UNIVERSITY OF MANITOBA

FACULTY OF SOCIAL WORK

THE IMPLEMENTATION OF SUPPORT GROUP INTERVENTION
FOR PARENTS OF PERSONS WITH DEVELOPMENTAL
DISABILITIES LIVING IN A RESIDENTIAL CENTRE:

A STUDY OF STRESS, COPING AND SOCIAL SUPPORT

A Practicum Report Submitted to
the Faculty of Graduate Studies in
Partial Fulfillment of the Requirements
for the degree of Master of Social Work

BY

IVY F. KOPSTEIN

(C) JUNE, 1992

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ABSTRACT

THE IMPLEMENTATION OF A SUPPORT GROUP INTERVENTION FOR PARENTS OF PERSONS WITH DEVELOPMENTAL DISABILITIES LIVING IN A RESIDENTIAL CENTRE: A STUDY ON STRESS, COPING AND SOCIAL SUPPORT

Parents of persons with developmental disabilities may not have access to the type of support within their own network of family and friends that can provide them with the understanding and empathy that another family in a similar circumstance can provide. This study was designed to implement a support group for parents who have young and adult children living in a residential and resource centre for individuals with developmental disabilities.

Parents participated in a three-hour session each week for eight consecutive weeks to discuss issues relating to developmental disability in the family. Quantitative and qualitative measures were used to gain information regarding group members' coping abilities, support they received from family, their contentment with life and their satisfaction with the group intervention.

Parents perceived that their families were skilled in utilizing coping strategies. While parents reported limited satisfaction with family support they reported an overall satisfaction with their life. Higher scores

on coping were generally associated with higher perceived family support and satisfaction with life; lower scores on coping were generally associated with lower family support and satisfaction with life.

The group provided the opportunity for members to obtain social support that may not have been available to them in their existing social network. The mutual aid processes enabled parents to share feelings, experiences and ideas in a trusting and accepting environment. Individuals felt supported and less isolated as a result.

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CHAPTER 1

INTRODUCTION

1.1   Introduction to Problem Area

Families are constantly changing and adapting to life
transitions and changes that arise from within and
outside the family unit (Hill, 1949, 1958; Walsh, 1982;
McCubbin, Cauble and Patterson, 1982). Families with
children who have developmental disabilities experience
life differently from other families (Seligman and
Darling, 1989), as a consequence of having to adapt to
the many psychosocial and practical implications
resulting from the disability (Beamish, 1988). Given
that developmental disability will have long term
effects, it will continually challenge the family system
to redefine how it will continue to function (Seligman
and Darling, 1989).

The shift from a being a couple to being parents, is
often viewed as a pivotal, life changing transition
point (Walsh, 1982). The common experience of parents
from childbirth and rearing of non-disabled children is
the many options for social support from their family,
friends and neighbours. Unger and Powell (1980)
suggested that social networks provide instrumental
support (material goods and services), emotional support

(communication that the individual is esteemed and loved, and mutually obligated to members of his/her network), and information and referral (information about and location of other, perhaps formal resources). It is this type of support that assists parents in coping with new and/or difficult situations (Gottlieb, 1981). In many of his works, Gottlieb (1981, 1985, 1987), underscored the role of social support as a coping resource and protective factor during times of stress.

The birth of a child with a disability happens relatively infrequently. Therefore the opportunities for the social support that families can gain from sharing their common feelings and experiences with families in a similar situation are limited. Even though family and friends may be supportive, parents still need the special type of support offered by others in a similar situation (Seligman and Darling, 1989). Research has shown that in families with children with disabilities, social support operates as a moderating variable under stressful conditions (McCubbin, Cauble and Patterson, 1982; Crnic, Friedrick, and Greenberg, 1983; Dunst, Trevette, and Cross, 1986). It often becomes necessary to augment the support systems of these families (Gottlieb, 1985).

The social support/mutual aid group is one intervention that professionals have utilized to mobilize social support. According to Gitterman (1986) "the group mutual aid system has the potential to universalize individual problems, reduce isolation, and mitigate stigma" (pg.53). Parent support groups were suggested as a family-based intervention for families who have children with disabilities (Zeitlin and Rosenblatt, 1985).

1.2 Objectives for the Practicum

The purpose of this practicum was to develop, implement and evaluate a parent support group for families who have significantly developmentally disabled children who live at the St. Amant Centre, a centre providing residential and community outreach/support services to developmentally disabled children and adults. It was the hope that this support group would assist parents with the adjustment of having a child with a developmental disability.

The first set of objectives for this practicum relate to the support group intervention and the second set of objectives relate to the expected educational benefits for the student.

Objectives for the Intervention:

(a) To plan, implement and evaluate the parent support group for parents who have developmentally disabled children living at the St. Amant Centre;

(b) To utilize an adaptive perspective involving the concepts of family stress, coping and social support in understanding and intervening with families with handicapped children;

(c) To develop recommendations outlining a mechanism for its continued implementation.

Learning Objectives:

(d) To develop an understanding and current knowledge base regarding the impact of developmental disability on the family through a review of the literature and practical experience;

(e) To develop knowledge of the concepts of social support and mutual aid in coping with the stress as it relates to the family with a handicapped child, through a review of the literature and practical experience;

(f)   To enhance knowledge and skill in group facilitation.

1.3   Practicum Committee

The practicum examining committee comprised two representatives from the University of Manitoba and one external agency representative. The principal examiner was Dr. Don Fuchs, Professor, University of Manitoba Faculty of Social Work. Dr. Fuchs, also Director of the Neighbourhood Parent Support Research Program, has knowledge and expertise in the areas of social work research, social networks, and social support which was relevant for this practicum. Ms. Ellen Tabisz MSW, Adjunct Professor, University of Manitoba School of Social Work, and Social Work Supervisor at the St.Boniface General Hospital was the second member of the committee. Ms. Tabisz has expertise in the area of social work in health care particularly in the areas of research and regarding a variety of support programs. The committee's external member was Dr. Carl Stephens, Assistant Executive Director of Programs at the St. Amant Centre. Dr. Stephens has expertise in the field of developmental disability, research methods, and a working knowledge of program issues related to residents, families and the St. Amant Centre as a whole.

1.4   Organization of this Report

This practicum report explores the theory in the area of
stress, coping and social support that relates to the
implementation of a parent support group for families
with developmentally disabled child. The introductory
chapter describes the focus of this practicum, the
objectives and the practicum committee. In Chapter 2,
the impact of a child with a disability in the family
will be explored through the literature with reference
to the role of social support, mutual aid, and support
groups in helping families cope with stress. Chapter 3
focuses on the planning of the intervention, including
the setting in which the practicum operated, the process
of identifying needs, and recruitment and interviewing
of group members. The standardized and subjective tools
for evaluation will also be described in Chapter 3. In
Chapter 4, attention is drawn to the findings related to
the intervention itself. Individual case examples are
shared as well as the implications of findings on
individual dimensions. Evaluative findings and
implications related to the group as a whole and the
value of the support group as an intervention strategy
is presented in Chapter 5.   Chapter 6 contains an
evaluation and discussion of student learning.

Chapter 7, the final chapter, sets out recommendations for future planning and research and the conclusions of the practicum.

CHAPTER 2

LITERATURE REVIEW

2.1 An Adaptive Perspective

There has been considerable research documenting the hardships and difficulties families experience with a disabled child (Fowle, 1968; Farber and Rowitz, 1986). The literature is now however balanced with research focussing on family strengths and factors that lead to positive adaptation to a handicapped child (Longo and Bond, 1984; Trute, 1987; Trute and Hauch, 1987; Trute and Hauch, 1988).

In addition to suggesting more optimistic effects, the literature also discloses more holistic and adaptive frameworks that can be employed when working with these families. An ecological systems model (Germain, 1977, 1981, 1985) is the underlying premise from which social work practice currently operates. The perspective of the family being a "microunit of society, an environment and source of resources for all its members including a handicapped member" (Buboltz and Whiren, 1984:5) recognizes the transactional processes between people and their environments. The assumption is that people change and adapt to changes in their physical and social

environments. The central concept of 'person-environment-fit' refers to "the degree of congruence between an individual's needs, capacities, and aspirations and his environment's resources, demands and opportunities" (Coulton, 1985:5). The need to adapt to change causes disturbances in the "'goodness-of-fit' between individual needs and capacities and environmental qualities" (Schulman and Gitterman, 1986:4) which in turn often create stress and tension. Stress can be a motivating force unless the demands on energy and resources are too great when the intensity can be overwhelming and can result in breakdown of the family system (Buboltz and Whiren, 1984). The social work role/goal is to assist the individual to improve this fit by intervening at a variety of different levels. Interventions may be focused on the individual, the family, the environment, or a combination of these.

It became apparent upon the review of the literature that stress reduction and mediation of stress would most likely be the focus of intervention with families with handicapped children (Gallagher, Bechman and Cross, 1983; Buboltz and Whiren, 1984; McCubbin and Patterson, 1984). A review of the literature also suggests that social support is a mediator of stress caused by childhood disability (Crnic, Friedrick and Greenberg,

1983; Kazak and Marvin, 1984;) and mobilizing such support (Gottlieb, 1985; Shulman and Gitterman, 1986) is perhaps the most natural way professionals can assist families in addressing these life changes.

Therefore, the research and theory in the areas of stress, coping and adaptation, and the role of social support and mutual aid in helping families adapt to the continuing changes that result from childhood disability, provides the literary framework and rationale for this practicum. The social support group receives particular attention as an intervention strategy to assist parents to cope with the stress associated with the challenges imposed by developmental disability of their children.

2.2   Impact of Developmental Disability on the Family

At various points so far in this report reference has been made to the concepts of family stress, coping and adaptation. These concepts will be expanded upon in this section. Although the literature supports the notion that families with children with developmental disabilities experience stress, this notion must be accepted with caution. Crnic et al. (1983) summarize many of the limitations of the research. Not only does

the research yield inconsistent findings but it is uni-dimensional in that it focusses most frequently on only one parent (usually mothers) and often only measure one variable. The research is also unimodal in that studies generally have only used one type of measure. Furthermore, many studies are descriptive in nature and while they offer valuable case specific information, it is difficult to generalize the findings. There is also a lack of longitudinal research that studies family adaptation and functioning over time (Crnic, Friedrich, and Greenberg, 1983). The adaptational model was chosen because of its holistic or ecological base and has been helpful in understanding and explaining the inconsistent findings and variability of family response. Finally, the role of social support and mutual aid in mediating the effects of stress is discussed with reference to the social support/mutual aid group.

2.2.1 Family Stress, Coping and Adaptation

The literature has linked specific child characteristics to stress experienced by parents of mentally retarded children. Responsiveness, temperament, repetitive behaviors, maladaptive behaviors, and additional or unusual care demands were examples of child characteristics that were significantly related to the

amount of stress reported, mainly by mothers (Bristol and Schopler, 1984; Beckman, 1983). According to Erickson and Upshur (1989) increased burden of care related to child characteristics was also reported by mothers of children with Down's Syndrome and developmental delays as compared with mothers of non-disabled infants.

Other studies further support the notion that child characteristics play a part in the creation of stress. Stress was measured and compared, in a recent study conducted by Cameron, Dobson, and Day (1991), from the experience of parents of developmentally delayed and non-delayed preschool children. They found that there was a significant difference between the mothers' scores in child acceptability, demandingness, and distractibility.

Another study involved mothers who reported that the additional and often unusual caregiving demands sometimes associated with caring for a handicapped infant were significantly related to increased feelings of depression and decreased feelings of parenting competence (Gowen, Johnson-Marten, Goldman and Applebaum 1989).

Gallagher, Beckman and Cross (1983) identified socioeconomic status, nature of education program and attitudes of others as more general stressors affecting families with disabled children.

Wikler, (1981) identified predictable stressor events in families of handicapped children by distinguishing 10 periods of emerging and re-emerging stress. Five of the 10 critical periods are defined by the chronological age of the child and are related to the ages a non-handicapped child would be reaching developmental milestones. The stress during these periods involves the reality that the child's performance is discrepant from expectations for what should have occurred had the child been non-handicapped. These gaps are always painful reminders for parents of what is expected and what in fact occurs. The five developmental crises Wikler (1981) identifies occur when:

1)   the child should have begun to walk (ages 12-15 months);

2)   the child should have begun to talk (ages 24-30 months);

3)   the child should be starting kindergarten in public school (the child will probably be labeled and may be placed in a special class);

4)   the onset of puberty (tension between physical appearance vs. mental-social ability); and

5)   the 21st birthday (symbolic of independence from the family).

The other 5 periods are considered transitional rather than developmental and are not experienced by parents with non-handicapped children. These periods refer more to discrepancies in expectations of the parenting experience rather than expectations of the child. Often these periods require involvement from professionals which would not be required if their child were non-handicapped. This second group of crises occur when:

6)   the initial diagnosis is made;

7)   a younger sibling with a lower chronological age performs at the same and then higher developmental age;

8)   parents consider others rearing the child (the
        possibility of placement);

9)   child management problems, medical or behavioral,
        require professional help;

10)   it becomes necessary to make decisions about
        guardianship to an outsider or family member, as
        parents age.

Wikler hypothesizes that parent adjustment and
vulnerability to stress are interrelated. Firstly, he
maintains, parent adjustment to a mentally retarded
child is periodic rather than time bound and that the
anticipation of the crisis is, in itself, an
ameliorating factor. Higher family vulnerability is
expressed by Wikler when parents periodically perceive
discrepancies between their expectations and the actual
performance of the child. Wikler adds that when the
expectations of the parenting experience are different
from what occurs, parents and the family become
vulnerable to the negative effects of stress.

McCubbin, Cauble and Patterson (1982) summarized common observations based on the literature of the impact of a child with cerebral palsy (CP) on the family in the following categories:

1.   Altered relationships with friends and neighbors due to their reactions to the CP child along with parental and sibling embarrassment at how the CP child looks and acts leading the family to social isolation.

2.   Major changes in family activities, such as reduced options for family vacations, tightening parental work schedules, reduced flexibility in the use of leisure time, and shared family tasks and responsibilities.

3.   Medical concerns related to side effects with medications, parents learning more specialized medical procedures, home treatment responsibilities, and problems with handling equipment for CP children.

4.   Intra-familial strains including overprotectiveness, rejection of child, denial of disabilities, ongoing worries about the CP child's

safety and care, concerns about the extended parenthood, increase in the amount of time focused on the CP child at the possible expense of other family members, as well as discrepancies between children as a result of uneven physical, emotional, social, and intellectual development. Additional strains emerge from extended family members who may lack the understanding and appreciation of the concerns that parents and siblings CP children have.

5. Medical expenses arising from the costs of specialized treatment and equipment.

6. Specialized child care needs and difficulties related to limited community resources, difficulties in finding the best day care and services, and the extra costs of specialized care.

7. Time commitments that disrupt family routines, such as extra appointments to medical facilities, consultations associated with special education programs, and the predictable although disruptive situation of extra demands on family life due to CP child's personal and emotional needs in the home setting.

8.   Medical consultations, which call for repeated
      efforts to clarify and verify medical information,
      learning and implementing medical and treatment
      plans, and frustrations with the general quality
      of medical care.

The literature referred to in the next few paragraphs
examines multiple variables and factors that contribute
to adaptation.   Friedrich and Friedrich, (1981)
conducted a multidimensional study comparing parents of
handicapped children to parents of non-handicapped
children. Parents of handicapped children experience
more stress and less marital satisfaction, psychological
wellbeing, social support and religiosity. Kazak and
Marvin (1984) also confirmed that parents of handicapped
children experience more personal stress than parents of
non-handicapped children. Although there was no
difference between the marital satisfaction of parents
with and without a handicapped child, many mothers
presented as suffering from "parental burnout", a
condition where it is difficult to even identify the
specific sources of stress to which they are subjected.
The result is that they often feel less competent as
mothers than is appropriate. These authors (Kazak and
Marvin, 1984) suggest that a more highly developed

friendship network through encouraging families to join parent support groups would be beneficial. Support programs may also help to rebuild the confidence and self esteem that is lost from "parental burnout."

In another study Frey, Greenberg and Fewell (1989) examined the mediating influences of child characteristics, social network, parent beliefs, and coping styles on parenting stress, family adjustment and psychological distress of mothers and fathers. Parents reported more stress when their child's communication skill is low. Fathers were affected by the sex of the child more than mothers were. According to the authors, the traditional role of fathers, particularly with sons is one that emphasizes recreation over caregiving. When a child has severe impairments, it limits the father's opportunities to fulfill this aspect of his role.

Another interesting finding is that mothers and fathers differ in the relative importance they attach to social support and criticism. The authors (ibid.) suggest that because mothers shoulder most of the responsibility for child care, they may value child related support more than fathers do. Mothers may also have more contact with people who can provide support, for example other

parents, teachers, and health care professionals. Social support was less important and less available to fathers while criticism was much more important to fathers.

In the same study, the most powerful correlate of parent outcomes involved parental beliefs. Criticism of parental beliefs could in turn, affect parent coping and cause psychological distress. The study also found that the degree that parents negatively viewed their child's disability varied dramatically. Parents would often compare their child's disability to others. For example, one family compared an intellectually gifted child to their child with Down's Syndrome, and another family expressed thankfulness that their Down's Syndrome child does not have a degenerative disease and is physically healthy. The comparative frame of reference utilized by parents in the last example, was found to be an important moderator of parent stress and coping.

The last factor in that study that related to parent coping was the parent's perception of their ability to control their lives. The authors confirm through their literature review the importance of perceived control for psychological well-being.

2.2.2 Factors Involved in Out-of-Home Placement

There is limited literature available on specific factors that lead to the placement of a mentally retarded adult. The most notable research on factors leading to placement was conducted by Black, Cohn, Smull and Crites (1985). These researchers conducted a study of the individual and family characteristics of severely mentally retarded adults referred for placement at a residential facility. They concluded that there is the risk of institutionalization in families where the disabled adult has elderly parents, maladaptive behaviors, high dependency needs and where there is a lack of alternative day program and community living options. Meyer's (1980) study revealed that parents often opted for institutional placement over community residences because they lacked confidence in the stability of community placements.

Minnes (1988) found that characteristics of the child including the child's age, was a significant predictor of parental stress. The concept of higher levels of parental stress as the child grows older was also proposed by Gallagher, Beckman and Cross, (1983). However, while stress associated with a child's cognitive impairment diminished with age, the degree of

stress associated with preference for institutional care increased with age. The reason for this, according to Minnes may be that parents come to terms with their child's cognitive impairment as the child ages, but increased management difficulties due to the child's increasing size, strength and behavior cause considerable disruption and become a greater concern. With the increase in the supervision/care, families may begin to consider residential placement. This decision may be accompanied with considerable stress particularly given the current de-institutionalization trends. Minnes' (1988) study involved findings related to how parent perceptions/expectations of their child's cognitive ability changed over time. It considered the parents' conflict of values in their desire to keep their child at home versus their need to place, but it also considered the environmental pressures that affect families.

Following the theme of placement decisions, Bromley and Blacher (1989) conducted a study of parents of severely handicapped children who were placed out of their home. Parents were interviewed as to what factors delayed the ultimate placement of their child. This study identified some parent perceptions about placement that made the decision to place their child very stressful. Placement

of the child was often viewed as an admission that the parent could not cope with the child or had failed at childrearing. Results stated that guilt feelings were greater the older the child was when he/she was placed. For these parents, separation from the child and the sense of loss may be very intense. For parents of very young children, strong guilt feelings may result from factors related to the child's helplessness and vulnerability.

The literature also indicates that many parents of institutionalized, developmentally disabled children have minimal contact with the setting serving their children (Anderson, Schlottmann and Werner, 1975; Klaber, 1968). The research on parent-child attachment has some relevance here. It is possible that difficulties and disappointments in parent-child interactions offers some explanation as to why contact with the child is limited. Interactions with the child may not have sufficiently developed even prior to the admission therefore parent-child contact continues to be limited once the child is placed.

Zirpoli and Bell (1987) examined the potential effects on parent-child interactions when children, because of severe mental and physical impairments, are unable to

exhibit most social responses. The authors claim that the development of parent-child interactions could move toward risk status if the child is perceived to be unresponsive by parents. They utilized a behavioral approach for explaining parent-child interaction. One important consideration were the expectations the caregiver had of the child. If the expectations are too high, the interactions may be considered unrewarding and this will have an adverse effect on future interactions. On the contrary, if the expectations are too low, current behaviors may not be recognized and rewarded. Because children with severe disabilities may have a limited repertoire of behaviors, parents may not know what to look for as possible interactive behaviors. Using concepts from behavior modification, the authors suggest that an "extinction" phenomena may be involved here. Parents do not receive the same reinforcement for attempts to interact with the child that they have experienced in the past from other children. They therefore interact less and less with the child. Parents also judge their adequacy by their child's responsiveness. Parents with a handicapped child who has a limited repertoire of responses may consider themselves ineffective or failures as parents. Limited parent-child interaction, has serious implications in the attachment process. With any baby, attachment grows

out of the process of parent-child interaction (Seligman and Darling, 1989). The implication is that adjustment to the child's disability is affected by parents' attachment to the child. The authors Zirpoly and Bell (1987) also believe that parental expectations of the child are key in the ability to form attachments to their child.

One more factor that may affect a parent's ability to form attachments to their child is the nature of their physicians early counselling about the child's disability. In a study by Springer and Steele (1980), parents of a child with Down's Syndrome indicated that advice from physicians on certain aspects of their child's future had been quite pessimistic. Based on a literature review these authors found that in the 1950's, most parents of children with Down's Syndrome viewed their physician's opinion as the most important factor regarding where their child should live.

While the current philosophy encourages family care of children with developmental disabilities, there is significant variability in the extent to which families successfully adapt to the presence of a significantly developmentally disabled child in the family. According to the literature the additional factors contributing to

families' level of stress and subsequently to a decision
to place a child in an institutional setting are the
lack of community options and lack of confidence in
community residential services that do exist. Parental
values and beliefs and the availability and quality of
formal and informal supports were also factors related
to family stress and could ultimately influence a
placement decision. It can also be hypothesized that
parent-child attachment affects the ongoing parental
contact once the child is placed.

2.2.3 Impact on Siblings

Research on the impact of a child with a disability on
the family should extend beyond parents, however
research on siblings still lags behind. Given that
"sibling relationships are usually the longest and most
enduring of family relationships" (Seligman and Darling,
1989:111), one would hope that this oversight reverses.
The research that exists suggests that the presence of a
handicapped child in the family provides opportunities
for both growth as well as dysfunction.

Trevino (1979), stresses the importance of including
siblings in the determination of the impact a child with
brain damage has on the family. He asserts that there

are certain characteristics determined by the family system that affect a family's response that are independent of the type and degree of brain damage. This author contends that the likelihood of problems with non-handicapped siblings occur in families in which:

*   there are only two siblings (one handicapped and one non-handicapped);

*   the non-handicapped sibling is close in age or is younger than the handicapped child, or is the oldest female child;

*   the non-handicapped and the handicapped child are the same gender; or

*   the parents are unable to accept the handicap.

Breslau, Weitzman, and Messenger (1980) conducted a study comparing siblings from families with children who had chronic and multiple disabilities to a control group. They found that:

*   the proportion of siblings with impairments was not higher than in the control group;

*   the study sample of siblings did score higher in
       fighting and delinquent behaviors;

*   birth order had a significant interactive effect
       with gender: (Among siblings younger than the
       disabled children, male siblings had greater
       impairment than female siblings, whereas among
       siblings older than the disabled children female
       siblings had more psychological problems.)

Of note also was that the level of disability of the
children bore no relationship to the psychological
adjustment of the sibling. However, the findings
relating age and gender supports some of the earlier
research. For example, Farber (1968) explained that the
presence of a mentally retarded child alters the
family's life cycle in that younger, non-handicapped
siblings will surpass the child with a handicap, and
will often assume adult caretaking functions. Fowle's
(1968) research also supports the notion of role tension
in siblings of children with mentally retardation,
particularly in the eldest female.

On the other hand, most children in Wilson, Blacher, and
Baker's (1989) study, reported their interactions with

their older siblings with severe disabilities in a positive light. They had a high degree of involvement and feelings of responsibility for the child. These children did however, admit to hardships in terms of impact, for example extra stress, more effort, limitations on family activities, anxiety in relation to peers' reaction to the child. Another important finding related to older children and children from lower SES families reporting more caretaking responsibility. The other finding of significance which contradicts previous findings related to age and gender is that children of the same gender and close in age to the child with mental retardation reported more positive impact. Over half these children were interested in participating in supportive sibling groups.

In a study by Dyson, Edgar, and Crnic (1989), psychological predictors of self-concept, behavior problems, and social competence of siblings were identified and compared with siblings of non-disabled siblings. The results showed that a child's adjustment was related to certain family psychological factors. The family's resources that mediate adjustment involve the family's emphasis on personal growth, a positive attitude toward parenting a disabled child, and a

nurturing and cohesive family relationship. This study emphasizes that positive family adaptive responses enhance sibling adjustment.

The above findings indicate the possibility of positive or negative effects accompanying the presence of a child with a disability in the family. The important factors to keep in mind are firstly that siblings are vulnerable, and secondly that sibling reaction is largely influenced by parental values and coping behaviors.

2.2.4 An Holistic Model for Grieving

One of the first reactions to the awareness of a disability is often referred to as a grief reaction. Many authors suggest that parents of children with disabilities pass through a series of stages not unlike the sequence related to death and dying before they can accept the reality of the birth of a child with a disability. Schneider (1984) for example, asserts that in every life 'change event' there is some potential for loss whether the change event is perceived as positive, negative or neutral. He suggests that loss is a source of stress and that change in life contains the potential

for both growth and loss" (pg.5). Although change and loss is a part of everyday life, one rarely relates loss to the birth of a child.

The initial diagnosis of disability warrants special consideration as the crisis of first information or suspicion is viewed by some authors as the most difficult (Seligman and Darling, 1989; Bristor, 1984). Bristor (1984) explored the concepts of loss and grief as they relate to the birth of a handicapped child. She asserted that all parents-to-be form a "mental picture" of their baby with hopes and expectations derived from their own experience. If the baby is born with problems, the "parents must grieve the loss of the `dreamed-of infant' to make the necessary adjustments to begin the process of attachment" (Bristor, 1984:29).

Bristor (1984) applied four elements that Schneider (1983) identified as relating to the nature of the loss experienced by parents following the birth of a handicapped child that affected individual reaction.

The first element is the degree of attachment the person has to the object of loss. Attachments occur when the object, person or belief becomes associated with a particular need of the individual. Examples of needs

early in life might be for protection, food and shelter. Examples of needs later in life might be feelings of competence and belonging and a sense of meaning in life. Where the need for feelings of competence are the basis for an intense emotional attachment formed prenatally, the birth of a handicapped child may result in feelings of failure.

The second element to affect an individual's reaction to loss is the impact of the change in the individual's daily life. The degree of developmental delay and amount of independence a child will reach is unknown in the early life of the child. Parents will not often be sure of the type and degree of care required or the impact the disability will have on their lives. The ambiguity or uncertainty in the amount of care required and of the implications for the family system often lead to confusing feelings of hope and despair. Conflicting emotions may also result when a parent is told that their newborn may not live beyond a certain time period. Conflict may emerge as to whether or not to form attachments to the infant.

The third element has to do with the way the individual has coped with stress in the past. If an individual experienced stress in the past, s/he has already

developed some coping strategies that s/he can utilize when experiencing a loss. Often an individual will utilize the same coping patterns. Bristor (1984) presumes, however, that the magnitude of the loss experienced by the birth of a disabled child, may cause stress that an individual may not have experienced before and may require additional coping resources.

The fourth element that influences an individual's reaction to the birth of a handicapped child is the support system available to the individual. "The support of family and friends gives the individual permission and freedom to grieve" (Bristor, 1984:26). Bristor suggests that a lack of support to grieve may cause a parent to block the process which may then lead to unresolved grief. Unresolved grief can lead to ongoing stress and energy consumption.

Stage theory has often been applied to parents of disabled children and suggests that the birth of a disabled infant is often experienced as the death of the expected normal, healthy baby. Elizabeth Kubler-Ross (1969), one of the most popular writers on the subject of death and dying, and many others have characterized reactions to death and impending death (Appendix 1). Schneider (1984) has proposed similar phases and Bristor

(1983) has applied them to parental, particularly maternal experience in the birth of a handicapped child. Schneider (1984) proposes a holistic model for grieving which emphasizes facilitating the grief process in a way that the possibility of growth may be experienced (Bristor, 1984). The following describes Schneider's phases, with additional explanation and examples adapted from Bristor's (1984) work.

1.   Initial Awareness - In this stage the loss becomes apparent. Physical and mental shock are characteristic of this phase, as is disorganization in the individual's routine and ability to function. Following the birth of a disabled infant, parents may be shocked and overwhelmed physically and mentally. It would be very difficult for new parents to attempt to fully comprehend the situation following the effects of delivery and when the facts are often unclear. The rest of the family may also be shocked and suffer a "loss of balance" and have difficulty knowing how to react to the unexpected situation.

2.   Attempts to Limit Awareness: Holding On and Letting Go - The two coping strategies in this phase individuals employ, are "holding on" and

"letting go" of the object of concern. "Holding on" strategies are those behaviors with which the individual intends to find some way to prevent, overcome, or reverse a loss. "Letting go" strategies involve attempts to conserve energy through diminishing the true significance of the loss. These strategies seem particularly salient when referring to the often ambiguous loss in the case of a handicapped child. In this situation where there cannot be specific answers regarding the child's future, conflicting emotions result and the parent struggles with holding on to the hope for their perfect image of the child and dealing with the reality of the changes that would be resulting from a disability. Another example would be the parent, in the previous example, who lives in fear of their child's imminent death. S/he may experience conflict around whether or not to allow him/herself to become attached to that child.

3. <u>Awareness of Loss</u> - This phase is characterized by feelings of exhaustion, sadness, anger, and loneliness. The individual has used up all defense mechanisms and now acknowledges the reality of the loss. The "purpose" of this stage is to explore

the extent of the loss and its implications. Parents are beginning to comprehend the realities of the disability and the potential implications for the child and the family. During this stage parents may question their beliefs and their ability to control their lives. A mother may reason that she had followed a healthy lifestyle during her pregnancy to insure the child would be healthy, so she may question why has she not produced a healthy child? Often the energy expended in this stage results in exhaustion and self neglect. With this, simple tasks and decisions in daily life become arduous. Feelings of helplessness and hopelessness result.

4. Gaining Perspective - This phase begins the termination of the grieving process. Individuals may do this in one of three different ways. Some individuals may return to strategies that limit awareness because they believe they cannot tolerate any more suffering. In these cases the loss may never be re-explored except when there is a subsequent loss. For others, it is the beginning of healing and acceptance. "It represents a sense of resignation, a perspective on factors outside of their control, and a reassumption of whatever

remains that is predictable in their lives."
(Schneider, 1984:71) This represents a more
passive acceptance of the situation. Thirdly, some
individuals engage in the process of gaining
perspective of the loss regarding its
significance, with a more objective understanding
of the extent and limits of their own
responsibility for the cause and for subsequent
coping. Parents may let go of some of the guilt.
The energies freed from grief may be directed
towards other activities. Parents will continue
to feel loneliness in this phase, but the sadness
and pain are less intense.

5. Resolution and Reformulations - These next phases
    depend on how the individual chose to complete
    previous phases. If the awareness of the loss is
    limited, so will the resolution be. If the
    individual is working towards acceptance, it may
    mean the individual has simply resigned
    his/herself to the inevitable. In a healthier
    direction, the individual begins to focus outward.
    An interest in outside activities returns and the
    person may feel a sense of personal power and
    ability to begin carrying out tasks. A parent may
    begin to cope better with the care needs of her

child and the rest of the family. In fact, out of
acceptance, parents see some of the positive
aspects in the situation and joy the child can
bring. There may still be some things however,
that trigger emotions or a previous stage of
grief, for example watching a non-disabled child
of similar age playing, exclusion of the child
from activities due to his/her disability.

6.   Transcending Loss -   The purpose of this final
      phase is for the person to develop an holistic
      balance in their life. "In transforming, the loss
      is frequently seen as an alteration of the nature
      of the relationship, rather than a complete and
      utter severing or discontinuity. It is the period
      in the grieving process where both the extent and
      the limits of what was lost is integrated into the
      life energies of the person" (Schneider, 1984:74).
      Parents of a handicapped child begin to see more
      options for themselves and for their child. In
      other words, effective coping strategies have been
      developed and have become part of daily life. The
      family feels empowered having developed an
      acceptance of the reality and the belief that the
      family will be able to cope with the challenges
      presented. A balance is achieved between the needs

of the child and the needs of the family. Further energies freed from grief are directed towards other activities and enjoyment of life.

According to stage theorists, people move through different phases of grief throughout life because losses continue to occur. However people may become frightened after the first stage and not proceed any further. Therefore individuals may not have resolved other losses before the next one presents itself (Schneider,1984). What is of prime importance Schneider asserts, is the direction of grieving a person chooses - either one of limiting awareness, or acceptance, or of resolving and reformulating. Often a person will use the same direction and strategies in dealing with losses unless there is a conscious effort to change those strategies. When either of the first two limiting directions are chosen, the individual would not be completing the process. Schneider stresses the importance of completion in order for growth to occur.

> "The resolution and reformulation theme includes all phases and shows a progression through the periods of limiting awareness and awareness, as well as the cycle of growth from grief that involves the later stages. Once some kind of reformulation is reached for one loss, it seems generally less likely that the individual will remain

> in initial phases for as long and is less
> likely to become immobilized by the
> assumptions and self-fulfilling prophecies
> that were associated with the loss."
> (Schneider, 1984:76)

Bristor (1984), suggests that by completing the grieving process, parents' willingness and ability to relate to the infant, and form the attachments needed to accept and care for the child, will be enhanced. In other words, the grieving processes facilitate adjustment to having a child with a disability.

Schneider also implies in his model that people can create their own vulnerability to the negative consequences of stress by neglecting self-care needs. He also believes that people are more vulnerable if they are young (under 10 when adaptive and conceptual skills are not yet developed), older (retired or without resources or friendships), lacking in a solid sense of identity, or isolated from supportive individuals. Those who experience multiple losses over a short period or experience loss while under stress from other sources are also considered more vulnerable. Schneider (1984) adds that an individual has the ability to avoid many of the negative long term consequences of stress, provided s/he has the internal resources and a supportive environment. He promotes the view that vulnerability to

the negative consequences of stress decreases not just by working towards eliminating the source of stress, but by developing new behaviors and accessing a supportive environment.

Bristor (1984) also declares the importance of supportive ties such as family and friends as well as the need for self help, and support groups since the "common denominator" of grief is loneliness.

The Schneider model presents grieving as a dynamic, repetitive, individual, but normal process. The model is holistic in that it is based on the belief that grieving has important biological, intellectual, emotional, behavioral, and spiritual elements. It can be a framework from which to illustrate how the birth of a child with a disability is often perceived as a loss and the process by which individuals, based on personal factors an well as their support system can affect the outcome of the grieving process.

2.2.5 The Life Model

The Life Model is presented by Schulman and Gitterman (1986) as an approach to understanding and helping people deal with life stresses and their repercussions.

The model is based on an ecological perspective which assumes that "people are changed by their physical and social environments and in turn change them through a process of continuous reciprocal adaptation" (pg.4). Stress is created when there is disruption in the balance or the "goodness-of-fit" "between individual needs and capacities and environmental qualities" (pg.4). Clients' "problems-in-living" are classified as arising from three possible and interrelated sources: 1) life transitions, 2) environmental pressures, and 3) maladaptive interpersonal processes.

The notion that people proceed through "life-cycle" changes is frequently proposed in the literature (Appendix 2: Stages of the Family Life Cycle). These dynamic processes are shaped by psychological, socioeconomic, and cultural forces. Therefore it is difficult to define what 'normal' is (Walsh, 1982). There is agreement however that people move through a series of stages in which roles, relationships, and resources change in relation to task accomplishment. "Each stage requires changes and redefinitions in relationships with significant others, negotiations with the external environment, and the struggle with one's self-definitions and self-identity" (Schulman and Gitterman, 1986:4). The authors submit that it is the

subjective interpretation an individual has of their situation and of their ability to meet the demands which affects whether the event will be perceived as a crisis. When an individual perceives that s/he lacks the personal, family and environmental resources, s/he will perceive difficulty in mastering the tasks of that particular life stage, which will then pose problems at later stages. Another concept central to this process is the potential for reciprocal fulfillment between generations. For example a "goodness-of-fit" would exist between "a child's need to be nourished and parents' own stage specific need for intimacy and caring" (pg.5).

The Life Model also proposes the environment not only as a potential source of support or hindrance to development as noted above, but it can generate stress as well. The Model classifies elements of the social environment into **organizations** and **social networks.** Examples of **organizations** would be health, education and social services. While their function is to provide services, organizational structures may be overwhelming to vulnerable individuals and organizational maintenance may supersede client needs. The Model states that **social networks** can provide a mutual aid system where there can be exchanges of instrumental needs such as child care or money and emotional supports. "When a goodness-of-fit

exists between an individual's concrete, social and emotional needs and available resources, it buffers intra-psychic, interpersonal, and environmental pressures" (pg.7). However some individuals do not have access to a support network because it is unavailable to the individual or non-existent. Some individuals choose not to use the available network. Others have adopted negative communication processes and/or encourage negative behavior.

Maladaptive family or group interpersonal patterns generate tension in the system, and therefore mutual aid processes weaken. The potential for maladaptive patterns to develop is generated by a variety of sources. Group composition, for example, may set up the potential for scapegoating if one person may be perceived by the others as deviant or different from the others. Family or group structures may also be a source of interpersonal problems when boundaries are too loose or too rigid. When loose boundaries exist members enjoy a high degree of autonomy and privacy, however they would also "lack a sense of reciprocity, coordination and integration" (pg.8). However when boundaries are enmeshed, individuals enjoy a sense of security but freedom and growth are inhibited. Environmental expectations and limitations may also be a source of

interpersonal difficulties. Non-nurturing or oppressive environments produce maladaptive patterns as can transitional stages of development. When maladaptive communications are operating, potential resources for mutual aid become weaker.

Schulman and Gitterman (1986) consider small groups to be an example of the symbiotic relationships between people and society. The concept of mutual aid is grounded in this belief. The authors recommend the mutual aid group as an effective intervention in assisting people with their problems-in-living. They suggest that "the purpose of a group mutual aid system is to help members to help each other with the day-to-day problems in living" (pg.9). They discuss a number of processes that contribute to mutual aid which will be discussed in subsection 2.3.2 of this practicum report.

The following are examples adapted from Schulman and Gitterman's (1986) work and will demonstrate the Life Model's applicability to a group of parents of disabled children, and how the mutual aid group can support individuals. The mediating role of the social worker will also be discussed in that context.

Mediation has been suggested as a way of assisting parents with handicapped children in developing coping strategies for meeting the individual and joint needs of family members (Girdner and Erheart, 1984). These authors propose that it is through mediation that families "learn how to solve problems, manage feelings of stress, and accommodate to circumstances perceived to be resistant to change" (pg.193).

In a group of parents who have disabled children, members may complain about their sense of loneliness and isolation. After further clarification it might be determined that members may be asking for help with the life transition, that is the emotions they are feeling related to the birth of a disabled child. Through the sharing of similar experiences, thoughts and feelings, the parents realize that they are not alone. The realization that one is not alone in one's feelings is suggested as a powerful element in the healing process. Following this it may be necessary for the social worker to encourage the group to help each other problem solve regarding some of the changes in their life as a result of the disability. The worker would support these adaptive problem solving efforts.

In another scenario members with the same complaint, may be saying that they feel lonely and isolated because they are lacking social support. The mutual aid group worker would encourage members to share information about resources and encourage the utilization of available organizational and network resources and also to motivate them to influence the environmental resources to be more responsive. "Mobilizing and strengthening the goodness-of-fit between natural and formed groups and their social environments provides social work with its core mediation function" (pg.19).

In the final example, the loneliness and isolation expressed may be related to interpersonal concerns either experienced in the group or in other aspects of their life. For example if the group polarizes around a particular issue such as placement of a disabled child with each side taking opposing views and not even listening to each other, rather than taking sides or offering an opinion, the worker would need to acknowledge the emotions on both sides, and identify the commonalities between views. This would help clarify the emotions and issues so that members can recognize where they may be impeding the mutual aid process and begin to communicate in a more constructive way.

A mutual aid group may also be able to provide feedback
in a supportive way to parents in identifying some of
the problems in communication through their own
observations. Once the problems are identified, the
group can assist the individuals in learning to
communicate more directly and openly.

The Life Model proposes a normative view of client
"troubles". It therefore offers a theoretical basis for
understanding families with disabled children as
managers of life problems. How an individual or family
copes with the birth of a disabled child will depend on
what life stage they are in, what the type and quality
of environmental support exists and if their are any
interpersonal processes operating that might obliterate
or add stress to the mutual aid system. Through a mutual
aid group process, members are able to develop
supportive relationships, learn about themselves and
about reciprocity in relationships. The concept of
mutual aid in assisting people with problems-in-living
and mediating function of the worker in groups provides
further impetus for the subject matter of this
practicum.

2.2.6 The ABCX Model

The most influential theory of family stress, coping and adaptation has been the ABCX Model developed by Hill (1949) as a result of his research on war induced separations and reunions. This model provides a framework from which the factors contributing to family adaptation to a child with a developmental disability can be understood. The benefit of this model is that it considers the **family as a system** acting and reacting to internal and external changes imposed on it. The "rollercoaster" of family adjustment that Hansen and Hill (1964) refer to involves the stages of disorganization, angle of recovery, and a new level of reorganization. This Model helps to explain why some families can seem almost invulnerable to stress while others seem to lapse into crisis at the smallest sign of stress. Following a presentation of the model, its application to families with handicapped children by McCubbin et al. will be discussed. The model is summarized as follows:

> "A (the event) - interacting with B (the family's crisis-meeting resources)- interacting with C (the definition the family makes of the event) - produces X (the crisis)" (Hill, 1958).

From this model, McCubbin and Patterson (1984) developed the Double ABCX Model which recognizes that a crisis precipitates a series of adaptations over time, not just the ones immediately following a crisis. According to Hill, a crisis (X), experienced by a family is dependant upon three variables. The first variable, the stressor event (A), is an event or transition that produces change in the family social system (Burr, 1984). The family's boundaries, goals, patterns of interaction, roles, or values may be threatened by change caused by a stressor (McCubbin and Patterson, 1984). McCubbin, Cauble and Patterson (1984) differentiate between what they call **normative** and **non-normative** stressor events that impact on family functioning over the lifespan.

Normative events "include predictable developmental changes over the lifespan in individual members of the family unit and in the family unit as a whole" (ibid.:xii). Walsh's (1982) outline of family life cycle stages and tasks provides examples of this concept (Appendix 2). She highlights the view that "the central underlying process to be negotiated (in families) is the expansion, contraction, and realignment of the relationship system to support the entry, exit, and development of family members in a functional way" (pg.

175). Because normative events are for the most part, anticipated, families are generally prepared for their occurrence and the resulting adaptations required in family structure and maintenance.

Non-normative events have been described by McCubbin etc. (1982) as "unanticipated situational family experiences which usually place the family in a state of instability, and which call for some creative efforts to cope with the situation." Since non-normative events are often unforseen, families are not generally prepared to cope and may not have the social, psychological, or material resources needed to manage such events (McCubbin, et al. 1982).

The concepts of normative and non-normative events are important when discussing the adaptation described in this model. McCubbin et al. in McCubbin and Patterson (1984) propose the Double A factor, to involve not only the initial stressor event, but also the normative family life changes that occur over time, and the long term impact of the demands and tasks that result due to either or both of these changes. Another central concept of the model is described as "pile-up" which recognizes the multitude of demands and adaptations that families may experience when a combination of events and strains

are occurring simultaneously. For example, families with handicapped children need to cope with the anticipated events that occur in most families over the life cycle, and the events related specifically to the child with the disability that also occur over time. Gallagher, Beckman and Cross (1983) articulate a similar concept by explaining that these families are being subjected to the same pressures and tensions that today's families face, while at the same time they are faced with a unique set of problems as they attempt to adapt to the presence of handicapped children in the family unit.

Burr (1984) utilizes the concepts of vulnerability and regenerative power. He contends that families vary in their ability to prevent a stressor event from becoming a crisis. This "pile-up" of stressors may be a significant factor increasing a family's vulnerability to stress and reducing their regenerative power in which the family's ability to recover from the disruptiveness may be diminished (Walsh, 1982).

Hill's "B" factor is the second variable and refers to the internal and external resources or means with which families have to meet stress or crises. McCubbin and Patterson (1984), put forth two types of family

resources in explaining the Double B factor. The first type involves the resources the family already have available to them, and the second type are the personal, family and social resources that the family strengthened or developed in response to the crisis situation. The coping resources that these authors identified through their research include self-reliance and self-esteem, family organization and integration, social support and social action.

Pearlin and Schooler (1978), provide other helpful definitions of resources. Resources, according to these authors, are what is available to people in developing their coping repertoires. Strategies to cope with stress involve the activating of social-psychological, community and financial resources (McCubbin et al., 1984). This practicum is primarily concerned with the first type. Pearlin and Schooler (1978) distinguish three types of social-psychological resources:

1.   Social Resources - Social resources are present within the individual's interpersonal network. Examples would be: family, friends, co-workers, and neighbours.

2. <u>Psychological Resources</u> - These are the personality characteristics that people draw upon to help them withstand threats posed by events in their environment. Examples of these inner resources are: self-esteem (positive attitude towards oneself), and mastery (belief one is in control of one's life changes).

3. <u>Specific Coping Responses</u> - Specific coping responses are people's concrete efforts to deal with stress. These may be influenced by the psychological resources of the individual. For example, responses that are aimed at altering or eliminating the source of strain (problem solving); responses that function to control the meaning of the problem (i.e. positive comparisons); and responses or beliefs that help people to accommodate the stress without being overwhelmed by it ("Take one day at a time...").

The final variable is the family's subjective definition of the stressor event. "Crisis-proneness in families ... proves related to outlook - to whether or not the event is defined as challenging or crisis-provoking" (Hill, 1958:145). Hill (ibid.) also notes that a family's

definition of an event relates to its value system, and to its previous experience in dealing with change and meeting crises. The Double C factor adds the family's interpretation of the crisis and the resulting effects (McCubbin and Patterson, 1984). It is the meaning attributed to the stressor, to the related hardships and, to the pile up of other life events, by the family. The concepts of vulnerability and regenerative power can also apply here. The definition that the family makes of the seriousness of the changes influences the family's vulnerability to crisis which is likely to reduce their regenerative ability.

Walsh (1982) summarizes the role of the family in controlling the impact of a stressor,

> "Because the family is a system, coping involves the simultaneous management of various dimensions of family life: maintaining organization; promoting member independence and self-esteem; maintaining coherence and unity in family bonds; developing and maintaining social supports; and controlling the impact of the stressor and the amount of change in the family. Coping is thus seen as a process of achieving a balance in the family system that facilitates organization and unity while promoting individual growth and development." (pg.32)

There has been some research conducted on family coping and adaptation to a child with developmental disability with the ABCX Model in mind. McCubbin, Nevin, Cauble, et al. (1984), conducted a study based on the Double ABCX Model, of 217 families who had children with cerebral palsy. They studied family adaptation to a child with cerebral palsy and suggest some conclusions about what the major areas of family conflict are, and what the parental coping behaviors and strategies are that prevent total family dysfunction and breakdown.

The major sources of difficulty and conflict for these families did not center around the medical and daily care of the handicapped child but around work-family transitions (for example: promotions, work stoppage, and other employment related stress) and other major family-life changes (for example: family finances, death of a relative, intra-family tensions within the various subsystems, children increasingly more involved in activities outside of the family). It was interesting to note that parents viewed the chronicity of care more and more difficult over time than the child becoming ill episodically.

From these findings, the authors were able to suggest which families with a child with CP would be most vulnerable to crises. The most vulnerable families are those who are experiencing a pile-up of life events and where neither mother nor father have yet developed helpful coping behaviors to manage these stressors. A moderately vulnerable family would be one where there is a pile-up of life changes and it is only partially being managed because only one parent is coping effectively. The other possibility is that parents have high scores on coping but the family system is pushed to the point of exhaustion. In these cases one or both parents are at risk of "burning out" and not being able to sustain the positive coping efforts. The least vulnerable family would be ones who are not experiencing a pile-up and therefore have a relatively low level of stress. As well, at least one of the parents score high on coping. Families who indicated a low level of stress and low scores on coping would also be in the low vulnerability group, but they could become more vulnerable if they began to experience more stress and did not develop the coping behaviors in response.

It should not be assumed however, that families being under stress leads to family dysfunction. McCubbin, etc. (1982) state that while "family members struggling with

these stressor events may emerge less healthy and more vulnerable than before ... it may be argued conversely that changes during family crises may move towards increased health and maturity...". These authors also argue that parental coping behaviors and patterns play a positive and supportive role in a) managing stress in the family and in b) keeping the family unit in balance and stabilized in the face of stressors. Parental response to a child with a disability, should be considered a normal response to a stressful situation, rather than an abnormal response. This in turn, affects how the rest of the family responds.

Another important finding was that families who had the greater internal resources - such as feelings of esteem and mutual support involving the sharing of feelings and decision making with an overall optimistic outlook- appear to be under less stress. These families have a sense of emotional stability and are able to maintain a sense of mastery over life's hardships and demands.

Trute (1987) studied well adjusted families who have children with disabilities in the areas of family functioning, coping strategies and social support network characteristics. His findings strengthen the findings of McCubbin et al. in the linkage established

between marital satisfaction and family strength. This highlights the importance of cohesion and adjustment in the couple subsystem for family functioning. Family functioning includes positive communication patterns, high affective expression, emotional involvement and shared values and norms.

Coping style was measured by the Family Crisis Oriented Personal Scales (McCubbin, Larson, and Olson, 1982) which will be explained in subsection 3.7.1. Results indicated that employment of external resources such as "acquiring social support" and "mobilizing family to accept help" were scored higher than the norms and were utilized over internal strategies such as "reframing" or "passive appraisal." Spiritual support was utilized the least and was significantly lower than the norm.

The findings of McCubbin et al. are again substantiated in Trute's (1987) study in that parents did not see the presence of a disabled child in the family as a major crisis that had a long term, negative effect on family life. Parents' cognitive appraisal of their situation was largely positive or neutral. The author notes that single parent families, families on social assistance and families with a number of children were absent from the sample of well adapted families. "At the most

fundamental level it can be seen that families containing disadvantaged children cannot easily cope when they are also disadvantaged in terms of material and human resources" (pg.20).

Trute (1987) concurs that the crisis of normal childbirth is emphasized by the birth of a disabled child. Psychological adjustment and family reorganization are required in order to accommodate the new disabled member. Well adjusted families were positive or neutral in their subjective appraisal of the birth of a child with a disability, and they were strong in their ability to use coping strategies and network resources. This study also implies vulnerability of those families who may be experiencing a 'pile-up' of life strains and fewer resources. In addition, while the size of the network was not found to be a concern to the families, "it has been suggested that the lack of 'weak links,' particularly in the friendship network, may act as barriers against novel advice" (Hauch, 1990:40).

2.2.7 Summary: Family Stress, Coping and Adaptation

The Holistic, Life and ABCX models, and the findings from related research, provide a rationale for this practicum. Coping is understood as a continuous, complex

interchange of factors involving the child, the family and the environment. Potential vulnerabilities are identified not based on the individual with the disability so much as the capacities of the individual/family involved and the quality of support and resources in the environment. These frameworks are broad enough to account for the variability in response to stress and allow for intervention at the individual, family, environmental levels or combinations of the three.

Within the environment, a family's social support network has been identified as a primary resource for parents in assisting them to adjust to the affective and child caring difficulties imposed by disability. The mutual aid group was recommended as an intervention that can enhance the social support networks of people experiencing life problems. A mutual aid group developed for parents with children with disabilities would provide opportunities for members to exchange information and encouragement in order to develop and utilize internal and external coping strategies and resources. The next section will give special attention to the literature on social support which will generate further understanding of its attributes.

2.3   Social Support and Mutual Aid

Social support has received considerable attention
recently as a coping attribute for the stressors of
life. The importance and impact of social support on
stress is quite prevalent in the literature. Some of the
benefits, types, structure and definitions of social
support will be outlined from the literature, as well as
intervention strategies in the mobilization of social
support.

Many researchers have studied social support in the
context of general well being, health, and as an overall
buffer in times of stress. Israel and Antoinucci (1987)
found that the provision and receipt of emotional
support are the most significant predictors of
wellbeing. Cobb (1976) has reviewed the literature
concerning roles of social support in illness,
hospitalization, pregnancy, bereavement, childbirth and
employment termination. In general, the presence of
social support was associated with improved reactions to
patients and they recover from illness and
hospitalization. In addition, social support was
associated with better morale, reduced complaints and
less depression in circumstances where a loss has been

suffered. Hagarty (1980) confirmed the value of social support systems in dampening the effect of physical illness.

Gottlieb (1981,1987,1988), a major contributor to the literature, demonstrated the role of social support both as a general contributor to health and morale, and as a coping resource and protective factor during times of stress. When people seek and receive help from members of their social network, the resources that are provided are intended to contribute to their ability to regulate emotions and/or deal with the instrumental demands imposed on them (Gottlieb, 1987). Gottlieb (ibid.) utilizes an ecological perspective when he states "social support should be properly conceived as socially-mediating coping, an avenue for restoring equilibrium which is influenced by such factors as personality and social skills of the individuals, the specific demands imposed by the stressor at different stages in the stress and coping process" (pg.51). The concepts of individual capacity and cognitive or subjective appraisal are implied in Gottlieb's (1985) work. He suggests that people who believe that they can mobilize support will feel less threatened about the implications of a stressor for their well-being and bring greater confidence to the coping process. He also

describes a psychological sense of support which comes from the belief that peers are ready and able to help, which can increase feelings of self-esteem, security and the conditions which contribute to positive emotions.

The term social support network has been defined by Garbarino (1983). The elements of interconnectedness and familiarity between people, the closeness and patterns of nurturance of the relationships, and the ongoing nature of those relationships, are what provide reinforcement for coping with daily life issues.

Gottlieb (1985) recommended, in order to optimize the quality of support which people give and receive, that informal resources be mobilized. Often the "social ecology in which people are embedded is not always capable of rendering support to the victims of life crisis" (Gottlieb, 1985:6), it therefore becomes necessary to create or augment the individual support system.

According to Gottlieb, (1988), social support can be mobilized utilizing individuals, or groups. The first set of interventions may involve a "key network member" or it may involve volunteers (new network ties) who are matched to the individual on the basis of certain

demographic characteristics or common past or present life stressors. When the type of support is specialized (other than to provide companionship and general emotional support) for example, like support conducive to the moderation of stress, professionals often play an active part in facilitating the expression of support. The second set of interventions are geared towards creating "more durable and responsive support systems" (pg.23). These interventions reflect the advantages provided by the peer or primary group. They can take the form of improving the quality of the support an individual receives from the members within existing personal communities such as in **network-centered interventions** or supplementing support with a specialized new set of associates such as in **support group interventions**. The latter would involve the mobilization of informal resources to create a grouping composed of people experiencing common stressful life situations or transitions. Guidelines for Designing Interventions Involving Social Support by Gottlieb (1988:45) are attached in Appendix 3.

The type of supportive intervention utilized in this practicum was of the latter type, essentially a support group that supplements or substitutes for the network of ongoing social contacts that people maintain in their

daily lives. Social support for and between parents of a child with a disability is not often readily available within families or communities, therefore bringing people together who might not otherwise have the opportunity to meet becomes a necessary and important social work function.

2.3.1 Research on Social Support and Adjustment in Families with Children who have Developmental Disabilities

As noted earlier, social support operates as a moderator variable under conditions of stress (Crnic, Fredrick, and Greenberg, 1983; McCubbin, Cauble and Patterson, 1982). However, "the moderation of stress depends on the proper fit between the specialized supportive provisions of certain actors in the social field and the special demands and needs provoked by different stressors at different stages" (Gottlieb, 1988:16).

The research identifies certain attributes of social networks that affect the "fit" between social support and families with disabled children. Families with disabled children obtain support from many of the same members of a "small, interconnected, family dominated network" (Kazak and Marvin, 1984:75). A closed system

such as that prevalent in these families would normally be of concern, however these networks are reported to be functional for these families. Trute and Hauch (1987) also reported that although networks tended to be smaller, the families of the handicapped children in their study who were viewed to be positively adapting, were also reported to be employing social network resources in an appropriate, efficient manner. Considerable energy, however, was expended in mobilizing those resources. While families and friends were sources of information, advice, and emotional support, families were called upon the most for physical assistance, tangible help and respite resources. Social and recreational activities most often involved friends.

Bristol (1979) found that mothers of autistic children who reported the least stress were receiving more help from all sources of support including their spouse, friends, relatives and parents of handicapped children.

In a series of studies conducted by Dunst, Trivette and Cross (1986) of 137 parents of mentally retarded, handicapped and developmentally at risk children, found that both the child's level of retardation and the number of sources of support available to the parents were related significantly to the number and frequency

of parent-child games played. In another of their studies (Dunst, 1984), mothers were more likely to show attempts to maintain their child's interactions with objects and people when they were satisfied with support available to them. Dunst and Trivette, (1986) supported their previous work that mothers' personal well-being and social support would have moderating influences on the styles of interaction from a mother to her child. At times a lack of parenting ability results from the lack of opportunity to develop these skills. In this case, the primary issues were practical ones such as assistance with household chores and child care responsibilities so that this mother would have the opportunity to maintain interactions with her child.

Crnic, Fredrick and Greenberg (1983) also found that families with adequate support systems remained more satisfied with life and were better at facilitating child development. However this finding only yielded such positive findings for intimate contacts, not friends in general.

Cameron et al. (1991) suggest support, respite and home intervention programs to assist parents in times of difficulty. This support should include the opportunity

for parents to work through some of the psychological issues, such as the loss of the "hoped-for" infant, as well as the practical issues.

These findings identify some of the characteristics of social support networks in families with children with disabilities. In summary, indications are that these families activate functional, smaller, high density networks. Family and friends were supportive in different ways as were other parents of disabled children. Social support was associated with well-being and both of these factors were important in parent/child interaction. This information is important in characterizing the supports necessary to help families adjust. Therefore, there is a basis for identifying gaps and targets for intervention in the family's social environment.

2.3.2 Support Groups

As indicated previously, meeting other parents of disabled children is important to many parents when family and friends react negatively, are unavailable, or even when members of the social network try to be helpful. In this practicum, the support group was the modality of choice to meet this need. The benefits of

the group modality will be presented later in this
section. The majority of the literature on support
groups is descriptive, outlining the way the groups are
structured, themes addressed by members, and the
perceived needs. The evaluation of the group's impact
has almost always been based on general consumer
satisfaction (Gottlieb, 1988). Gottlieb, however,
suggests that the quantity and quality of support that
is provided is determined by the group's size,
composition, norms, degree of centrality, and the types
and intensity of interaction that occur between members.
In this section the literature will be reviewed on
support groups, including relevant definitions, and
elements related to their functions, composition, size,
structure, leadership and processes.

Schulman and Gitterman (1986) define a group in the
following way:

> "The group is an enterprise in mutual aid,
> an alliance of individuals who need each
> other, in varying degrees, to work on
> certain common problems." (pg.9)

It is also helpful to clarify how the support group
differs from on the one hand, a therapy group, and on
the other hand, a self-help group. The support group

differs from a therapy group because in a support group leadership reinforces interdependency, the helping functions are relinquished to group members, and the focus is on supportive rather than interpretive issues (Rosenberg, 1984). Rosenberg (ibid.) further clarifies the difference between support groups and therapy groups:

> "The main thrust of the support group constitutes the development of cohesion and the enhancement of self-esteem, which in turn produce better coping patterns in society at large. Group therapy, on the other hand, usually focusses on problem-solving, increased awareness, and individual self-analysis through generic insights with a deliberate attempt at personality change."
> (pg.181)

Rosenberg (ibid.) further highlights the differences between support groups and self-help groups. The main differences are in the leadership and in the spontaneous, informal and almost anti-intellectual nature of self-help groups. Support groups generally do not engage in social action, lobbying, advocacy, and or public education (Gottlieb, 1988). Rosenberg (1984) stated:

> "They (self-help groups) are very similar to support groups, for they are based on homogeneity of members' problems and are effective due to the development of strong

cohesive units that build trust and
confidence and often build self-esteem. The
basic and most critical difference between
self-help and support groups is the role of
the leader. Leaders of self-help groups must
be experiencing or have experienced the same
stressed situation. Experience with the
problem usually constitutes the authority
necessary to lead the group. In support
groups, authority for leadership emanates
from expertise and training in groups or
human development." (pg. 183)

The function of support groups was articulated by

Gottlieb, (1988). When people undergo normative life

transitions such as for example, new parenthood or

retirement, they tend to restructure their networks by

developing new ties with peers who are in "the same

boat". Rosenberg (1984) also maintained that "the main

thrust of a support group constitutes the development of

cohesion and enhance self esteem, which in turn produce

better coping patterns." (pg.181)

Toseland and Rivas, (1984) suggested three important

principles of composition to consider:

1.   Homogeneity of purpose and certain personal

       characteristics can help facilitate communication

       because members can identify with each others'

       concerns, problems, and tasks. Stress, coping and

social support groups are composed of members who share a common status or predicament that entails some degree of stress (Levy, 1979).

2.   Heterogeneity of member coping skills, life experience, and expertise generates options, alternatives and choices which fosters learning in members.

3.   A range of member qualities, skills and expertise ensures a optimal mix of general qualities to aid in interaction and build group cohesion.

In relation to this practicum, the common ground is clearly identified in that all members are parents with a disabled child who is living at the St. Amant Centre. The group would have had some different issues if members had their children living at home, or if it were a group of siblings. The group should be heterogeneous in terms of members' ages, length of their child's admission and type of child's disability. This should give the younger members or parents of recently admitted children the benefit of the experience of the older members or members who have had their child at the Centre for longer. This variability should facilitate mutual aid because there would be a range of experiences

and coping skills from which members could draw from. It should allow others to compare their situations, experiences and skills to one anothers'. These comparisons can be reassuring or threatening, but in either case could facilitate learning. Finally, the group should be structured in a way that membership would be voluntary and thus individuals would be motivated to attend. "Recognizing the reasons members join a group and the helping them to satisfy these reasons is a powerful way of building strong healthy groups" (Dimock, 1983:21). With the willingness to participate, the ability to communicate is also necessary. While it is not always possible to predict how members will interact, it is necessary to give these factors some consideration (Tosland and Rivas, 1984).

When deciding the size of the group, the social worker needs to consider the purpose of the group, the needs of the members, the requirements to accomplish the task and the advantages and disadvantages of large and small groups. Because the support group in this practicum was specialized in terms of the problem area, and it required the development of cohesion and close, face-to-face interaction, the group was small.

A support group can be structured as "a distinct and separate cluster of ties, or it can be integrated in the network by linking support group members to natural network members" (Gottlieb, 1988). For example, group members may begin to involve each other in their own personal networks by periodically inviting family members to group meetings, or social functions organized by the group. Similarly "veteran" members could "sponsor" new members who are similar peers in their own communities.

The group can be structured as "open" or "closed" to new members. According to Toseland and Rivas (1984),greater cohesion and a greater sense of stability results in a closed group. One of the drawbacks of a closed group is that when members drop out or are absent there is no opportunity for the group to replace these members building to an optimal number again. Also these authors believe that without new members bringing in new ideas and skills, the group runs the risk of becoming ineffective due to the avoidance of change and degree of conformity that results. Although cohesion was important in the group proposed for this practicum, it was equally important for the group to be open to allow for parents of children who were admitted to the Centre throughout the year to join.

Indelicato and Goldberg (1986) made some further suggestions regarding the structural aspects which are helpful for this support group implementation. "Time boundary and limit of planned short term groups help members to focus quickly and maintain purpose, direction and sense of urgency" (pg. 198). According to Gitterman (1979), he stated " 'open ended' membership seems to result in groups becoming stuck at a particular stage of development and ongoing, long term groups may lead to a loss of validity and purpose" (pg.198). All the issues for parents would likely not be resolved in a time limited group, however, they will have developed or affirmed their own coping skills and developed new supports.

According to Gottlieb (1983), the most widely adopted strategy for mobilizing support to counteract the stressors caused by changes or transitions in life is the "event-centered support group". He described this type of group as hybrid in that it borrows elements of design from mutual aid, self-help groups, psycho-educational groups and therapy groups. It is usually comprised of 8-10 individuals who are attempting to come to terms with a common life stressor. The process of empathic understanding, joint problem solving and a

social comparison are employed. This type of group is
often initiated by a professional who utilizes
facilitation skills in order to optimize the
interpersonal processes and cognitive impact of the
group (Gottlieb,1983). It was this type of group that
the practicum initiated.

Mutual aid processes do not necessarily happen by
themselves, and it is often difficult for a group to
engage in change and growth without a group facilitator
(Schulman and Gitterman, 1986). Although there may be a
commitment to the mutual aid concept, it is also widely
accepted that at a certain comfort level, people tend to
resist change. Assistance is needed to develop and
initiate the group processes that lead to positive
outcomes. The role of group facilitator also has
important implications for a support/mutual aid group.

The following is a summary of the personal qualities
that the group leader must possess for effective group
facilitation, according to Anderson and Robertson
(1985):

1.   Relationship stance: The group facilitator
      displays genuineness, honesty (congruence),
      acceptance, and empathy.

2.   Self-Awareness: The group facilitator is aware of her strengths, weaknesses, fears, natural preferences, and modes.

3.   Belief System: The group facilitator has an internalized personal belief system about helping and about the use of groups as a medium for change.

In addition to possessing the above personal qualities the group leader must understand her role. The major emphasis for group workers, according to Garvin (1987), is "how the worker facilitates the members in helping one another to achieve their individual and collective aspirations" (pg.5). Rosenberg (1984) proposes four functions of leadership in a support group:

1.   Leadership transparency is high. The leader is an active role model demonstrating positive supportive attitudes that members are able to pick up on and assume toward each other. The leader may also share a personal experience or question a member's behavior but only in the way that it will

benefit the group and individual member. During the times the group is working effectively, the worker will only provide nonverbal support.

2.   The leader emphasizes the building of trust, support and communication among group members. S/he brings out strengths, recognizes hurt feelings, and establishes connections between members' contributions which enhance the group's cohesion.

3.   The leader needs to be aware of the group dynamics, particularly in interpreting or analyzing the discussion process.

4.   The leader's role is to help the group become an effective support system, providing a safe environment where people feel cared about, respected and esteemed so that they are able to reveal negative aspects of self that normally would remain hidden.

The goal of prime importance is to facilitate the development of group cohesion. Rosenberg (1984) asserted that cohesion is the most curative factor in support groups in that it lowers the sense of isolation. Dimock

(1987), described cohesion as "the glue that holds groups together" (pg.23), and the attractiveness that the group has for its members. Solidarity is another factor tied in with cohesion which was described by Dimock (1987) and Rosenberg as the sense of "we"ness in a group.

According to Frew (1986), it is not only the interpersonal level of involvement that operates in a support group. Group members need to identify their own internal thoughts, feelings and sources of support as well as being able to be aware of the group as a whole and its supportive qualities (i.e. source of affiliation). Frew (1986) asserted that "the task of leadership, then, is to assist individual group members to draw upon the three sources of support available within themselves (intrapersonal), from other group members (interpersonal) and from the group or community itself" (pg.96).

Another task of leadership identified by Frew related to the concept of individuation. Though in the early stages of group process, commonalities are explored to facilitate member to member affiliation, another important task of the group leader is to clarify differences among participants (Frew, 1986). Olson

(1987) stressed the importance of "individuation" in groups. Individuation not only "contributes to mutual aid by making members' differences available to each other," (pg.45) but also fosters self-determination (ibid.).

The literature also addresses the mechanisms and processes involved with social support groups that promote change in people and facilitate adaptation to stress. Gottlieb (1985) stressed the health protective impact of support groups by their normalizing, supportive and modelling functions. Leiberman (1979), and Dimock (1983), referred to similar functions and properties of small groups which are useful in facilitating supportive experiences. The "normalizing" function of the group comes from sharing thoughts and feelings in common and learning that members' problems are not unique. "Universality", is another word to describe a similar concept.

Some of the properties small groups possess, according to Lieberman (1979), which facilitate change, whether it is a self-help group, professionally facilitated support group, or therapy group are:

1. <u>Cohesiveness</u> - The capacity to generate a sense of belonging and "we-ness" amongst the participants. This can also be defined as the attractiveness to the group of its participants. This attractiveness becomes the motivation to remain with the group. Factors that influence cohesiveness include unconditional acceptance, and a supportive atmosphere for taking risks.

2. <u>Control</u> - The capacity of the group to control behavior. The group is able to influence adherence to rules, its structure and even things like "the way" one individual is talking to another. Consensual validation appears to be important to people.

3. <u>Induces Affective States</u> - The capacity of the group to induce powerful emotional expressions such as those of pain, anger and profound sadness.

4. <u>Social Comparison</u> - The group provides a context for individuals to compare their attitudes and feelings about things. Such comparisons facilitate an individual's review and revision of his/her

identity by suggesting new possibilities for feeling, perceiving and behaving. Modelling is an example of this.

Schulman and Gitterman (1986) identify nine elements that seem to capsulize the processes which operate to promote mutual aid in groups. They are:

1.   Sharing Data - Group members share ideas, facts, beliefs, and resources that they have found helpful in coping with similar problems.

2.   Dialectical Process - A group member can put forth an idea for the rest of the group to respond as "sounding boards."

3.   Entering Taboo Areas - This involves the encouragement of members to discuss a taboo subject where necessary.

4.   "All-in-the-Same-Boat" Phenomenon - This is the healing process when one realizes that one is not alone in the feelings, doubts, etc.

5. <u>Mutual Support</u> - When a group member is experiencing difficulty, other group members through direct and indirect efforts can provide empathic support.

6. <u>Mutual Demand</u> - In order for the change process to be complete, confrontation and demand must take place in order to move the group beyond avoidance behaviors.

7. <u>Individual Problem Solving</u> - Group members can help each other with specific problems, and when they do so they are also helping themselves with their own variation of the problem.

8. <u>Rehearsal</u> - Individuals practice what might be a difficult task, with support and advice from the group members, by engaging in a form of role play.

9. <u>Strength in Numbers</u> - Individuals often feel powerless when dealing with large tasks, involving large institutions and agencies. The strength to make change is often found from a unified front.

These processes, according to Schulman and Gitterman, promote a sense of commonality and integration which are necessary to building a mutual support system. These will be discussed in more detail in terms of their applicability to this practicum intervention in subsection 5.3.

Anderson and Robertson (1985) summarized similar change agents in groups:

> "In summary, we believe that the change agents in groups are related to the opportunities to self-disclose feelings about self and others in the group, to give and receive feedback, to conceptually validate a variety of perceptions, and to practice new behaviors-all in an atmosphere of acceptance and psychological safety" (pg.142).

2.3.3 Social Work or Peer Leadership?

While it is possible for professionals to be involved with support groups, and have positive effects in terms of promoting change and development in members, there are some risks to this involvement that need to be addressed. Gottlieb (1982) identified the major concern as being the possibility of the professional taking the control away from the group contrary to the group's

goals. Schwab (1986) suggested that when professionals take a primary leadership role in the group, they run the risk of turning the group into a counselling or therapy group.

Guttmann (1989) compared counselling groups led by professionals to groups led by peers. He found that groups led by professional counsellors were more therapeutic, risk oriented, work oriented, and less socially oriented than groups led by peer counsellors. He asserted that professionals need to be clear of their role when they are involved in group work. It is important to ensure that the social support function of a professionally facilitated parent support group does not lose out to more therapeutic goals. As far as group members are concerned, "the most credible 'experts' are the parents themselves." (pg.104) One of the tasks of the group worker is to increase members' awareness of the sources of support available in the group.

Concerns have been articulated in the literature about peer facilitated groups or, self-help groups. For example, Rosenberg (1984) cautioned that there is often no leader designated whose responsibility it is to foster the processes that lead to the satisfaction of all its members. Often there are individuals who are

able to fill this role, however, "as the intensity of
the problem situation increases, the objectivity of the
spontaneous leader often is threatened, if not
overwhelmed." (pg. 183) According to Rosenberg, the risk
that the group process can become negative, may involve
the possibility that peer pressure will force members to
conform, that cliques may develop, and that scapegoats
may emerge. They tend to be less stable because these
problems are not worked through to the satisfaction of
the members. This is not to say that self-help groups
are not effective vehicles for change. When leadership
roles pay attention to these processes, there can be
significant behavioral change.

The role of the worker can and most often does change
over the life span of a group. When a group is new, the
worker takes a very active, central role in helping the
group develop. The worker reduces this role as the group
becomes clearer of its purpose, structure, and goals.
Lang (1970) proposed a developmental model which three
types of groups are classified:" allonomous,"
"autonomous," and "allon-autonomous." She examined the
role of the group worker on the basis of the skill level
of the group. In the allonomous group the worker would
need to take a more central role in assisting the

members to learn how to interact with each other in a supportive way and to facilitate the processes that promote positive change. These responsibilities are gradually passed on to group members as they develop their skills. In the allon-autonomous group, group members have some of the skills which the worker attempts to build upon in order to encourage autonomy.

The model is helpful for the parent support group being implemented in this practicum. Being able to assess group functioning in this way, strategies can then be planned to assist the group to move towards their potential-complete autonomy.

2.3.4 Support Groups for Parents of Children with Disabilities

The literature often identifies the need for a parent support group for parents with disabled children to facilitate coping and adjustment. Seligman and Darling (1989) suggested that support groups for families with disabled children alleviate loneliness and isolation, provide information, provide role models, and provide a basis for comparison.

In an interview study of mothers of handicapped children, Segal (1985) found that the most common sources of support were other mothers of handicapped children. Participants also discussed the importance of organized parent support groups where they meet with other mothers on a regular basis.

Groups have been shown to have a beneficial effect for both parents and children (Ruiz, 1979) in parents' increased ability to explore alternatives and to provide meaningful solutions to common problems.

In most cases the research involves mothers, however Vadasy, (1985) conducted research with fathers of young, handicapped children. Fathers who participated in an early intervention program reported lower stress and depression and higher satisfaction with social support than newly enrolled fathers. Zeitlin and Rosenblatt (1985), suggested that family based intervention activities should provide programs for fathers, including special workshops, respite care, and parent support groups.

Despite the lack of research in this area, the literature that does exist suggests that the support group is an effective intervention for families with children with disabilities.

2.3.5   Summary

This section addressed how mutual aid and social support moderate the effects of stress induced by life events. The literature acknowledges the importance of "fit" between the family and their social support network in coping with life events. Social support's effect on coping is influenced by a number of factors related to the individual, various attributes of the support network and the individual's perception of that support. Research discloses important findings related to families with disabled children. Findings related to the small size of support networks, to the differential utilization of family and friendship supports, suggest that all three of the above factors need to be congruent for successful coping. However when the environment is not a source of support, "environmental modification" may be in order to provide more opportunities (Coulton, 1985). The social support/mutual aid group for parents involved in this practicum, will aid in the formation of new ties whereby a common life event can be shared. In order to maximize the groups mutual aid function, many elements need to be considered including the role of the group leader. The next chapters involve the planning and

implementation of the parent support group where the elements in formation of groups will become evident for this practicum.

CHAPTER 3

PRACTICUM CONTEXT, INTERVENTION METHODS

AND EVALUATION PROCEDURES

3.1   Practicum Context

The St. Amant Centre is a residential care setting that provides a range of services to 260 children and adults who have severe or profound developmental disabilities. The Centre provides outreach services as well as an integrated children's day care centre, a respite program, a community support program and alternative living options such as group homes and apartments.

The Centre is a private, non-profit organization owned and operated by the Order of Grey Nuns. It receives its mandate from the provincial government Department of Family Services to provide care and treatment to developmentally disabled children and adults. The St. Amant Society, which is an auxiliary organization to the St. Amant Centre, comprised of parents and interested others, has primarily been involved in fundraising to support projects of benefit to the residents. The Society is also involved in public education and advocacy on behalf of the Centre.

Services are provided to residents using a multi-disciplinary approach, and the Social Work Department is one of nine professional departments operating within the organization.

The Social Work Department conducts its functions based on an "ecological" orientation which views stress and coping as a transactional process between person and environment (Germain, 1985). Interventions are therefore focussed at different levels: individual, family and/or social environment.

With a focus on improving the "fit" between individual needs and capacities with environmental qualities, the principal functions of the Department are to:

* Co-ordinate intake to the Centre,

* Provide direct services such as counselling, advocacy, locating\arranging resources,

* Coordinate discharge planning,

* Consult in high risk situations,

* Operate the Resident's Council,

* Manage the Community Support Program,

* Co-Administer the Respite Program,

* Provide education to staff and students.

(Social Work Department: Scope of Service)

The Social Work Department employs 3 social workers who currently share 1.83 positions. Reflective of the overall economic climate, the Department's mandate exceeds it resources and it is understood there is no possibility for increases until the economic climate improves.

A Parent Support Group has in fact been a goal for the Department for the last few years, however resource limitations and other priorities prevented its pursuit beyond the discussion stages. This practicum enabled this student to evaluate a need/benefit, provide a service and examine the possibility that a group program could be an effective and efficient way to support families whom would normally be worked with on an individual basis.

3.2   Parent Survey

The need for more family support became evident at the St. Amant Centre in a number of ways. Numerous discussions took place involving interested parents, the Director of Pastoral Care at the time, administration, and social work staff, all of whom identified the need particularly for a parent support group. Resulting from

these discussions, the Social Work Department conducted
a survey of parents to determine the nature and scope of
the need.

The survey was conducted in 1988 and was delivered to
approximately 160 homes of parents who have children
living at the St. Amant Centre. Sixty-six percent
(approximately 100) of the surveys were returned.
Thirty-two percent of parents indicated the desire to
participate in a support group. The response was split
equally in terms of the need for professional
involvement. Some parents felt that it was necessary to
have professional involvement as a facilitator while
some parents felt that the group could be organized and
run by parents. Almost the same number (32%) indicated
that they would have preferred one-to-one support from
other parents prior to or during their child's
admission. Some parents would have liked group and
individual support from other parents. The need was
expressed both by parents of adult children and parents
of recently admitted young or adult children. The survey
also addressed key issues such as: impact of the child
on the family, feelings about placement, and visiting.
Many parents used the survey as an opportunity to
express details about their feelings and experiences
which suggested that even though their children had been

living at the Centre often for many years, they had feelings they needed to express. (See letter in Appendix 4a for a summary of the survey results)

3.3   Interviews with Key Informants

In addition to the parent survey, it was necessary to interview individuals who were knowledgeable about families in order to gather more information. A meeting was held with the social workers who were able to identify families who they thought would benefit from a support group. The social workers were also able to provide some insight into what some of the issues might be for these families. For example: coping with the separation from their child, feelings of loss of control in their child's life, how to share in the care of their child, difficulties visiting, and relationships with Centre careproviders.

The Pastoral Care Director, through her contact with parents and through personal experience had an important cautionary note. She felt that the group needed to be socially - supportively focussed, as only a select group would benefit from an educationally focussed group. She feared that the group may be intimidating to some, and

encourage passivity. There was also some concern regarding duplication with the goals of the St. Amant Society if the group was educationally focussed.

The president of the St. Amant Society is a parent of a disabled child living at the Centre and has contact with many other parents. Her opinion was that the group should be professionally facilitated because parents' emotions may prevent them from facilitating well. She was also helpful in sharing her own experience as a group facilitator in terms of some of the techniques for opening sessions as well as open vs. closed groups. We discussed the perspective of family stress and social support and some additional topic suggestions were discussed.

Nurses who have daily contact with families were interviewed and they provided their impressions of parent involvement, coping, adjustment of the families of residents living on their living units. Six nurses representing 6 out of 8 living areas were interviewed. Their observations were interesting and are listed as follows:

*   parents with younger children tended to be more involved,

*   parents of older children become more detached over the years,

*   parents have more difficulty admitting an adult than a younger child who has been living at home,

*   parents visit more, if the child is able to communicate or at least can respond to them,

*   parent lack of involvement was viewed as a coping mechanism,

*   they indicated that there were involved parents whom they felt were not adjusted (used overprotectiveness as an indicator, having unrealistic expectations of their child, overly demanding of staff),

*   parents may need an adjustment period immediately following admission of their child where they may not wish to participate in a group.

3.4   Recruitment of Group Members

A letter (Appendix 4a) was sent to parents who had requested a summary of results from the 1988 survey. The letter also notified parents that a support group would be developed and if they had not indicated an interest on the survey form, but were interested now, they should contact myself. A second letter (Appendix 4b) was sent to parents of children who had

been admitted to the Centre after the survey was conducted informing them of the nature of the group. They were also advised that they would be receiving a phone call to determine if they were interested. Nursing, social work staff, and Pastoral Care were also advised of the group so that they could make referrals.

A phone call then followed to all surveyed parents who expressed an interest and to all parents of children more recently admitted to the Centre. The purpose of the phone call was for personal introduction, a brief review of the purpose of the group and to answer any questions and deal with any concerns that became evident.

A total of 41 parents were contacted by phone. Of those, 25 were survey parents, and 16 were parents of children more recently admitted. The phone contacts resulted in 25 interested parents who were then interviewed individually except in the case of couples who were interviewed together.

3.5   Pre-Group Parent Interviews

The interview process involved gathering information about the child and the family, a discussion on previous group experience, feelings about participation in this

group, and expectations of the group (see Appendix 5 for interview form). At this point as well, more detail was provided about the purpose of the group, the role of the facilitator, and confidentiality. Parents were also requested to complete standardized measures: F-COPES, PSS-fa (pre-test), and GCS (pre-test), at the interview. The administration and purpose of the standardized measures are discussed in subsection 3.7.1.

3.6 Recording of Sessions

Each session was video recorded so that meetings could be reviewed to evaluate facilitation, process and to recall content. Written records of each session were completed on a Group Recording Form (Appendix 6) to keep track of the attendance, objectives, activities, analysis, etc.

3.7 Evaluation Measures

The content of group discussions provided much information about the impact of a developmentally disabled child on the family in terms of the positive and negative aspects, as well as some of the coping strategies parents utilized. The standardized measures added to the information about how parents are coping

and the range of strategies they use. The three
standardized measures are: the Family Crisis Oriented
Personal Evaluation Scale - (F-COPES) by McCubbin,
Larsen and Olson, (1982); the Perceived Social Support-
Family - (PSS-Fa) scale by Procidano and Heller (1983),
and the Generalized Contentment Scale - (GCS).

Using Hill's (1949) model of family adaptation to stress
as a framework, McCubbin, et al. (1982) created **F-COPES**
"to identify effective problem-solving approaches and
behaviors used by families in response to problems or
difficulties" (pg.101). **F-COPES** (Appendix 7) is a 29
item scale measuring 5 different coping attributes which
parents completed at the end of the initial interview.

F-COPES measures 5 variables that reflect a variety of
problem-solving approaches and behaviors that involve
the utilization of resources internal to the nuclear
family system, and the behaviors family members utilize
in order to solicit resources outside of the nuclear
family unit. Each of the 5 sub-scales has shown internal
consistency and test-retest reliability which will be
reported below. External validity measures were not
available. The five subscales are as follows:

Acquiring Social support. Nine items measure a family's ability to actively engage in acquiring support from relatives, friends, neighbours, and extended family. (Cornbach's Alpha=.83; test-retest=.78 at a four week interval).

Reframing. This dimension with eight items assesses the family's capacity to redefine stressful events in order to make them more manageable. (Cornbach's Alpha= .82; test-retest= .61 at a four week interval).

Seeking Spiritual Support. The focus of four items on this scale is the family's ability to acquire spiritual support. (Cornbach's Alpha= .80; test-retest= .95 at a four week interval).

Mobilizing Family to Acquire and Accept help. Four items measure the family's ability to seek out community resources and accept help from others. (Corbach's Alpha= .71; test-retest= .78 at a four week interval).

Passive Appraisal. This dimension in four items assesses the family's ability to minimize reactivity by accepting problematic issues as a fact of life. (Cornbach's Alpha = .63; test-retest = .71 at a four week interval).

Internal consistency and reliability for the total scale were respectively: Cornbach's Alpha = .86; and test-retest = .81. The authors suggest two possible explanations for the lower test-retest reliability scores in the second and fifth items. The lower scores may be attributed to the possibility that those items that require cognitive adjustment such as **"reframing"** and **"passive appraisal"** provide less consistent responses than the more concrete behavioral items. The other explanation relates to the possibility that these cognitive factors change more frequently.

Perceived Social Support from Family (PSS-fa) (Appendix 8) is a 20 item scale designed to measure "the extent to which an individual perceives that his/her needs for support, information, and feedback are fulfilled by family" (Procidano et al., 1983:2). This was a pre-test, post-test measure for which parents completed the pre-test at the end of the initial interview. The same form with a covering letter and return date was mailed to group members within 2 weeks of the final meeting. Self-addressed, stamped envelopes were provided for the return of the survey forms. The post-test was administered to determine whether the group intervention had any effect on parents' perception of their family support. The measure had high test-retest reliability

(r=.83 over a 1-month interval), was internally consistent (Cornbach's alpha=.90) and valid which was established in three studies conducted by the authors.

The final measurement tool was the **Generalized Contentment Scale (GCS)** (Appendix 9) which was developed by Hudson (1982) along with eight other standardized scales in a Clinical Measurement Package. This package was designed for single system research in clinical social work practice. This scale was also a pre-test, post-test measure, the pre-test being completed with the others at the end of the initial interview and sent with the **PSS-Fa** to parents two weeks following the last session. The **GCS** as with all the scales in the Clinical Measurement Package have internal consistency and test-retest reliabilities of a minimum of .90 and are reported to have high face, concurrent and construct validity (Bloom and Fischer, 1982). While there are no norms for these scales, the use of these scales by the author has shown that the higher the score, "the greater the degree or magnitude" of problems in the area being measured, in this case non-psychotic depression. The authors suggest that attaining the level 30 is a "very rough guide as to the existence or absence of problems." Although not completely validated, these guidelines can give us some indication of how satisfied the parents in

this support group are with their lives and whether their scores improve following the support group intervention .

The qualitative measures consisted of short surveys completed after each session to determine parent satisfaction with that session. Verbal feedback was also provided and noted. A summary of the results is in Appendix 14 and is discussed in subsection 5.4.

The **Group Leadership Rating Scale** (Cory and Cory, 1977) (Appendix 10) was used to evaluate my facilitation skills. This was a way for me to evaluate my strengths and weaknesses and to understand how my behavior influenced or could have influenced the group process. Fifteen skills are identified which include: active listening, reflecting, clarifying, summarizing, interpreting, questioning, linking, confronting, supporting, blocking, diagnosing, evaluating, facilitating, empathizing, and terminating. A brief explanation of these terms is provided on the **Group Leadership Rating Form** in Appendix 10 and the results are discussed in Chapter 5.

CHAPTER 4

EVALUATIVE FINDINGS AND IMPLICATIONS:

INDIVIDUAL DIMENSIONS

4.1   Introduction

Evaluation for this practicum is formative and
summative. Formative evaluation is information provided
in the developmental stages of the program and it
"supplies information directly pertinent to a particular
practice or program" (Tripodi, 1983:4). For example, in
this practicum, information received during group
implementation in terms of stressors experienced by
parents, topic areas to be discussed, group process
issues, and client satisfaction would be formative.
Summative evaluation requires the completion of the
program and is to provide more generalizable information
(Tripodi, 1983). Examples of summative information would
be information related to the coping abilities and
strategies used by parents with children who have severe
developmental disabilities and the effectiveness (in
this case, parent satisfaction) of a support group in
assisting parents to cope with stress.

Quantitative and qualitative methods were used in
gathering information to both maximize objectivity and

to subjectively tap the experience of parents with disabled children (Rubin and Babbie, 1989). The limitation of this practicum is that it was not designed as a comprehensive research project with the appropriate controls. Because there is no control group and members were not chosen randomly, there are limitations in generalizability and the ability to make causal inferences from the data presented by this practicum.

This chapter presents data on the findings related to individuals in the group. It includes 3 case examples so that the reader can appreciate the diversity of members' personal experiences. Other data include a sociodemographic profile of parents/families, resident characteristics, the length of time the resident has lived at the Centre, parent involvement with their child, and results on standardized measures relating to parent coping styles, perceived social support from family and general contentment with life. Parents' goals and expectations for participation in the group are also summarized.

4.2 Case Examples

Given the number of participants in the group, it was not possible to describe each member in detail in this

report. Appendix 11 provides a brief biography of each member and this section provides a sample of group members in order to elaborate the experience of three parents. An attempt was made to include parents who would adequately represent the range of variation with regards to age of the developmentally disabled child, length of admission and family characteristics. Some of the facts have been altered to maintain confidentiality.

Mr. and Mrs. C

This middle aged couple were both employed, financially secure and had one child who was severely developmentally disabled who had lived at the St. Amant Centre for 15 years. Mary was a young adult, had severe mental retardation, seizures, and was wheelchair dependant. She fed herself with supervision but was dependant for other self-care activities (i.e. dressing, toiletting, grooming, etc.). She recognized her parents by smiling and it was also apparent that she anticipated home visits with excitement. She was able to move her wheelchair on her own and understand simple instructions, but she could occasionally be aggressive and self-abusive, which coupled with her size, made her difficult to manage.

Mr. and Mrs. C took their daughter home almost every weekend. They were concerned that visits were getting more and more difficult as their daughter was getting bigger and they were getting older. The fact that Mary was the C's only child raised concerns for them regarding who would be able to visit and care about Mary when they have passed away.

The C's scored slightly higher than the norm on the F-COPES, which indicates that they generally coped with stress quite well and utilized a variety of coping strategies (refer to **Table 3**, Parents G and H). They did not, however, use spiritual support as a coping strategy as much as the other strategies, or as compared with the norm means. Mrs. C also did not utilize passive appraisal as a coping strategy as much as her husband did or as compared with the norm mean. As a couple, the C's were not satisfied with the support they received from their families. Individually, however there were some important differences in their scores. For example, Mrs. C felt more positive about family support prior to the group than after, whereas although lower than Mrs. C's pre-test score, Mr. C's score remained stable. Mrs. C also had a tendency to be depressed. While her score improved slightly after the group, it was still within the high risk range.

The support group for the C's was an opportunity to meet other parents and share some of their feelings and concerns related to their child, probably for the first time. The group filled a gap in support that they felt they were missing from family members. They established relationships with the other group members which extended beyond group meetings, thereby reducing isolation. In addition, they were able to provide support to other parents which enhanced feelings of self-worth.

Mrs. M

Mrs. M, a young mother, recently had gone back to work full time after admitting her 2 year old son to the Centre 6 months prior to the group's beginning. Prior to the child's admission, there were marital problems which resulted in a separation and subsequent divorce. There was another preschool child for whom the parents were sharing joint custody. Leon, born with microcephaly, had severe mental retardation, is blind but could walk with assistance. Leon was a very active little boy and was aware of activity around him.

This mother reported numerous disappointments in the relationships with her mother and with her husband. She also carried feelings of resentment towards the community agencies whom she perceived as not being supportive enough when she had her child at home. The support group that she had participated in while her child was living at home had been a positive experience for her, however she felt the support dissipate once she decided to place her child at St. Amant. Mrs. M was also finding visits to be difficult in that she had overwhelming guilt every time she brought Leon back to the Centre following a home visit.

Although Mrs. M's score on F-COPES was lower than average compared to the group, she still reported higher coping than the norm mean (refer to Table 3, Parent M) Mrs. M's highest score was in "acquiring social support" which suggests that she spent significant time and energy trying to acquire resources that were not satisfactory to her. Not surprisingly, Mrs. M's dissatisfaction with family support was confirmed on her PSS-Fa results and although the score increased slightly, following the group, it was still significantly low. There was no evidence of depression according to Mrs. M's GCS score. At the time of the

group, Mrs. M was involved in a common law relationship with someone from whom she felt support and whose family also was supportive.

Mrs. M had many life stressors, some of which may have been beyond the scope of the group's help. However, as for the C's, the group was able to fill a gap in Mrs. M's support network which support she was missing from family and friends. Group members empathized with her and demonstrated concern and support. These elements along with the group's encouragement about positive coping efforts were factors that enhanced self-esteem.

Mrs. I

The I's are a two parent family with 4 children. Mr. and Mrs. I are both employed full time and are very active in community work. Joseph, the child living at the Centre, was 12 and was the second oldest child. He had been living at the Centre for 11 years. Joseph had profound mental retardation, his communication skills were severely impaired, he was wheelchair dependant and he was a challenge to feed. It was also very difficult to assess if he recognized special people in his life. The family visited Joseph at the Centre approximately once every 2 to 3 weeks. They generally visited in his

room, took him for a walk, or had a meal in the cafeteria where Joseph was able to be present and was benefitting from the different surroundings and the sounds of his family interacting during the meal.

Mrs. I's immediate concerns related to the challenge meeting the multitude of demands of her family, her job, community responsibilities and having time to spend with Joseph. She admitted to not having time for herself and likely there was not much time for the couple. She also expressed concern over coping with the possibility of Joseph's deteriorating health since he was becoming acutely ill more and more frequently. As well, she wondered how to ensure her other children were coping.

While Mr. I did not attend the group meetings, he did complete the pre-tests (refer to Table 3, parents I and J). Results showed that these parents used the range of coping strategies. As a couple, they used "reframing" the most and used "passive appraisal" the least. Mrs. I "acquires social support" more than her husband, but he "seeks spiritual support" more than his wife. They both reported high satisfaction with family support and were satisfied with their lives, in general.

Mrs. I considered the group a time in which she was doing something for herself. The friendships that she developed with people whom she would not normally have crossed paths with, seemed refreshing for her. At meetings, she was able to express the feelings that she normally felt she needed to suppress in order to carry out her responsibilities of daily life. She was able to share common experiences with group members and obtain support and suggestions in terms of prioritizing responsibilities and having family members participate in household chores.

The preceding examples attempt to identify the various perceived stressors that impact on parents related to their disabled child in combination with perceived stressors from other normative and non-normative life events. The parent coping styles were presented together with the impact of their perceived support and their overall satisfaction with life. Individual change as a result of the support group was demonstrated within the context of the lives of individual group members.

4.3   Family Characteristics

Twenty parents attended the group at least once. They were parents of 14 residents who lived at the St. Amant

Centre during that time. There were 13 mothers and 7
fathers, and of those, 6 were couples. The mean age of
mothers (x=46.3, SD=10.5) was not significantly
different from fathers (x=52, SD=11.58). Mothers'
education level was generally higher than fathers'.
While only 4 fathers had attained grade 10 or higher,
all mothers had attained this level. Two parents
reported a college level education and only one parent
reported a university education. All fathers, except one
who was retired, were employed full time. Ten mothers
were also employed and of those, 6 were employed full-
time and four part-time.

Ten families contained 2 consanguinal parents. One
family was a former foster family of the resident. Three
single mothers attended and one couple was common law,
the mother being the consanguinal parent.

There was diversity in birth order although in 3
families, the child with a disability was the only
child. Of those who had siblings, 3 were the eldest. In
5 families the child was the youngest, and in the other
4 the child was second or third of three or four
children. The mean age of the siblings was 15.6, and
although there was a range in ages (SD=8.4), there were
few under 7 years. According to the literature, in 5 of

these families, brothers or sisters of the disabled child are more at risk for problems in adaptation. In one family with three siblings there was a younger male sibling. In four families one of the female siblings was older. In two of these four families, there were only two siblings. From the information available through the group and prior knowledge of the families, 5 female siblings all from different families, in fact had or were experiencing difficulties. Of these 5, 3 fell into the "risk" categories identified above (1 - family of 2 siblings, 2 - older female sibling).

Of the 11 families who answered the question, 7 had incomes of under $29,000 per year. Two families had annual incomes of $30,000 to $39,000, and the other two had each $40,000 to $49,000 and $50,000 to $59,000. Statistics Canada compiled guidelines (See Table 1) by which to assess the point where a family will likely have difficulty meeting its basic needs. According to these guidelines, four families were above the cutoff point according to the number of persons in the home, three families were below and three families were close to the cutoff either above or below.

TABLE 1	
STATISTICS CANADA LOW INCOME CUTOFFS	
NUMBER OF PERSONS	INCOME LEVEL
1 PERSON	14,155
2 PERSONS	19,187
3 PERSONS	24,389
4 PERSONS	28,081
5 PERSONS	30,680
6 PERSONS	33,303
7 PERSONS	35,818

Most families lived in Winnipeg, except for two who lived within one hour from the City.

Except for 3 single mothers, families in this practicum were nuclear, with two consanguinal parents who were middle-aged, non-professional, and although represented all income groups, more tended to be middle to lower income earners.

4.4   Resident Characteristics

The mean age of the child with the disability was 16.2 years (SD= 7.8). Eight of the children were under 18 years of age, and all but three were male. Compared with the Centre's population, this study sample contained a higher proportion of males under 18 years of age.

Given the population that this sample is drawn from, it is not surprising that all of the individuals except one had severe and multiple disabilities. All conditions involved severe or profound intellectual impairments along with sensory, motor and other neurological deficits. One young adult had a mild level of intellectual impairment but severe physical impairment. Almost half of the children had no definite diagnosis, in other words there was no known cause for their developmental delay. This compares to the Centre's overall population of which 45-50% of individuals have no known cause. In the general population of individuals with mental retardation, there would be 60% who do not have a diagnosis. The other diagnoses include: Hydrocephalus (2), Rubella Syndrome (2), Microcephaly (1), Recideoblastosis (1), Down's Syndrome (1), Non-accidental insult to the brain (child abuse) (1). Even when there is a diagnosis, in many cases the cause may still be unknown.

Nine residents had physical disabilities, although of those, a small number could walk with assistance. Five were ambulant, however severe behavior problems were noted in most of those cases. In addition, at least half were reported to have sensory deficits such as hearing

and/or vision loss, most had seizure disorders, but only one individual was tube (gastrostomy) fed. One-half required frequent medical attention.

Five of the individuals had some self-care skills, for example toiletting, supervised dressing or self-feeding. However at that time, none of these individuals would be able to master more than 2 of these activities. Expressive communication was always non-verbal, and in many cases severely impaired, however a few individuals were able to use gestures and sign language.

The young adult mentioned earlier is intellectually quite capable. He has a high degree of physical impairment and however uses an electric wheelchair for mobility and communicates through an electronic device. The characteristics of the residents whose parents attended the support group had severe multiple disabilities and require a high degree of assistance to meet their needs. This sample was quite representative of the Centre's population except for the high number of males.

Parent representation of children from each living unit is documented in Table 2. In the following paragraphs, the living units are described to give the reader an

understanding of the resident characteristics. It is helpful for planning purposes to know what living areas generated the highest interest or need. Affirming the above resident characteristics, the highest complement of parents were of residents under 18 years. Representation was highest (parents of 4 residents) from 1 East living unit where the majority of children are between the ages of 7-17 and 60% are ambulant and display behavior management problems.

Parents of residents from other units were represented as well. For example, the total representation from the units 2 East, 3 East, and 3 North were parents of four children. The living units 2 East, 3 East and 3 North are comprised of children and who are non-ambulant and have high physical and dependency needs.

Parents of 2 adult residents from 3 West also attended. Three West is a living unit where the majority of individuals are 18 years and over, all are non-ambulant and have high physical care and dependency needs.

There was also representation of parents from 3 residents living in Birchview and Cedarview cottages. Individuals living in this area are all ambulant adults also with high dependency needs.

The last set of parents were of the resident who lives on 1 West. This living unit is comprised of young adults who are physically disabled but 35% of them have a mild or moderate intellectual impairment which represent the residents with the highest cognitive abilities in the Centre.

TABLE 2	
PARENT REPRESENTATION BY LIVING UNIT	
LIVING UNIT	NUMBER OF PARENTS
1 EAST	5
2 EAST	1
3 EAST	2
1 WEST	1
2 WEST	0
3 WEST	2
3 NORTH	1
ABC	2
MAPLESIDE/RIVERSIDE	0

There was no representation from parents of 2 West which is comprised of residents who are 18 years or over, non-ambulant and require have high nursing care needs. As well, there was no representation of parents of children who live in Mapleside and Riverside cottages. These children are mostly between 7-17 and 75% of them are ambulant and although may have severe intellectual handicaps represent some of the more physically and

cognitively able residents at the Centre, in terms of participating in some activities of daily living (i.e. personal care and toiletting, self-feeding, dressing etc.).

4.5   Length of Admission

It was anticipated that one of the major functions of the group was to be a support for parents who had recently admitted their child. As it turned out only 3 children had been admitted within the past 6 months. The mean length of admission was 8.3 years (s.d.=5.07). Of the 8 families who had admitted their child within the year, 2 were adults. Many of the children were from young families who had other children.

Reasons given by parents for not attending group sessions included: other children at home, other commitments, work schedules, transportation problems, and other family problems. When the problem was one of childcare, there was usually another problem like one of the others listed. Had there been a need, childcare on site would have been explored. One family felt that they had worked through their feelings and other commitments were a higher priority so that they were not interested at the time.

4.6   Parent Involvement

Practicum parents visited their children living at the Centre frequently. Most parents reported that they visit at least once per week, if not more. Parents from two families who had other young children at home reported visiting less frequently (once every two to three weeks; once every four to six weeks). The disabled family member in both of these cases were also the most impaired both physically and in their ability to interact with people.

The location where families chose to visit with their son/daughter varied. Five families chose to visit at the Centre because the individual is medically unstable, or the physical management is too difficult. Other families (5) who could manage, visited with their family member at home. Three families reported that they visited both at home or at the Centre depending on, for example, the health of the individual or the resources available to the family at the time.

Parent involvement was also defined as participation in the planning of the resident's program, having input into decisions about daily care and activities and

ongoing communication about health and well being. All parents were involved in these aspects of their child's life. There was no difference in the frequency of contact or amount of involvement after the group intervention.

4.7   Previous Group Experience

Approximately 65% of parents had been previously involved in at least one support group. In 25% of the responses one of the groups mentioned was the St. Amant Society. Others groups included a church group, a foster parent group and those related to the child with a disability. All of the parents who were in the latter type of group had begun their involvement prior to their child's admission and most reported that when they were deciding about admission or had admitted their child, they did not receive the support they felt they needed. Two families reported negative feedback about their decision to place or about the St. Amant Centre from individuals in these groups. The families who had participated in other groups reported positive experiences.

4.8   Coping Styles

It may be a surprise to those predicting fewer coping strategies utilized by parents who choose to place their children, that in fact these parents' mean score on the total **F-COPES** scale were higher than the norm mean (**Table 3**). There was greater homogeneity in responses among this group than the norm. These results are consistent with Trute and Hauch's (1988) study. They found that the network density of families with handicapped children is higher than one finds in families without a handicapped member. He attributes this to be an outcome of productive efforts on the part of family members such as would be indicated in the active coping strategies of "acquiring social support" and "mobilizing family to accept help". In terms of the "acquiring spiritual support" sub-scale, however, both studies reported scores lower than the norm mean. Some parents in this study indicated a disappointment with religious institutions in the acceptance of their child.

Interestingly it depended on whether it was a mother or father completing the questionnaire as to whether the family was perceived as utilizing internal or external coping strategies. Mothers reported higher utilization than fathers in seeking external resources as indicated

TABLE 3				
F-COPES SCORES: STUDY FAMILIES COMPARED TO FORM MEANS AND TRUTE'S (1987) STUDY				
F-COPES SUB-SCALE	PARENT (M=12) (F-4)	STUDY FAMILY MEAN SCORES (s.d.)	F-COPES NORM MEANS (s.d.)	TRUTE (1987) MEAN SCORES (s.d.)
ACQUIRING SOCIAL SUPPORT	MOTHERS FATHERS	32.2 (5.36) 27.5 (6.02)	27.8 (6.5) 26.5 (6.4)	33.1 (5.2)
REFRAMING	MOTHERS FATHERS	32.5 (4.76) 35 (2.54)	30.4 (4.86) 30.4 (4.91)	31.6 (4.1)
SEEKING SPIRITUAL SUPPORT	MOTHERS FATHERS	15.1 (2.1) 12.2 (.8)	16.6 (2.88) 16 (3.14)	13.2 (5.2)
MOBILIZING FAMILY SUPPORT	MOTHERS FATHERS	15.5 (1.9) 12.2 (3.2)	12.7 (3.31) 11.8 (3.27)	15.3 (3.1)
PASSIVE APPRAISAL	MOTHERS FATHERS	9.4 (2.76) 10.5 (1.65)	8.2 (3.05) 8.4 (2.95)	7.2 (2.9)
TOTAL SCALE	MOTHERS FATHERS	104 (10.5) 97.5 (7.2)	95.6 (13.24) 93.1 (14.05)	100.4 (12.3)

in the scores of the individual dimensions, such as: "acquiring social support", "seeking spiritual support" and "mobilizing family to acquire and accept help." Fathers scored higher in the internal resources dimensions: "reframing" and "passive appraisal". The norm means also reflect these differences in perceived coping styles between women and men.

The husband and wife of 4 out of 6 couples completed the pretests. In two couples, the wives' total F-COPES score was higher than their husbands and in the other two, the couple scores were similar.

While the mean scores of parents in this practicum reflect a feeling of overall higher family coping than the norm, individual differences in parents' scores are also worth noting (**Table 4**). A correlation between **F-COPES** scores and **PSS-Fa** and **GCS** is suggested on the extreme higher or lower scores. For example, parents O, P, Q, and S, had very high scores on coping and were also very satisfied with their support from family and were generally satisfied with life. Conversely, parents C, F, and K, had lower coping scores and also had low satisfaction with family support as well as a low contentment with life, thus a high potential for depression.

	TABLE 4A									
	PARENTS' INDIVIDUAL TEST SCORES									
PARENT	F C O P E S 1	F C O P E S 2	F C O P E S 3	F C O P E S 4	F C O P E S 5	F C O P E S TOTAL	P S S F A PRE	POST	G C S PRE	POST
A	28	30	15	16	6	95	11	14	38	-
B	-	-	-	-	-	-	-	*11	-	-
C	27	20	17	16	13	93	9	3	44	62
D	26	33	16	16	7	98	17	13	21	23
E	34	35	14	12	9	104	7	11	39	24
F	19	38	13	7	10	87	0	1	37	24
G	35	32	12	18	8	105	11	2	49	36
H	36	31	12	16	12	107	8	9	18	19
I	32	33	13	12	8	101	16	14	29	27
J	27	35	16	13	8	96	20	-	27	-
K	26	29	10	16	10	91	6	9	29	-
L	-	-	-	-	-	-	-	*18	-	-
M	27	39	13	14	5	98	2	6	15	-
N	28	36	11	13	12	100	17	14	6	-
O	37	40	17	15	15	124	16	-	20	-
P	38	33	16	16	10	113	20	20	11	-
Q	44	36	17	19	9	125	20	-	28	-
R	-	-	-	-	-	-	-	*17	-	*27
S	35	32	16	16	13	112	14	8	24	36
T	29	31	17	16	9	102	14	-	23	-

TABLE 4B

GROUP MEANS AND STANDARD DEVIATIONS

GROUP MEANS:	(* SCORES IN TABLE 4A ARE NOT INCLUDED IN MEANS)			S.D.	
F-COPES:	1. ACQ. SOC. SUP.		31.05	5.86	N=17
	2. REFRAMING		33.12	4.47	N=17
	3. SEE. SPIR. SUP.		14.41	2.25	N=17
	4. MOB. FAM.		14.76	2.7	N=17
	5. PASS. APPR.		9.64	2.58	N=17
	TOTAL SCALE		103	10.30	N=17
PSS-FA:	PRE-TEST	–	12.24	6.0	N=17
	POST-TEST	–	9.54	5.3	N=13
GCA:	PRE-TEST	–	26.94	11.32	N=17
	POST-TEST	–	31.38	12.9	N= 8

4.9   Perceived Social Support (PSS-Fa)

Parents who participated in this practicum do not see themselves as having the same supportive family relationships compared with the norm (**Table 5**). The post-test revealed even greater dissatisfaction with family support than prior to the group experience. It is likely that through the group experience members became more aware of the lack of supportive relationships within their families.

TABLE 5			
PERCEIVED SOCIAL SUPPORT FROM FAMILY (PSS-FA) SCORES: STUDY FAMILIES COMPARED TO NORM MEAN AND TRUTE AND HAUCH'S (1987) STUDY			
PARENT **STUDY FAMILY SCORES PRE-TEST**	**POST-TEST**	**PSS-FA NORM MEANS**	**TRUTE & HAUCH 1987**
MOTHERS mean = 12.5 s.d. = 5.3 n = 13	mean = 10 s.d. = 5.39 n = 10		mean = 16.6 s.d. = 3.6 n = 36
FATHERS mean = 11.25 s.d. = 7.85 n = 4	mean = 8 s.d. = 5.35 n = 3		
TOTALS mean = 12.2 s.d. = 6.0 n = 17	mean = 9.53 s.d. = 5.34 n = 13	mean = 13.4 s.d. = 4.83	

Parents of this study were also less satisfied with their family support than the families with handicapped children in Trute and Hauch's (1988) study. Where the husband and wife both completed the pre-tests, all 4 had similar scores in their satisfaction with family support.

Upon reviewing parents' individual scores (**Table 4**), it appeared that in most cases that high perceived support from family was associated with satisfaction with life (parents D,J,N,O,P,Q,S,T). The converse was also true (parents A,C,E,F,G,J,K).

4.10 Generalized Contentment Scale (GCS)

The mean pre-test score of parents who participated in this practicum showed that they were generally content with their lives given that they were below the "clinical cutting score" of 30 (**Table 6**). However 7 parents had scores of 29 or over which indicates some cause for concern. Mothers' pre-test scores were higher than fathers and because these scores were close to the cutoff these mothers had a higher potential for depression. Three out of four husbands and wives who completed the pre-tests had similar scores to their spouses in their satisfaction with life. The post-test, although limited to a 50% response rate, revealed even higher scores for mothers and lower scores for fathers. Because the practicum comprised such a small number of fathers, it is difficult to assess the significance of these lower scores. Given their mean age, it is possible that fathers' overall lower scores were again reflective of society's (perhaps changing) norm regarding men not expressing emotions.

Fathers, as demonstrated in this study, more often utilized internal strategies to cope with stress such as "passive appraisal" or "reframing" which may have prevented them from even identifying a stressor as such.

Scores for mothers however, were high enough to be concerned about the potential for depression or lack of contentment with their life; following the group intervention these feelings increased. It is possible that participation in the group brought more feelings to the surface that needed to be expressed and addressed.

TABLE 6 GENERALIZED CONTENTMENT SCALE PRE-TEST AND POST-TEST SCORES		
PARENTS	GCS PRE-TEST SCORES	GCS POST-TEST SCORES
MOTHERS	mean = 28.5 s.d. = 10.8 n = 13	mean = 34.6 s.d. = 13.2 n = 6
FATHERS	mean = 22 s.d. = 11.4 n = 4	mean = 21.5 s.d. = 2.5 n = 2
TOTALS	mean = 26.94 s.d. = 11.32 n = 17	mean = 31.4 s.d. = 12.9 n = 8

As indicated in the previous sections, parents' satisfaction with life was related to their coping abilities and their satisfaction with family support. This is consistent with the literature, according to Trute and Hauch (1988), Crnic et al. (1983), and Vadasy (1985).

Despite the small sample size, some of the findings related to couples are worth noting. The fact that 4 out of a possible 4 couple systems had similar satisfaction with family support, and 3 out of 4 had similar satisfaction with life, indicate that mothers and fathers appeared consistent in their appraisals of those dimensions. However, mothers tended to rate family coping higher or the same as their husbands. This may suggest that mothers are more optimistic than their husbands regarding family coping.

4.11 Individual Goals

At the initial interviews, most parents articulated in some way, a desire to meet other parents of residents living at the Centre. Nine parents (4 couples and 1 mother) saw their role as helping others, particularly parents who more recently admitted their child. Having gone through the process themselves, they felt they could offer parents some understanding, reassurance, and support. There may also have been the feeling amongst some parents who had older children living at the Centre that these parents should no longer require help.

Most parents specified feelings and issues that were of importance to them which they wished to discuss with other parents, for example: their child's deteriorating health, coping with home visits, trends in the community, balancing competing commitments (handicapped child, other children, job, and community service), effects on siblings and other family members, understanding the service system, and relationships with careproviders.

4.12 Discussion of Findings Related to Individual Dimensions

The fact that more mothers attended the group than fathers corroborates findings from standardized measures that mothers utilized the active external coping strategies such as seeking social support whereas fathers tended to utilize internal coping strategies. Recalling Greenberg and Fewell's (1989) study, mothers value child related support more than fathers. Lower educational level may also have been a factor in the limited attendance by fathers as it may generate fears about participating in an intervention that required people to be verbal. The fathers in attendance were active participants and appeared to benefit as much and

in some cases more than mothers. They were encouraged to share feelings and provide support which they otherwise may not have had the opportunity to do. Therefore, one cannot generalize about the inappropriateness or ineffectiveness of support group interventions for fathers.

Parents whose child had lived at the Centre for a number of years were in the majority. Perhaps their attendance had something to do with their stage of adjustment to their child's disability and their achievement of a certain comfort level in their decision to place their child. They were interested in meeting other parents who had children with developmental disabilities that lived at the Centre and were interested in sharing their experiences and feelings related to this commonality. They were able to perceive themselves as helpers by having their own experience available for others as well as seekers of help to obtain emotional support for difficulties they were facing.

There were other parents that the program did not attract. Many of the reasons outlined in subsection 4.5 may provide some explanation. However a number of hypotheses regarding non-attenders in general can be

made to explain this finding utilizing concepts from the literature and some demographic information of the Centre's population.

Some of the factors that determine why people do not seek out social work services even though they would likely benefit from them are outlined by Breton (1985) and may apply to parents who have children/young adults living at the St. Amant Centre. That is, some parents may not perceive the admission of their child as a life transition or crisis point with the potential for problems or the need to reduce stress. For example, a common perception may be that the stress is bound to disappear soon after the child is admitted. There are others who feel a sense of powerlessness and a sense that they cannot be helped. These individuals do experience stress and emotional pain, but believe that nothing can be done about it (passive appraisal). There are those who are aware of the group program but either through past experience or preconceived ideas have convinced themselves that groups do not work or will lead to more problems. Some parents believe that the price is too high to change behavior. Their life is in order and the reawakening of feelings and dealing with the difficult issues is not worth the disruption it will cause in their life. A parent may wish to avert risk

because they doubt they have the ability to perform as a group member similar to the fathers who have concerns about their verbal skills and therefore doubt their ability to help. Finally, there may also be parents who despite recruitment efforts are simply not aware of the program.

Demographic characteristics of the Centre's population may provide some insights into whom the group did not attract. Approximately 40% of families of residents live in rural areas, where distances may likely preclude their involvement in a support group in the city. The fact that 50% of the Centre's population are adults may imply that a number of residents may have elderly or ill parents who would find it difficult to attend. Parents whom the group also did not attract were parents of aboriginal descent whose children comprise 20% of the population at the Centre.

Parents' participation in the program may also have to do with the timing or stage in a life transition. The immediate goal of parents who had recently admitted their child was perhaps to reorganize family life to a sense of normalcy and to devote attention to other

children or other interests that have been put on hold over the years in favor of the child with the disability.

With regards to parent involvement, it is difficult to assess whether the reason for less contact with the child in the two families mentioned in subsection 4.6 related to the child's limited response or the child caring demands of those at home. Rather than it being one reason or the other, it is probably both. The perception that their disabled child is well taken care of, and perhaps does not need them as much as the other children do, frees them to focus on the other children. The fact that there was no notable change in overall parent involvement following the intervention was not surprising in that the parents appeared to be as involved as they were able or wished to be from the start.

The results of the standardized measures also have implications for discussion. According to the F-COPES scores, families in this group have a high degree of positive coping behaviors/strategies. However, the outcomes of the families' efforts in the active support seeking strategies reflected in the F-COPES were not reflected in the PSS-Fa. A possible explanation is that

most of the factors measuring the active strategies in the F-COPES refer to friends, neighbours, and professionals rather than relatives. The parents involved in this sample may have been more successful acquiring support from friends, neighbours, and the service system than from family.

The relationship among perceived family coping abilities, perceived support from families and general contentment with life also has important implications. The correlation between contentment with life and perceived satisfaction with family support again substantiates Trute and Hauch's (1987) research which suggests that low satisfaction with life is an indicator of problems in the family. The findings from this practicum further suggest that in these situations, family coping will also be limited. The literature previously reviewed is referred to again when discussing the implications of these findings. Trute and Hauch (1987) found that although emotional support was provided by family and friends, concrete help (i.e., material aid, physical assistance, and respite) was provided more by family than by friends. The actual or perceived presence or absence of concrete help affects a family's ability to cope with stress. It could be argued as well, that it is only when the family has the

material resources, physical assistance and a break from the ongoing care of the child that they can also begin to deal with the emotional issues. This lack of family support could have been a major factor in the decision parents in this practicum made to place their child at the St. Amant Centre. Single parenthood (potential for lack of physical assistance, material resources and emotional support) and financial insecurity or low income (lack of material resources) are also risk factors that may have played a part in parents' decision to place their child.

While the above discussion suggests some potential consequences of low perceived family support, it is necessary to speculate as to the factors that may contribute to low perceived family support. Firstly, certain factors may arise from problems existing previous to the birth of the disabled child. For example, maladaptive interpersonal processes may exist or life problems may be experienced by extended family, thus weakening the support available. Secondly, extended family may not be available due to distances between parents and their extended family, or due to aging or illness of extended family members. Thirdly, it is possible that extended families find it difficult to accept the disabled child or adult and withdraw or do

not offer support. On the other hand, there may be families who will not accept help, trust or allow others to look after the disabled child. In these situations, although support is available it may not be used. A final possibility may be that because such a heavy physical and emotional burden is felt by parents, few extended families are capable of rendering enough support. Further research is necessary in order to determine what factors affect the perceived support (including spiritual support) in parents of disabled children generally.

Although parents were the focus of this study, high family coping scores, satisfaction with family support or contentment with life did not necessarily preclude families from experiencing difficulties with siblings. Without more information however, it is difficult to make any inferences on siblings that relate to anything other than the factors contributing to family stress as a whole including the parents' ability to cope.

These findings are helpful in terms of the practice of social work with families with developmentally disabled children. Firstly, these findings have identified what life situations or risk factors contribute to the type of stress that put a family "at risk" for placing their

child outside of their home. The findings also confirm the literature on the saliency of the perceived fit between the parent/family and their support network, specifically family support in coping with stress and in their feelings about life in general.

The implications of the findings related to individuals in the group have been discussed in this chapter. These findings have further implications for program development which will be discussed in the final chapter. The next chapter focuses on the findings related to the group as a whole which will provide some insight into whether or not the support group was an effective intervention in providing support to families with children with developmental disabilities.

CHAPTER 5

EVALUATIVE FINDINGS AND IMPLICATIONS:

THE GROUP AS A WHOLE

5.1   Introduction

This chapter will focus on findings within the group context. Firstly, the goals of the group will be reviewed. Secondly, specific elements will be examined in terms of the group sessions to give the reader an overview of the group's functioning. Parent satisfaction of the program will also be reviewed. Finally, these findings will be discussed in relation to the experience of families with developmentally disabled children and on support groups as a valid intervention to assist these families.

5.2   Group Goals

The following were the Parent Support Group goals based on information from the parent survey, key informants, parent interviews and review of the literature:

1.   To provide an opportunity for parents of residents living at the St. Amant Centre to be able to share common experiences, stressors and concerns in a supportive group atmosphere;

2. To decrease social isolation of parents who lack a support system to meet their needs;

3. To increase individuals' self-esteem as they are able to feel support from and help each other;

4. To increase the quantity or improve the quality of parent-child contact.

5.3 Overview of Group Sessions

Introduction

For the purpose of this practicum, general comments and important highlights will be made rather than providing a detailed account of each session. A summary of each session is provided in Appendix 12. This section will focus on attendance, topic areas, structure, content and process.

Group meetings were held in 2 or 3 hour sessions weekly for eight consecutive weeks at the St.Amant Centre. The meetings were held in one of the dining rooms where the space, lighting, and seating created a climate of comfort. The Centre provided coffee and juice for what

might have been a social time at the end of a 1½ or 2 hours of meeting. The social time however turned out to be in the middle of a 3 hour meeting. Although there were no new members admitted during the sessions, the group was not closed to parents wishing to join.

Attendance

Over the eight weeks the group averaged 12 members per session. Two parents did not return following the first meeting. Otherwise almost all members were absent at least once. The average number of times these members were absent was between 2-3 times. Members who were absent the most, a) lived out of town and had young children, b)were experiencing other personal problems, or c) had many other commitments. Other reasons related to illness, another Centre parent meeting and work commitments. When members were absent but did not phone, the group decided that a member would phone to let people know that they were missed and to remind them about the topic for next session. Most of the individuals had employment or other responsibilities during the day, summer was just around the corner, and yet they attended most of the sessions. As well, the length of the sessions extended from 1½ hours to almost 3 hours by the end of the 8-week session. The parents

seemed to enjoy the opportunity to share experiences with each other and they were all willing to make the sessions longer. This could have meant that the amount of time that would be needed to adequately cover the topic areas was underestimated. Nevertheless, the high attendance and increased length of meetings showed a high degree of motivation and commitment to the group.

Topic Areas

A list of potential topic areas was compiled and distributed at the second meeting based on the stressors identified at the first meeting. The topic areas were grouped more broadly to provide opportunity for some cognitive learning. Rather than leaving the group meetings completely open, it was felt that one topic area identified for each week would help the group to focus during the sessions and to cover the areas identified before the sessions were over. This may have been more the facilitator's need for structure than the parents' need. Topics for the subsequent weeks were scheduled as follows:

Week 3: Stress and Coping
Week 4: Impact on the Family

Week 5: The Grieving Process

Week 6: Working with Professionals

Week 7: Issues Facing Parents of Children/Adults

Week 8: Wrap-up Session

As it turned out, the topic related to the grieving process needed more than one session. In some ways issues from sessions 6 and 7 had been dealt with in earlier sessions particularly in sessions 3 and 5 and the session on grieving carried over to the next session. The discussion on feelings towards professionals expanded to include lack of community acceptance of their child.

Structure

Sessions generally began by providing the opportunity for parents to share any thoughts or feedback about the previous session. The opening statement introducing the topic area would then be provided. The bulk of the session was devoted to discussion around the topic area, leaving some time at the end of each session for summary and evaluation.

Techniques/ Formats Utilized

A variety of techniques were utilized over the course of the eight sessions in order to assess which techniques were most helpful in fostering cohesiveness, relationship building and mutual aid.

One of the first techniques used was self-introduction. During the first session it provided an opportunity for members to share factual self information without having to get into emotionally laden areas. Members were then asked to share more information about the more difficult aspects, such as the factors that led to their child's placement.

More structure was used in the earlier sessions to facilitate interaction and affiliation between members. For example, an icebreaker exercise was utilized to bring out commonalities beyond their children's disability. The group seemed to enjoy the exercise and it prompted discussion of commonalities and differences in areas of interest, personal characteristics and how different people deal with stress in different ways. Throughout the sessions the facilitator connected people's experiences to one another's so that members would begin to see some commonalities.

Dividing into smaller groups to prioritize topic areas and to identify stressors was an attempt to encourage more interaction between members. Although group members preferred to be in the larger group, there tended to be more interaction in the smaller groups. They felt that they would be missing out on contributions of members who were not in their group even though they would be meeting back in the larger group to summarize. However, the quieter members remained quiet even in the small groups. It appeared that these quieter members benefitted from encouragement and the opportunity to speak and whether it was in the small or large group did not seem to be the issue. Because the group preferred to stay in the large group for discussion, the facilitator did not return to this method. The "larger" group was not very large in most instances, in any event.

Brainstorming was also used to generate thoughts and feelings related to, for example, what support meant to individuals, the signs and symptoms of stress, grief and loss. In most cases this generated thought and to some degree, it was useful in "normalizing" some of the concepts of stress, grief and loss, but it did not promote very much discussion or member to member interaction. There was also some presentation of theory

for example, on stress, to create cognitive understanding of their situation and also to "normalize" the stress experience.

Some handouts were utilized to stimulate discussion. 'The Child Within Us' (Appendix 13a) which was presented at the session on "Stress" evoked an emotional response and prompted interaction and mutual aid. The 'Dear Friend' letter (Appendix 13b) which was presented at the session on "Impact on the Family" elicited discussion on the issues siblings may face. Some parents wished they had seen this when their children were younger to promote discussion with them.

Throughout the eight sessions direct and non-direct methods were employed to facilitate member responsibility for the group and to promote group members helping each other to problem solve. Questions were redirected to the group, group members were encouraged to respond to each others' comments, and to provide support and/or information based on their own experience that would be of benefit to other group members. Each one of the techniques in the **Group Leadership Rating Form** (Cory and Cory, 1977) was used, however some of the techniques were used more than

others due to the nature of the group. The results of
the Group Leadership Rating Form are discussed in
Chapter 6.

Content and Process

Group content and process are also briefly summarized
for each session in Appendix 12. The purpose of this
subsection will be to summarize content and process for
the series of sessions overall.

The content of discussions reflected a series of
normative and non-normative events that impacted on
study families. Examples of normative life changes were:
balancing the competing demands within a family with
young children (ie. family, jobs and community service);
children entering adolescence or adulthood (role and
boundary shifts); and changes imposed on the family
later in life such as physiological decline and/or
illness.

The non-normative perceived stressors were identified,
both related and unrelated to the disabled child. The
majority, though, were related to the disability in the
family and issues related to placement. Some parents

found characteristics such as profound communication impairments and severe behavior problems difficult to cope with. Further to this, feelings related to the discrepancies between the physical development of a young adult and their cognitive level were discussed. Involvement with professionals and the social service system, feelings about placement and, for some parents, visiting was also stressful.

Examples of the non-normative events not relating to the disability, but impacting on the family were marital breakdown and single parenthood. Maladaptive communication patterns were also present in situations where family problems resulted in lack of family support.

Not all of the content reflected negative outcomes. Some parents referred to positive outcomes. They felt that the child with a disability contributed to the caring and tolerant attitudes of siblings as well as to the strengthening of the couple's relationship.

There was a mixture of external and internal coping strategies exchanged by parents. Internal strategies were often used when referring to stressors related to

the disabled family member and the placement. For example, parents looked at the positive aspects of their child's life at the Centre to cope with the feelings around placement. They looked at the alternatives, and believed that for their children, the Centre was the best option. The Centre was considered their child's "home" and the staff were extended family. Another example of an internal coping strategy used was the family who found difficulty finding activities during visits because of their child's severe limitations. They finally conceived that they could have a meal together as a family at St. Amant with the child present. It was the idea of "sharing a meal together" that became an important family function which could include the disabled member. In discussions about home visits, parents generally accepted as fact that they would not be able to have their child home for visits forever. While this may in fact be true, there were few suggestions of involving external resources such as family or formal services to assist. External strategies were suggested in coping with other normative and non-normative events, not involving the disabled child. There seemed to be an indication that parents of a disabled child did not wish to burden anyone.

Some useful suggestions were made to help younger siblings adjust to the disability and feel comfortable visiting. For example they could be involved in decorating their brother's or sister's room, they could make toys or articles for his/her use, and they could also interact with him/her by learning appropriate games to play.

Group process changed and developed in terms of the types and depth of interactions over the life span of the group. Although information was shared at the initial meeting, it was in narrative form and mutual aid processes were not apparent yet. This is not to negate the therapeutic value of narrative (Borden, 1992). Session 3 appeared to be a turning point in that members were more comfortable with each other and there was opportunity not only for empathic listening but for supportive interaction. This continued through the fourth session. In the fifth session (The Grieving Process) cohesion tended to be lower which could have related to the return of three group members who were absent in the fourth and second half of the third session. As well, there was likely discomfort with the topic and a limited understanding of the relevance of this topic to disability. Following increased cohesiveness and mutual aid in session 6, session 7 and

8 had lower intensity or depth of interaction though cohesion was still high. This was likely due to the group's preparation for termination of this series of sessions.

It appeared that all but one of the mutual aid processes that Gitterman and Schulman (1983) proposed (refer to subsection 2.3.2.) were present in this group in varying degrees. The most prominent were "sharing data", the "all-in-the-same-boat" phenomenon, and "mutual support." Other processes that were beginning to develop were "dialectical processes," "mutual demand," and "individual problem solving." Parents however, never shared fears of their child's death, angry feelings towards their child, guilt related to either negative feelings about their child or related to the relief they felt after placement, or issues related to their child's sexuality, as examples. Furthermore, although issues in marriages did come up at least once or twice, it was not a topic people were ready/willing to discuss in detail. These were considered "taboo" areas for this group at that time. There was no opportunity during the course of the group sessions to use "rehearsal" although I believe that given an appropriate situation, this group would enjoy and benefit from it. In terms of the "strength in numbers" concept, while the group did not identify any

advocacy functions, the bond developing between group members had become a source of emotional strength and identity.

5.4   Sessional Evaluations

Evaluation was done both orally and on paper by members at the end of each session. This was an opportunity to receive ongoing feedback to ensure that the group was meeting member's needs. A compilation of the written evaluations are in Appendix 14.

The feedback was generally quite positive in both the sessional ratings and comments sections of the evaluation forms. Sessions 3 and 6 received the highest ratings. This was not surprising, as session 3 was referred to earlier as the "turning point" where the mutual aid processes were becoming more evident. In session 6, cohesiveness and supportive interaction were also noted to be higher. Session 5 was rated as the lowest of all the group sessions. In this session there were new members, some key members absent, and perhaps a gap in the understanding of the relevance of the topic to this group. The overall cohesiveness and positive interaction in this session was poor. What is clear from this is that members are able to sense when the group is

operating cohesively and there is definitely greater satisfaction when the mutual aid processes are working well.

The benefits of the support group as perceived by parents was evident from the feedback received. Parents felt it important to be able to share their feelings and experiences in a relaxed, trusting, accepting environment. It was important for them to meet with and listen to others who had a disabled child so that they did not feel so alone. This promoted the development of friendships and the sharing of different ideas and viewpoints.

Through verbal feedback many parents noted that their experience in the group went beyond their expectations firstly, because it brought feelings to the surface that they did not know they had, secondly, because of the support they received from the group, thirdly, because they came to the realization that others have similar feelings and experiences, and finally because of the relationships that developed. Some of the comments at the last session were as follows:

*   "It's nice to recognize people in the hallways, it makes you realize you are not alone."

*   "We all seem to 'fit' with each other."

*   "Everyone shared, it felt like friends, time went
so quickly."

*   "We can trust people here, and there is an
attitude of acceptance."

*   "I have never talked to friends about this. I felt
for the people here. I'm surprised how it still
hurts over the years."

*   "It was great meeting people with the same
problem."

5.5   Discussion of Findings Related to the Group: Common Trends

For the most part, parents seemed to have adjusted to
their child's disability. In most cases parents were
realistic about expectations and needs, and had frequent
involvement with their child. They were able to perceive
positive outcomes and maintain a sense of humor. For
those individuals whose child had lived at the Centre
for more than a year, a certain comfort level had been
achieved regarding their decision to place their child.
While the content of group discussions tended to focus
on issues related to a child with developmental

disability in the family, there were a number of issues
that had to do with other life transitions, some
normative and some non-normative.

A small number of parents were still in the
disorganization phase of adjustment after having
recently admitted their child. They were in the process
of working through the impact of the admission on the
rest of their life, and redefining their child's place
in the family and their own parenting role. These
parents were able to seek comfort from the parents in
the group whose child had lived at the Centre for
longer. Although many of the other parents had reached
the stage of reorganization, there were some ongoing
strains that did not disappear.

The double ABCX Model can be used, to summarize the
implications of this chapter (see subsection 2.2.4 for
the double ABCX model). The initial event (the A factor)
was the first knowledge of the disability, either the
child's birth, or diagnosis, etc.. For some families,
certain child characteristics such as profound physical
and communication impairments and severe behavior
problems were also perceived strains. Certain issues
related to acceptance of a discrepancy between the
physiological development and the cognitive abilities of

their adult child. Some parents were also concerned about sibling adjustment. Families also found the decision to place their child and the events leading up to placement as stressors subsequent to the initial event. There were also strains associated with the placement itself, such as the feelings at the time of placement and those that continue to erupt and subside depending on the health of the child or other circumstances. The life cycle stage of the family is also pertinent in the double A factor, as are other non-normative events and strains. This substantiates the literature that suggests that families who have children with disabilities need to cope with the stressors produced by the disability, as well as other life events.

In terms of the double B factor (the family's internal and external coping resources), this study has produced some interesting findings. The results from the standardized measures indicated high overall coping using external strategies more with friends than with their families. From the content of group discussions, the use of internal strategies was more prevalent. One could speculate that the external resources were utilized mainly with problems unrelated to their disabled child. This confirms the literature that

parents choose family over friends to assist with the
emotional and practical issues that related to their
disabled child. Even when the parents perceive a lack of
support from their families they did not approach
friends to fill the gap as they might have for stressors
unrelated to their child. Other possibilities are that
once a child is placed parents feel less inclined to
mobilize resources due to either the lack of perceived
need, an actual or perceived lack of resources, or a
sense of powerlessness in their ability to change things
related to their child.

The "C" factor (perception) in the ABCX Model includes
both perception of family resources and perception of
the event. The results of the practicum suggest that a
perceived lack of family support increases the
likelihood of a negative perception of the event.

Trute (1987) found that family's subjective
interpretation of the impact of a disabled child was
primarily positive or at least neutral. Although
subjective interpretation was not measured
quantitatively in this practicum the impression is that
parents did not appear to view the event as primarily
positive, though some positive outcomes were identified.

It is important to examine the differences in the study samples between Trute's study and this practicum in order to suggest some explanations.

Firstly, the mean age of children in Trute's study was 3 years, compared to 16.2 years in this practicum. The impact of a disabled child over time on Trute's study families may not have been fully realized. Secondly, in that study, while the children ranged in levels of mental and physical handicap from mild to severe, only 20% were identified as severely intellectually compromised and only 10% were physically compromised. In this practicum all but one of the residents had severe disabilities involving severe to profound intellectual impairments and approximately 60% were physically disabled. This suggests the possibility that these characteristics affected parents' perceptions of the impact of disability on their families.

Individual goals that parents had initially stated were met and in many cases exceeded (refer to subsection 4.11 for individual goals). They were able to meet other parents and to assist them in a variety of ways. They were also able to obtain support for their own personal situations.

Except for the final goal of increasing the quantity and quality of home visits the group goals were met (refer to subsection 5.2 for group goals). As indicated in the previous chapter, it was difficult to assess whether or not the group had any impact on visits or parent child interaction. Visits had not increased following the group, however no data was kept in terms of the quality of visits. Group members did benefit from being able to share common experiences, stressors and concerns in a supportive group atmosphere.

The second group goal of reducing social isolation was also met. The group acted to replace emotional support from family which seemed to be lacking for the parents who participated in this practicum. In addition, both the recognition that others share a common life event and in many cases common feelings and because friendships had also developed social isolation had decreased.

Perceived support according to Cobb's (1976) definition (refer to section 2.3) enhances a person's feelings of self-worth and self-esteem and relates to the third group goal. The group process normalized and validated the experiences of families. As well, group members

learned that through their own experience and capacities they offered something of value to other parents. Self-esteem derives from identifying and feeling part of a group. The "all in the same boat" phenomenon can have a positive effect on feelings of self-worth by providing validation and reducing social isolation and stigma (Olson, 1986:46).

According to Lang's (1972) developmental model (see subsection 2.3.3) the parent support group in this practicum could be assessed as "allon-autonomous". By the end of the sessions parents were at the stage where they were taking over mutual aid functions and developing some leadership skills.

CHAPTER 6

EVALUATION OF STUDENT LEARNING

The opportunity to conduct the practicum at the
St. Amant Centre was valuable in that the experience
could directly relate to the practice of social work in
my work setting. The exploration of the literature and
the implementation of the group provided an opportunity
to gain knowledge and understanding, to strengthen
clinical skills and to reevaluate the priorities/goals
for social work practice at the Centre.

After reviewing the literature on developmental
disability in the family, the need became clear for a
universal or comprehensive model that would help to
explain the diversity in response to the birth of a
disabled infant. Ecological theory established the
foundation from which stress, coping and social support
were viewed. It was helpful in conceptualizing the
reciprocity between people's social environments and
their adaptive behaviors. Normalizing family experience
by the concepts of stress and adaptation to explain
family response to a disabled child was important in
"depathologizing" these families. Concepts from the
three frameworks were helpful in assessing the impact of
developmental disability on the study families from an

adaptive perspective and in terms of what they perceived to be stressful, and how they generally coped with stress. Social support was referred to as a coping resource, but it was the family's perception of that support and their ability to utilize it that was most helpful in the assessment rather than simply the awareness or the existence of family support.

The literature on social support expanded knowledge and understanding in terms of the attributes of social support systems. This assisted in defining the supportive intervention for this practicum from within the broader range of support network interventions. The understanding of the crucial role of family support when there is a disabled child, was critical in evaluating the implications of this study.

A review of the literature on support groups was also very helpful in differentiating between the types of group interventions which further defined the intervention for this practicum and, in keeping with an ecological approach, clarified the role of mediator of mutual aid processes in the present group, and identified other, perhaps future social work role possibilities.

Through the practical experience, skills in group work were developed and abilities as a group facilitator were assessed. The Group Leadership Rating Form (Appendix 10) was helpful in providing a format for rating skills. The ratings showed that strengths were in empathizing with, supporting, and listening to group members. Linking people's feelings or experiences to one another's, bringing out commonalities and promoting affiliation between members were utilized well. Open expression of feelings was encouraged in a climate of trust and safety. It appeared that the group benefitted from the results of these skills/techniques as indicated by their feedback.

Diagnosing was another important skill utilized, as there were certain individuals who had difficulties that needed more than a support group could provide. Two of the three would be able to benefit from the support group as well. In each case, referral to an alternative source of help was offered.

Skills utilized the least effectively were those related to confrontation and blocking. The focus in the group initially was to facilitate the sharing of information

and feelings related to their child, however discussion could have focussed also on members' feelings about the process, especially those processes that may have been detrimental to the group's growth. There were at least two situations which may have benefitted from more direct intervention, however effective mediating may have benefitted the group rather than a confrontational approach.

Another unused strategy that surfaced in my self-evaluation was blocking although there was little reason to utilize this technique. The only situations where it might have been appropriate were when members engaged in story-telling. I could have simply asked the individual, for example, to "tell us how this relates to your feelings about your child."

The opportunity to utilize standardized measures was also helpful as the findings of the study were very much influenced by the results of those measures. The opportunity to explore the range of standardized measures was also of assistance in terms of possibilities for future research. However there were a few difficulties with their interpretation. Firstly, with regards to the F-COPES, it was unclear if parents

were completing the scale in terms of how they perceive that _they_ as individuals cope, or how they perceive their families cope. If the scores reflect perceptions about family coping, it would be difficult to determine whether mother's or father's scores would be most reflective of the family. It would also have been interesting to survey siblings to obtain their perspectives.

This practicum provided germane findings for the group of participating parents. The use of the standardized measures and comparisons to norms in other studies involving parents with children with disabilities permitted a degree of generalizability within the group of study parents. However, generalizing the results to the Centre's parent population would be imprudent. It is difficult to know if the sample of parents in this study are representative of the Centre's parent population. The post-test results were also limited in their validity with a return rate of 60% which included only two fathers. As well, it is difficult to prove that the increase in mothers' post-test scores was attributable to the group. The attempts at objectively measuring outcomes of the group failed to produce meaningful results. So whether the parent support group facilitated adjustment can only be answered indirectly. If perceived

social support affects adjustment then the support group did improve adjustment. Other objective measures need to be explored.

Overall, through the practicum experience, a comprehensive understanding of the impact of a child with developmental disability on the family, particularly parents was acquired. An understanding of the contribution of social work in working with these families was also gained. The knowledge of family stress, coping and social support can be utilized in assessments to determine vulnerability or risk factors in families as well as identifying potential areas for intervention.

The experience has also reinforced the belief that a support group is an appropriate intervention with families with disabled children. By augmenting their support network, parents have access to a new set of ties from which to engage in the mutual aid process. Social work's role in the process is to "help members identify and use their capacity for mutual aid" (Olson, 1986:46).

CHAPTER 7

RECOMMENDATIONS, FUTURE RESEARCH AND CONCLUSION

Group members clearly indicated their desire to have the parent support group continue. Given the skills of the group members, and the foundations of Social Work practice reflected in the goals of empowerment, self-determination, and autonomy, it would be appropriate for the group to move towards peer leadership.

Based on this practicum experience, the following recommendations are made:

1.   That the parent support group move towards parent leadership by:

     (a)   electing a small group of members who will be responsible for re-establishing the group in the fall; and

     (b)   parents beginning to organize, arrange for speakers when needed etc. and "chair" or "facilitate" meetings.

2. That the parent support group focus on recruitment by utilizing a personalized approach such as suggested by Breton (1985) in subsection 2.3.2.

3. That consideration be given to limit the number of support group sessions (to 8 or 10) and that it operate weekly or biweekly in order to maintain focus and energy.

4. That other supportive interventions be identified for group members who wish to take on another supportive role such as: individual supports to families, to be the parent contact on the living units, to become group facilitators for future group(s).

5. That the group consider having representation on the Family Support Committee of the St. Amant Society to contribute to the identification of needs and/or provide support to parents/families where it is identified.

6. That since the Society has formed a Family Support Committee to assess the need for and develop a Family Support Program it would seem very

appropriate that consideration be given that this Committee be responsible for the implementation of the parent support group.

7. That the Social Work Department be available to provide consultation, training, assistance with group facilitation, referrals, research, or input in other ways within its available resources.

8. That the Social Work Department maintain a formal link with the Family Support Committee of the St. Amant Society to exchange information and have input into the development of family support programs.

9. That the Social Work Department incorporate the use of inventories utilized in this practicum (or others that the student has come across) in assessments to identify coping abilities, and the risk factors associated with poor coping such as low satisfaction with social support, with spiritual support, and low contentment with life. Support groups (or other supportive interventions) can then be designed to focus on these areas.

10. That other specific or 'hard to reach' populations be targeted for their differential needs for support, such as: fathers, single parents, couples, elderly parents, young families, families of new admissions, siblings, aboriginal families, rural families.

Future research would determine whether low satisfaction with family support, spiritual support and low contentment with life are common to families with children with disabilities in general, and in comparison to a random sample of families of the Centre's population. Future research should also include siblings. Another research suggestion would be to evaluate the effect of social network interventions as preventive approaches to placement.

This practicum provided an excellent learning experience and at the same time it provided the opportunity for a much needed service. It validated that families' experience and response to a life event was linked to and mediated by certain factors including their own perceptions and social support.

The support group was an effective intervention to supplement the support networks of families in this study. Supportive interventions, however need not stop here. Because of the limitations of formal services in providing certain types of support, interventions within the natural helping system also need to take place. Social Work has a role in expanding the repertoire of social network interventions so that individuals can obtain the social support that they need.

BIBLIOGRAPHY

Alissi, Albert S. (Ed.) (1980). _Perspective on Social Group Work Practice_. New York: MacMillan Publishing Co.

Anderson, L. Francis and Robertson, Sharon E. (1988). "Group Facilitation: Functions and Skills," _Small Group Behavior_, 16(2), May, 139-156.

Beamish, Megan (1988). _Social Work Practice With Chronically Ill Children and Their Families: An Ecological Approach_. An Unpublished Practicum Report, University of Manitoba, Winnipeg, Manitoba.

Beckman, Paula J. (1983). "Influence of Selected Child Characteristics on Stress in Families of Handicapped Infants", _American Journal on Mental Deficiency_, 88(2), 150-156.

Black, Maureen M., Cohn, Jeffrey F., Smull, Michael W. and Crites, Linda S. (1985). "Individual and Family Factors Associated With Risk of Institutionalization of Mentally Retarded Adults", _American Journal on Mental Deficiency_, 90(3), 321-276.

Bloom, M. and Fischer, J. (1982). _Evaluating Practice: Guidelines for the Accountable Professional_. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Borden, W. (1992). "Narrative Perspectives in Psychological Intervention Following Adverse Life Events", _Social Work_, 37(2), 97-192.

Bristol, Marie M. and Schopler, Eric (1984). "A Developmental Perspective on Stress and Coping in Families of Autistic Children" in Jan Blacher (Ed.) _Severely Handicapped Young Children and Their Families_. New York: Academic Press.

Bromley, Barbara and Blacher, Jan (1989). "Factors Delaying Out-of-Home Placement of Children With Severe Handicaps", _American Journal on Mental Retardation_, 94(3), 284-291.

Bubolz, Margaret M. and Whiren, Alice P. (1984). "The Family of the Handicapped: An Ecological Model for Policy & Practice", Family Relations, 33, 5-12.

Cameron, S.J., Dobson, L.A. and Day, D.M. (1991). "Stress in Parents of Delayed and Non-Delayed Preschool Children", Canada's Mental Health, 39(1), March, 13-17.

Cobb, S. (1976). "Social Support as a Moderator of Life Stress", Psychosomatic Medicine, 38(3).

Coelho, George V., Hamburg, David A. and Adams, John E. (1974). Coping and Adaption. New York: Basic Books, Inc.

Crnic, K., Fredrich, W.N. and Greenberg, M. (1983). "Adaptation of Families with Mentally Retarded Children: A Model of Stress, Coping and Family Ecology", American Journal on Mental Retardation, 88, 125-138.

Crickson, M. and Upshur, C. (1989). "Caretaking Burden and Social Support: Comparison of Mothers of Infants With and Without Disabilities", American Journal on Mental Deficiency, 94(3), 250-258.

deRosenroll, D. (1989). "A Practitioner's Guide to Peer Counselling Research Issues and Dilemmas", Canadian Journal of Counselling, 23(1).

Dimock, Hedley (1983). "Part I of Leadership and Group Development", reproduced from Factors in Working with Groups, University of Guelph, Guelph.

Dimock, Hedley (1985). "Part II of Leadership and Group Development", reproduced from Factors in Working with Groups, University of Guelph, Guelph.

Dunst, Carl J. and Trivette, Carol M. (1986). "Looking Beyond the Parent-Child Dyad for the Determinants of Maternal Styles of Interaction", Infant Mental Health Journal, 7(1), Spring, 69-80.

Dunst, C.J., Trivette, C.M. and Cross, A. (1986). "Mediating Influences of Social Support: Personal, Family and Child Outcomes", American Journal on Mental Deficiency, 91, 403-417.

Farber, B. (1959). "Effects of a Severely Mentally Retarded Child on Family Integration", <u>Monographs of the Society for Research in Child Development</u>, <u>34</u>(2).

Farber, Bernard and Rowitz, Louis (1986). Families with a Mentally-Retarded Child: International Review of Research on Mental Retardation, <u>14</u>.

Flynt, Samuel W. and Wood, Thomas A. (1989). "Stress and Coping of Mothers of Children with Moderate Mental Retardation", <u>American Journal on Mental Deficiency</u>, <u>94</u>(3), 278-283.

Fowle, Carolyn M. (1968). "The Effects of the Severely Mentally Retarded Child on His Family", <u>American Journal on Mental Deficiency</u>, <u>73</u>, 468-473.

France, M. Hornoré (1989). "Residents as Helper; Peer Counselling in a Long Term Care Facility", <u>Canadian Journal of Counselling</u>, <u>23</u>(1).

Frew, Jon E. (1986). "Leadership Approaches to Achieve Maximum Therapeutic Potential in Mutual Support Groups", <u>Journal For Specialists in Group Work</u>, May.

Frey, Karen S., Greenberg, Mark T. and Fewell, Rebecca R., (1989). "Stress and Coping Among Parents of Handicapped Children: A Multidimensional Approach", <u>American Journal on Mental Deficiency</u>, <u>94</u>(3), 240-249.

Friedrich, William N. and Friedrich, Wanda L. (1981). "Psychosocial Assets of Parents of Handicapped and Non-Handicapped Children", <u>American Journal on Mental Deficiency</u>, <u>85</u>(5), 551-553.

Fuchs, D. (1982). "Network Analysis and Social Group Work Practice With Self-Help Groups" in Norma Lang and Christine Marshall (Eds.), <u>Patterns in the Mosaic</u>, <u>11</u>, Committee for the Advancement of Social Work With Groups, Inc.

Gallagher, J., Beckman, P. and Cross, A. (1983). "Families of Handicapped Children: Sources of Stress and It's Amelioration", <u>Exceptional Children</u>, <u>50</u>, 10-20.

Garvin, C.D. (1987). Contemporary Group Work. Englewood Cliffs, New Jersey: Prentice Hall, Inc.

Getzel, G.S. (1986). "Social Work Groups in Health Care Settings: Four Emerging Approaches", Social Work in Health Care, 12(1), Fall.

Girdner, Linda K. and Eheart, Brenda K. (1984). "Mediation with Families Having a Handicapped Child", Family Relations, 33, 187-194.

Gitterman, Alex (1986). "Developing a New Group Service: Strategies and Skills" in Alex Gitterman and Lawrence Schulman (Eds.), Mutual Aid Groups and the Life Cycle. Illinois: F.E. Peacock Publishers.

Gottlieb, Benjamin (1986). "Put Them Together and What Have You Got?", Journal for Specialists in Group Work, May.

Gottlieb, Benjamin (1987). "Using Social Support to Promote Health", Journal of Primary Prevention, 8(1-2), Fall-Winter.

Gottlieb, Benjamin (1985). "Social Networks and Social Support: An Overview of Research, Practice and Policy Implications", Health Education Quarterly, 12(1), Spring.

Gottlieb, Benjamin H. (1988). Marshalling Social Support: Formats, Processes, and Effects. California: Sage Publications.

Gowen, J.W., Johnson-Marten, N., Goldman, B.D. and Applebaum, M. "Feelings of Depression and Parenting Competence of Mothers of Handicapped and Non-Handicapped Infants: A Longitudinal Study", American Journal on Mental Retardation, 94(3), 259-271.

Guttman, Mary Alice Julius (1989). "Verbal Interactions of Professional and Peer Led Group Counselling Sessions", Canadian Journal of Counselling, 23(1).

Hansen, D.A. and Hill, R. (1964). "Families Under Stress" in Christensen (Ed.), Handbook of Marriage and the Family. Chicago: Rand McNally.

Hansen, D.A. and Johnson, V.A. (1979). "Rethinking Family Stress Theory: Definitional Aspects" in Contemporary Theories About the Family. Burr. W.; I. Reiss & I. Nye (Eds.) 1, New York: Free Press.

Hauch, C. (1990). Social Networks and Social Support in Families Successfully Adjusted to the Birth of a Developmentally Delayed Child. An Unpublished Practicum Report. University of Manitoba, Winnipeg, Manitoba.

Hill, R. (1958). "Social Stresses on the Family: Generic Features of Families Under Stress", Social Casework, 39, 139-150.

Hill, R. (1949). Families Under Stress. New York: Harper & Brothers.

Holroyd, J., Brown, N., Wikler, L. and Simmons, J.Q. (1975). "Stress in Families of Institutionalized and Non-Institutionalized Autistic Children", Journal of Community Psychology, 3, 26-31.

Indelicato, S. and Goldberg, P. (1986). "Harassed and Alone: Parents of Learning Disabled Children" in Alex Gitterman and Lawrence Schulman (Eds.), Mutual Aid Groups and the Life Cycle, Itasca, Illinois: F.E. Peacock Publishers.

Israel, Barbara A. and Antonucci, Toni C. (1987). "Social Network Characteristics and Psychological Well-Being: A Replication and Extension", Health Education Quarterly, Winter.

Kazak, Anne E. and Marvin, Robert S. (1984). "Differences, Difficulties in Adaptation: Stress and Social Networks in Families With a Handicapped Child", Family Relations, 33, 67-77.

Lang, N.C. (1972). "A Broad-Range Model of Practice in the Social Work Group", Social Service Review, 46, 76-89.

Lawson, Diane (1989). "Peer Helping Programs in the Colleges and Universities of Quebec and Ontario", Canadian Journal of Counselling, 23(1).

Lazarus, R.S., Averell, J.R. and Opton, E.M. Jr. (1974). "The Psychology of Coping: Issues in Research and Assessment" in G.V. Coehlo, D.A. Hamburg & J.E. Adams (Eds.), Coping and Adaptation. New York: Basic Books.

Lieberman, Morton A. (1979). "Help Seeking and Self Help Groups" in Morton A. Lieberman and Leonard D. Borman (Eds.), Self Help Groups for Coping with Crisis. California: Jossey Bass.

Lieberman, Morton A. (1979). "The Nature of Self Help Groups" in Morton A. Lieberman and Leonard D. Borman (Eds.), Self Help Groups for Coping with Crisis. California: Jossey Bass.

Lieberman, Morton A. (1979). "Analyzing Change Mechanisms in Groups" in Morton A. Lieberman and Leonard D. Borman (Eds.) op cit.

Longo, Dianne C. and Bond, L. (1984). "Families of the Handicapped Child: Research and Practice", Family Relations, 33.

Maitick, Mildred (1985). "The Impact of Severe Illness on the Individual and Family: An Overview" in Carel B. Germain (Ed.), Advances in Clinical Social Work Practices. National Association of Social Work.

McCubbin, H.I., Cauble, A.E. and Patterson, J.M. (1982). Family Stress, Coping and Social Support. Springfield, Il.: Charles C. Thomas.

Meyer, R.J. (1980). "Attitudes of Parents of Institutionalized Mentally Retarded Individuals Towards De-institutionalization", American Journal on Mental Deficiency, 85, 184-188.

Minnes, Patricia M. (1988). "Family Resources and Stress Associated With Having a Mentally Retarded Child", American Journal on Mental Retardation, 93(2), 184-192.

Olson, M. (1986). "When Is It Social Work? Another Look at Practice With Groups in Health Care", Social Work in Health Care, 12(1), Fall, 46.

Oshansky, Simon (1962). "Chronic Sorrow: A Response to Having a Mentally Defective Child", Social Casework, 43,190.

Powell, Thomas (1987). Self Help Organizations and Professional Practice. National Association of Social Workers, Silver Spring, Maryland.

Rosenberg, Pearl P. (1984). "Support Groups: A Special Therapeutic Entity", Small Group Behaviour, 15(2), May.

Rubin, A. and Babbie, E. (1989). Research Methods for Social Work. California: Wadsworth Publishing Company.

Ruiz, Edmunds J. (1979). "Parents of Profoundly Mentally Retarded Children in Group Therapy", Group. 3(1), Spring.

Schilling, R.F., Gilchrist, L.D. and Schinke, S.P. (1984). "Coping and Social Support in Families of Developmentally Disabled Children", Family Relations, 33, 47-54.

Schneider, John (1984). Stress, Loss & Grief: Understanding Their Origins and Growth Potential. Maryland: University Park Press.

Schwab, Reiko (1986). "Support Groups for the Bereaved", Journal for Specialists in Group Work, May.

Segal, Marilyn M. (1985). "An Interview Study with Mothers of Handicapped Children to Identify Both Positive and Negative Experiences That Influences Their Ability to Cope." Paper presented at the National Center for Infants Programs, (4th Washington, D.C., December 6-8).

Seltzer, M.M. and Krauss, M.W. (1984). "Placement Alternatives for Mentally Retarded Children and Their Families" in J. Blacher (Ed.), Severely Handicapped Young Children and Their Families. New York: Academic Press.

Seltzer, M.M. and Krauss, M.W. (1984). "Family, Community Residence and Institutional Placements of a Sample of Mentally Retarded Children", American Journal on Mentally Deficiency, 89(3), 257-266.

Springer, A. and Steel, Mark W. (1980). "Effects of Physician's Early Parental Counseling on Rearing of Down Syndrome Children", American Journal on Mental Retardation, 85(1), 1-5.

Suelzle, M. and Keenan, V. (1981). "Changes in Family Support Networks Over the Life Cycle of Mentally Retarded Persons", American Journal on Mental Deficiency, 86(3), 267-274.

Toseland, Ronald W. and Rivas, Robert F. (1984). An Introduction to Group Work Practice. MacMillan, U.S.A.

Tripodi, T. (1983). Evaluative Research for Social Workers. Englewood Cliffs, New Jersey: Prentice-Hall, Inc.

Trute B. (1987). "Family Care of Developmentally Disabled Children: Appraisal, Coping and Social Support in Well Adjusted Families", Child and Family Services Research Group, School of Social Work, University of Manitoba, Winnipeg, Manitoba.

Trute B. (1987). "Vulnerable Children in Early Childhood: An Exploration of the Home Care Circumstances of Developmentally Disabled Children in Strong, Well Adapted Families", Child and Family Services Research Group, School of Social Work, University of Manitoba, Winnipeg, Manitoba.

Trute B. and Hauch C. (1987). "Social Network Attributes of Families With Positive Adaptation to the Birth of a Developmentally Disabled Child", Child and Family Services Research Group, School of Social Work, University of Manitoba, Winnipeg, Manitoba.

Unger, Donald G. and Powell, Douglas R. (1980). "Supporting Families Under Stress: The Role of Social Networks", Family Relations, 29, 566-574.

Vadasy, Patricia F. and Others (1985). "Supporting Fathers of Handicapped Young Children: Preliminary Findings of the Program Effects", Analysis and Intervention in Developmental Disabilities, 5(1-2).

Verstraete, Josephine A. (1991). An Evaluation of a Residential Respite Program for Families of Persons With Developmental Disabilities: Client Satisfaction and Staff Perspectives. An Unpublished Practicum Report. University of Manitoba, Winnipeg, Manitoba.

West, M., McIlvaine, R. and Sells, C.J. (1979). "An Interdisciplinary Health Care Setting's Experience with Groups for Parents of Children Having Specific Disabilities", Social Work in Health Care, 4(3) Spring.

Whittaker, James K., Garbarino, J. and Associates (1983). Social Support Networks. New York: Aldene Publishing Co.

Wikler, Lynn (1981). "Chronic Stresses of Families with Mentally Retarded Children", Family Relations, 30.

Wikler, Lynn M. (1986). "Periodic Stresses of Families of Older Mentally Retarded Children: An Exploratory Study", American Journal on Mental Deficiency, 90(6), 703-706.

Yanagi, G., Yee, S., Sutter, P., Mayeda, T. and Cole, T. (1980). "Comparison of Successful and Unsuccessful Community Placed Mentally Retarded Persons", American Journal on Mental Deficiency, 85(3), 262-267.

Zirpoli, Thomas J. and Bell, Richard Q. (1987). "Unresponsiveness in Children With Severe Disabilities: Potential Effects on Parent-Child Interactions", The Exceptional Child, 34(1), March.

THE STAGES OF THE FAMILY LIFE CYCLE

Family life cycle stage	Emotional process of transition: Key principles	Second-order changes in family status required to proceed developmentally
1. Between families: The unattached young adult	Accepting parent–offspring separation	a. Differentiation of self in relation to family of origin b. Development of intimate peer relationships c. Establishment of self in work
2. The joining of families through marriage: The newly married couple	Commitment to new system	a. Formation of marital system b. Realignment of relationships with extended families and friends to include spouse
3. The family with young children	Accepting new generation of members into the system	a. Adjusting marital system to make space for child(ren) b. Taking on parenting roles c. Realignment of relationships with extended family to include parenting and grandparenting roles
4. The family with adolescents	Increasing flexibility of family boundaries to include children's independence	a. Shifting of parent–child relationships to permit adolescents to move in and out of system b. Refocus on midlife marital and career issues c. Beginning shift toward concerns for older generation
5. Launching children and moving on	Accepting a multitude of exits from and entries into the family system	a. Renegotiation of marital system as a dyad b. Development of adult to adult relationships between grown children and their parents c. Realignment of relationships to include in-laws and grandchildren d. Dealing with disabilities and death of parents (grandparents)
6. The family in later life	Accepting the shifting of generational roles	a. Maintaining own and/or couple functioning and interests in face of physiological decline; exploration of new familial and social role options b. Support for a more central role for middle generation c. Making room in the system for the wisdom and experience of the elderly; supporting the older generation without overfunctioning for them d. Dealing with loss of spouse, siblings, and other peers, and preparation for own death. Life review and integration.

Walsh (1982)

GUIDELINES FOR DESIGNING
INTERVENTIONS INVOLVING SOCIAL SUPPORT

(1) The investigator should invoke theory and data (from the existing literature) to explain why the planned support intervention will lower the risk among members of the target population. In addition, he or she should indicate whether certain subgroups are expected to make greater gains than others and why.

(2) The investigator should furnish evidence that the target population is at risk and specify clinically relevant states, disorders, or behaviors that are to be averted or ameliorated via the intervention. Moreover, the investigator should specify whether the risk is immediate or long-term (e.g., disruption of normal developmental processes) or both.

(3) The investigator should demonstrate his or her ability to recruit a sample sufficiently large to detect clinically meaningful changes in the functioning, morale, and health status of the target population. Allowing for sample attrition, statistical calculation of the effect size should be made at the time of the proposal's submission for funding.

(4) The investigator should describe the intervention in sufficient detail to allow replication and should indicate how the intervention will be documented as it unfolds. Details are necessary about the measures used to substantiate the claim that the target population suffers from a deficiency of certain types of support, the measures used to document the actual delivery of support, the characteristics of the support providers and the reasons why they are deemed to be suitable or desirable sources of support, and the rationale for the "dosage level" of support (its duration and intensity).

(5) The investigator should describe how the mediating processes implicated in the intervention's effects will be documented, once again invoking theory or past research to explain social support's hypothesized mechanisms of change.

(6) The investigator should specify components of the intervention "package" other than social support, if any, and show what efforts are being made to ensure that the final analyses can discern the relative contribution of these cointerventions to the obtained outcomes. In this regard, the investigator should also take steps to monitor spontaneous or naturally occurring cointerventions during the course of the planned intervention. In short, efforts should be made to identify all the active ingredients of the intervention, with special attention to social support's unique contribution to the desired end-states.

(7) the investigator should indicate how he or she plans to gain information about the reasons why some participants dropped out of the intervention, why some received a lower "dose" of support than planned, and why certain participants benefited less than others from the intervention.

(8) The investigator should take steps to monitor the immediate and delayed side-effects of the intervention (both desirable and undesirable) as they affect both the support provider(s) and the intended beneficiaries.

(9) Efforts should be made to ensure the integrity of the data in terms of its freedom from bias and its validity. It is recommended that investigators incorporate at least one measure of social support and one measure of the intervention's outcomes that is not based on self-report.

(10) The investigator should indicate how he or she plans to assess the extent to which gains accruing from the intervention are maintained over time. The investigator should indicate whether and why follow-ups are called for at particular intervals.

(11) The investigator should describe the steps that are being taken to prevent contact (contamination) between the participants in the intervention and the members of the control or comparison group(s).

(12) Ethical issues surrounding the intervention should be addressed.

Gottleib (1988)

April 12, 1990

Dear

In September of 1988, a survey was conducted by the Social Work Department at the St. Amant Centre to help identify the needs of families/parents whose child lives at the Centre. On behalf of the Social Work Department I would like to thank each of you for the openess with which you shared your observations and feelings. We truly appreciated the time you took to complete the survey and the response we received.

The primary focus of the survey was to determine the need for a parent support group. Since only a small number of parents had expressed interest, we wanted to find out how widespread the need was, and how the following issues were relevant to parents at different points of their child's admission.

All parents who have children living at the Centre were surveyed. Sixty percent (almost 100) of those surveys were returned. We had feedback from parents in rural and urban areas, parents of more recently admitted children as well as parents of children (including adult children) who have lived at the Centre for longer periods.

The first issue that the survey dealt with was how the presence of a handicapped child affected the families. Families appeared to be affected in a variety of ways. Most parents suggested that their stress was associated with the increased and prolonged care demands. Feelings of exhaustion and anger were expressed. Some experienced difficulty in finding babysitters, therefore, respite from the care demands were limited. Opportunities to spend time with their other children were also limited.

Many parents, however, felt that the experience of having a handicapped child had a unifying effect on the family. Some admitted it was difficult, but they managed without any resulting negative effects. Others reported that particularly the marital relationship was strained and issues had not been resolved.

When asked about their feelings when the actual placement of their child occured, most parents stated that they experienced feelings of guilt, of abandonment of their child, of failing to succeed at parenting the child, feelings of loss or void in their life and concern over the ability to visit their child. Most parents also commented on the helpfulness and sensitivity of the staff during this difficult time.

Visiting regularly was reported to be difficult for some parents. Reasons noted mostly related to long distance travel and work and/or family responsibilities. Other important reasons related to the range of emotions that parents felt when they visited.

Approximately 60% of parents surveyed responded that they would have liked an opportunity to talk to other parents who had placed their children at the Centre indicating a need for a parent support group. Parents expressed that they would like to know that they are not alone with their feelings.

You have confirmed our belief that parents can be resources to one another either on a one-to-one basis or in a supportive small group atmosphere. I now have the opportunity as a graduate student of the School of Social Work at the University of Manitoba to develop and implement a parent support group for parents who have children living at the St. Amant Centre.

Many parents who live in rural areas or out of province, will unfortunately miss out on the opportunity to participate in this group. However, as an outcome of this project, information will be made available to parents and professionals who wish to develop a support group for parents.

I will be contacting parents who live in Winnipeg or within a distance of approximately 60 miles, and who have expressed interest in participating in a parent support group. If you did not indicate interest at the time of the survey and you are interested now, please let me know. If you have any further questions about the survey, do not hesitate to call.

Once again, many thanks for your outstanding co-operation.

Yours sincerely,

Ivy Kopstein, B.S.W.
Director, Social Work Department
Home Phone Number

IK/lm

April 12, 1990

Dear

The reason that I am writing to you is to let you know of an opportunity to participate in a support group with other parents who have children living at the St. Amant Cente.

Some parents expressed interest in talking to other parents about some of their observations and experiences related to the presence of a developmentally disabled child in their family. In 1988, the Social Work Department conducted a survey, which also confirmed the interest in a parent support group. As a graduate student of the School of Social Work at the University of Manitoba I have the opportunity to develop and implement this group program.

I will be contacting you within the next week or so, and if you are interested, I can provide you with more details.

Sincerely,

Ivy Kopstein, B.S.W.
Director, Social Work Department
Home Phone Number

IK/lm

St. Amant Centre Inc.
440 River Road Winnipeg. Manitoba R2M 3Z9

Centre St. Amant Inc.
Telephone: 256-4301 Area Code 204 Code Regional

August 8, 1990

This is just a reminder to please complete and return the surveys I sent you last month. If you have any questions, or need another copy of the forms, please call me at work or at home.

Thank you for your cooperation. I hope you are enjoying this warm weather.

Yours sincerely,

Ivy Kopstein, B.S.W.
Director, Social Work Department
M.S.W. Student
Home Phone Number
Work Phone Number

IK/lm

ST. AMANT CENTRE INC.

APPENDIX 5   PRE-GROUP INFORMATION

DATE: _____

FAMILY NAME: _____

ADDRESS: _____

_____

POSTAL CODE: _____

HOME PHONE # _____

CHILD CHARACTERISTICS

NAME: _____ AGE: _____ SEX: _____

DATE OF BIRTH: _____

DATE OF ADMISSION: _____ LENGTH OF ADMISSION: _____

DIAGNOSIS OR PHYSICAL/DEVELOPMENTAL/BEHAVIOUR ATTRIBUTES:

_____

_____

_____

_____

VISITING PATTERN:

VISITS ARE: SATISFACTORY: ☐   UNSATISFACTORY: ☐

PLEASE EXPLAIN: _____

_____

FREQUENCY: ONCE PER WEEK OR MORE: ☐   ONCE EVERY 2 WEEKS: ☐

ONCE PER MONTH: ☐   ONCE EVERY SIX MONTHS OR LESS: ☐

OTHER: ☐

OTHER RELEVANT INFORMATION:

_____

_____

_____

_____

_____

_____

PRE-GROUP INFORMATION

PREVIOUS GROUP EXPERIENCE/FEELINGS AND EXPECTATIONS

1. Have you been involved with a group before?

2. What was it like?

3. How do you feel this group could help you?

4. How do you feel about participating in a group? What are your concerns/apprehensions, if any?

5. What are your expectations of the group?

   Describe the Group: Purpose, methods, membership, role of leader, expectations of members, i.e., confidentiality

6. Do your think the group described would be of benefit to you?

7. Do you have any further questions/comments about the group and/or it's membership?

ST. AMANT CENTRE INC.

PRE-GROUP PARENT SURVEY

FAMILY INFORMATION:

FAMILY TYPE:
_____ TWO PARENT   _____ SINGLE FAMILY

_____ NUCLEAR   _____ BLENDED

_____ BIOLOGICAL   _____ EXTENDED

_____ ADOPTIVE

Please list ALL FAMILY MEMBERS living in your house, their AGES, EDUCATION and whether or not they are EMPLOYED.

DO NOT COUNT YOUR FAMILY MEMBER WITH A DISABILITY IN THIS LIST BUT REMEMBER TO INCLUDE YOURSELF. Please only write down the family member's relationship to the disabled person (mother, father, aunt, brother, grandmother, etc.) NO NAMES PLEASE.

	Relationship	Age	Education	Employed Full Time	Employed Part Time	Not Employed
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						

What was the total taxable family income last year (1989) of primary wage earners in your household (please check one only)

_____ $ 0 - 9,999   _____ $ 30,000 - 39,999

_____ $ 10,000 - 19,999   _____ $ 40,000 - 49,999

_____ $ 20,000 - 29,999   _____ $ 50,000 - 59,999

What is the Postal Code area of your home ___ ___ ___ ___ ___ ___

APPENDIX 6

ST. AMANT CENTRE INC.

GROUP RECORDING FORM

DATE OF SESSION: _____   SESSION NUMBER: _____

MEMBERS PRESENT

MEMBERS ABSENT

PURPOSE OF GROUP

GOALS FOR THIS SESSION

ACTIVITIES TO MEET GOALS

ANALYSIS OF MEETING

FUTURE GOALS

F-COPES

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

		RESPONSE CHOICES		
1	2	3	4	5
Strongly Disagree	Moderately Disagree	Neither Agree Nor Disagree	Moderately Agree	Strongly Agree

1. Sharing our difficulties with relatives. _____

2. Seeking encouragement and support from friends. _____

3. Knowing we have the power to solve major problems. _____

4. Seeking information and advice from persons in other families who have faced the same or similar problems. _____

5. Seeking advice from relatives (grandparents, etc.). _____

6. Asking neighbours for favours and assistance. _____

7. Seeking assistance from community agencies and programs designed to help families in our situation. _____

8. Accepting that we have the strength within our own family to solve our problems. _____

9. Accepting gifts and favours from neighbours (e.g., food, taking in mail, etc.). _____

10. Seeking information and advice from the family doctor. _____

11. Facing problems "head on" and trying to get solutions right away. _____

12. Watching television. _____

13. Showing that we are strong. _____

14. Attending church services. _____

15. Accepting stressful events a a fact of life. _____

16. Sharing concerns with close friends. _____

17. Knowing luck plays a big part in how well we are able to solve family problems. _____

18. Accepting that difficulties occur unexpectedly. _____

19. Doing things with relatives (get-togethers, dinners, etc.). _____

20. Seeking professional counselling and help for family difficulties. _____

21. Believing we handle our own problems. _____

22. Participating in church activities. _____

23. Defining the family problem in a more positive way so that we do not become too discouraged. _____

24. Asking relatives how they feel about problems we face. _____

25. Feeling that no matter what we do to prepare, we will have difficulty handling problems. _____

26. Seeking advice from a minister. _____

27. Believing if we wait long enough, the problem will go away. _____

28. Sharing problems with neighbours. _____

29. Having faith in God. _____

April 20, 1992

Ivy Kopstein

Dear Ms. Kopstein:

I am pleased to give you my permission to use the **F-COPES: Family-Crisis Oriented
Personal Evaluation Scales** instrument. We have a policy to charge $5.00 (one time
charge only) *per instrument* to individuals who seek permission. We apologize for this
necessity. We also ask that you please fill out the enclosed abstract form and return it to
this office.

The manual, **Family Assessment Inventories for Research and Practice, Second
Edition** should be cited when using the instrument. The publication was printed at the
University of Wisconsin-Madison in 1991 and edited by Hamilton I. McCubbin and Anne
I. Thompson. It is not advisable to use the Family Inventories manual by David Olson
to score the instruments due to errors in it's scoring section.

A sample copy of the instrument is enclosed. Additional copies can be obtained at this
address for 10 cents each. When large quantities are requested, the cost of postage is also
added to the order.

If I could be of any further assistance to you, please let me know.

Sincerely

Hamilton I. McCubbin
Dean

HIM/kme

Enclosures

DIRECTIONS: The statements which follow refer to feelings and experiences which occur to most people at one time of another in their relationships with their families.   For each statement there are three possible answers: Yes, No, Don't' Know.   Please circle the answer you choose for each item.

YES   NO   DON'T KNOW   1.   My family gives me the moral support I need.

YES   NO   DON'T· KNOW   2.   I get good ideas about how to do things or make things from my family.

YES   NO   DON'T KNOW   3.   Most people are closer to their family than I am.

YES   NO   DON'T KNOW   4.   When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.

YES   NO   DON'T KNOW   5.   My family enjoys hearing about what I think.

YES   NO   DON'T KNOW   6.   Member of my family share many of my interests.

YES   NO   DON'T KNOW   7.   Certain members of my family come to me when they have problems or need advice.

YES   NO   DON'T KNOW   8.   I rely on my family for emotional support.

YES   NO   DON'T KNOW   9.   There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.

YES   NO   DON'T KNOW   10.   My family and I are very open about what we think about things.

YES   NO   DON'T KNOW   11.   My family is sensitive to my personal needs.

YES   NO   DON'T KNOW   12.   Members of my family come to me for emotional support.

YES   NO   DON'T KNOW   13.   Members of my family are good at helping me solve problems.

YES   NO   DON'T KNOW   14.   I have a deep sharing relationship with a number of members of my family.

YES   NO   DON'T KNOW   15.   Members of my family get good ideas about how to do things or make things from me.

YES   NO   DON'T KNOW   16.   When I confide in members of my family, it makes me uncomfortable.

YES   NO   DON'T KNOW   17.   Members of my family seek me out for companionship.

YES   NO   DON'T KNOW   18.   I think my family feels that I'm good at helping them solve problems.

YES   NO   DON'T KNOW   19.   I don't have a relationship with a member of my family that is as close as other people's relationships with family members.

YES   NO   DON'T KNOW   20.   I wish my family were much different.

socialwk\miscell\family

St. Amant Centre Inc.
440 River Road Winnipeg, Manitoba R2M 3Z9
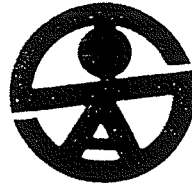
Centre St. Amant Inc.
Telephone: 256-4301 Area Code 204 Code Regional

May 6, 1992

Dr. Mary E. Procidano
Department of Psychology
Fordham University
Bronx, New York
U.S.A.
10458

Dear. Dr. Procidano:

RE: PERMISSION TO USE PSS-FA INVENTORY

Further to our conversation last week, I am requesting permission to use the above scale in my practicum, the completion of which is the final requirement towards a Masters Degree of Social Work from the University of Manitoba, in Winnipeg.

My practicum topic is stress, coping and the role mutual aid in families with a developmentally disabled child. The intervention is a social support/mutual aid group for parents whose family member lives in a residential and resource centre for children and adults with significant developmental disabilities. A number of measures including the PSS-FA are used to measure group members perceived support and coping strategies to determine the need and rational for a support program for parents.

Your signature below will indicate that you grant permission for my use of the PSS-Fa in the above described practicum. Please advise if you require anything further. Thank you for your attention to this matter.

Yours sincerely,

Ivy Kopstein, R.S.W.

I hereby give permission for Ivy Kopstein to use the PSS-FA Inventory in the above study.

_____
SIGNATURE

        5/13/92
_____
DATE

IK/lm

GCS

This questionnaire is designed to measure the degree of contentment that you feel about your life and surroundings. It is not a test, so there are no right or wrong answers. Answer each item as carefully and accurately as you can by placing a number beside each one as follows:

1. Rarely or none of the time
2. A little of the time
3. Some of the time
4. Good part of the time.
5. Most or all of the time

Please begin:

1. I feel powerless to do anything about my life. _____

2. I feel blue. _____

3. I am restless and can't keep still. _____

4. I have crying spells. _____

5. It is easy for me to relax. _____

6. I have a hard time getting started on things that I need to do. _____

7. I do not sleep well at night. _____

8. When things get tough, I feel there is always someone I can turn to. _____

9. I feel that the future looks bright for me. _____

10. I feel downhearted. _____

11. I feel that I am needed. _____

12. I feel that I am appreciated by others. _____

13. I enjoy being active and busy. _____

14. I feel that others would be better off without me. _____

15. I enjoy being with other people. _____

16. I feel it is easy for me to make decisions. _____

17. I feel downtrodden. _____

18. I am irritable. _____

19. I get upset easily. _____

20. I feel that I don't deserve to have a good time. _____

21. I have a full life. _____

22. I feel that people really care about me. _____

23. I have a great deal of fun. _____

24. I feel great in the morning. _____

25. I feel that my situation is hopeless. _____

Dr. Walter Hudson has granted permission to reproduce and use any or all of these scales presented in Figures 6.2 through 6.10 in any quantity needed provided that the following three conditions are met: the format and wording of each scale must not be altered, the copyright notation at the bottom of each scale must be retained, and none of the scales may be reproduced for commercial purposes. Further information about the scales can be obtained in Hudson (1982) or by writing to Dr. Walter Hudson, Florida State University, School of Social Work, Tallahassee, Florida 32306.

Bloom and Fischer (1982)

GROUP LEADERSHIP SKILLS RATING SCALE

Rate each item on a scale of 1 to 7.
   1 = I am very poor at this.
   7 = I am very good at this.

__|__   1. **Active Listening:** I am able to hear and understand both direct and subtle messages.

__|__   2. **Reflecting:** I can mirror what another says, without being mechanical.

__|__   3. **Clarifying:** I can focus on underlying issues and assist others to get a clearer picture of some of their conflicting feelings.

__|__   4. **Summarizing:** When I function as a group leader, I'm able to identify key elements of a session and to present them as a summary of the proceedings.

__|__   5. **Interpreting:** I can present a hunch to someone concerning the reasons for his or her behaviour without dogmatically telling what the behaviour means.

__|__   6. **Questioning:** I avoid bombarding people with questions about their behaviour.

__|__   7. **Linking:** I find ways of relating what one person is doing or saying to the concerns of other members.

__|__   8. **Confronting:** When I confront another, the confrontation usually has the effect of getting that person to look at his or her behaviour in a nondefensive manner.

__|__   9. **Supporting:** I'm usually able to tell when supporting another will be productive and when it will be counterproductive.

__|__   10. **Blocking:** I'm able to intervene successfully, without seeming to be attacking, to stop counterproductive behaviours (such as gossiping, storytelling, and intellectualizing) in group.

__|__   11. **Diagnosing:** I can generally get a sense of what specific problems people have, without feeling the need to label people.

__:__   12. <u>Evaluating</u>: I appraise outcomes when I'm in
              a group, and I make some comments concerning
              the ongoing process of any group I'm in.

__:__   13. <u>Facilitating</u>: In a group, I'm able to help
              others openly express themselves and work
              through barriers to communication.

__:__   14. <u>Empathizing</u>: I can intuitively sense the
              subjective world of others in a group, and I
              have the capacity to understand much of what
              others are experiencing.

__:__   15. <u>Terminating</u>: At the end of group sessions,
              I'm able to create a climate that will foster
              a willingness in others to continue working
              after the session.

(Corey & Corey, 1977)

BIOGRAPHY OF SUPPORT GROUP MEMBERS
AND INDIVIDUAL GOALS

Parents A and B:
This couple is in their mid-thirties with one
parent self-employed. They have a teen-age son who
has lived at St. Amant Centre most of his life, and
two younger children at home. The handicapped child
has profound mental retardation, a seizure
disorder, is gastrostomy fed and wheelchair
dependent. His communication skills are severely
impaired and his parents feel he does not recognize
them. His family lives aproximately one hour
outside of Winnipeg and visits him approximately
once per month to six weeks at the Centre.
Goals: To meet other parents,
       To provide support to new parents,
       To recieve support when needed (ie. child's
       deteriorating health).

Parent C:
This mother in her early thirties and is married
with two teen-age children. She and her husband are
both employed full time. The older teen-age boy was
admitted to the Centre as a pre-schooler. He has
severe mental retardation, severely impaired
communication skills and good walking skills. His
daily living skills such as dressing or feeding are
very limited and his behavior can be very
aggressive. His family feel that this young man is
able to recognize them and enjoys going home for
weekend visits. This mother finds that the child is
very resistant to return therefore finds it
difficult to bring him back to the Centre.
Goals: To meet other parents.

Parent D:
A middle aged single mother raised her only child
well into his adult years and admitted him to the
Centre recently. He has severe mental retardation,
seizures, has poor hearing and vision and is
wheelchair dependent and dependent for all of his
needs. His communication skills are severely
impaired although his mother feels that he is able
to recognize and respond to her. His mother visits
him at the Centre a number of times per week.
Goals: To meet with other parents,
       To help parents work through the service
       system,
       To discuss issues related to relationships
       with staff,
       To discuss feelings around placement.

Parents E and F:
The adult daughter is the only child of this middle
aged couple and has been living at the Centre since
school age. The young woman has a chromosomal
abnormality causing severe mental retardation and
seizures. Although she is able to walk with
assistance, demineralization of bones is
restricting this ability more and more. Her
communication skills are severely impaired and she
is dependent for activities of daily living such as
feeding, dressing, etc..Her parents feel that she
recognizes and responds to them. They visit with
her once or twice a week mostly at the Centre.
Goals: To help other parents with similar
       experiences to what they had gone through.
       To help parents of recently admitted
       children.

Parents K and L:
This couple in their late fourty's are both
employed full time and have four adult children,
three of whom do not live at home. The youngest of
the four is in his early 20's, has lived at St.
Amant for 6 years, has severe mental retardation,
seizures, and is profoundly hearing impaired. He
walks, but can be aggressive and requires frequent
medical attention due to diabetes. He is able to
feed himself, and dress himself with supervision
but is dependent for all other self-care
activities. His parents visit every one or two
weeks usually at home.
Goals: To meet other parents.

Parent O:
This father is married with four children. His son
is the second oldest in the family of three
children and has been living at the Centre since he
was a pre-schooler and for the past 8 years. He has
profound mental retardation as well as hearing and
vision impairments. He is able to walk well, can
feed himself, and can participate in dressing, but
his communication skills are severely impaired. He
also demonstrates behavioral difficulties. His
parents are able to take him home for visits at
least once a week.
Goal: To meet other parents.

Parent P:
This mother, separated from her husband at that
time, is employed full time. She has two children,
the older one being severely disabled. The daughter
living at the Centre is in her mid-teens and has
been living at the Centre for six years. She has
severe mental retardation and seizures. She is also
able to walk very well, can feed herself with
supervision, but has behavioral difficulties. Her
mother attempts to take her daughter home for
visits approximately once per month however she
finds her behavior very difficult to manage, and
therefore tends to visit at the Centre.
Goal: Would enjoy talking to other mothers.

Parent Q:
This couple has a disabled son living at the Centre
and have three other children, none of whom still
live at home. Father is retired and mother is
employed full time. The disabled son is the
youngest child and has lived at the Centre since
his mid-teens. He has mild mental retardation, but
is severely physically disabled. He is non-verbal,
but is able to operate an electronic communication
device. His parents visit him at the Centre two
times per week and on occasion he goes home to
visit.
Goals: To talk to other parents and know that you
       are not alone,
       To help parents who have recently admitted
       their child,
       To talk about siblings as they have
       experienced some difficulties.

Parent R:
This single mother of four children is working
part-time and has a son living at the Centre in his
mid-teens. This young man has profound mental
retardation, seizures and feeding difficulties. He
is ill frequently and is dependent on others for
all his daily care needs. He is wheelchair
dependent and his communication skills are also
severely impaired. His mother visits once every two
weeks mainly at the Centre.
Goals: To hear how other parents have come to terms
       with having a child with severe
       disabilities,
       To have a safe environment to share
       feelings.

Parent S:
This previous foster mother of a one year old girl
has recently admitted her child to the Centre. The
child has severe mental retardation, blindness and
seizures. This little girl is both responsive to
people and generally to what is going on around
her. Her foster parents visit her at the Centre and
take her home approximately once per month. They
live about one hour outside of Winnipeg.
Goal: To be able to talk about feelings related to
      placing a child.

Parent T:
This single mother is has two adult children. The
eldest is the young man who has lived at the Centre
since his late teens. He has severe mental
retardation, seizures and severely impaired
communication skills. He has good walking skills
and can assist with some self-care activities. This
mother visits her son once or twice per week at the
Centre.

SUMMARY OF GROUP SESSIONS

Session 1: Introductory Session

Attendance: 16

Content: Welcome
Confidentiality, videotaping
Goal of group
Introductions-Information sharing about
disabled family member, the decision to
place, and member's expectations of group
sessions.
Stressors leading to placement-
-perceived unresponsiveness of
community agencies
-limited family support
-marital breakdown
-single parenthood coping with young
children
-impact of disabled child on siblings

Feelings related to admission-
-giving up control of children
-difficulty bringing child back to
the Centre from visits
-increasing difficulty managing child
at home during visits
-coping with a child who has severely
impaired communication skills

Statements and beliefs parents used to cope
with their situation involved:
a) positive aspects of their child's
life at the Center:
-children are happy and well looked
after,
-children have more freedom of
movement than they would at home,
-child has opportunities to
interact with a variety of people
ie.staff and residents
-observations of positive resident-
staff interactions
-residents always are clean,well
dressed and groomed.
b) other perceptions about placement
issues:
-parents should have the choice
(of living alternative for their
child) about what they feel is
best for their child and family
-constant care demands interfere
with the quality of the parent-
child relationship ie. resentments
build.
-consider St.Amant a "home" rather
than an "institution" and the staff
were extended family

Process/Interaction: Verbal and non-verbal
communications were reserved. Information was
presented by parents in narrative form, but there
was little dialogue.

Session 2: Discussion of future topics and meaning of
              support.

Attendance: 13

Content: a) Development of group norms ie.listening,
confidentiality, honesty, being non-judgemental,
constructive criticism, right to own feelings, a
right to be heard.

          b) Prioritizing topic areas for future
meetings.

Process/Interaction: Divided into small groups where
interaction was more free-flowing, however generally
members were still speaking through the facilitator.

Session 3: Stress and Coping

Attendance: 12

Content: Icebreaker- "Common Interests"
Stress Overview-Signs and signals
                        Perceptions
Stressors identified:
-balancing competing demands and needs
-loneliness following admission of child
-child's unpredictable behavior during
visits
-guilt around placement (resulting in
possible overprotectiveness)
-aging of parents
-family activities to involve the severely
disabled individual

Factors that contributed to individual
member adjustment:
-problems suspected early in life prevented
parents from developing unrealistic hopes
and dreams
-honesty, support and non-judgemental
attitude of child's physician.
-identification of spiritual issues "why
does this happen"
-involving self in activities to combat
loneliness
-suggestion of using handi-transit to
transport adults to and from Centre on
visits
-positive factors ie. joys, child's
accomplishments, likes and dislikes,
humorous stories that highlight a
characteristic about their child
-mobilizing family to participate in
household chores (suggestion for competing
demands)

Process/Interaction: There was more interaction
between members and mutual aid processes were
apparant. Members were probing for information
clarifying and supporting each other. They were
sharing ideas on coping and were able to voice
individual differences of opinion. Comparisons took
place between one another. They also were able to
maintain a sense of humor which was encouraging to
parents who more recently admitted their child.

Session 4: Impact of Disability on the Family.

Attendance: 9

Content: -difficult relationships with family of
origin
-examples of non-support from extended
family members
-general public's awareness and attitudes
towards individuals with disabilites
-handicapped child becoming an adolescent
or adult
-caring attitudes towards handicapped child
of siblings
-parents of an only child concerned about
whether there will be someone to "be there"
to care about their child after their death

Process/Interaction: Supportive interactions
continued in this meeting. Much of the time was
devoted to one group member who recently admitted her
child.

Session 5: The Grieving Process

Attendance: 11

Content: -venting about professional services prior
to their child's admission
-attitudes of pessimism from physicians
which prompted parents to attempt "prove
them wrong" in many cases
-"safe" issues

Process/Interaction: Lower cohesion than had been in
previous sessions. Avoidance of topic. Interaction
was narrative with less support offered.

Session 6: The Grieving Process

Attendance: 11

Content: -addressed difficulty in discussing the
topic
-experiences were shared in relation to the
death of a close friend or relative
-parallels were made relating the feelings
of loss that may be felt by parents with
children with disabilities.
-the loss experience was perceived as
negative, although attempts were made to
"normalize" the experience by discussing
loss as a part of change in daily life where
there is potential for growth or positive
outcomes.
-sharing of feelings about the group's
termination
-evaluative feedback regarding whether the
group was meeting members' expectations
(most of the comments are reflected in the
summary of sessional evaluations in
Appendix 14)

Process/interaction: Return of higher group cohesion
and mutual aid processes. Greater interaction between
members and support was provided to one particular
member in need.

Session 7: Working with Professionals

Attendance: 10

Content: -venting about the legal requirements and
         implications of placing a child or adult at
         the Centre
         -venting that St. Amant was not suggested as
         an option for some families when they were
         considering placement
         -discussion about "parenting" a child at the
         Centre and what that means
         -strategies to help young siblings adjust
         ie. involving siblings in decorating
         child's/adult's room; making toys of other
         items for their brother or sister; play
         appropriate games, where possible
         -discussion about the possibility of
         continuing the group

Process/Interaction: High degree of interaction, and
mutual support but less intense than previous
sessions.

Session 8: Wrap-up Session

Attendance: 12

Content: -met each other's children - reestablished
         common bond between members
         -shared ideas for the group's continuation
         -decided on a small committee who would work
         with the social worker to get things under
         way for the fall
         -verbal evaluations
         -social time

Process/Interaction: By this point the group had
reached a high comfort level and were able to
dialogue fairly openly. They were able to express
warmth and interest in each other as individuals
beyond their commonality.

THE CHILD WITHIN US

There is a child within each of us crying out:

"Listen! I am sick and tired of being ignored day after day. You go to work, out with your friends, to sleep, to eat, live your life as if I do not exist. Every once in a while you notice me when you are depressed or homesick in bed. But do you really care about me? Do you really ask what I want?

Here I am sitting around waiting, forever waiting for you to recognize me. First your parents began ignoring parts of me and gradually you continued where your parents left off.

Remember me? I am your feelings, your dreams and fantasies. I am the one who used to enjoy going to the park. I am the one who likes pizza, candy, long talks, sunshine, and who wants to play. I am also the one who likes to be held and told I am loved, I am the child within you, I am you.

I don't care if you are an adult now. Why does that mean you have to forget about me? Why can't adults enjoy themselves as childrren do? Why must being an adult mean that the child in you must try not to exist?

Believe me, living in your adult world of constant struggle, is not easy. Ho do you think I feel when you stuff me with lots of food during dinner while you talk with your important friends, people you really don't like?

Where am I supposed to go when I am angry and you don't recognize me? Then you wonder why you have indigestion or weight problems.

Where do you think your problems come from?

I know you need your important friends. I know you have to make a living. I know you have to take care of others. But have you ever thought if you really become my friend, you wouldn't need some things from others so much?

Have you ever thought that if you took care of your feelings and appreciated your little desires that you wouldn't need so mucch income to appease me? Have you ever thought that if you were nicer to yourself, taking care of others would not be so mucch of a burden?

I know you are trying to get a better position so you will have more time to be with me. I have felt the different therapies you have tried which reintroduce you to parts of me. But I want you to know all of me. I am tired of others pushing and shoving, fishing around for me. I want you to know me.

I don't expect you to change overnight. I have been waiting for you to recognize me long enough. To be honest, a part of me will never understand how you can treat me that way you do. Why is it so difficult for you to be as you want?

If I was literally your child, you would listen to me and care how I am. Well, I am literally your child, you have just learned not to see me."

"The Magical Child Within you"
Bruce Davis, Celestial Arts, 1977

"Don't go where the path leads;
Go where there is no path and leave a trail".

(Russ Berrie)

Dear Friend,

So you have a brother or sister who is different? Your friends call your sister a "retard" or your brother a "cripple"? You are asking, "Why did this happen to me?"

If you answered yes to any of these questions, you're probably feeling sorry for yourself, and you have that right - for a little while. All people feel sorry for themselves and for a handicapped person once in awhile. But feeling sorry for yourself much of the time does not help. "Sorry" does not change things much. "Sorry" does not improve a handicap either.

There is something you can do to help yourself and your brother or sister. You can learn to understand. Ask your parents questions such as: "What does mental retardation mean?" or "Will my sister always be crippled?" or "Will my brother ever learn to talk?" Ask your teacher and your brother's or sister's special teachers about what is wrong and what that means for you and your family. You have a right to know. Learn all you can. As you truly begin to learn, you will begin to understand.

You will understand why Mom gets tired after lifting a heavy brother or sister who cannot walk yet, day after day. You will understand why Dad is more worried. (Special equipment or training costs money, and he may be concerned about paying for it.) You will begin to understand why Mom and Dad don't spend as much time with you and why they expect you to do more to help out around the house. You may also understand why it is sometimes difficult for them to talk about handicaps. You see, all parents dream that their children will be healthy, strong, and intelligent. It is very difficult for them to understand why they have a "special" child.

There is one more thing you may be worried about: whether your brother's or sister's handicap is "catching". Sometimes other children get the idea that it's like chicken pox or a virus. But you cannot "catch" a handicap. Many handicaps are determined before a child is born or during the birth process. Others are a result of a severe disease or infection. Other handicaps can be caused by accidents.

When you talk to your friends, it's a good idea to teach them the things you've learned. If they see that you know more about your brother's or sister's handicap than they do, they may begin to ask questions because of their desire to learn and help. Some children will tease you about your special brother or sister because they don't understand. If they hear you using the words retarded, crippled, or brain damaged to describe your brother or sister in a realistic manner, they will no longer enjoy using these words to get on your back. If you don't get "hairy" about it, they will soon learn to understand, as you have done.

There is one more thing that you can do as you are learning to understand: ꞏ ꞏꞏ ꞏ ꞏꞏ, c ꞏ r kids ꞏꞏ ꞏ ꞏꞏ ꞏ ꞏꞏ ꞏ ꞏꞏ ꞏ ꞏꞏꞏ ꞏ ꞏꞏꞏ ꞏꞏ ꞏ ꞏꞏꞏ ꞏꞏꞏ, ꞏ ꞏ ꞏ ꞏ ꞏꞏ ꞏꞏꞏ ꞏꞏꞏ ꞏꞏ ꞏ ꞏꞏꞏꞏ community, but why wait until they are? Organize one yourself. Visit ꞏ ꞏꞏ ꞏꞏ brother's or sister's teacher ꞏꞏ therapists. They can be of help in suggesting others who might join your group.

Sincerely,

Sara L. Brown

P.S. Good luck to you! You are healthy and full of life. Make the most of it. You have the right. (pp. 67-68)

From the book authored by Brown and Moersch (1978), Parents on the Team, Sara Brown pens the above letter to siblings - a message laced with compassion, honesty, and good advice.

APPENDIX 14

ST. AMANT CENTRE INC.   DATE: _____

EVALUATION

1. Overall, how did you feel about this session?

NOT
HELPLFUL   HELPFUL
   1   2   3   4   5

   _____

   _____

   _____

2. What did you find useful or helpful about the session?

   _____

   _____

   _____

3. What did you find not helpful?

   _____

   _____

   _____

4. General Comments:

   _____

   _____

   _____

   _____

   _____

SUMMARY OF SESSIONAL EVALUATIONS					
S E S S I O N	TOPIC	SESSION RATING: 5-MOST HELPFUL 1-LEAST HELPFUL	HELPFUL	NOT HELPFUL	GENERAL COMMENTS
1	INTRO	N/A	VERBAL FEEDBACK ONLY		
2	PRIOR-ITIZE TOPICS AND DEFINE SUPPORT	OVERALL GOOD	-lot of listening -everyone willing to listen and share -knowing I am not the only one with the problem		-room warm -facilitator v.g., fine, gentle
3	STRESS AND COPING	10-5'S	-all have some of same feelings loss, guilt -the openness, friends sharing feelings -discussions -people open up and talk about their problems -can talk about your own feelings -more communic'n and involvement in this session -being able to give and express feelings with others		-good meeting -nice to hear people open up -I look forward to weekly meetings -this is something I am doing for myself -even there are no solutions to our problems, I think we feel better talking about them -v.g. meeting, most interesting and helpful -beneficial to get together and share our feelings with each other
4	IMPACT ON FAMILY	5-5'S 2-4'S	-finding out how family and friends deal with a handicapped child -talked openly -feelings towards each other -knowing how other families felt -knowing that other families had the same experiences with the siblings -different viewpoints -feelings of sharing family reactions, some same, some different	-a little more on siblings -people seamed to get off the subject	-it's great to feel the support from other families that are involved -there are a lot of good feelings generated at these meeting -we can laugh together and it feels good
5	GRIEF AND LOSS	2-3'S 5-4'S 3-5'S	-sharing feelings and attitudes towards prof. people -many of the same concerns -expressing grief	-strayed too much from the topic	-it's good to share openness about different things -it's easy to talk to the other people -these types of discussions relieve stress -good learning experience -v.g.discussion on grief

6	GRIEF AND LOSS	10-5'S	-feelings of togetherness -talking about things we don't always talk about to others -helped to clarify feelings about the child's handicap -talked freely and openly -sharing emotions on how to deal with different problems and how others dealt with same -that I'm not alone in my feelings -parents really care about each other -honesty of people	-filling out this paper	-these sessions encourage people to participate. -feelings of friendliness -and support for each other -made me feel some emotions that I never faced before, but it made me stronger at the same time -would like to continue seing on another -maybe we could meet each others children -good to know parents want to continue meeting next fall
7	FEEL/ ATT TOWARDS PROFES- SIONALS	1-3 4-4'S 6-5'S	-talking about frustrations -listening to others' concerns and them listening to me -sharing different ideas -everyone agreeing that they were pleased about the care at St. Amant -always feel good at these meetings -hearing other people's hurts and joys -the openness of the meeting and how everyone is interestedin remaining in close contact	-too long	-not one of our better meetings -the hardest topic to talk about -group should continue and recruit more people -it was interesting to learn what everyone had to say about professionals -v.g.meeting -helped listening to others and know how they feel, coped, and understand. I really felt relaxed and comfortable talking about the topics
8	WRAP-UP	1-3 1-4 8-5'S	-meeting the children -being able to speak out to people to people who understand the situation -hearing everyone's veiwpoints -caring attitude and friendliness -helpful in learning and getting to know others in the same or similar situations -good to put faces to names of the children -good to know it was a success and that everyone wants to meet again		-it helps knowing you are not alone -we all have become trustful of one another -looking forward till we get together again -good chairman who has empathy with the group -I feel I have made friends here