the impact of parent education and parental empowerment. Empowerment, in this context, speaks to the issue of understanding, becoming more aware, and feeling more in control over the decisions that need to be made about accessing supports and services (Mahoney & Filer, 1996;

Thompson et al., 1997). Answering the question of whether the parent education group contributed to greater empowerment necessitates looking at four factors: awareness and increased knowledge, a shift in thinking, parental beliefs and rights, and a decrease in fear and isolation.

AWARENESS AND INCREASED KNOWLEDGE

A practicum finding that emerged repeatedly is that parents increased their awareness and knowledge. Parents now understand the extent to which they can and should be involved in seeking and accessing services. One parent stated that now she understands services are based on family needs and not on what services are available. This demonstrates the almost immediate adoption of the values and beliefs of family-centered practice.

Baxter (1986) emphasized that parents report the most important type of help they received from professionals, over sympathy and emotional support, was information. This was clearly the case for the parents who decided to participate in the group. Each parent came to the session wanting some type of information, whether it was information about getting services, getting some ideas about how to deal with others, getting information about how the system works, understanding rights, or getting information and support from other parents. Since this practicum provided parents with information about what family-centered practice is, what the role of their worker is, what their rights are as parents, what an Individualized Family Support Plan is, and what supports and services exist, there was enough evidence to suggest that these parents' awareness and knowledge increased as a result of this intervention. This statement is consistent with the findings of the following

researchers: Darling and Baxter (1996), Gowen et al. (1983), Hornby (1994), Greene (1999), Mahoney and Filer (1996), and Summers et al. (1990).

A SHIFT IN THINKING

A shift in parents' thinking was highlighted post-group as most parents indicated that they have rights, that they have equal powers in the decision-making process, and that their family's needs are what dictate which services and supports best fit their family. This is consistent with Campbell, Strickland, and La Form's (1992) findings that parents who attended informational workshops felt more confident and were found to be more active in the goal-setting process. Hornby and Murray (1983) also found that parents of children with special needs who attended parent education groups reported that they experienced more confidence in their ability to parent their children, felt more knowledgeable about themselves, and other resources. Since the concept of empowerment implies a process whereby individuals gain control over their own lives (Singh & Curtis, 1995), a shift in thinking demonstrates a move towards parental empowerment.

PARENTAL BELIEFS AND RIGHTS

Another striking theme is the change of attitude and beliefs that resulted for these parents. They began the process with little or no sense of parental rights. In fact, some parents had fear around asking for too much and losing services, or felt dependent on what service providers offered without understanding their role as consumers of services. These feelings corroborate what the literature says about

shifting the thinking for parents around the relationship between service providers and themselves (Zipper et al., 1993).

All the parents participated in creating a Bill of Rights. Some of these rights included the right to have information and access to training, the right to be treated with respect, and the right to make decisions for their children. These rights reflected what the literature says about parents' desire for respect for their capacity to make informed decisions, the right to be involved in the planning, implementation, and evaluation of services, and the right to accept or decline service that best fit their family circumstances (Hodges, 2000; Joanning et al., 1994).

A DECREASE IN FEAR AND ISOLATION

Several parents stated that, as a result of the training, they felt less afraid to deal with accessing supports and services. Some parents felt confident that they could now carry on with a sense of clarity and purpose. The knowledge they obtained helped them feel assertive enough to approach others from a position of power. In addition, most parents stated that hearing others' stories made them feel like they are no longer alone. The connection with other parents provided them with encouragement and support.

Seligman (1993) reported that although there is very little empirical research on the effectiveness of parent education groups specifically, the available findings suggest that parents feel less isolated, more confident, and that these groups offer strength and support to members. Many of the parents in this practicum indicated they enjoyed the opportunity to be with other parents and expressed feeling as though

they are not alone in their journey. This finding mirrors what the literature says about parental involvement in a group context and the ability to interact, share, and listen with others. More importantly, this finding is supported by Seligman (1993) who found that parent education groups have been linked to decreasing parental isolation, increasing coping skills, and a decrease of stress. In addition, Hornby and Murray (1983) found that parents appreciated the sharing and identification with other parents.

Parents who stated that feelings of fear and isolation decreased as a result of receiving information and gaining knowledge also indicated that they felt more confident and assertive enough to become more involved in planning for their family. Given this link, there is enough compelling evidence to suggest that these factors contribute to the parents feeling more empowered.

PROMOTING COMMUNITY PARTNERSHIPS AND INTERAGENCY COLLABORATION

The values inherent in parent education fostered community networking. Promoting community partnerships in an attempt to provide parents with a more holistic understanding of how the systems operate and are linked with one another proved to be very successful. For example, having representatives from daycare, education, and family services together in one room provided parents with an opportunity to learn about the functions, roles, and responsibilities of each service system, what parents should expect from each worker in that department, and the timelines inherent in transitional planning to school for their children. It also provided parents with the opportunity to ask specific questions related to their

individual circumstances. Interagency collaboration worked very well in this setting, and parents indicated they benefited from the presentations. Walter and Petr (2000) state that interagency collaboration is a key strategy in efforts to turn fragmented human services into a system that addresses the multiple needs of children and families in a more comprehensive and efficient way. They state that shared visions and values are crucial to successful collaborative efforts. These authors suggest that without anchoring goals, objectives, and all other dimensions of the collaborative process in a shared value base, interagency collaboration is futile.

Adopting family-centered values as the core value system for interagency collaboration consistently reinforces each agency's responsibility to focus on the family (rather than the child) as the unit of service, maximize families' choices and abilities for informed decision making, apply a strengths perspective rather than a pathology focus, and ensure culturally sensitive services. Parent education, as an empowerment practice, will further this effort, making agencies responsive to needs of those families who have been educated and will accelerate the movement of family-centered practice in Manitoba.

<u>A FAMILY-CENTERED APPROACH TO PRACTICE WITH FAMILIES</u> <u>WHO HAVE CHILDREN WITH SPECIAL NEEDS</u>

The first educational objective that I identified was to gain more experience in utilizing a family-centered approach to practice with families who have children with special needs. All the parents talked about the effect their son or daughter with special needs has on the entire family. This is consistent with family-centered practice literature, which argues that children should not be viewed in isolation from their

family. Rather, a child with special needs has an effect on each of the other family members which has a direct impact on the family unit (Lynch & Morley, 1995). Furthermore, the systems that impact the family unit must not be viewed in isolation. Instead, families of children with special needs must be viewed in the context of all of the systems that impact and influence the entire family.

Kaplan and Girard (1994) maintain that ecological theory moves the focus from the child to the family and the family's interaction with the broader community. An ecological view of the family includes the microsystem (the interpersonal relationships within the family), the mesosystem (the range of settings that the family participates in such as extended family, health care professionals, friends/neighbours, work, and the local community), the exosystem (those settings which the family participates in such as welfare, healthcare, and education), and the macrosystem (the political, economic, social ideologies that influence a family). Parent education in the area of family-centered practice embraces the concept of a total systems approach to meeting families' needs.

Parent education impacts all of the systems that a family is influenced by in a manner that promotes a shift in thinking and in practice. As the purpose of parent education is to provide parents with information that will help them understand how they are to be viewed, what their rights are, and what the nature of the helping relationship between service providers and family members should be, parents who receive such education should be better equipped to define themselves as equal and active partners in the process. Whether parent education occurs in a group, through being provided with written material, or a combination of the two, it will ultimately

impact all of the systems that a family is directly or indirectly involved with.

Increased knowledge and parental involvement within a family unit will influence the relationships with other service providers, other systems, and ultimately other programs. Parent education, therefore, should accelerate the movement to family-centered practice in service delivery across all levels and all types of systems.

The concept of utilizing an ecological approach was maintained throughout the parent education groups and was one of the leading principles that is reflected in the orientation guide. Parents were provided with information about the roles and responsibilities of service providers including social workers, day care staff, school staff, and staff from community-based organizations. The orientation guide provided links to families' needs including early intervention services, in-home supports, and transitional planning to adult services. This approach allowed parents to understand that their family does not and need not operate in isolation.

FACILITATING PARENT EDUCATION GROUPS

As I have had no experience facilitating groups prior to my practicum, I relied quite heavily on what the literature indicated about the essential characteristics of parent education groups. Firstly, Toseland and Rivas (2001) were correct in stating that the primary purpose of all educational groups is aimed at "increasing members' information or skills" (p. 25). I learned about the importance of providing information in the educational groups. This was confirmed by the responses each parent made in terms of the usefulness of the group.

As a structured group, the parent education model is based on the assumption that problems emerge from deficiencies in skills and information. The parent education groups that I conducted corroborated what Seligman and Darling (1997) stated which is that education groups are primarily focused on providing families with information and serve to inform families about their rights and benefits, and where and how to obtain needed services. In addition, Seligman (1993) stated that the parent education model assumes that family members can cope adaptively when they are provided with accurate and relevant information. This was clearly demonstrated by some of the feedback I received from parents.

Parent education groups, however, must be viewed as one component of parent education. Issues such as time commitment, life stressors, and obligations to work and family limit the number of parents who are able to attend a workshop.

Although it appears that committing to a full day workshop was more successful than two evening sessions, as it relates to the number of families who attended, one cannot ignore the reality that out of potentially 29 families, only seven were able to participate. It would seem reasonable to suggest that for many parents, attending an informational group is not possible given their life circumstance and time constraints. This finding begs the question of whether alternate forms of parent education could reach families who simply cannot or do not want to attend informational workshops. Access to written material and one-on-one orientation sessions between social workers and families must operate in conjunction with parent education groups. These approaches will reach those families who would still benefit from obtaining information.

GROUP PROCESS/GROUP STAGE DEVELOPMENT

It was evident that both the single session group and the successive two evening sessions mirrored what Shulman (1984) suggested about the evidence of a beginning, middle, and end stage of group development. Corey and Corey's (1987) description of the characteristics that make up each stage was corroborated in this practicum. Getting acquainted, clarifying the purpose of the group, establishing group cohesion, and learning how the group functions were characterized in the beginning stage. Accomplishing the objectives, goals, and tasks developed, practicing new skills, listening to new ideas, and providing feedback to one another characterized the middle stage of group development (Toseland & Rivas, 2001). Achieving the objectives of the group, giving members an opportunity to talk about what they had learned regarding the information and skills acquired, characterized the ending stage of group development. These stages were evident in both the single session and the evening sessions.

I have learned that parent education groups, although informational in nature, have some of the same characteristics as multiple-session groups. Although condensed, group process, group dynamics, and group stage development were characteristics that were evident in these groups. This confirms the importance of being knowledgeable about group facilitation and being aware of some of the issues that might come up for members. Since I prepared myself in this area, I was able to be aware of group process and was, therefore, better prepared to facilitate the group.

ADULT LEARNING PRINCIPLES

Some of the training strategies such as the use of concrete study materials (both written and visual), discussion, demonstration, and small group activities (such as brainstorming) are suggested by adult learning principles and were useful in facilitating the parent education groups. Reflection exercises, or having each member write about what the term "family-centered" means, brainstorming exercises used to help parents create a Bill of Rights, and panel discussions with guest speakers were specific techniques used in both groups to encourage parents' participation and facilitate learning. Overhead transparencies, handouts, and demonstrations were some of the tools I used to deliver the concrete information.

All of the activities proved to be effective because every parent participated in each exercise. Discussions resulting from each exercise demonstrated that parents seemed interested in what was being covered, and the level of enthusiasm to engage in all the activities was observed to be high. No one complained about having to do an exercise and each activity was completed by every parent.

In part, the success of this group stemmed from incorporating a variety of learning techniques. I believe that if I had chosen to present information using only a lecture-based format, parents' learning would have been less dynamic and the information shared would have been quite dry. In addition, a lecture-based format would have prevented parents from engaging actively in their learning. As this was the primary objective I wanted to achieve, I chose to incorporate activities that the literature suggested. The importance of learning what strategies promote adult learning was essential.

THE IMPACT OF PROFESSIONAL/PARENT CO-FACILITATION

Evident in the parent education groups I ran was the benefit of having a parent co-facilitate with me. Co-leadership or co-facilitation proved to be beneficial in the context of these parent education groups for several reasons. As Toseland and Rivas (2001) suggest, there is an increased level of support for both facilitators, there are several opportunities to receive and give feedback to one another, there are alternative frames of references to provide to the parents, and there is a sharing of the power that group facilitation assumes. Both the co-facilitator and I shared responsibilities in leading modules and we were able to support one another by providing additional points that were not covered. In addition, having the co-facilitator speak allowed me some time to gather my thoughts and prepare for my presentation. It also allowed me opportunities to gauge the group, make observations, and participate in the discussion.

Another significant finding was what co-facilitation with a parent modeled to the parents of the groups. Parent-professional partnership balanced the power that I, as a social worker, inherently possess. Having a parent facilitate the group with me demonstrated the sharing of knowledge and experience with a willingness to work co-operatively in a respectful manner. The parent co-facilitator was able to connect with the other parents in a way that I, as a social worker, would never be capable of because of the professional role. This parent was able to reach out to all the parents in a way that allowed the parents to relate with one another. Also, because this parent has an adult child with a disability, she was able to share some of her experiences, insights, and knowledge in a meaningful way. The impact of professional-parent co-

facilitation was significant and proved to be a very powerful message of partnership—one of the core principles of family-centered practice.

RECOMMENDATIONS

This practicum suggests that there are exciting possibilities for future work in the area of parent education. These endeavours include: (1) facilitating parent education groups; (2) a follow-up to the practicum; (3) evaluating the effectiveness of parent education groups; and (4) studying the effects of parent education in the area of family-centered practice. Each category will contain several recommendations for practitioners.

(1) FACILITATING PARENT EDUCATION GROUPS

Based on my experience in facilitating two groups, I have identified several practice recommendations for those practitioners interested in facilitating future parent education groups. These have been organized as follows: background knowledge for the facilitator, pre-group planning, and group work.

Background Knowledge For The Facilitator

Prior to facilitating parent education groups, it is strongly recommended that practitioners have a solid working knowledge in the area of family-centered practice, parent education, adult learning principles, and group facilitation. This knowledge base is critical because it not only provides a firm foundation for developing a training curriculum, but it guides the manner in which practitioners view and work

with parents, the manner in which practitioners respond to issues as they arise during the group, and how group process is interpreted.

Pre-Group Planning

It is recommended that practitioners consider pre-group planning as a critical component to effectively and successfully facilitating parent education groups. This includes careful consideration of the following key issues: (a) setting for the groups, (b) structure of the groups, (c) size of the groups, (d) timing of the groups, (e) essential training content, (f) who should facilitate the groups, (g) recruiting members, and (h) pre-group contact.

(a) Setting For The Groups

Parent education groups may be facilitated at government and/or community-based organizations. It may be provided by the Department of Family Services and Housing's Children's Special Services Department as an orientation to new parents and/or it may be provided by community-based organizations. It may be advantageous to consider providing orientation sessions to families who meet the criteria of Children's Special Services when they enter the system. Community-based organizations can only provide parent education groups for those families seeking support at that particular organization.

A key consideration regarding where these groups should be held is based on ensuring that parents are provided with an environment that not only welcomes them, but is accessible to them. The site should be centrally located, have adequate parking,

and be wheelchair accessible. The room should accommodate the equipment that is needed to facilitate the session, be large enough to accommodate the parents, have comfortable seating, and adequate lighting.

Although budget implications for securing a location in my practicum were not a factor, it is an important consideration when deciding where to hold the parent education groups. As many organizations may offer space at their agency free of charge, it is recommended that practitioners explore the most cost-effective options.

(b) Structure Of The Groups

Parent education groups may be provided as a stand-alone orientation workshop or they may be incorporated into parent support groups already in existence. They may also be incorporated into parent advocacy workshops or any family advocacy organization. These sessions may be conducted as a full-day workshop or as two evening sessions, depending on the time commitments of parents. Although my practicum findings indicated that full day sessions were more successful in terms of attendance and popularity than the evening sessions, I would suggest that both options still be made available for parents. Both options need to be considered in order to accommodate the availability of as many parents as possible.

(c) Size Of The Groups

The parent education groups that I co-facilitated involved actively engaging parents in their own learning. By providing parents with opportunities to participate in group discussions and interact in small group activities, the size of the group is an

important consideration. It is recommended that a maximum of six to eight families, which could potentially involve a maximum of 12-16 parents, participate in each group. A larger group size would restrict parent participation and would inevitably change the delivery of the information to a more dry and lecture-based format.

(d) Timing Of The Groups

It is recommended that if sessions are to be made available to parents who have entered into the social services system, then they could be offered on a monthly basis. Since some parents may require time to cope with their child's diagnosis and make necessary adjustments in their family's lives, parents could decide when it would be best to attend.

(e) Essential Training Content

It is strongly recommended that the material to be covered during the sessions include the principles of family-centered practice, the role of the social worker, the rights of parents, and the development of the IFSP. This information should be provided in language that is plain and parent-friendly. Secondly, an orientation to supports and services should be incorporated in the curriculum. This will help parents understand the process involved in accessing services and provide them with an opportunity to ask specific questions. Finally, it is imperative that representatives from day care, education, social services, and community advocacy groups be invited to present concrete information about services that parents may already be involved with or will soon encounter. Inviting representatives from various systems reflects

the principle of interagency collaboration and has proven to be an essential component to educating families.

(f) Who Should Facilitate The Groups

It is strongly recommended that only those practitioners who have experience in working with families who have children with special needs, have a solid background on family-centered practice, and have experience in group facilitation should facilitate these groups. It is also recommended that practitioners facilitate these groups with a parent of a child with special needs. Parent co-facilitators are able to share some of their experiences, insights, and knowledge in a way that practitioners simply cannot. In addition, professional-parent co-facilitation conveys a powerful message of partnership, which punctuates the core value of family-centered practice.

(g) Recruiting Families

Recruiting families may be accomplished by sending letters to existing clients, posting notices at community agencies, or advertising in community newsletters.

Regardless of the method chosen, it is recommended that the following information be contained in the initial invitation: who will be facilitating the group; a description of the group; when, where, and what time the group will be held; an invitation for both parents; what parents could bring (i.e., a family picture); the voluntary nature of the group; whether child care will be made available; whether meals will be provided;

whether there is a cost to attend; and a contact name with a telephone number for registration and/or additional information.

(h) Pre-Group Contact

If possible, whether it is at the time of registration or whether a pre-group visit could be arranged, it is strongly recommended that practitioners obtain key information from parents in order to gain an understanding of what their current level of knowledge is and what issues/concerns they might want addressed. It is also recommended that a letter of confirmation be sent to the families who have agreed to participate.

Group Work

It is strongly recommended that practitioners have an understanding of group process. Understanding the characteristics of groups stage development will assist practitioners in creating a climate of group cohesion and will aid in responding to issues that may arise.

It is important to provide parents with an opening comment of who the facilitators are, the purpose of the group, an ice-breaker introduction of each member, a discussion of the goals of the training, and establish the rules. These fundamental activities characterize the beginning stage of group development. Two exercises are worth highlighting. Beginning the session with the provision of a poster board for family pictures is highly recommended. This useful tool helps engage parents in discussions about their family life and it makes the group experience more

meaningful and realistic. Secondly, the individual reflection on what family-centered practice means to each individual proves to be a very useful exercise. This allows parents to tune in to family-centered thinking and helps them engage in a personal reflection on their own thoughts.

It is important to fully understand the principles of adult learning strategies and to utilize successful learning tools such as small group exercises, brainstorming, and individual reflection exercises. The use of flip chart, transparencies, and handouts should be considered as the best methods of presenting information. These methods will enhance parents' learning and promote participation during the middle stage of group development.

It is strongly recommended that practitioners have some method of evaluating parents' learning. Asking for parents' feedback regarding their learning is one of the most reliable and effective ways of accomplishing this. Finally, it is important to have some type of evaluation form for parents to complete. This will provide practitioners with important information in terms of the effectiveness and usefulness of the group experience. Key areas for parents' feedback should include what was done well, what could be done better, what aspects of the session should remain, what should be left out, an overall rating of the group, and space for additional comments. Feedback on these areas will assist practitioners in improving future parent education groups.

To conclude, it is critical that practitioners reflect on their own assumptions, perspectives, attitudes, values, and leadership styles. This will assist practitioners in

recognizing their personal biases and developing their own value-based approach to group facilitation.

(2) A FOLLOW-UP TO THE PRACTICUM

As a follow-up to this practicum, there are several recommendations specific to the parents who participated in the groups, the orientation guide, and the training manual.

The Parents Who Participated In The Groups

Given seven families have participated in this practicum, it would seem reasonable to consider several follow-up recommendations. Firstly, it is my understanding that the FSCD project will be conducting follow-up interviews with these families. It would be interesting to explore how the group experience has impacted their lives in terms of what they've learned, whether they've made any changes with respect to the approach they take with service providers, and how this knowledge has made them feel about themselves and their family, their community, other parents, and their service providers.

Secondly, it would be useful to determine how these parents are using the orientation guides. Whether this is accomplished by forming a focus group with these parents or individual interviews, it would be very interesting to ask the following questions: Did they find the guide useful? Is there any particular part of the guide that they focused on the most? Did the guide give them a basic knowledge about how to access supports and services? Do they have any suggestions on how to improve the guide?

Thirdly, it may be beneficial to provide the parents who were unable to attend the parent education groups with a copy of the orientation guide. Some of the parents who were not able to attend the parent education groups asked whether they would be able to have a copy of the guide book that I had developed. Under a regular practicum, I would have distributed copies of this guide for the parents who asked. However, in an effort to not complicate or confound the project's research, I was restricted from distributing the guide to the remainder of the parents during my practicum. It is my understanding that at the completion of the project, parents who requested the guide will be able to receive a copy.

Finally, it would be interesting to explore whether any parent who participated in the groups would be interested or willing to participate in any future parent education groups as the co-facilitator.

The Orientation Guide

With regards to the orientation guide, it is recommended that (1) the orientation guide be made available and accessible to parents at every level of their involvement with the social services system, beginning with the Child Development Clinic as well as Children's Special Services and the Society for Manitobans with Disabilities; and (2) the distribution and usefulness of the guides be tracked by the author with the organizations who would agree to distribute them to parents.

The Training Manual

It is recommended that the training manual be made available to anyone who might be interested in facilitating future parent education groups.

(3) EVALUATING THE EFFECTIVENESS OF PARENT EDUCATION GROUPS

For those practitioners interested in clinically evaluating the effectiveness of conducting parent education groups, there are several ways that group effectiveness can be assessed. Certainly, one may design a basic pre-test/post-group evaluation similar to the one used during my practicum; however, there are other possibilities to consider.

Although the interview questions for my practicum were limited in an effort not to overwhelm the parents who were already participating in the FSCD project, a family empowerment scale could be used to gather information about parents' knowledge, attitudes, and beliefs. The answers to the questions would give a more comprehensive idea of what level parents are at in terms of their empowerment. This questionnaire could be used again at the end of the intervention and used as a comparative tool.

A pre-test questionnaire could be developed and employed to represent a base line measure of where parents were at before the group began. The same questionnaire could be used again in the post-test in an effort to measure any changes or progress with respect to what the parents had learned at the end of the session. The tests could be designed in a manner that reflects the parents' learning objectives. Finally, a follow-up interview several months after the group ends could be conducted to gain an understanding of the meaning each parent ascribed to what s/he learned. A follow-up interview would be very interesting to administer as it would allow practitioners to gain some insight into how parents' knowledge of family-

centered practice has impacted their lives, how they view their role within the interaction of various professionals, and how this acquired information has been integrated in their daily lives.

(4) STUDYING THE EFFECTS OF PARENT EDUCATION IN THE AREA OF FAMILY-CENTERED PRACTICE

Broadening our understanding of parent education interventions that foster family empowerment is of great significance. Practice, programs, and public policies must reflect the growing demand for family empowerment practices. Future research in the area of parent education would provide evidence of empowerment intervention in terms of feasibility, efficiency, and efficacy for families of children with special needs. Researchers may want to investigate the impact of parent education on any of the following areas:

- (1) Studying the levels of family empowerment operationally defined as: the degree to which parents gain positive control of their lives; the quality of the professional/parent relationship; the intensity of professional involvement in the lives of parents; and/or the degree of involvement parents have with policy/program reform;
- (2) Studying the exposure of parent education: comparing the effects of combining parent education groups with the distribution of the orientation guide to those parents exposed to only the orientation guide against a control group of parents who receive no education; and
- (3) Tracking the dissemination of the orientation guide to organizations and key stakeholders.

CONCLUSION

My overall practicum objective was to advance my practice skills in parent education in the area of family centered practice with families of children with special needs. I believe this practicum has provided me with the opportunity to achieve this objective by allowing me to accomplish the following educational goals:

1. To advance my skills in utilizing a family-centered approach to practice with families who have children with special needs.

This practicum has allowed me the opportunity to gain a solid understanding of family-centered practice. The literature review that I conducted exposed me to the vast amount of research studies that have been conducted over the last 20 years. This knowledge provided me with the confidence to create a curriculum based on my own research, and it allowed me to present the information with ease. I was prepared to answer any question that was asked with confidence. What made this process quite easy was the fact that I believe in the principles that guide family-centered practice. As a result, it was effortless to embrace the concepts. It has definitely provided me with a solid basis to develop the skills and techniques that were necessary to carry out this practicum.

2. To develop skills in facilitating parent education groups

Although I have been a practicing social worker for over seven years, I have never facilitated any groups. When I first decided to pursue this practicum, I had some reservations in terms of whether or not I would be able to facilitate this type of group. The only experiences I could draw upon was my work as a social worker facilitating family conferences, attendance at courses in group process, and my own

approach to developing a training curriculum that had as many detailed steps as possible. I really needed a clear guide to help me through the process. Thus, I used other training manuals and perused other modules and incorporated some of those approaches to create my own approach.

As I facilitated the first group, I was very happy to know that the session was a success. I felt confident in my abilities, I was responsive to the needs of all the parents through my observations, and I paid particular attention to group process. By the time I facilitated the second group, I felt more prepared and was able to facilitate the group with greater ease and certainty. The feedback I received from the parents validated the accomplishments I believe I achieved.

3. To develop skills in creating an orientation guide for parents and a training manual for practitioners $\frac{1}{2}$

This practicum provided me with an opportunity to improve an orientation guide that I had developed one year ago in British Columbia's Community Living Services Department of the Ministry of Children and Family Development.

Advanced knowledge in the area of family-centered practice allowed me to modify the guide so that the format would reflect a family-needs approach to accessing supports and services. The evolution of this guide has provided me with opportunities to further expand this guide and make it available for families in the city of Winnipeg. Future initiatives with respect to the distribution of this guide to other cities are currently being considered.

This practicum also provided me with an opportunity to learn how to develop a training manual. Incorporating particular sections of my literature review in the

area of family-centered practice, group process, and adult learning principles allowed me to develop an outline for my presentations. This material was then transferred into the training manual. Having facilitated the parent education groups provided me with knowledge about group facilitation, which was then incorporated into the manual.

4. To understand, from the parents' perspective, how parent education can be a useful intervention

Although the focus of the practicum was not on evaluating the effectiveness of this type of group, I did take steps towards evaluating my practice. The pre-session interview allowed me to gain some sense in terms of where parents were at in their knowledge and awareness of some of the issues that I would be discussing. At the beginning of the session, I was able to establish learning goals by getting a sense of what brought parents to this group (or what interested them in agreeing to participate). At the end of the session, I asked each parent to tell me one thing they had learned that they didn't know before. Finally, I asked each parent to fill out an evaluation form that provided me with feedback on how well the groups were conducted. These tools provided me with a very basic approach to evaluating the effectiveness of the parent education groups.

This practicum provided me with an opportunity to meet many professionals who supported me in my learning, provided me with feedback, and offered me assistance in achieving my goals. Of great significance was getting involved with the parents who participated in my practicum. I learned a great deal about myself in their

company. They have inspired me, and their experiences, stories, and learning has had a tremendous impact on my learning as a student, as a social worker, and as a person.

IMPLICATIONS FOR SOCIAL WORK PRACTICE, PROGRAMS, AND POLICY

One of the most fundamental aspects of social work is understanding the process of integrating theories or concepts into practice. In general, theories, concepts, or philosophies are sets of ideas or beliefs that help practitioners define and interpret the world from a particular perspective. Consequently, it is this perspective that ultimately influences how practitioners approach assessment and intervention when working with families.

Social workers who work with families who have children with special needs often coordinate services with the family. As service coordinators, it is imperative that practitioners not only understand the significance of practicing from a family-centered perspective but be responsible for providing parents with information and education in an effort to facilitate capacity-building.

A family-centered approach to social work practice represents a shift in delivering services and supporting families. Implementing this approach creates a climate of partnership between the social worker and the family, the community, and service delivery systems—opening doors to more individualized support that meets the unique needs of each family and demanding interagency collaboration. Family-centered support requires a family-directed, individualized, flexible, and most importantly, portable service delivery.

Practices, programs, and public policies must reflect the ever-evolving needs of people with disabilities as well as the societal expectations regarding full citizenship and equal rights. The knowledge that parents obtain could pave the way for a political movement that focuses on children's rights to actively participate and to be fully included.

The Federal/Provincial (except Quebec)/Territorial Ministers Responsible for Social Services have acknowledged in the 1998 document In Unison: A Canadian Approach to Disability Issues that, because Canada is a nation, it has the responsibility to ensure that it is accessible as a nation. This document established a set of national objectives that must be met provincially in the areas of disability and service delivery.

Policy reform and subsequent program changes must reflect the following principles: inclusion and full citizenship, family strengths, shared responsibility, partnership and collaboration, individualized planning, transparent, accountable, and portable service delivery. A comprehensive approach to supporting families of children with special needs must be embraced by all systems. The Manitoba strategy on disability, Full Citizenship, would provide an excellent foundation for further dialogue, further recommendations, and further initiatives in the area of advancing family-centered practice as a national approach to supporting families of children with special needs.

Maintaining a collaborative relationship between families of children with special needs, government departments, community organizations, and stakeholders is the key to advancing family-centered practice not only in Manitoba, but the rest of

the nation. With the adoption of family-centered practice in Manitoba, parent education is a logical step to further accelerate the movement.

STRENGTHS AND LIMITS OF PARENT EDUCATION

Parent education, in the area of family-centered practice, is an area of interest that represents exciting possibilities. It has been identified as a pilot project and regarded as the "next step" for rigorous research with the Family Strengths in Childhood Disability Project. To date, training has been completed with staff in the Manitoba government's Department of Family Services and Housing, Children's Special Services program. In addition, further training in Individualized Family Support Plans was made available to some workers through a Faculty of Social Work M.S.W. practicum. Parent education, therefore, represented a timely evolution of this project.

Parent education serves to reflect, in a practical and educative manner, the very principles that guide family-centered practice. As I firmly believe that knowledge is power and education is a key aspect to empowering families, I am very excited to know that the group and the orientation guide has begun to equip parents with the competencies that will enable them to not only define what is best for their family, but define an informed context for parent/professional collaboration.

Although parent education has enormous potential, it must occur in conjunction with continued training efforts with community service providers. It is not enough to have workers in CSS and SMD trained in family-centered practice.

Training efforts must be expanded to community agencies. Agencies and government

departments that, for example, still practice from a child-centered approach, may be at odds with including the family in the planning process. Parent education builds a foundation, but parents must not feel that they are solely responsible for educating service providers about how services should be provided. Having parents who are knowledgeable about the principles of family-centered planning and a worker who may not practice from this approach can lead to a strained working relationship and increased parental frustrations. In addition, as some parents may not be able to commit to attending a group, parent education groups must not be the only forum for providing parents with information. Continued efforts to educate parents must occur at the level of the service provider. Social workers must provide parents with information about services. Written information must also be made available for parents who cannot attend informational workshops. These options must co-exist in order to reach as many families as possible.

A family-centered approach to working with families who have children with special needs is not based on a set of procedures. Rather, it is an attitude that defines how families are to be viewed, what their rights are as active consumers of support services, what the nature of the helping relationship between the service coordinator and family should be, and the extent to which family functioning is strengthened.

This practicum added a new dimension to the growing adoption of family-centered practice. Practitioners have an obligation to provide parents with information that will offer them the necessary knowledge and competencies that will help them become active consumers of mobilizing support services. Providing

parents with a firm foundation will guide them in their endeavour to procure family-defined and, more importantly, family-governed supports and resources.

It is evident that this practicum provided the parents who have participated in this practicum with a firm foundation—a foundation that will guide them in their endeavour to access supports and services. Parent education in family—centered practice not only served to define, clarify, and augment the relationship between families who have children with special needs and the service delivery systems, but it served to re-affirm one of the most basic humanitarian and egalitarian objectives of social work practice—family empowerment.

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APPENDIX A

THE ORIENTATION GUIDE

A FAMILY-CENTERED ORIENTATION TO SUPPORTS AND SERVICES FOR CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES

A FAMILY-CENTERED ORIENTATION TO SUPPORTS AND SERVICES FOR CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES

A GUIDE FOR PARENTS



Knowledge Is Power, And Information Is The Key

(Author Unknown)

Developed By: **Dona Camara, B.S.W.**Family Strengths in Childhood Disability Project

In Consultation With:

Child Development Clinic, Association for Community Living (Winnipeg), Children's Special Services, and Society for Manitobans with Disabilities

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As a social worker in the field of Community Living Services for Children with Special Needs, I have learned that one of the most important supports that parents ask for is information. Over the years, parents have shared with me their need to have a resource guide that would enable them to navigate their way through understanding and accessing the supports and services they require. As a response, this guide has been developed to reflect their request. I would like to thank those parents who shared their stories and provided me with the insight to develop this guide.

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INTRODUCTION

Becoming a parent has its joys and its challenges. When parents are informed that their child has special needs, they not only experience a range of feelings, but they may express certain concerns that are specific to their situation. Depending on each family's circumstance, parents may need to seek out supports that will help them deal with some of the issues they face.

The world of a family who has a child with special needs may consist of a world with numerous professionals, numerous responsibilities, and numerous tasks. Understanding the range of supports and services that may meet a family's needs is essential.

On behalf of the Family Strengths in Childhood Disability Project, I am pleased to provide you with this guide which serves as a resource to help you understand and access the specific supports and services you need for your child and family.

This guide is divided into two main sections. The first section begins with answering some of the more frequently asked questions made by parents. These questions include:

- How is eligibility determined?
- Who may be involved in my family's life?
- What is the role of my worker?
- What will my worker need to know about my child and my family?
- What are my rights as a parent?
- How are my family's support needs assessed?
- What is an Individualized Family Support Plan?
- Is there a waitlist for services?
- If I am not happy with a decision that has been made regarding the services my family needs, where can I turn for assistance/support?

The second section provides you with an overview of family needs. Designed to assist you in identifying your own family's needs, these may include any of the following:

- Child Assessment and Development;
- Early Intervention;
- Supplies, Equipment, and Home Modifications;
- Child Care/Preschool, and School Support;
- Relief/Respite;
- Behavioral Support;
- In Home/Homemaker Support;
- Special Health Care Support;
- Personal/Family Support;
- Recreation, Leisure, and Summer Support;
- Transitional Planning to Adult Services.

Each identified family need includes answering four important questions:

- 1. What type of service can meet my family's needs?
 - a brief description of the service designed to meet that specific need;
- 2. How do we qualify for the service that we require?
 - the eligibility criteria;
- 3. How do we access this service?
 - the referral process; and
- 4. Who can we contact for more information?
 - some of the community contacts that provide that service.

By combining information about family supports offered through the social services, health services, and the educational system, it is my hope that the information contained in this guide will prove to be useful, meaningful, and a resource for you and your family.

There may be words in this guide that you are not familiar with and will probably encounter as you become more involved with various professionals. So, these words have been *highlighted* throughout this guide to let you know that you can find the meaning of the word in the glossary section on page 43.

Should you require more information on any of these services or require assistance in accessing supports, please contact your worker or the specific organization you are wondering about for assistance.

In the spirit of community partnership, I wish you and your family all the best in your future efforts.

SECTION ONE:

ANSWERS TO COMMONLY ASKED QUESTIONS

1. How is eligibility determined?

You will frequently encounter the word "eligible" or "eligibility" as you begin to contact departments and agencies. These words simply mean to "qualify" for services. Eligibility for supports and services varies depending on the program. Since each program has its own rules, it is important that you ask if your child and family can be eligible for the service you feel you need.

For some services, your child's diagnosis is one of the first factors that determines which supports you can access. It is important to understand this requirement when you are looking for services. So, documents that confirm your child's diagnosis are necessary in order for you to begin the process.

2. Who may be involved in my family's life?

As you begin receiving support from different services, you will be involved with various professionals. Some of these professionals may be employed with the government and some may be employed with community-based agencies.

These professionals may provide direct services such as speech therapy, physiotherapy, behavioral support, day care etc. Others may be responsible for coordinating services. It is important that the professionals in your family's life explain to you what each of their role is.

3. What is the role of my worker?

Once you have been determined to be eligible for family support services, a worker who is responsible for coordinating services with you may be assigned to you.

Workers who are responsible for coordinating services may be referred to as "family service workers", "service coordinators", "case managers", or

"rehabilitation counselors". These professionals are responsible for offering and coordinating appropriate referrals to services that are available in your local community. In partnership with you, workers are responsible for reviewing the effectiveness of a support plan developed with you, and assisting you with any changes that need to be made to increase the effectiveness of your plan.

Service co-ordination reflects a family-centered approach to providing supports to families who have children with special needs. Your entire family is considered the most important and constant people in your child's life. So, services must be provided in a manner that maintains your family unit, focuses on the quality of life for your children, focuses on your strengths, and reflects a community partnership that is respectful of your unique needs.

The partnership that exists between you and your worker should be a partnership based on mutual respect, loyalty, trust, and open communication.

4. What will my worker need to know about my child and my family?

In order to provide families with comprehensive, family-centered support and services, it is important to obtain information that reflects your support needs.

These are the questions commonly asked by workers:

- Family members' names and birth dates
- Your child's special needs
- Your child's daily living skills, interests, strengths, health status, behavior, and support needs
- Your family's strengths
- Your child's preschool program/school program
- Your supports in the community, including professional involvement
- Your family's current circumstance
- Your understanding of your child's diagnosis
- Your needs and service priorities

5. What are my rights as a parent?

- You are consumers of support services. As consumers, you have the right to be as actively involved in every aspect of accessing services as you deem necessary. The amount of involvement is up to you.
- Since family support services are voluntary, you have the right to ultimately accept or decline services.
- Your permission must be obtained before any information is shared between professionals/service providers.
- You have the right to look at and/or ask for a copy of any paperwork on your child's assessment, eligibility, and Individualized Family Support Plan.
- You have the right to make final decisions about what assessments are done and what services are provided for your child.
- Your needs and concerns drive all aspects of the process.

6. How are my family's support needs assessed?

The most important sources of support begin with identifying and pooling together assistance from *informal supports* such as other family members, friends, neighbours and/or your community. These are natural sources of support for any family.

All supports and services for children with special needs and their families are voluntary. Therefore, the type and amount of service your family may receive depends on three essential and interdependent elements:

- (1) your family's assessed need;
- (2) whether your child's diagnosis meets the program's eligibility criteria; and
- (3) the extent to which resources are available.

Remember that all three factors are taken into consideration when access to family support services is considered. The type and amount of services you receive will not be the same as any other family receiving services because each family's circumstance is unique.

7. What is an Individualized Family Support Plan?

An Individualized Family Support Plan is a document that reflects your family's individualized support needs. This plan is developed in partnership with your worker. The components of this plan include the following information:

- A statement of your child's strengths and current levels of functioning;
- A statement of your family's strengths and interfamilial (family members) resources;
- A record of the services, programs, community agencies, and other community supports currently in place;
- A list of your family's identified needs, aspirations, and desires in the order of priority;
- The sources of support and resources that will be mobilized to meet your child and family's needs;
- The actions that will be taken to mobilize resources;
- An evaluation of the extent to which your family's needs were met; and
- The name of your worker (Dunst, Trivette, & Deal, 1988)

8. Is there a waitlist for services?

Services are limited by the available resources within each program. Waitlists may be created when funds and/or resources are limited. Please ask your worker or community staff person whether a waitlist exists for the service you are in need of.

Access to some services is prioritized based on the date of referral and assessed need or a combination of the two. If you would like to know how waitlists are managed, please ask the worker involved.

9. If I am not happy with a decision that has been made regarding the services my family needs, where can I turn for assistance/support?

If you are dissatisfied with a decision that has been made, please contact your worker for immediate assistance. Should contact with your worker not resolve your issue, please contact the supervisor of that program/service.

If you are still dissatisfied with the outcome of you complaint, please ask for information regarding that organization's appeal process.

SECTION TWO:

A ROADMAP TO MEET YOUR FAMILY'S NEEDS Child Assessment And **Trensitional** Development Early Planning to Intervention Adult Services Family Recreation. Supplies, Leisure, And Equipment, Summer And Home Support Modifications CHILDREN WITH SPECIAL Friends Neighbors **NEEDS AND** Personal/ Child Care/ Family THEIR FAMILY Preschool Support School Support Community Special Health Care Relief/ Support Respite In Home/ Behavioral Homemaker Support **Support**

Access to services is based on assessed needs, whether your child's diagnosis meets the program's eligibility criteria, and the extent to which resources are available to meet your family's needs

The need for ... CHILD ASSESSMENT AND DEVELOPMENT

Upon your child's diagnosis or suspected diagnosis, your child may be in need of further assessments or interventions that will aid in his or her development.

DESCRIPTION

Child Assessment and Development, a *multidisciplinary* approach to providing family support services, works in partnership with families and community services to provide diagnostic and treatment intervention services (Child Development Clinic, Family Support).

ELIGIBILITY CRITERIA

The program serves families of children between the ages of birth and seven years who have a *developmental delay*, a suspected delay or a diagnosed disability.

REFERRAL PROCESS

Referrals can be made by parents, pediatricians, family physicians, public health nurses, day care centres/nurseries, departments of the hospital, and social service agencies.

COMMUNITY CONTACT

Child Development Clinics: Children's Hospital

840 Sherbrook Street

Winnipeg, MB

R3A 151

787-4389

Primary diagnostic centre for preschoolers

St. Boniface Hospital

409 Tache

Winnipeg, MB

R2H 2A6

235-3078

The need for EARLY INTERVENTION

During the preschool years, your son or daughter may require direct assistance in his or her development.

Your child may require child development, physiotherapy, occupational therapy, and/or speech and language therapy.

DESCRIPTION

Early Intervention provides a network of support to preschool children with special needs and their families. These services include child development, physiotherapy, occupational therapy, speech and language therapy and family support.

ELIGIBILITY CRITERIA

There are a number of Early Intervention programs that you and your family can access. Eligibility for this service is specific to your child's disability. In order to begin the process, you need to have documentation that establishes your child's diagnosis.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or through the Society for Manitobans with Disabilities, you may ask your worker for more information. You and your worker will together assess your need for child development services. Should this service be needed, your worker will make the appropriate referral for a child development counselor.

A professional (doctor, therapist) may refer your child to the Provincial Outreach Therapy for Children for community-based services or to Children's Hospital, St. Boniface Hospital or other hospitals to provide hospital-based developmental interventions such as physiotherapy, occupational therapy, speech and language therapy.

You may want to inquire about whether your own private health insurance benefits may cover some of the costs of early intervention therapy.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

> Children's Special Services Child Development Counselors Contact your social worker

Provincial Outreach Therapy for Children

825 Sherbrook Street Winnipeg, MB R3A 1M5 975-3265

Self-referral

Rehabilitation Centre for Children

633 Wellington Crescent Winnipeg, MB **R3M 0A8**

452-4311

Self-referral

St. Amant Centre

440 River Road Winnipeg, MB

R2M 3Z9

256-4301

Web site: www.stamant.mb.ca

Self-referral

Children's Hospital

Child Development Clinic 840 Sherbrook

Winnipeg, MB

R3A 151

787-4389

A referral is required

St. Boniface Hospital

Child Development Clinic 409 Tache Winnipeg, Manitoba 235-3078 A referral is required

For a list of private therapists:

Manitoba Society of Occupational Therapists
Main Floor-425 Elgin Avenue
Winnipeg, Manitoba
R3E 0Z6
957-1214 Web site: www.msot.mb.ca

Manitoba Speech and Hearing Association

2-333 Vaughan Street Winnipeg, Manitoba R3B 3J9

453-4539

Web site: www.msha.ca

Canadian Physiotherapy Association 200 Main Street Winnipeg, MB R3C 4M2

925-5701

The need for.... SUPPLIES, EQUIPMENT, AND HOME MODIFICATIONS

You may require supplies, equipment, and home modifications in order to support your child's special needs.

Your child may require augmentative/alternative communication devices.

DESCRIPTION

The costs of certain supplies, equipment and home modifications directly related to your child's disability may be considered.

In addition, although transportation is a parental responsibility, <u>exceptional</u> transportation costs related to your child attending appointments and recreational activities may also be considered.

ELIGIBILITY CRITERIA

Most programs that offer financial assistance in covering the costs of supplies, equipment, and/or modifications to your home are directly related to your child's disability. Documentation that establishes your child's special needs is necessary in order to begin the process.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or through Society for Manitobans with Disabilities, please ask your worker for more information. Your worker will assist you in providing additional information, assessing your individual needs, and requesting funding to meet your need.

Agency-based programs that do not require worker referral encourage parents to self-refer.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

Children's Special Services
Contact your worker

Society for Manitobans with Disabilities Contact your worker

Kiwanis Club of Winnipeg 430 Webb Winnipeg, MB R3B 3J7 **956-0250**

Variety, The Children's Charity of Manitoba
611 Wellington Crescent
Winnipeg, MB
R3M 0A7
982-1058 Web site: www.varietyclubofmb.ca

Open Access
980 Palmerston Avenue
Winnipeg, MB
R3G 1J9
949-2430

The need for.... CHILD CARE/PRESCHOOL, and/or SCHOOL SUPPORT

CHILD CARE/PRESCHOOL

You may require child care while you attend work or school;
You may need child care to alleviate stress; or
Child care may be in your child's best interest in terms of enhancing his/her
life and social skill development.

DESCRIPTION

Child Care/Preschool provides opportunities for children to develop socialization and daily life skills under a structured program at a community day care centre, family or group child care home, or nursery school. Families of children with special needs may request support for their child in order to enhance his/her experience in the child care centre and many nursery schools.

ELIGIBILITY CRITERIA

In order to be eligible for extra support in a community day care, family child care home, or nursery school, your child must meet the following requirements:

- 3 months to 12 years of age
- medical, developmental, emotional or behavioral concerns (Child Day Care Office)

In order to be deemed eligible for child care services, you must either be employed, attending an educational facility, have special social needs, or it has been recommended by a professional that it is in your child's best interest for him or her to attend a day care setting.

Parents are responsible for covering the basic cost of the child care spot. However, subsidy (financial assistance to help cover the cost) can be applied for by parents, providing the eligibility criteria is met for subsidy.

REFERRAL PROCESS

Parents may contact the Manitoba Child Day Care office directly for assistance.

You may ask your worker for assistance in accessing this service.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

Manitoba Child Day Care

2nd Floor, 114 Garry Street Winnipeg, MB R3C 1G1

945-2197

Web site: www.gov.mb.ca/childcare

The Family Centre of Winnipeg

401-393 Portage Avenue

Winnipeg, MB

R3B 3H6 **947-140**1

Web site: www.familycentre.mb.ca

You may contact this service directly.

SCHOOL SUPPORT

As your child enters the school system, s/he may require additional supports directly related to his or her special needs. These supports may involve one on one support full days, assistance during lunch hour, or before and after school.

DESCRIPTION

School support provides assistance for children with special needs to be successfully integrated into public school and enjoy a meaningful educational experience. This process includes assessing your child's support needs and developing an *Individualized Education Plan* before your child's school program begins.

ELIGIBILITY CRITERIA

All children have a right to an education. A child's special needs should not prevent him or her from full inclusion. Eligibility for program funding is determined by assessing your child's functional skills and available resources. Please note that each school division has different ways in which children can access support programs.

REFERRAL PROCESS

Early contact with the school system is very important. Parents should contact their district's school principal or the school division office to begin the planning process. Please be aware that an early transition protocol exists and is used to ensure a smooth transition for your child into the school system.

If you are receiving services through Children's Special Services or the Society for Manitobans with Disabilities, please ask your worker for more information.

If your child is enrolled in a preschool, you may ask the child care worker for assistance during this process.

COMMUNITY CONTACTS

Contact your local School Division
Ask to speak with the Student Services
Administrator/Coordinator

Manitoba Department of Education and Training
Program and Student Services Branch
W-130 197 Ness Avenue
Winnipeg, MB
R3J 099
945-7922 Web site: www.edu.mb.ca/metks4
You may contact this department directly.

The need for ... RELIEF/RESPITE

There may be times where you require a temporary break from the day to day care needs of your child. You may not have family, friends, or neighbors who could assist you with temporary childcare.

DESCRIPTION

Respite services provide short term or periodic rest/relief for families with children who have special needs. These services may be provided in your own home or outside of your home. In-home or Out-of-Home Respite options may include a referral to a community-based agency or families may be eligible to administer this type of support themselves.

ELIGIBILITY CRITERIA

A number of respite options exist for families who have children with special needs. In order to be eligible for this type of service, documentation that establishes your child's diagnosis is necessary. In addition, your family must be in need of this type of support. For some agencies, an assessment may be done in order to determine your need.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or the Society for Manitobans with Disabilities, you may ask your worker for more information.

Referrals for Children's Special Services Respite program are made by your worker. Respite options include agency-administered in or out-of-home respite. In addition, Children's Special Services provides direct funding for parents to administer their own respite needs. Self-administered respite allows you to hire your own caregiver.

You and your worker will together assess your need. Your worker will also determine your eligibility and the extent to which available respite exists.

Community-based respite programs encourage parents to self-refer.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

Children's Special Services

Respite Program Contact your worker

Society for Manitobans with Disabilities

Contact your worker

St. Amant Centre

400 River Road Winnipeg, MB R3A 1M5

256-4301

Web site: www.stabmant.mb.ca

You may contact this centre directly

- · Out of home respite
- Based on an eligibility criteria

Community Respite Service

825 Sherbrook Street Winnipeg, MB R3A 1M5 **953-2400**

In and Out of home respite

If you wish to access this service, prior approval through the Department of Family Services must be obtained. If you are not eligible for Government funded respite, respite

care can be purchased for a fee (Community Respite Service).

The Family Centre of Winnipeg

401–393 Portage Avenue Winnipeg, MB R3B 3H6

947-1401

Web site: www.familycentre.mb.ca

The need for ... BEHAVIORAL SUPPORT

Your child may show signs of frustration, anger, or violence. You may require assistance in helping your child develop alternative ways of communicating his/her wants and needs.

You may require some assistance in providing your son or daughter with a behavioral program designed to assist you in supporting your child with developing skills in the area of toiletting, bathing, dressing, and feeding.

A crisis situation may warrant immediate behavioral support services.

DESCRIPTION

Trained professionals provide behavioral support for children, with direct involvement of the families, caregivers, and other relevant professionals or community members. This includes determining behavioral change goals, developing plans, and the use of behavior management strategies.

Behavioral support services may also include: child specific training and hands-on demonstration of child management techniques; service coordination; and liaison around a specific child in partnership with families and other service providers.

ELIGIBILITY CRITERIA

Most Behavioral Support programs require documentation that establishes your child's diagnosis. You will probably be asked what your family's concerns and needs are during the assessment process. In addition, you will be asked to be part of the process in receiving behavioral support services.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or the Society for Manitobans with Disabilities, you may ask your worker for more information. You and your social worker will together assess your individual needs. Your worker will establish your eligibility and let you know the extent to which this service is available.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

Children's Hospital

Child Development Clinic 840 Sherbrook Street Winnipeg, MB R3A 1S1 787-4389

St. Amant Centre

440 River Road Winnipeg, MB R2M 3Z9

256-4301

Web site: www.stamant.mb.ca

MacDonald Youth Services

175 Mayfair Avenue Winnipeg, MB R3L 0A1 477-1722

Manitoba Adolescent Treatment Centre

120 Tecumseh Street Winnipeg, MB R3E 2A9 477-6391

Crisis intervention

Health Sciences Centre

Child and Adolescent Psychiatry 820 Sherbrook Street Winnipeg, MB R3A 1R9 787-7889

The need for ... IN-HOME/HOMEMAKER SUPPORT

You may require in-home support while you are unable to provide care to your child.

You may be recovering from surgery or are ill and have no one to provide the assistance you need.

Or your child's needs may exceed your capacity to provide his/her day to day care requirements.

DESCRIPTION

Homemaker/in-home support services are provided by trained personnel and include direct care of children and household management. They may be provided on a short-term, periodic or on an as needed basis.

ELIGIBILITY CRITERIA

There are only a few in-home/homemaker services you may be able to access. Eligibility for this service is specific to your family's individual circumstance and your child's special needs. Please note that this service is limited to families who are unable to find alternate arrangements. As well, since most in-home/homemaker programs are limited to who they can support, not all children with special needs can qualify.

In order to begin the process of accessing this support, you will probably require documentation that establishes your child's diagnosis and *level of functioning*.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or through Society for Manitobans with Disabilities, please ask your worker for more information on how to access this type of support.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own criteria for eligibility.

The Family Centre of Winnipeg 401-393 Portage Avenue Winnipeg, MB R3B 3H3

947-1401 Web site:

Web site: www.familycentre.mb.ca

Winnipeg Child and Family Services 835 Portage Avenue Winnipeg, MB R3G 0N6 944-4200

The need for SPECIAL HEALTH CARE SUPPORT

If your child has lifelong complex medical care needs, she/he may require special health care supports. Complex medical care needs include those children who depend on life-support technology and require professional assistance.

DESCRIPTION

Special Health Care Support provides children who have lifelong complex medical care needs with appropriate professional support services. Professional support services include nursing support and other specialized health care services.

ELIGIBILITY CRITERIA

Eligibility for special health care supports are specific to children with lifelong complex medical needs which result in a dependency on medical technology. These include:

- Children requiring complex health care procedures that must be performed by a registered nurse.
- Children requiring health care support that can be performed by a non-health-care personnel trained by a registered nurse (Unified Referral and Intake System).

REFERRAL PROCESS

Referrals for professional support services may be made by your worker.

In order to support a child with lifelong complex health care needs in the community, referrals may also be made by schools, licensed child-care facilities, recreational programs, or respite programs.

COMMUNITY CONTACT

Contact your worker for more information

St. Amant Centre 440 River Road Winnipeg, MB R2M 3Z9

256-4301

Web site: www.stamant.mb.ca

The need for PERSONAL/FAMILY SUPPORT

You may require additional emotional, educational, or informational support through connections with other parents or by joining community-based support groups.

You and your partner may benefit from additional support.

DESCRIPTION

Personal/Family Support Services can provide a range of services in order to assist parents, couples, and/or children to develop skills, seek emotional support and access information and/or community programs. Services may include:

- Parenting skills training
- Parent support groups
- Counseling for parents
- Family/couple counseling

ELIGIBILITY CRITERIA

Eligibility for personal/family support varies depending on the criteria established by that particular organization.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or through the Society for Manitobans with Disabilities, you may ask your worker for more information and/or assistance in accessing this type of support.

COMMUNITY CONTACT

Association for Community Living (Winnipeg) 980 Palmerston Avenue Winnipeg, MB R3G 1J9

786-1414

Web site: www.aclwpg@escap.ca

Autism Society of Manitoba

825 Sherbrook Street Winnipeg, MB R3A 1M5 **783-9563**

Down Syndrome Society of Manitoba

825 Sherbrook Street Winnipeg, MB R3A 1M5 992-2731

The Cerebral Palsy Association of Manitoba

825 Sherbrook Street Winnipeg, MB R3A 1M5 **774-9427**

Family Centre of Winnipeg

401-393 Portage Avenue Winnipeg, MB R3B 3H6

947-1401 Web site: <u>www.familycentre.mb.ca</u>

Elizabeth Hill Counselling Centre

3-321 McDermot Avenue Winnipeg, MB R3A 0A3

956-6560 Web site: www.elizabethhill.ca

SMD Self-Help Clearing House

825 Sherbrook Street Winnipeg, MB R3A 1M5 **975-3037**

The need for RECREATION, LEISURE, AND SUMMER SUPPORT

RECREATION AND LEISURE SUPPORT

Your child may benefit from recreation and leisure opportunities.

DESCRIPTION

Recreation and leisure services include children/youth accessing various recreational activities and/or day camps throughout Manitoba.

ELIGIBILITY CRITERIA

Community-based recreational and leisure activities are available for children with special needs. Eligibility varies depending on the program's established criteria and available resources.

REFERRAL PROCESS

You may contact any recreational program for more information.

You may ask your worker for more information and/or assistance in accessing recreation/leisure supports.

COMMUNITY CONTACT

Special Olympics Manitoba

200 Main Street Winnipeg, MB

R3C 4M2

925-5628

Web site: www.specialolympics.mb.ca

Self-referral

Community Services Program (formerly Parks and Recreation) 291 Provencher Blvd. Winnipeg, MB R2H 0G4 986-5663

YMCA - YWCA 301 Vaughan Street Winnipeg, MB R3B 2N7 947-3044

Society for Manitobans with Disabilities 825 Sherbrook Street Winnipeg, MB R3A 1M5 975-3010

Manitoba Camping Association 194-A Sherbrook Street Winnipeg, MB R3C 2B6 784-1134

SUMMER SUPPORT

Your child may require assistance during the summer months while he or she is participating in a summer program. This assistance may include extra supports at day care, recreational programs, day camps, or residential comps.

DESCRIPTION

Summer programs may be available to provide your son or daughter with activities that can promote his or her life and social skill development.

ELIGIBILITY CRITERIA

A number of summer support programs exist. Eligibility for extra supports for your child is based on your child's diagnosis and his or her need for support. In order to begin the process, you will be asked to provide documentation that establishes your child's special needs and will probably be asked questions about what supports your son or daughter needs.

REFERRAL PROCESS

You may contact any agency for more information about what supports are available.

If you require additional assistance, your worker may help you in providing you with more information.

COMMUNITY CONTACT

Association for Community Living (Winnipeg) 980 Palmerston Avenue Winnipeg, MB R3G 1J9

786-1414 Web site: www.aclwpg@escape.ca

Special Olympics Manitoba

200 Main Street

Winnipeg, MB

R3C 4M2

985-4230

Web site: www.specialolympics.mb.ca

Self-referral

Community Services Program (formerly Parks and Recreation)

219 Provencher Blvd.

Winnipeg, MB

R2H 0G4

986-5663

Self-referral

YMCA - YWCA

301 Vaughan Street

Winnipeg, MB

R3B 2N7

947-3044

Self-referral

Manitoba Camping Association

194-A Sherbrook Street

Winnipeg, MB

R3C 2B6

784-1134

The need for ... TRANSITIONAL PLANNING TO ADULT SERVICES

Now that your son or daughter is in his/her mid teens, it is time to begin to think about whether your young adult will require or be interested in Adult Community Living Services or Vocational Rehabilitation Services.

Transitional planning to adult services should begin as soon as your son or daughter turns fifteen.

DESCRIPTION

Adult services for community living may include such things as income support, life skills development, day program/supported employment, vocational training, health services and a range of residential options.

ELIGIBILITY CRITERIA

In order to be eligible for community living or vocational rehabilitation services, documentation that establishes your child's diagnosis and level of functioning is required. Please be aware that there is a well-defined eligibility requirement for adult services, so early planning is very important.

REFERRAL PROCESS

If you are currently receiving services through Children's Special Services or the Society for Manitobans with Disabilities, you may ask your worker for more information. Your worker will assist you and your son or daughter in planning issues related to his or her needs.

To ensure a smooth transition, your son or daughter's school should also be involved in the planning process.

In the event your son or daughter does not meet the eligibility criteria for Community Living Services for adults with developmental disabilities, your worker may explore with you appropriate referrals to other services.

COMMUNITY CONTACT

You may contact any of these organizations directly for more information. Please be aware that each organization has its own eligibility criteria.

St. Amant Centre

440 River Road Winnipeg, MB

R2M 3Z9

256-4301

Web site: www.stamant.mb.ca

Association for Community Living (Winnipeg)

980 Palmerston Avenue

Winnipeg, MB

R3G 1J9

786-1414

Web site: www.aclwpg@escape.ca

Autism Society of Manitoba

825 Sherbrook Street

Winnipeg, MB

R3A 1M5

783-9563

Supported Living and/or

Vocational Rehabilitation Services for Adults

3-139 Tuxedo

Winnipeg, MB

R3N 0H6

945-1335

Web site: www.gov.mb.ca/fs/programs

Community Living Division

Adult Services Branch

119-114 Garry Street

Winnipeg, MB

R3C 4V4

945-4974

Web site: www.gov.mb.ca/fs/programs

Society for Manitobans with Disabilities Adult Services 825 Sherbrook Street Winnipeg, MB R3A 1M5 975-3099

CONCLUSION

As your child and family's needs change over time, so will the supports and services you require. Navigating your way through the various service systems (social services, health, and education) can be an overwhelming and confusing experience for anyone.

Your son or daughter will grow and develop through many life and developmental stages: toddler, preschool, school-age, teenager, and young adult. As you prepare to support your child's development through these life stages, your family's needs may also change. It is important to be aware of the supports and services that exist to meet your family's needs. This awareness will prepare you and your child for those changes.

Understanding what is available in your local community and how to access those services are essential in getting the supports that you require. It is hoped that you will find that the contents of this package answer many of your questions and continue to be useful to you as you continue your life journey.

Remember that your worker plays a very important role in helping you through this process. The partnership established between you and your worker is based on the essential principle of family-centered practice—strengthening your family.

Take good care,

Dona Camara Social Worker

p.s.

I value your opinion! If you would like to provide me with some feedback or have any suggestions on how to improve this resource guide, you may contact me at 694-5417 or email me at donacamara@yahoo.ca. Thanks a lot!

GLOSSARY OF TERMS

Assessment—The procedures used to identify your child and family's needs, your family's strengths and resources, your priorities and concerns, and the supports and services to meet your needs.

Augmentative/Alternative Communication -- Different forms of communication in addition to or instead of verbal communication.

Developmental Delay -- A delay in the development of your child's daily living skills and abilities (fine/gross motor, speech/language, self-help, cognitive, and social skills) in relation to your child's age.

Individual Education Plan -- Your child's school-based plan that has been developed with you and your child's school staff.

Intervention -- A specific way of providing help or assistance.

Level of Functioning -- Your child's ability to engage in daily living activities (some examples: communicate with others, walk, dress, eat, toilet etc.).

Multidisciplinary -- Professionals who come from different areas of specialization.

Respite -- Relief/rest/break.

Service Coordination -- A way of organizing and requesting/accessing the kinds of services that you need.

REFERENCES

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice.* Cambridge, MA: Brookline Books.

Original Source of Schematic Diagram on Page 14 (not contents)
Community Support Services, Program Inventory and Evaluation Framework,
Ministry of Social Services, British Columbia, 1994

All organizations listed have been contacted and have given permission to be cited in this resource guide.

PARENTS' STORIES

Welcome to Holland!

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By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michalangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you will never be free to enjoy the very special, very lovely things ... about Holland.

Celebrating Holland—I'm Home By Cathy Anthony

(My follow-up to the original "Welcome to Holland" by Emily Perl Kingsley)
Used by permission of the author

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned. I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger, the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

APPENDIX B PRESENTATION TRANSPARENCIES

GOALS OF THE PARENT EDUCATION GROUP

- to provide you with a set of "tools" that will equip you as you continue your journey in obtaining supports that meet your family's individual needs.
- to assist you in developing more skills that will help you define for yourself what is best for your family
- to equip you with ability to access the kinds of supports that reflect your individual needs

How?





By Understanding:

- (1) what family-centered practice means;
- (2) what your worker's role is;
- (3) what your role is;
- (4) what your rights are;
- (5) what an Individualized Family Support Plan is; and
- (6) how to access the supports and services you require



AN OVERVIEW OF THE PRESENTATION

Part One

- family-centered practice
- the role of your worker
- your role as parents
- your rights
- the development of an Individualized Family Support Plan

Part Two

- guest speakers
- discussion
- orientation to services: resource guide
- wrap up
- evaluation

WHAT IS FAMILY-CENTERED PRACTICE?

History

- a direct departure from the more traditionally based approaches (McWilliam, 1992).
- last 30 years: several historical, social, and political influences marked this shift:
 - prior to 1960, few early intervention services for families of children with special needs existed. Institutionalized care was the dominant belief and practice.
 - the development of early intervention programs in Canada coincided with changes in the perception about people with disabilities as well as the strong rise of parent advocacy groups (McWilliam, 1992; The Roeher Institute, 1996).
 - the self-help and grassroots efforts that emerged in the late 1960s (Dunst, Johnson, Trivette, & Humbly, 1991).

THESE MAJOR INFLUENCES FORCED THE FEDERAL GOVERNMENT TO ADDRESS PARENTS' DESIRE TO HAVE THEIR CHILDREN LIVE IN THEIR OWN COMMUNITIES (Johnson, Gallagher, LaMontagne, Gallagher, Huntinger, et al., 1994).

IN RESPONSE:

- the Federal and Provincial Government made it possible for parents and professionals to influence the creation of institutional alternatives (The Roeher Institute, 1996).
- political and social movements in the 1970s, in addition to increased public funds, resulted in a rapid growth of many community-based services for families of children with special needs (Briar-Lawson, 1998; Johnson et al., 1994).
- by the mid-1980s, every Canadian province and territory had community-based early intervention services (The Roeher Institute, 1996).

HOWEVER:

- community-based early intervention services were still based on a traditional medical model.
 - professional interventions were child-focussed,
 pathologically oriented, and disability-based.

RESPONSE:

- mid-70'S
 - RECOGNITION and NEED to identify the family as a constant and an important component of a child's life (Seligman & Darling, 1997)
 - the family's interdependent RELATIONSHIP with larger social systems (Bronfenbrenner, 1979)
 - propelled a shift away from childfocussed intervention strategies to a more family-focused, home-based model of early intervention services (Briar-Lawson, 1998; Wayman, Lynch, & Hanson, 1990).
- the rise of family empowerment-based services resulted in the creation of mandated family-centered services in the United States in 1986.
- in Manitoba, family-centered practice with families of children with special needs has been embraced

WHAT IS FAMILY-CENTERED PRACTICE?

- it is a belief
- it is an attitude
- it is a way of thinking
- about how services should be delivered:
- about the role of a service provider and parent;
- about the relationship that should exist between parents and service providers

Your Family:

- your family is a constant in your child's life
- your family is the central focus of attention
- your needs and concerns drive all and every aspect of services
- each family member is influenced by the actions of one other
- your child is not viewed as separate from your family
- your family does not operate in isolation
- your family exists within communities: extended family, health care professionals, friends/neighbors, and work and society: attitudes

CORE VALUES OF FAMILY-CENTERED PRACTICE

A. Partnership and Collaboration

- 1. Develop mutual relationships that reflect family and partnerships.
- 2. Share tasks and work activities to achieve family-identified goals.
- 3. Create reciprocal relationships based on loyalty, trust, honesty, and full disclosure.
- 4. Respect parental authority and final decision making in matters concerning children.
- 5. Respect the dignity and integrity of the family.

B. Strengths-Based

- 1. Recognize and build on family strengths, abilities, and competencies.
- 2. Help families to develop skills, competencies, and resources that can be translated as strengths.

C. Empowerment-Based

Empowerment Defined:

- a process by which families access knowledge, skills, and resources that enable them to gain positive control of their lives as well as improve the quality of their life-styles (Singh & Curtis, 1995)
 - Providing you with opportunities to help you develop the necessary skills and competencies that will help you define for yourself what is best for your family; and
 - 2. helping you become active consumers of mobilizing support services (Dunst, Johnson, Trivette, & Humbly, 1991)

Three central beliefs:

- 1. you are already competent or you posses the capacity to become competent;
- 2. failure to exercise competence is not associated with individual deficits but rather the barriers that exist with other social systems;
- 3. empowerment comes from a belief that individuals are able to change in a manner that redefines their position in the decision-making process.

D. Family-Friendly

- 1. Your child can and deserves to grow up with your family.
- 2. As much as possible, services should be provided in-home and in your family's community.
 - your family's home is the ideal setting to gather information about your needs and priorities, to plan interventions, and to provide you with information and education abut services that would reflect your needs (Wayman et al. 1990)
- 3. As your family's needs change over time, services should be provided in a manner that is adaptive, flexible, and responsive (Kinney, Haapala, Booth, 1991)
 - supports and services provided to your family should be designed to fit your family's needs because every family is unique and each family requires services and supports that reflect their individual circumstance (Dunst et al., 1994)

- 3. Supports must be community-friendly
 - those community-based services that are responsive to and designed to meet your unique needs

E. Cultural Responsiveness

- 1. Respecting ethnic and cultural diversity.
- 2. Being sensitive to and aware of cultural differences.
- 3. Respecting and honoring your family's cultural beliefs, tradition, religion, socioeconomic status and styles.
- 4. Valuing and strengthening ethnic resources and community supports.
- 5. Creating a relationship that is supportive of your family and demonstrates and understanding of the your values, beliefs, and practices.

What's the Ultimate Goal of Family-Centered Practice?

TO EMPOWER AND STRENGTHEN YOUR FAMILY

WHAT IS THE ROLE OF MY WORKER?

RESPONSIBILITIES

- 1. Work together with you and your family.
- 2. Offer and coordinate appropriate referrals to services that are available in your local community.
- 3. Monitor the effectiveness of those services being provided.
- 4. Assist you with any changes that need to be made to ensure that services are being delivered effectively
- 5. Provide you with information you need to make decisions about the supports and services you require to meet the needs of your child and family, assist you in choosing and obtaining those resources
- 6. Encourage a working relationship based on loyalty, trust, honesty, respect and full disclosure (Zipper et al., 1993)
 - 7. Focus on your needs and priorities

8. Engage in an open process of assessing, listening, and negotiating with you

The First Contact:

- home visit
- provide you with an overview of services
- gather information:
 - your family members' names and birth dates;
 - your child's special needs;
 - your child's daily living skills, interests, strengths, health status, behavior, and support needs;
 - your family's strengths;
 - your child's preschool program/school program;
 - your supports in the community, including professional involvement;
 - your family's current circumstance;
 - your understanding of your child's diagnosis; and
 - your needs and service priorities

WHAT IS MY ROLE AS A PARENT?

- You and your family play a crucial and central role
- You are the most important advocate for your child and family
- By sharing what you know about your child and family to your social worker and other service providers, you and your family assist them in providing the services that best meet your overall needs
- Your needs and concerns drive all aspects of services
- It is up to you to decide who should be involved in the decision-making and planning process for your family and to what extent these people will be involved
- Your team evolves and is directed by your service needs
 - Each parent and professional brings something unique to the team, and the experience, knowledge, and skills of each team member can be used to make good decisions.

- You may want to participate actively from the time you first make contact, or you might choose to play a less active role in the beginning. For most families, the level of involvement will vary over time, depending on the changing needs of your child and family.
 - Your social worker should try to make sure that the entire team understands your desires and needs.
 - It is up to you to decide which meetings to attend.
 - If you decide not to attend a meeting, your social worker can represent you family's views to other team members.
- Who is on your team will depend on the needs of your child and family, your family's desires, and the professionals who are in your community.
- You may want to include grandparents, other family members, or friends.

- Your team may include some of the following professionals:
 - The nurse
 - The pediatrician
 - The occupational therapist
 - The physical therapist
 - The nutritionist
 - The psychologist
 - The speech and language specialist
 - · The audiologist
 - Other social workers
 - The teacher
- You will decide, based on your family's resources, priorities, and concerns, how much involvement you will have in the planning process.
- You may have as little involvement or as much involvement in this process.

WHAT ARE MY RIGHTS?

- You have the right to be an active participant in planning for your child
- You have the right to have certain information kept confidential by the professionals working with you and your child
- Service providers must have your permission to send or receive information to other professionals
- You have the right to look at the paperwork on your child's assessment, eligibility, and Individualized Family Support Plan
- You have the right to decide what should be included in the IFSP for you child
- You have the right to make the final decisions about what assessments are done and what services are provided for your child
- You have the right to know that services should not be provided without your informed written consent
- You have the right to decide how much you want to be involved in this planning process

WHAT IS AN INDIVIDUALIZED FAMILY SUPPORT PLAN?

- a document that reflects your family's individualized support needs.
- Your worker will initiate this process.
- This plan is developed in partnership with your social worker.
 - a working document;
 - an action plan;
 - contains information on obtaining the supports and services that are necessary to strengthen your family (Fewell, 1991; Moroz & Allen-Meares, 1991)
 - identifies family strengths, competencies and sources of support, and
 - includes an evaluative component to achieving family-defined goals (Boone, Moore, & Coulter, 1995)

Four values that ENABLE, EMPOWER, SUPPORT, and STRENGTHEN families

- (1) the development of the IFSP is done in partnership between you and your worker;
- (2) any and all information included in the IFSP is done so with your explicit permission and authorization;
- (3) the development and the revision of the IFSP should be responsive to your needs, although no worker or program can be expected to offer support to meet all your needs; and
- (4) both the development and carrying out the IFSP should emphasize the abilities of your family (Dunst et al)

Developing Your Individualized Family Support Plan

(1) Assessment Planning

May involve:

- collecting and pulling together information from those who are familiar with your child
- seeking new information in order to identify your child's strengths and needs.

(2) Your Child's Assessment

Two main ways:

- 1. Various professionals may talk with your family and others who know your child
- 2. Specialists may observe and test your child's behavior and abilities
- Your worker is responsible for ensuring that your wishes and concerns guide the assessment
- You help to see that your child receives appropriate services by participating actively in this assessment process

(3) Identifying Your Family's Concerns, Priorities, and Resources

- Your worker will do a family assessment with you in order to understand the needs of your child and family
- Your worker may use some measures to help get to know your family:
 - Family Needs Scale
 - Family Functioning Style Scale
- You can share as much or as little information as you wish.

(4) Developing Your IFSP

- You and your worker will work together to develop your IFSP
- In developing your IFSP, you may need to make choices about priorities, and about the activities and services which could help your family in caring for your child and achieving what you want for your family.
- This is the time to talk about your child and ask as many questions as you deem necessary.

Components of the IFSP

Two Parts:

PART ONE

- includes the following information:
 - 1) the name of the human services practitioner,
 - 2) a statement of your child's strengths and current levels of functioning,

example: curious, happy, persistent

- 3) a statement of your family's strengths and interfamilial resources,

<u>example</u>: family and extended family devoted to Sarah's progress

- 4) a cumulative record of the specific services, programs, community agencies, and other community supports and programs accessed by you

example: Early Intervention Program
Church
Extended family

Part Two

- referred to as the "working" document
 - 1) a list of your family's identified needs,
 aspirations, and desires in order of priority,

example: Family will obtain a physical therapy evaluation for Ricky in order to plan activities to encourage independent walking

2) a series of statements regarding the sources of support and resources that will be mobilized to meet your child and family's needs,

example: Physical therapist will assess Ricky's motor skills

- 3) a series of statements regarding the actions that will be taken to mobilize resources, and

example: Parents will make an appointment with the physical therapist and participate in the assessment

- 4) procedures for evaluating the extent to which your family's needs are met (Dunst et al., 1988).

(5) Carrying out your IFSP

- after the IFSP has been developed, the activities specified in the plan should be carried out
- Your worker is responsible for coordinating this process, and should be in regular contact with you through phone calls and informal meetings as well as more formal meetings
- These meetings should be held at a place and time that is convenient for you

(6) Review of the IFSP

- you and your worker will periodically review the IFSP to see how well the needs of your child and family are being met
- the IFSP may be modified at any time to meet your family's needs as they emerge or change
- updated information from you and your family is a critical part of the review process

APPENDIX C:

TRAINING MANUAL

FACILITATING PARENT EDUCATION GROUPS WITH PARENTS OF CHILDREN WITH SPECIAL NEEDS

IN THE AREA OF:

FAMILY-CENTERED PRACTICE

A Training Manual For Practitioners

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INTRODUCTION

Intervention that provides parents with knowledge and skills, and encourages active participation in decision making is the key to facilitating parental empowerment (Heflinger & Bickman, 1997). Researchers suggest that parent education is an essential intervention that promotes family involvement and facilitates parental empowerment (Boone, Moore, & Coutler, 1995; Campbell, Strickland, & La Forme, 1992; Judge, 1997).

As a graduate student in the Faculty of Social Work at the University of Manitoba, a component of my practicum involved facilitating two parent education groups in the area of family-centered practice with parents who have children with special needs. The first group consisted of a one day, six-hour workshop; the second consisted of two evening, three-hour workshops. These education groups provided parents with an opportunity to learn about the principles of family-centered practice, the role of their worker, their role as parents and rights as active consumers of support services, and the development of an Individualized Family Support Plan.

As there was no training manual designed specifically to assist me in running this particular type of group, I pulled information from various sources in order to facilitate the education groups. These sources included literature on families who have children with special needs, family-centered practice, adult learning, group work, training modules designed for service providers, and my own experience as a social worker supporting families who have children with special needs. This manual includes the sources of information that I utilized to develop my own approach to designing and conducting my

parent education groups and has been developed to provide you with a comprehensive framework for running your own group.

This training manual contains three parts. Part One begins with including some background information that is required in order to be able to facilitate your parent education group. This includes awareness of issues related to parent education groups, principles of adult learning, and group process/group stage development. Part Two contains information on pre-group planning as well as post-group planning issues in order for you to effectively organize this group. **Part Three** reflects the heart of this manual, as it contains information on how to run the group. Each module contains the following: (1) what you need to know (where applicable), (2) what you need to cover with parents, including further details on the procedures used, the time period required to cover each module, materials needed to conduct the presentation, and most importantly, key points to cover in parent-friendly language, and (3) group stage development issues, including member issues and facilitator functions.

The six modules included in this training manual are:

Module One:

Introduction

Module Two:

What Is Family-Centered Practice?

Module Three: What Is The Role Of My Worker?

Module Four:

What Is My Role/Rights As A Parent?

Module Five:

What Is An Individualized Family Support Plan?

Module Six:

An Orientation To Supports And Services

I hope that you will find the information contained in this training manual to be helpful, and I invite you to critically examine your own assumptions, perspectives, values, and working styles as you read this manual. In the spirit of partnership, I wish you all the best in your endeavours to facilitate parent education groups.

PART ONE



BACKGROUND INFORMATION

PARENT EDUCATION GROUPS

A parent education group provides one type of context for helping parents learn about essential elements of family-centered practice. Seligman (1993) states that a parent education model of group work is one of the most effective ways of providing parental support. This model is based on the ideology that difficulties emerge in coping with the demands of raising a child with special needs as a result of lack of information, skills, and resources. The assumptions, in this model, are that families can cope when there is an opportunity to learn relevant information and that adequate resources will diminish problems related to caring for a child with special needs.

Although there is significant overlap, educational groups differ from treatment groups in terms of group purpose, objectives, member issues, and facilitator functions (Toseland & Rivas, 2001). Radin (1974) points out the fact that group facilitators take on the educational role with the "socioeducation" group. He asserts that this implies a different orientation in the way the group facilitator views his/her role and states the following: "there is more equality and the worker teaches, but also learns from members. This egalitarian relationship is the heart of the worker-member relationship in socioeducational groups" (p. 29).

Although the primary purpose of this educational group is to provide parents with information, this type of group operates within a supportive environment in that parents' experiences, insights, and knowledge are validated, encouraged, and celebrated.

PRINCIPLES OF ADULT LEARNING

Strategies to enhance parents' learning stem from early work on adult learning and the principles that guide this type of approach. Knowles' (1984) theory of adult learning is based on the following five assumptions: 1) adults are autonomous and self-directed, 2) adults have accumulated a foundation of life experiences and knowledge, 3) adults are goal-oriented, 4) adults are relevancy—oriented, and 5) adults are practical. Given these assumptions, Brookfield (1995) identified three types of learning that work well with adults. These are 1) self-directed learning, 2) critical reflection, and 3) experiential learning.

Galbraith (1991) states that adult learning is a transactional process that reflects challenging, sharing, and reflective activities. Brookfield (1986) adds that the nature of the teaching-learning transaction occurs within the context of mutual respect, negotiation, and collaboration.

Bennett, Lingerfelt, and Nelson (1990) summarize some of the training strategies that reflect adult learning. These authors suggest that the use of concrete study materials (both written and visual), discussion, demonstration, and small group activities such as role-plays and brainstorming are important components of adult learning methods.

Although the types of adult learning strategies that are utilized depend on the format of the educational group, many of the techniques reflect the principles found in

competency-enhancing and capacity-building skills used during one-on-one professional and parent interactions. Some of the strategies I used to foster learning included the use of overhead transparencies, flip chart, and handouts. Activities that I used to encourage participation and active involvement included small group brainstorming, discussions, and individual reflections. These will be discussed in greater detail in Part Three of this manual.

An awareness of the principles of adult learning will help you choose the types of activities that will foster learning, encourage participation, and promote enthusiasm in parents.

GROUP PROCESS AND GROUP STAGE DEVELOPMENT

It is important to pay attention to group process, which refers to group stage development and the interactions that characterize each stage (Corey & Corey, 1987, p. 12). There are a number of theories on stages of group development, and it is essential that you understand how group stages impact on parent education groups. Understanding the characteristics that make up each stage will provide you with a valuable perspective that will allow you to better respond to some of the issues that group members may face.

Toseland and Rivas (2001) state that there is evidence to suggest that stages of group development may be affected by the type of group, the needs of the members, the goals of the group, the setting, and the orientation of the leader. Although several authors have different ideas about the number and types of stages, most of these models propose that groups pass through three stages of development—beginning, middle, and end (Toseland & Rivas, 2001). Unlike multiple session groups, the beginning, middle, and

ending phases of group stage development will be encompassed in a single session.

Although this limits the development of group cohesion, Shulman (1984) suggests that it is possible to structure single session groups so that information may be presented in a manner that still allows members to participate and interact and enables participants' experiences to be more meaningful.

I would like to include two additional stages, which I believe will provide you with a more comprehensive understanding of group stage development. These are the pre-group planning stage and post-group stage which will be discussed in Part Two of this manual.



My Values and Approach

So, now that you have some basic knowledge about parent education groups, principles of adult learning, and stages of group development as it relates to facilitating your parent education group, it is essential that you begin to explore your own values and perspectives. Allow me to present you with my mine.

I strongly believe that in order to facilitate a group, I not only need to be clear about what my values are, but I need to have a firm understanding of the factors that must be considered in order to facilitate this type of group as effectively as possible. I'll begin by stating that my values stem from an inherent belief in the code of ethics of the professional standards of social work practice as well as from having adopted a family-centered approach to working with families. I firmly believe that every person possesses

personal strength and has the internal resources to cope with life's difficulties. In addition, I believe that personal empowerment is achieved by validating, promoting, and celebrating people's capabilities and competencies. My humanistic values set the tone for my practice and guide my approach to working with families who have children with special needs.

Knowledge around parent education groups, adult learning theory, and group stage development is critical because it provides a foundation for facilitating group process. A value position provides a perspective and a clear orientation to facilitating a parent education group as it guides the manner in which you view and work with the parents, how you interpret group process, and the manner in which you intervene as issues arise. It's all about values!

PART TWO



PRE-GROUP AND POST-GROUP PLANNING ISSUES

PRE-GROUP PLANNING

There are several factors to consider when you are forming a parent education group. Kurland, Getzel, and Salmon (1991) identify seven components: 1) agency context, 2) need, 3) purpose, 4) structure, 5) composition, 6) content, and 7) pre-group contact (1986, pp. 61-62). I will briefly link these components with the issues that need to be considered when you form your parent education group.



1. Agency Context

As the setting can impact group development (Toseland & Rivas, 2001, p. 89), you need to carefully consider this planning issue. The key consideration when making this decision is based on ensuring that you are providing parents with an environment that not only *welcomes* them, but is *accessible* to them (e.g., adequate parking). If you choose

to run this group at your agency, you need to ensure that you have the necessary support from staff and the resources available to meet the needs of your group. Some of these resources include the equipment that is needed to facilitate each session, a space large enough to accommodate parents, and a comfortable atmosphere where there is adequate seating and lighting.

2. Need

It has been my experience, in working with hundreds of families, that parents view obtaining information as crucial. Unfortunately, obtaining information is rarely accomplished through individual contact between the social worker and family. Believe me, I've been in contact with many parents who have had services for years (as well as several social workers before me), and they have had no idea what they were able to access, what the role of their social worker was, how they should have been treated, and what their rights were!! A group approach, as it has already been mentioned, is one form of intervention that will address this need for information.

Recruiting group members can occur either by contacting the families you support or by interviewing social workers who work with families. If this is not possible, you may be able to contact the supervisor or executive director of a community organization and propose this idea to him/her.

3. Purpose

You need to be clear about the purpose of running a parent education group, which in this case is to help parents understand family-centered practice, the role of their worker, their role as parents and their rights as active consumers of support services, and the process of developing Individualized Family Support Plans. The overall objective is

to empower parents by providing them information within a supportive learning context.

A secondary objective, should this occur, is to foster support and offer networking opportunities to the parents in the group.

4. Composition

The composition of the parent education group is another factor that needs to be carefully planned. Who do you want in this group? Are they parents who have just been assigned a social worker? Are they parents who have been in receipt of services and are not aware of family-centered practice? Do you want parents who have children with similar special needs or are you in favour of a heterogeneous group? Personally, I'm drawn to a heterogeneous group in terms of child disability because I believe the special needs of the children will not have a direct impact on the nature of this group.

5. Structure

There are a number of ways of structuring a parent education group. The parent education groups I facilitated included two formats. The first group format was a one day, six-hour workshop. The second group format occurred over the course of two, three-hour evening sessions.

In order to incorporate and foster participation and discussion, the ideal number of parents for a group is between six and twelve (Hornby & Murray, 1983; Seligman & Darling, 1997).

You may consider the benefit of co-facilitating the group with a parent. I co-facilitated the groups with a parent of an adult child with special needs. This parent/professional partnership allowed power to be shared equally and provided parents with opportunities to hear perspectives from both the professional and the parent.

6. Content

The content of this parent education group must be educational in that it provides parents with information about family-centered practice, the role of the worker, the role and rights of parents, and the development of an Individualized Family Support Plan.

Activities need to reflect the principles of adult learning and provide parents with opportunities to develop new skills and insight. The group itself may also provide a source of comfort for parents as they share ideas, thoughts, and feelings with one another.

My sessions included presentations from guest speakers. Parents were provided with the opportunity to hear speakers from various community-based organizations and therefore allowed to ask questions. In addition, I developed and distributed a guide book for each parent who participated in the group. This guide contained information that provided parents with a family-centered orientation to understanding and accessing supports and services. You may want to consider what I've included when you design your own groups.

7. Pre-group contact

You need to consider the advantages of contacting potential group members prior to the parent training. This contact will allow you to confirm the registration, answer any questions, and provide parents with an opportunity to fill out a pre-test questionnaire or engage in a pre-group interview. A pre-test questionnaire/interview will allow you to assess members' existing knowledge and their needs and will provide you with a basis for addressing members' concerns/questions and conducting an evaluation.

It is my strong belief that pre-group contact must also include personal reflection in terms of re-affirming your own attitudes, values, and leadership styles. It cannot be

stressed enough that you take ample opportunities to do your own pre-group planning. In addition, this is also a good opportunity for you to ascertain what the needs, concerns, and issues are for parents as they will make up the membership of your group. This early information will help you design a program that will meet their needs.

POST-GROUP STAGE

Although not all models of group stage development include a post-group stage, it is important to acknowledge the benefits of including this stage. I strongly believe that this is an important component to the overall effectiveness of group work. According to Corey and Corey (1987), the post-group stage is an opportunity for you to conduct a further evaluation as well as a follow-up with members.

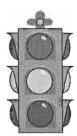
According to Toseland and Rivas (2001), evaluation is the process of obtaining information about the effects of a single intervention or the effect of the total group experience. In terms of a post-group evaluation, you may use informal or formal measures to obtain this type of information. One approach, for example, can involve analyzing the post-group evaluation completed in the last session.

A post-group evaluation will provide you with some valuable information about what members learned and found helpful. This information can then be compared with the pre-group interview. The comparison can highlight some of the changes that occurred, whether they were positive or negative. In addition, this information can provide you with insight into how the group format may be changed or modified in order to improve future parent education groups. Some of the follow-up procedures that could be utilized include conducting a follow-up interview with parents to find out the overall

effectiveness of this group, sharing the results of the pre- and post-test analysis, and making recommendations.

A thorough analysis of the evaluation tools and an implementation of a follow-up procedure reflect the belief that the work does not end with the last group session. And so, I would encourage you to include a post-group evaluation and consider implementing tools that assess the attainment of your goals.

PART THREE



GETTING STARTED

Now that you are familiar with the key background knowledge that is required to facilitate this type of group, group stage development, and pre-group and post-group planning issues, it is time to get started with facilitating the parent education group. Part three begins with an outline of the actual modules used in my parent education group. Each module is divided into its own section and contains the following: (1) what you need to know (where applicable); (2) what you need to cover with parents; and (3) group stage development issues, member issues, and facilitator functions.

A BRIEF SUMMARY OF THE SESSION MODULES

PART ONE

(Total Time: three hours)

MODULE ONE

OPENING

Purpose: introduce yourself and welcome members

Time: 10 minutes

Material Required: name tags

EXERCISE

Purpose: to help parents orient themselves to

understanding the term family-centered

Time: 2 minutes

Material Needed: paper and pen

Procedure: hand everyone a piece of paper and a pen

- ask them to write about what they think family-centered practice means
- "when I think about the term family-centered, this is what I think it means to me"
- when everyone is finished, ask them to put it away
- let parents know that when the group is finished, they can pull out the piece of paper, read what they wrote, and see if what they learned matches what they thought

INTRODUCTION

Purpose: to continue the process of getting to know one another, to understand what parents would like to get out of this training

Time: 15 minutes

Material Needed: flip chart, markers

Procedure: round robin check-in: their names, information about their child and family (optional), what they'd like to learn

OBJECTIVES

Purpose: to acquaint parents with necessary information about the goals of the training group, an introduction of each module, the role of the facilitator, the length of time, and basic housekeeping rules

Time: 15 minutes

Material Needed: overhead, transparencies

MODULE TWO

WHAT IS FAMILY-CENTERED PRACTICE?

Purpose: orient parents to family-centered practice

Time: 20 minutes

Material Needed: overhead, transparencies with principles of family-centered practice

Procedure: provide a brief history of how family-centered practice evolved, define family-centered practice, highlight the principles, values, and beliefs

MODULE THREE

WHAT IS THE ROLE OF MY WORKER?

Purpose: to provide information about the role of the worker

worker

Time: 15 minutes

Material Needed: overhead and transparencies

BREAK

20 minutes

- have refreshments and snacks

MODULE FOUR

WHAT IS MY ROLE AS A PARENT?

Purpose: to provide information about the role of parents

Time: 15 minutes

Material Needed: overhead and transparencies

Procedure: discuss needs and aspirations, strengths and capabilities, and sources of support

WHAT ARE MY RIGHTS?

Purpose: to provide parents with an opportunity to learn about what their rights are

Time: 5-10 minutes

Material Needed: flip chart paper, marker

Procedure: ask parents to form small groups and ask them to create their Bill of Rights (i.e., ask them to describe the manner in which they should be treated by service providers)

Discussion

Purpose: to come together as a larger group and share what each group came up with

provide the group with additional rights if any are missing

Time: 10 minutes

Material Needed: None

MODULE FIVE

WHAT IS AN INDIVIDUALIZED FAMILY SUPPORT PLAN?

Purpose: to acquaint members with the development of the IFSP, to share its process, elements, and components

Time: 30 minutes

Material Needed: overhead, transparencies, handouts

WRAP UP (for two-session group format) **Purpose:** to summarize, answer any questions, get parent feedback in terms of what they have learned

PART TWO

(Total Time: three hours)

MODULE SIX

INTRODUCTION

Purpose: to introduce the guest speakers

Time: 5 minutes

SPEAKER:

PARENT

Purpose: to speak about the experiences this parent has in

dealing with the social service system, advice to parents

around seeking supports, etc

Time: 30 minutes (with discussion)

BREAK

20 minutes

- refreshments and snacks

SPEAKERS:

Purpose: to speak about services, parent/professional

relationship, and transitions

Time: 60 minutes (with discussion)

GUIDE BOOK

Purpose: to provide parents with an overview of the guide

book

Time: 15 minutes

Material Needed: guide books

CHECK-OUT

Purpose: to allow each parent an opportunity to talk about

what they have learned and what they will take with them

Time: 15 minutes

EVALUATION

Time: 10 minutes

MODULE ONE

INTRODUCTION

OPENING

Purpose: introduce yourself and welcome members

Time: 10 minutes

Material Required: name tags

EXERCISE

Purpose: to help parents orient themselves to understanding the term family-centered

Time: 2 minutes

Material Needed: paper and pen

Procedure: hand everyone a piece of paper with pen

- ask them to write about what they think family-centered practice means
- "when I think about the term family-centered, this is what I think it means to me"
- when everyone is finished, ask them to put it away
- let parents know that when the group is finished, they can pull out the piece of paper, read what they wrote, and see if what they learned matches what they thought

INTRODUCTION

Purpose: to continue the process of getting to know one another, to understand what parents would like to get out of this training

Time: 15 minutes

Material Needed: flip chart, markers

Procedure: round robin check-in: their names, information about their child and family (optional), what they'd like to learn

OBJECTIVES

Purpose: to acquaint parents with necessary information about the goals of the training group, an introduction of each module, the role of the facilitator, the length of time, and basic housekeeping rules

Time: 15 minutes

Material Needed: overhead, transparencies

WHAT YOU NEED TO COVER WITH PARENTS

OPENING

10 minutes--provide name tags for parents

- welcome the parents
- introduction of presenter(s)
 - name
 - what you do

INTRODUCTION

15 minutes-- flip chart, markers

- exercise
 - hand everyone a piece of paper with pen/pencil
 - ask them to write about what they think family-centered means
 - "when I think about the term family-centered, this is what I think it means to me"
 - when everyone is finished, ask them to put it away
 - let parents know that when the group is finished, they can pull out the piece of paper, read what they wrote, and see if what they learned matches what they thought
- round robin check-in
 - ask each parent to state their name, talk a little bit about their family (optional), and what they hope to learn today

OBJECTIVES

15 minutes - overhead, transparencies

- your role
 - not an expert on your family
 - to provide information that will help you understand more about supports and services
 - help you navigate your way through the various service systems (social services, health, and education).
- the length of the group
 - time, breaks, lunch

• basic housekeeping rules

- bathrooms
- confidentiality exceptions: only in circumstances when information is shared that places a child risk
 - respect for people's shared opinions
 - allowing people to take turns speaking during discussion
 - asks questions when needed

goals of the education group

- to provide you with information that will help you obtain the supports that meet your family's individual needs.
- to assist you in developing more skills that will help you define for yourself what is best for your family
- to provide you with a set of "tools" that will equip you with the ability to access the kinds of supports that reflect your individual needs

How?

By Understanding:

- what family-centered practice means;
- what your worker's role is;
- what your role is;
- what your rights are;
- what an Individualized Family Support Plan is; and
- how to access the supports and services you require

An Overview of the Presentation

Part One

- family-centered practice
- the role of your worker
- your role as parents
- your rights
- the development of an Individualized Family Support Plan

Part Two

- a parent's perspective
- guest speakers
- discussion
- orientation to services: resource guide
- wrap up
- evaluation



Be (A)ware of ...

GROUP STAGE DEVELOPMENT ISSUES

The Beginning Stage of Group Development

To understand the beginning stage of group development, Corey and Corey (1987) highlight several characteristics that make up this stage. These include: getting acquainted, clarifying the purpose of the group, establishing group cohesion, establishing group norms, and developing trust. The activities that I have included in the introduction, which reflect the principles of adult learning (already discussed in the first section), accomplish these tasks. These include: an opening comment of who you are, clarification about what type of group this is, an ice-breaker introduction of each member, a discussion of the goals of this program, and establishing rules.

Member Issues

It is during this stage that members are getting acquainted. Members are learning how the group functions, what is expected of them, and what they will learn. It is also during this stage that members need to develop norms that will govern group behaviour. This is accomplished through being provided with opportunities to have their expectations and personal goals clarified.

Facilitator Functions

As the group facilitator, you are responsible for ensuring that members feel welcome and comfortable. This involves providing them with a clear understanding of who you are and what your role is. This is the time when you must provide members with a general understanding of the purpose of the group. You need to establish ground rules of behaviour, respect, and confidentiality. Your style and approach must reflect a genuine and caring response in order to foster the trust that is being established. This is vital.

You must model attending and listening skills, empathy, and respect. You are helping members establish goals, and are assisting members in sharing their thoughts, feelings and concerns. Therefore, modeling appropriate behaviour is essential.

The manner in which you facilitate this group will affect the dynamics that develop. Therefore, you need to be aware of the power you hold as a group facilitator and the approach you take in exercising that power. Although your role is as an educator who has legitimate power, you also benefit from learning about members' experiences. You must be skilled at sharing your power with other members. Sharing power and responsibility, from the beginning, establishes group cooperation, fosters participation, and demonstrates respect and dignity to all members.

MODULE TWO

WHAT IS FAMILY-CENTERED PRACTICE?

Presentation

Purpose: orient parents to family-centered practice

Time: 20 minutes

Material Needed: overhead, transparencies with

principles of family-centered practice

Procedure: provide a brief history of how family-centered practice evolved, define family-centered practice, highlight

the principles, values, and beliefs

WHAT YOU SHOULD KNOW ABOUT FAMILY-CENTERED PRACTICE

History:

Family-centered practice emerged as a direct departure from the more traditionally based approaches, where children's special needs were viewed as problems to fix or rehabilitate (McWilliam, 1992).

Over the last thirty years, several historical, social, and political influences marked this shift. Prior to 1960, few early intervention services for families of children with special needs existed. Institutionalized care was the dominant belief and practice.

The development and implementation of early intervention programs in Canada coincided with changes in the perception about people with disabilities as well as the strong rise of parent advocacy groups (McWilliam, 1992; The Roeher Institute, 1996). The most significant movement can be traced to the self-help and grassroots efforts that emerged in the late 1960s (Dunst, Johnson, Trivette, & Humbly, 1991). These major influences forced the federal government to address parents' desire to have their children live in their own communities (Johnson, Gallagher, LaMontagne, Gallagher, Huntinger, et al., 1994). In response, the Federal and Provincial Government made it possible for parents and professionals to influence the creation of institutional alternatives (The Roeher Institute, 1996). Political and social movements in the 1970s, in addition to increased public funds, resulted in a rapid growth of many community-based services for families of children with special needs (Briar-Lawson, 1998; Johnson et al., 1994). By

the mid-1980s, every Canadian province and territory had community-based early intervention services (The Roeher Institute, 1996).

Although community-based early intervention services emerged as an alternative to institutionalized care, services were based on a traditional medical model. Professional interventions, therefore, were child-focused, pathologically oriented, and deficit-based. During the mid-seventies, however, the growing recognition and need to identify the family as a constant and critical component of a child's life (Seligman & Darling, 1997) as well as the family's interdependent relationship with larger social systems (Bronfenbrenner, 1979) propelled a paradigm shift away from child-focused intervention strategies to a more family-focused, home-based model of early intervention services (Briar-Lawson, 1998; Wayman, Lynch, & Hanson, 1990).

The rise of family empowerment-based services directly resulted in the creation of mandated family-centered services in the United States in 1986. The passage of the Preschool and Early Intervention Act (P.L. 94-457), as an amendment to the Education for All Handicapped Children Act of 1975 (P.L. 94-142), clearly establishes the role of the family as paramount and directs intervention practices, specifically the development of Individualized Family Support Plans, in a manner that reflects the principles of family-centered practice (McGonigel, Kaufmann, & Johnson, 1991). Since the passage of this law, literature on family-centered practice has flourished (Bailey, Simeonsson, Winton, Huntington, Comfort, et al., 1986; Dunst, Trivette, & Deal, 1988, 1994). This philosophy, which also has its historical roots in the paediatric nursing field (Newton, 2000), continues to influence the growing adoption of a family-centered approach to practice in Canada. In Manitoba, family-centered practice with families of children with

special needs has been embraced with significant efforts being taken to facilitate a shift to family-centered practice in the field.

Family-centered practice is not a set of procedures that a social worker follows. It is a belief, an attitude, a way of thinking about the relationship that should exist between parents and professionals. So, it is based on a set of values that define a particular way of working with families. It identifies the role of the family as the central focus of attention where families' needs and concerns drive all and every aspect of services. The ultimate goal of family-centered practice is to empower and strengthen families.

There appears to be some debate over what constitutes family-centered practice (Dunst et al., 1991; McGonigel, Kaufmann & Johnson, 1991). In response, Dunst et al. (1991) created a framework for classifying and understanding existing philosophical orientations of various programs for children and their families. These orientations include professionally-centered, family-allied, family-focused, and family-centered services. In professionally centered services, professionals are viewed as the experts of delivering early intervention services. Within this orientation, parents are typically viewed as people who require help from the professionals who know what is best. In family-allied services, families are enlisted to help the professionals implement interventions. With this orientation, families are viewed as minimally capable of making positive changes without the assistance of professional expertise. In family-focused services, families and professionals work together to define how to make the family function best. Families are viewed positively but also as being in need of professionals' help and guidance. Family-centered practice is an approach that is based on a set of principles, values, and beliefs that identifies the role of the family as the central unit of

attention (McGonigel et al., 1991). Families' needs and concerns drive all aspects of services. Professionals work together to promote optimal family decision-making skills (Bailey, 1987; McCallion & Toseland, 1993), capabilities, and competencies (Dunst et al., 1991). The ultimate objective of family-centered practice is to strengthen family functioning (Dunst et al., 1991). Essentially, when services are truly family-centered, parents receive the support and information they require to be able to make the necessary decisions about their child and family (King, Rosenbaum, & King, 1997).

Core Values/Principles of Family-Centered Practice

The term "family-centered" refers to a combination of beliefs that define a particular way of working with families in a manner that reflects family driven (Bailey, 1987) and competency enhancing (Dunst et al., 1991) practices. Several authors who have written about family-centered practice (Ahmann, 1994; Bailey, 1989; Bailey, Palsha, & Simeonsson, 1991; Bailey, McWilliam, Darkes, Hebbeler, Simeonsson et al., 1998; Baird & Peterson, 1997; Bennett, Lingerfelt, & Nelson, 1990; Bradley, Parette, & VanBiervliet, 1995; Dunst et al., 1988 & 1994; Farel, Shackelford, & Hurth, 1997; Harman & Laird, 1983; Hodges, 2000; King et al., 1997; McWilliam, 1992; Notari & Drinkwater, 1991; Seligman & Darling, 1997) make reference to core principles that guide this approach. Hodges (2000) identifies the following core principles in family-centered practice: (1) partnership and collaboration, (2) strengths-based, (3) empowerment-based, (4) family-friendly, and (5) cultural responsiveness.

(1) Partnership and Collaboration

Partnership and collaboration involve developing mutual relationships that reflect family and professional partnerships and shared responsibilities (Bennett et al., 1990; Dunst et al., 1988; Seligman & Darling, 1997; Zipper, Weil, & Rounds, 1993).

Dinnebeil, Hale, and Rule (1996) assert that relationships between parents and professionals form the basis for all services provided to children with special needs and their families. Parents are viewed as full partners in the helping process, with all the rights, privileges, and responsibilities inherent in knowing their situation the best, thus shifting the focus of service provision from families (Sokoly & Dokecki, 1992).

Bailey (1987) states that collaborative goal-setting resolves the likelihood of parent-professional conflicts and recognizes the value and importance of parents' perspectives. He continues to state that active participation in goal setting helps parents learn to set goals and priorities for themselves. The service provider, therefore, is obligated to reach out to the family members, involve them, solicit their opinion, and respect their wishes (Williams, 1995), creating a reciprocal relationship based on loyalty, trust, honesty, and full disclosure (Zipper et al., 1993) by focusing on family priorities and by engaging in an open process of assessing, listening, and negotiating with families (Bailey, 1987).

(2) Strengths-based

A strengths-based approach recognizes and builds on family strengths and competencies (Dunst et al., 1988, 1994; Hartman & Laird, 1983; Hodges, 2000; Saleebey, 1997; Seligman & Darling, 1997; Walton, Sandau-Beckler, & Mannes, 2001).

The strengths approach moves away from the deficit model of finding and fixing problems to helping families develop skills, competencies, and resources that can be translated into strengths (Rappaport, 1981; Roberts, Rule, & Innocenti, 1998).

Family strengths are characteristics that family members identify as contributing to the growth and development of the child and the family (McGonigel et al., 1991). Dunst et al., (1988) suggest that there are 12 major, non-mutually exclusive qualities of a strong family. These include: (1) a belief in and sense of commitment toward promoting the well-being and growth of individual family members as well as that of the family unit; (2) appreciation for the small and large things that individual family members do well, and encouragement to do better; (3) concentrated effort to spend time and do things together, no matter how formal or informal the activity or event; (4) a sense of purpose that permeates the reasons and basis for "going on" in both bad and good times; (5) a sense of *congruence* among family members regarding the value and importance of assigning time and energy to what the family considers its goals, needs, projects, and functions; (6) the ability to communicate with one another in a way that emphasizes positive interactions among family members; (7) a clear set of family rules, values, and beliefs that establishes expectation about acceptable and desired behaviour, (8) a varied repertoire of coping strategies that encourage positive functioning in dealing with both normative and non-normative life events; (9) the ability to engage in problem-solving activities designed to evaluate options for meeting needs and procuring resources; (10) the ability to be positive and see the positive in almost all aspects of their lives, including the ability to see crises and problems as an opportunity to learn and grow; (11) flexibility and adaptability in the roles necessary to procure resources to meet needs; and (12) a

balance between the use of internal and external family resources for coping and adapting to life events and planning for the future.

(3) Empowerment-based

Family-centered practice is based on the model of family empowerment.

Rappaport (1987) suggests that empowerment is a process by which people gain a sense of mastery of their own affairs. Heflinger and Bickman (1997) define empowerment as a process through which people become more able to influence the people and organizations that affect their lives and the lives of those they care about.

Dunst et al. (1988) state three beliefs central to empowerment: (1) people are already competent or they posses the capacity to become competent, (2) failure to exercise competence is not associated with individual deficits but rather the barriers that exist within social systems, and (3) empowerment comes from a belief that individuals are able to change in a manner that redefines their position in the decision-making process. These authors suggest that empowerment practices involve taking a proactive stance with families and enabling or creating opportunities for families to develop competencies by encouraging personal and social change, promoting self-efficacy, and developing and strengthening competencies and skills that essentially promote positive family functioning. Ackerson and Harrison (2000) assert that the concept of empowerment is multi-dimensional as it encompasses a personal process of self-determination as well as a socio-political construct of large-scale competence building.

(4) Family Friendly

Family-centered practice is based on a proactive approach which views all families in a positive regard and focuses on family strengths and capabilities in a manner that supports and strengthens family functioning (Dunst et al., 1988). The focus of intervention is on promoting the development of skills and competencies by positive communication and addressing family needs with sensitivity, reassurance, and normalization (Bennett, Nelson, & Lingerfelt, 1992).

A family-friendly approach maintains the belief that children with special needs can and deserve to grow up with their families, that services should be provided in-home and in the family's community, and that, as families' needs change over time, services should be provided in a manner that is adaptive, flexible, and responsive (Kinney, Haapala, & Booth, 1991). According to Wayman et al. (1990), the family's home is the ideal setting to gather information about family needs and priorities, to plan interventions with families, and to provide families with information and education about services that would best reflect the family's needs. Judge (1997) found that greater parental involvement was reported by parents who participated in home-based programs, indicating that support and encouragement for families to be actively involved in making decisions and choices may be dictated by how and where services are delivered.

The concept of an "array of services" is used in family-centered services because a family's needs may be varied and complex (Dunst et al., 1994). The supports and services provided to the family should be designed to fit each family's needs because every family is unique and requires services and supports that reflect their individual circumstances. Furthermore, supports and services must be not only family-friendly but

also community-friendly if they are to be effective and long-lasting (Dunst et al., 1994). Community-friendly supports are those community-based services that are responsive to and designed for meeting the unique needs of families of children with special needs. These supports and services foster and enhance a sense of community that reflects strong, interdependent ties among people (Dunst et al., 1988). According to Dunst et al. (1994), strong communities, in turn, "increase the availability of needed supports and resources, and enrich the community environment for families and their members" (p.37).

(5) Cultural Responsiveness

Cultural responsiveness is a core value that underscores respecting ethnic and cultural diversity, being sensitive to and aware of cultural differences, respecting and honouring family cultural beliefs, traditions, socioeconomic status and styles, and valuing and seeking to strengthen ethnic resources and community supports (Beckman, 1991; Bennett, Zhang, & Hojnar, 1998; Degangi, Wietlisbach, Poisson, Stein, & Royeen, 1994; Gallagher & Desimone, 1995; Johnson et al., 1994). Wayman et al. (1990) state that culturally sensitive interventions can only occur when each family is viewed and treated as a unit that is influenced by culture but not defined by it. Family-centered practice involves creating a relationship that is supportive of families and demonstrates an understanding of the family's values, beliefs, and practices, and creating opportunities for increased respect, trust, and understanding (Hanson, Lynch, & Wayman, 1990).



Check ...

WHAT YOU NEED TO COVER WITH PARENTS

20 Minutes—overhead, transparencies

To understand family-centered practice, it is important to understand how it evolved.

<u>History</u>

- emerged as a direct departure from the more traditionally based approaches, where children's special needs were viewed as problems to fix or rehabilitate (McWilliam, 1992).
- over the last thirty years, several historical, social, and political influences marked this shift.
- prior to 1960, few early intervention services for families of children with special needs existed. Institutionalized care was the dominant belief and practice.
- the development and implementation of early intervention programs in Canada coincided with changes in the perception about people with disabilities as well as the strong rise of parent advocacy groups (McWilliam, 1992; The Roeher Institute, 1996).
- the self-help and grassroots efforts that emerged in the late 1960s (Dunst, Johnson, Trivette, & Humbly, 1991).
- these major influences forced the federal government to address parents' desire to have their children live in their own communities (Johnson, Gallagher, LaMontagne, Gallagher, Huntinger, et al., 1994).
- in response, the Federal and Provincial Government made it possible for parents and professionals to influence the creation of institutional alternatives (The Roeher Institute, 1996).

- political and social movements in the 1970s, in addition to increased public funds, resulted in a rapid growth of many community-based services for families of children with special needs (Briar-Lawson, 1998; Johnson et al., 1994).
- by the mid-1980s, every Canadian province and territory had community-based early intervention services (The Roeher Institute, 1996).
- although community-based early intervention services emerged as an alternative to institutionalized care, services were based on a traditional medical model.
- help was child-focussed, pathologically oriented, and disability-based.
- during the mid-seventies, however, the growing RECOGNITION and NEED to identify the family as a constant and an important component of a child's life (Seligman & Darling, 1997) as well as the family's RELATIONSHIP with the community (Bronfenbrenner, 1979) marked a shift away from child-focussed intervention strategies to a more family-focused, home-based model of early intervention services (Briar-Lawson, 1998; Wayman, Lynch, & Hanson, 1990).
- the rise of family empowerment-based services directly resulted in the creation of mandated family-centered services in the United States in 1986.
- in Manitoba, family-centered practice with families of children with special needs has been embraced with significant efforts being made to facilitate a shift to family-centered practice in the field.

What Is Family-Centered Practice?

it is a belief it is an attitude it is a way of thinking

- about how services should be delivered;
- about the role of a service provider and parent;
- about the relationship that should exist between parents and service providers

Beliefs About Your Family:

- your family is a constant in your child's life
- your family is the central focus of attention
- your needs and concerns drive all and every aspect of services
- each family member is influenced by the actions of one another
- your child is not viewed as separate from your family
- your family does not operate in isolation
- your family exists within communities: extended family, health care professionals, friends/neighbours, and work and society

Core Values of Family-Centered Practice

(1) Partnership and Collaboration

- developing mutual relationships that reflect family and professional partnership
- sharing tasks and work activities to achieve your family's goals
- creating relationships based on loyalty, trust, honesty, and open communication
- respecting parental authority and final decision-making in matters concerning your child

(2) Strengths-Based

- · recognizing and building on your family's strengths, abilities, and skills
- helping you to develop skills, abilities, and resources that can be seen as strengths

(3) Empowerment-Based

What is Empowerment?

- when families can access knowledge, skills, and resources that enable them to gain positive control of their lives (Singh & Curtis, 1995)
- providing you with opportunities to help you develop the necessary skills and competencies that will help you define for yourself what is best for your family; and
- helping you become active consumers of mobilizing support services (Dunst, Johnson, Trivette, & Humbly, 1991)

(4) Family-Friendly

- Your child can and deserves to grow up with your family,
- As much as possible, services should be provided in-home and in your family's community,
- Your family's home is the ideal setting to gather information about your needs and priorities, to plan interventions, and to provide you with information and education abut services that would reflect your needs (Wayman et al. 1990)
- As your family's needs change over time, services should be provided in a manner that is adaptive, flexible, and responsive (Kinney, Haapala, Booth, 1991)
- Supports and services provided to your family should be designed to fit your family's needs because every family is unique and each family requires services and supports that reflect their individual circumstance (Dunst et al., 1994)

(5) Culturally-Based

- Respecting your ethnicity and culture
- Being sensitive to and aware of cultural differences
- Respecting and honouring your family's cultural beliefs, tradition, religion socioeconomic status and styles,
- Valuing and strengthening ethnic resources and community supports



• Understanding your values, beliefs, and practices

Be(A)ware of ...

GROUP STAGE DEVELOPMENT ISSUES

The Middle Stage of Group Development

Toseland and Rivas (2001) state that the middle stage of group development is a time when "groups are focused on accomplishing the objectives, goals, and tasks developed earlier in the life of the group" (p. 255). Trust, cohesion, and open communication also characterize the middle stage of group process. Remember that this is also the stage where there may be a period of testing, conflict, and adjustment as group members attempt to establish themselves in the context of the larger group. This is a normal and natural part of the middle stage (Toseland & Rivas, 2001). I will identify possible issues that may come up during the group and provide suggestions for how you might respond to these issues.

Member Issues

Corey and Corey (1987) state that the middle stage (which they refer to as the working stage) is characterized by the members' willingness to explore personally meaningful experiences. This is a time when members are open to practicing new skills,

listening to new ideas, and providing feedback to one another. Activities that help members orient themselves towards achieving the objectives that have been pre-defined include brainstorming, small group activities, and large group discussions.

Facilitator Functions

As the facilitator, you must help members become fully included and encourage full participation. To empower group members, you need to focus on their strengths, and ensure that there is continued progress towards the group objectives and towards the objectives of the individual group members. The essential tasks of validating parents' experiences, concerns, and feelings will foster group cohesion and trust.

MODULE THREE

WHAT IS THE ROLE OF MY WORKER?

Presentation

Purpose: to provide information about the role of the

worker

Time: 15 minutes

Material Needed: overhead and

transparencies

WHAT YOU SHOULD KNOW ABOUT THE ROLE OF THE WORKER

A family-centered approach to service coordination is based on family-support principles that enable families to help themselves (Dunst & Trivette, 1989). Family support principles are predicated on the assumption that families possess the ability to set goals, make decisions, assess their needs, and determine what is best for themselves (Bennett et al., 1992). Essentially, family-centered service coordination is based on a belief that services must be provided in a manner that is respectful of the rights of parents, focuses on family strengths and competencies, maintains the integrity of the family unit, focuses on quality of life for children, and reflects a community partnership that is respectful of the family's unique needs. The service coordinator, therefore, is the link between the family and service delivery (Bennett et al., 1992).

Although service coordinators are commonly referred to as case managers, it is my opinion that this term negatively implies that families are cases to be managed and assumes that the social worker's role is that of a "manager". This is not a term that I wish to adopt. Consistent with the language of family-centered practice, the term "service coordinator" clearly identifies the role of the social worker as someone who is responsible for facilitating the coordination of services with families. Gallagher and Desimone (1995) suggest that if professionals are viewed as consultants instead of experts, family participation is likely to increase. Viewing the professional as a consultant reflects the view of the worker as a partner with family members who identify resources, rather than an expert who provides services (Dinnebeil, Hale, & Rule, 1996).

The interactions between families and professionals prior to goal planning are of critical importance in establishing a positive, trusting, and collaborative relationship with families (Bailey, Winton, Rouse, & Turnbull, 1990). Dunst and Trivette (1989) state that help-giving is most effective if professionals: (1) assume a positive and proactive stance toward families; (2) emphasize the families' responsibility for solving problems and meeting needs; (3) assume that all families have the capacity to understand, learn, and manage events in their lives; (4) build upon family strengths rather than correct deficits; (5) proactively work with families in an anticipatory fashion rather than wait for things to go wrong before intervening; and (6) promote acquisition of competencies that permit families to become better able to negotiate their developmental course. These authors further suggest that enabling and empowering professionals: (a) place major emphasis upon helping families identify and prioritize the needs from their own and not a professional's point of view; (b) encourage active family participation as part of mobilizing resources to meet needs; (c) use partnerships and parent-professional collaboration as the foundation for creating opportunities for families to become more capable and competent; (d) provide families with the necessary information to make informed decisions about their needs and courses of action to meet needs; and (e) accept and support decisions made by families.

Malone, McKinsey, Thyer, and Straka (2000) state that the service coordinator must have demonstrated knowledge related to child development, issues facing families who have children with special needs, and community resources that are available to meet the needs of families (Malone et al., 2000; Summers, Brotherson, & Turnbull, 1990). In cooperation with families, service coordinators:

- assess child and family strengths and needs;
- assist in developing Individualized Family Support Plans;
- link families with needed services and supports;
- listen to family members and support them in achieving their goals;
- monitor outcomes; and
- advocate on behalf of families (Bennett et al., 1992; Dunst et al., 1988, 1994).

Service coordinators can promote a family-centered atmosphere (Bennett et al., 1992) by viewing families as competent, helping families develop skills, establishing a partnership with families, empowering families to become active decision makers, and building on family strengths with sensitivity and respect (Summers et al., 1990).

Dunst et al. (1988) identified twelve help-giving principles: (1) be positive toward the family; (2) offer help rather than wait for it to be requested; (3) allow the family to make the decisions; (4) give help that is culturally familiar and does not imply incompetence on the part of the family; (5) give help that matches the family's perceived need for help; (6) make sure the cost (financial and psychological) of receiving help does not exceed the benefit to the family; (7) accept but do not expect some form of repayment that might be informational or emotional, and less often material; (8) try to arrange for immediate success in the family meeting its stated needs; (9) promote the use of the family's natural, informal support networks, rather than supplanting those with formal, professional networks; (10) convey a sense of partnership in meeting the need; (11) help the family acquire skills to meet future needs independently; and (12) promote the family's ability to see improvement and to feel responsible for producing the change.

Service coordinators can help parents decide for themselves to what extent they would like to actively participate in the planning, implementation, and the monitoring of services and supports. Relinquishing decision-making to family members as well as facilitating parental decision-making skills in order to enable parents to participate at a level that suits their needs is the ultimate goal of the service coordinator (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993).



Check ...

WHAT YOU NEED TO COVER WITH PARENTS

15 minutes—overhead and transparencies

KEY POINTS TO COVER WITH PARENTS:

- work together with you and your family
- offer and coordinate appropriate referrals to services that are available in your local community,
- monitor the effectiveness of those services being provided, and
- assist you with any changes that need to be made to ensure that services are being delivered effectively
- provide you with information you need to make decisions about the supports and services you require to meet the needs of your child and family, assist you in choosing and obtaining those resources
- encourage a working relationship based on loyalty, trust, honesty, respect, and full disclosure (Zipper et al., 1993)
- focus on your needs and priorities
- engage in an open process of assessing, listening, and negotiating with you (Bailey, 1987)

THE FIRST CONTACT

- home visit
- provide you with an overview of services
- gather information:
 - your family members' names and birth dates;
 - your child's special needs;
 - your child's daily living skills, interests, strengths, health status, behaviour, and support needs;
 - your family's strengths;
 - your child's preschool program/school program;
 - your supports in the community, including professional involvement;
 - your family's current circumstance;
 - your understanding of your child's diagnosis; and
 - your needs and service priorities



Be(A)ware of ...

GROUP STAGE DEVELOPMENT ISSUES

You are still in the Middle Stages of Group Development

As members become more comfortable in the group and cohesion is developing, communication within the group is becoming more open, members begin to interact more freely and directly, members begin to feel supported in their attempts to participate in group discussions and activities.

It is also important for you to be aware of the fact that this may be a time where potential tension might arise. It is essential that you understand that you cannot avoid conflict from surfacing. Remember, this is normal (Corey & Corey 1987; Toseland & Rivas, 2001). Conflict and group tension must be dealt with, otherwise it may continue to build and result in disrupting group cohesion.

Member Issues

There may be a time when a parent, or several parents talk about their negative experiences in dealing with social workers, obtaining services or coping with the demands of raising a child with special needs. Don't fool yourself into thinking that this would never happen. It happens! And it's important to be aware of some of the ways of dealing with these feelings and experiences.

Facilitator Functions

It is important that you continue to assess group process and ensure that members stay on task. At this stage, it may be easier to offer support by validating members' experiences and feelings but, as this is an educational group, you must also ensure that the discussions remain on track (that is why I've allocated time-limits for each activity!).

Parents who have had negative experiences with service providers and/or who have difficulty coping with the demands of raising a child with special needs may express those frustrations during group discussions. The best way to approach this issue is to validate and normalize parents' feelings. This conveys a genuine and caring acknowledgement of where they are at, and it helps them realize that their feelings are normal. Reframing is an excellent way to de-escalate intense emotions as it allows the discussion to focus on a more positive direction. Perhaps another group member may offer a constructive response based on his/her own experiences. Make sure, however, that the discussion does not deviate from the session topic. Should this occur, simply remind the group that what is being shared is important but there is still quite a bit of material to cover. You may want to suggest that, if at the end of group there is enough time, perhaps the issue could be further addressed. This approach conveys to the members that you care about where they are at, but you must ensure that there is enough time to conduct the rest of the session. Remember that consideration is needed when you attempt to balance expressed feelings related to the content of the session and educational objectives.

Perhaps, most importantly, you must realize your own emotional response to tension and conflict. Remaining calm and reacting in a non-defensive manner is critical.

As questions and comments may be directed towards you specifically (for example, "are you a parent?" or "what do you know about raising a child with special needs?"), it is important that you respond directly and honestly. This will convey genuineness to members who may feel upset.

MODULE FOUR

WHAT IS MY ROLE AS A PARENT?

Presentation

Purpose: to provide information about the role of parents

Time: 15 minutes

Material Needed: overhead and transparencies

Procedure: discuss needs and aspirations, strengths and capabilities, and sources of support

WHAT ARE MY RIGHTS?

Activity

Purpose: to provide parents with an opportunity to learn about what their rights are

Time: 5-10 minutes

Material Needed: flip chart paper, marker

Procedure: ask parents to form small groups and ask them to create their Bill of Rights (i.e., ask them to describe the manner in which they should be treated by service providers)

Discussion

Purpose: to come together as a larger group and share what each group came up with

- provide the group with additional rights if any are missing

Time: 10 minutes

Material Needed: None

WHAT YOU SHOULD KNOW ABOUT THE ROLE AND RIGHTS OF PARENTS

The involvement of the family in decision making is one of the key aspects of family-centered practice (Judge, 1997). Literature on the principles of a family-centered practice suggests that service provision must involve parents as equal collaborators who hold parental authority, are viewed as experts of their own situations, and are in the position of making final decisions in matters concerning their family (Dunst et al., 1988 & 1994; Farel et al., 1997; Shelton, Jeppson, & Johnson, 1987; Williams, 1995; Zipper et al., 1993).

McWilliam (1992) states that families' roles place more emphasis on decision-making, providing information, and using their own resources in the intervention process. In terms of decision-making, a family-centered approach to practice emphasizes the importance of giving families choices in how assessment, intervention planning, and interventions are conducted. More specifically, parents should be given the choices about what assessment process will be used (e.g., questionnaires, focused interviews, standardized testing, and/or informal observation), what interventions plans will be implemented and what the nature of those interventions will be. In terms of providing information, this relates to family members providing information that is important to the family, information about their child in the context of the family, and the functioning and resources of the family unit. With respect to the use of available resources, the family is responsible for deciding how much it wants to use its own resources. These include personal characteristics of the adults, physical resources, informal support, and formal support networks (McWilliam, 1992).

Hodges (2000) states that practitioners must support and encourage parents to be able to exercise these rights and allow for parents to be active participants in the planning process. Minke and Scott (1993) state that greater attention needs to be given to parental control of goal-setting and that parents who fill out summary forms of child and family strengths, needs, and goals have been found to be more active in the goal-setting process. These authors recommend that parents be given the option regarding how active they would like to be in this process. Judge (1997) found that parents experiencing highly effective help-giving practices that actively involved them in making decisions and choices indicated greater degrees of perceived control. However, the literature also suggests that the extent to which parents are involved in the planning, implementing, and monitoring process varies with each family and that variation must be honoured and respected (Joanning et al., 1994; McCurdy & Daro, 2001; Minke & Scott, 1993; Zipper et al., 1993).



Check ...

WHAT YOU NEED TO COVER WITH PARENTS

15 minutes—overhead and transparencies

POINTS TO COVER WITH PARENTS:

- You and your family play a crucial and central role
- You are the most important advocate for your child and family
- By sharing what you know about your child and family with your social worker and other service providers, you and your family assist them in providing the services that best meet your overall needs
- Your needs and concerns drive all aspects of services

It is up to you to decide who should be involved in the decision-making and planning process for your family and to what extent these people will be involved

Your team evolves and is directed by your service needs

- Each parent and professional brings something unique to the team, and the experience, knowledge, and skills of each team member can be used to make good decisions.
- You may want to participate actively from the time you first make contact, or you
 might choose to play a less active role in the beginning. For most families, the level
 of involvement will vary over time, depending on the changing needs of your child
 and family

YOUR TEAM

- Your social worker should try to make sure that the entire team understands your desires and needs.
- It is up to you to decide which meetings to attend.
- If you decide not to attend a meeting, your social worker can represent your family's views to other team members.
- Who is on your team will depend on the needs of your child and family, your family's desires, and the professionals who are in your community.
- You may want to include grandparents, other family members, or friends.
- Your team may include some of the following professionals:
 - The nurse
 - The paediatrician
 - The occupational therapist
 - The physical therapist
 - The nutritionist
 - The psychologist
 - The speech and language specialist
 - The audiologist
 - Other social workers
 - The teacher/preschool staff
- You will decide, based on your family's resources, priorities, and concerns, how much involvement you will have in the planning process.
- You may have as little involvement or as much involvement in this process.

WHAT ARE MY RIGHTS?

Flip chart and Markers

Ask parents to form small groups Ask them to create their Bill of Rights: describe the manner in which they should be treated by service providers

5 - 10 Minutes

Discussion:

To come together as a larger group and share what each group has come up with

10 Minutes

What Are My Rights?

- You have the right to be an active participant in planning for your child
- You have the right to have certain information kept confidential by the professionals working with you and your child
- Service providers must have your permission to send or receive information to other professionals
- You have the right to look at the paperwork on your child's assessment, eligibility, and Individualized Family Support Plan
- You have the right to decide what should be included in the IFSP for your child
- You have the right to make the final decisions about what assessments are done and what services are provided for your child
- You have the right to know that services should not be provided without your informed written consent
- You have the right to decide how much you want to be involved in this planning process
- You have the right to accept or decline services



Be(A)ware of...

GROUP STAGE DEVELOPMENT ISSUES

You are still in the Middle Stages of Group Development

Member Issues

Because this module addresses the role and rights of parents, members may begin to comfortably take risks in disclosing how difficult it has been to cope with the demands of raising a child with special needs. In light of funding cutbacks and lack of resources, this subject may be difficult for some parents to objectively explore with enthusiasm. How will you handle members who become emotionally upset over issues that have caused them significant stress? Or, how would you handle distractions or tension directed towards you as a service provider?

Facilitator Functions

Continue to validate and normalize parents feelings. Conveying a genuine and caring response acknowledges where members are at. Remember to try to steer back to the session topic.

For a member who is distracting or interrupting others, you may want to remind all the participants of the group's agreement of the ground rules. This will convey the message that you are aware that the rules are not being followed. Addressing it to the larger group delivers the message subtly and collectively. If you feel you need to take a

more direct approach, you may want to ask those members if they still wish to take part in this discussion and explain, in a respectful manner, that their behaviour is distracting others.

For the member who is dominating group discussions, you may want to ask for contributions from other members, particularly other members who have not had an opportunity to speak. In terms of addressing that particular member, state that you would like to hear from others in the group. These statements, whether they are subtle or more direct (depending on the nature of the disruption) will convey to the other members that rules need to be consistently followed and that you are being conscious of all members.

MODULE FIVE

WHAT IS AN INDIVIDUALIZED FAMILY SUPPORT PLAN?

Presentation

Purpose: to acquaint members with the development of the IFSP, to share its process, elements, and components

Time: 30 minutes

Material Needed: overhead, transparencies, handouts

WRAP UP (for two-session group format) **Purpose:** to summarize, answer any questions, get parent feedback in terms of what they have learned

WHAT YOU SHOULD KNOW ABOUT INDIVIDUALIZED FAMILY SUPPORT PLANS

The implementation of family-centered practice is guided by the development of what is commonly referred to as an Individualized Family Service Plan (Dunst et al., 1988; Bailey et al., 1986; Seligman & Darling, 1997). Bailey et al. (1986) provided a "goodness of fit" or functional approach for planning, implementing, and evaluating support services, whereas Dunst et al. (1988) developed a model based on helping families identify their own needs, aspirations, strengths, capability, supports, and resources. A modification of the word "service" to the word "support" reflects a broader range of resources that families access (Bennett et al., 1990), and is a term that I have adopted.

Individualized Family Support Plans are working documents that reflect a family-centered approach to not only identifying the individualized needs of families who have children with special needs, but include an action plan that contains information on obtaining the supports and services that are necessary to strengthen the family unit (Fewell, 1991; Moroz & Allen-Meares, 1991). This document is often referred to as the blueprint for identifying family strengths, competencies and sources of support, and it includes an evaluative component to achieving family-defined goals (Boone, Moore, & Coulter, 1995; Seligman & Darling, 1997).

The IFSP is guided by four values that "enable, empower, support, and strengthen family functioning" (Deal, Dunst, & Trivette, 1994, p. 67). The overall purpose of the IFSP is to develop and implement a program for not only the child with

special needs, but for the entire family (Joanning, Demmitt, Brotherson, & Whiddon, 1994). In addition, it outlines the child's and family's strengths, needs, and the goals, it identifies supports and services required to achieve those goals and is developed within the context of a multidisciplinary team-based approach (Joanning et al., 1994). The IFSP process includes three phases that overlap in an on-going process: (1) establishing rapport and assessment; (2) development of the IFSP; and (3) implementation of the IFSP (Joanning et al., 1994).

Procedures for identifying family strengths and needs are numerous and varied.

These range from the use of standardized and validated family assessment tools (Krauss, 1988; Meisels, 1988; Salisbury, 1989; Walker & Crocker, 1988), structured checklists to identify family needs (Dunst et al., 1988; Deal, Dunst, & Trivette, 1989), and semi-structured interviews (Bailey, 1988). Summers et al. (1990) discovered that parents were more receptive to the use of informal information-gathering processes, primarily in the initial stages of the assessment process. However, Sexton, Snyder, Rheams, Barron-Sharp, and Perez (1991) found that current best practices indicate that identifying family needs and strengths should involve the use of multi-methods, depending on the preferences of parents.

Slentz and Bricker (1992) assert that family assessment and intervention should be family-guided, rather than family-focussed. As the family guides the content of the assessment and intervention, service provision becomes individualized according to the family's membership, priorities, values, culture, and activities. These authors advise that the intent of collecting family information needs to been conducted in a manner that

enhances the development of the child in the context of the family and only information that facilitates meeting the family's objectives should be obtained.

The IFSP reflects the following principles: 1) the development of the IFSP is done within the context of collaboration and partnerships between the family and human service practitioners (McGonigel & Garland, 1988); 2) any and all information included in the IFSP is done so with the explicit permission and authorization of the family (Dunst & Paget, 1991); 3) the development and the revision of the IFSP should be responsive to the broad-based needs of families, although no human services practitioner or program should be expected to offer support to meet all family needs (Dunst et al., 1988); and 4) both the development and implementation of the IFSP should emphasize promotion of the competence of the family and interdependence with members of the family's community (Dunst et al., 1988).

The document includes eight elements that lead to the development and implementation of the IFSP. These are: 1) family concerns, 2) family needs, 3) outcome statement, 4) resources and support, 5) courses of action, 6) family strengths, 7) partnership, and 8) evaluation (Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne et al., 1984; Rappaport, 1981, 1987).

Dunst et al. (1988) developed a format for writing IFSPs. They divided the IFSP into two parts. Part one includes the following information: 1) the name of the human services practitioner, 2) a statement of the child's strengths and current levels of functioning, 3) a statement of the family's strengths and interfamilial resources, and 4) a cumulative record of the specific services, programs, community agencies, and other community supports and programs accessed by the family.

Part two, referred to as the "working" document, includes: 1) a list of family identified needs, aspirations, and desires in order of priority, 2) a series of statements regarding the sources of support and resources that will be mobilized to meet the family's needs, 3) a series of statements regarding the actions that will be taken to mobilize resources, and 4) procedures for evaluating the extent to which needs are met (Dunst et al., 1988, p.67).



Check ...

WHAT YOU NEED TO COVER WITH PARENTS

30 minutes—overhead and transparencies

- a document that reflects your family's individualized support needs.
- Your worker will initiate this process.
- This plan is developed in partnership with your social worker.
 - a working document;
 - an action plan;
- reflects a family-centered approach to identifying the individualized needs of your child and family
 - contains information on obtaining the supports and services that are necessary to strengthen your family (Fewell, 1991; Moroz & Allen-Meares, 1991)
 - identifies family strengths, competencies and sources of support, and includes an evaluative component to achieving family-defined goals (Boone, Moore, & Coulter, 1995)
- guided by four values that enable, empower, support, and strengthen families
 - 1. the development of the IFSP is done in partnership between you and your worker;
 - 2. any and all information included in the IFSP is done so with your explicit permission and authorization;
 - 3. the development and the revision of the IFSP should be responsive to your needs, although services are limited by their availability; and

4. both the development and implementation of the IFSP should emphasize promotion of the competence of your family

DEVELOPING YOUR INDIVIDUALIZED FAMILY SUPPORT PLAN

1. Assessment Planning

- May involve:
 - collecting and pulling together information from those who are familiar with your child
 - seeking new information in order to identify your child's strengths and needs.

2. Your Child's Assessment

- Two main ways:
 - 1. Various professionals may talk with your family and others who know your child
 - 2. Specialists may observe and test your child's behaviour and abilities
- Your worker is responsible for ensuring that your wishes and concerns guide the assessment
- You are in charge of the assessment and can help to see that your child receives appropriate services by participating actively in this assessment process

3. Identifying Your Family's Concerns, Priorities, and Resources

- Your worker will do a family assessment with you in order to understand the needs of your child and family
- Your worker may use some measures to help get to know your family:
 - Family Needs Scale
 - Family Functioning Style Scale
- You can share as much or as little information as you wish

4. Developing Your IFSP

- You and your worker will work together to develop your IFSP
 - In developing your IFSP, you may need to make choices about priorities, and about the activities and services which could help your family in caring for your child and achieving what you want for your family.

This is the time to talk about your child and ask as many questions as you deem necessary.

COMPONENTS OF THE IFSP

Two Parts:

Part One

- includes the following information:
 - 1) the name of the human services practitioner,
 - 2) a statement of your child's strengths and current levels of functioning,

example: Curious, happy, persistent

3) a statement of your family's strengths and interfamilial resources,

example: Family and extended family devoted to Sarah's progress

4) a cumulative record of the specific services, programs, community agencies, and other community supports and programs accessed by you

example: Early Intervention Program
Church
Extended family

Part Two

- referred to as the "working" document
 - 1) a list of your family's identified needs, aspirations, and desires in order of priority,

<u>example</u>: Family will obtain a physical therapy evaluation for Ricky in order to plan activities to encourage independent walking

2) a series of statements regarding the sources of support and resources that will be mobilized to meet your child and family's needs,

example: Physical therapist will assess Ricky's motor skills

3) a series of statements regarding the actions that will be taken to mobilize resources, and

<u>example:</u> Parents will make an appointment with the physical therapist and participate in the assessment

4) procedures for evaluating the extent to which your family's needs are met (Dunst et al., 1988).

5. Carrying out your IFSP

- after the IFSP has been developed, the activities specified in the plan should be carried out
- your worker is responsible for coordinating this process, and should be in regular contact with you through phone calls and informal meetings as well as more formal meetings
- these meetings should be held at a place and time that is convenient for you

6. Review of the IFSP

- you and your worker will periodically review the IFSP to see how well the needs of your child and family are being met
- the IFSP may be modified at any time to meet your family's needs as they change
- any updated information from you and your family is a critical part of this review process

PART TWO ORIENTATION TO SUPPORTS AND SERVICES

Introduction

Time: 5 minutes

A Parent's Perspective

Time: 30 minutes

Break

Time: 15 minutes

Guest Speakers

Time: 60 minutes

- Representatives from the Day Care
Office, the Department of Education, the
Department of Family Services, and the
Association for Community Living

Orientation Guide

Time: 10 minutes

- an overview

Wrap Up

Time: 15 minutes

- round robin check out

- what was one thing that each learned that s/her did not know

before?

- what will each person take with

them when they leave?

Evaluations

Time: 10 minutes



Be(A)ware of ...

GROUP STAGE DEVELOPMENT ISSUES

The Ending Stage of Group Development

Toseland and Rivas (2001) state that termination and consolidation characterize the ending stage. This is the stage where the group is coming to a close, the objectives of the group members are achieved, and the members are preparing for termination.

Member Issues

For members, the ending stage of group development is an opportunity to express what the group experience means to them (Corey & Corey, 1987). Members need to be given an opportunity to talk about what they have learned about the information and skills acquired, about themselves, and about other members. Consolidating learning also includes an exploration of how they can incorporate what they have learned in to their every day life. More importantly for some members, they may want to talk about the impact that the end of the group may have on them.

Facilitator Functions

Toseland and Rivas (2001) list several facilitator functions. These include: 1) dealing with any unfinished business; 2) helping members work through the members'

feelings about termination; 3) encouraging members to talk about what they've learned and review group experience; 4) highlighting members' strengths; and 5) planning for the future.

It is important for you understand your role, in this stage, is to help members deal with any issues they might have about ending the group. And it is therefore important to allow time for members to express their feelings, thoughts, and concerns.

The end of group is a time where you can share with members what this experience has been like for you as a facilitator. Being honest about your feelings and discussing the positive interactions you've observed will help members feel as if you are sharing your power with the group by conveying what *you* have learned.

This is also the opportunity for you to ask for member feedback in terms of the strengths and needs of this particular group. In addition to verbal responses, an evaluation form would provide this kind of feedback.

CONCLUSION

Parent education, in the area of family-centered practice, represents exciting possibilities. It is an empowerment practice that marks a dramatic shift in the way that families view themselves in the context of accessing supports and services. As I firmly believe that knowledge is power and education is a key aspect to empowering families, it is my belief that parent education will equip parents with the skills, abilities, and competencies to enable them not only to define what is best for their family but will guide them in their endeavour to procure family-defined and family-governed supports and resources. Parent education groups, therefore, represent one method of facilitating parental empowerment.

I hope that you have found this training manual to be informative and useful.

Although the primary purpose of this particular type of group is educational in nature, it is important that you understand not only the essential aspects of running this group, but most importantly, you create an atmosphere that encourages, offers, and facilitates support. An understanding of all the elements described in this manual will provide you with a comprehensive approach to developing your own curriculum.

To conclude, I would encourage you to reflect on your learning and identify your own value base as a group facilitator. The decisions you make and the approaches you take reflect the values that you possess. How will you share the power that you hold as a group facilitator? How will you ensure group dynamics develop in a positive manner? How will you effectively run your parent education group? The answer to these questions will form your foundation and will guide you in your own practice.

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APPENDIX D

LETTER TO THE PARENTS

April 22, 2002

Dear Parents,

As part of the Family Strengths in Childhood Disability Project we have decided to offer information sessions to a random selection of parents who are participating in the research. These parent groups will provide you with an opportunity to learn about accessing the supports and services you require. Topics to be covered will include:

- What family-centered practice means;
- Your rights as parents;
- The role of your social worker;
- How to develop a plan that is designed to meet your needs (Individualized Family Support Plan); and
- How to access the supports and services you require.

At this point, we are in the process of exploring the possibility of running two types of groups:

- (1) (1) A full-day workshop (six hours), or
- (2) Two evening sessions (three hours each)

Dona Camara, a social worker experienced in the field of childhood disability, will be facilitating these groups as part of her graduate work in the Faculty of Social Work at the University of Manitoba. She will be contacting you in the next week to discuss this opportunity with you, to provide further details, and to answer any questions you might have. Please note that your participation in this group is completely voluntary. We hope that you will consider taking advantage of this opportunity and that it will be beneficial to you.

If you have any questions, please feel free to contact me at 474-8283.

Sincerely,

Diane Hiebert-Murphy, Ph.D. Co-Investigator, Family Strengths in Childhood Disability Project

APPENDIX E

CONSENT FORM

Consent to Participate in the Parent Education Group

Further to my involvement in the Family Strengths in Childhood Disability Project, I consent to participate in the parent education group. I understand that this component of the project is being completed as part of a Master of Social Work program.

I understand that my participation in the parent group is voluntary and that my decision to participate or not will not affect the services I receive from Children's Special Services and will not affect my participation in the Family Strengths in Childhood Disability Project. My participation will involve attending the parent group session and providing feedback about the group. I understand that I do not have to answer any questions that I do not want to and that I am free to withdraw from the group at any time. I understand that any information I provide will be kept confidential and only shared with the research team, with the exception that if any information is shared about children being at risk of abuse this information must by law be reported to the mandated child welfare agency.

I understand that when completed the experience of providing parent education groups will be written about in a practicum report. The knowledge gained from this experience may be presented to professional audiences and may be written about in professional journals. I understand that my identity as a participant of the group will always be kept confidential in any sharing of information about the parent education group.

Date:		
Signature:		

APPENDIX F

THANK YOU LETTERS

June 10, 2002

Dear Parents:

Thank you for agreeing to participate in the parent group!

I know how busy you are, so I really appreciate the time you'll be taking to spend with us. I value your involvement and am looking forward to any feedback you would like to share with me.

See you soon, Dona

When:

June 22, 2002

Where:

Association for Community Living Winnipeg

980 Palmerston (off of Ruby St.)

- side entrance near the back of the building

- downstairs

- parking available

What Time:

9:00 a.m. - 3:00 p.m.

Refreshments and lunch will be provided

p.s.

We'll have a poster board for family pictures. So, if you'd like to bring pictures of you and your family, that would be great!!

Don't worry, they will be returned to you at the end of the session.

June 10, 2002

Dear Parents:

Thank you for agreeing to participate in the parent group! I know how busy most of you are, so I really appreciate the time you'll be taking to spend with us. I value your involvement and am looking forward to any feedback you would like to share with me.

See you soon, Dona

When:

June 26 and 27, 2002

Where:

Association for Community Living Winnipeg

980 Palmerston (off of Ruby St.)

- side entrance near the back of the building

- downstairs

- parking available

What Time:

6:00 - 9:00 p.m.

Refreshments will be provided

p.s.

We'll have a poster board for family pictures. So, if you'd like to bring pictures of you and your family, that would be great!!

Don't worry, they will be returned to you at the end of the session.

APPENDIX G

BILL OF RIGHTS

OUR BILL OF RIGHTS AS PARENTS

- To be WHO we are
- Do not pass judgment
- Do not assume what you call a support is a support to us
 We are capable of making decisions for our child—respect our choice
- Remember CONFIDENTIALITY
- To have information and access to training
- Education for ourselves and our family
- Our child has a right to inclusive education

From The Fathers:

- Treat us with respect
- We do our best—we have not failed
- We need to be understood and people need to take the time to understand us
- Don't assume that we don't need help (when we don't ask)
- Don't judge until you walk in our shoes
- Respect our separate views as fathers

The parents June 22, 2002

GROUP TWO:

OUR BILL OF RIGHTS AS PARENTS

- WE DON'T WANT TO ALWAYS HEAR ABOUT SCARCE RESOURCES. TALK TO US ABOUT ALTERNATIVES.
- WE WANT TO BE TREATED RESPECTFULLY REGARDLESS OF OUR SOCIO-ECONOMIC STATUS OR THE NATURE OF OUR CHILD'S DIAGNOSIS.
- WE HAVE A RIGHT TO KNOW ABOUT SERVICES.

The Parents June 26, 2002